## Continuation Application Summary Report
## Program Narrative

The Tennessee Department of Health, Early Hearing Detection and Intervention (EHDI) program is known as the Newborn Hearing Screening (NHS) Program. The Newborn Hearing Screening Program has been successful in meeting the majority of the National “1-3-6 EHDI Goals”. NHS increased the percentage of infants screened for hearing from 93.9 % (2008) to 97.1% (2009 January – June), therefore surpassing our goal of 95%. In addition, the program increased the percentage of infants receiving follow-up testing after the initial failed screen from 68% (2008) to 83.2%, surpassing the goal of 75%. Therefore, the lost to follow-up percentage decreased 31.1% to 16.8%. It continues to be a challenge to obtain confirmation of enrollment into an early intervention program prior to 6 months of age. The percentage of those reported to be enrolled decreased from 21% (2008) to 14% (2009 Jan. - Jun.). We did not meet our goal of 50%. It is believed that most of these children receive early intervention through Part C and Non-Part C agencies but are not reported to NHS and tracking strategies will continue. Data were calculated using a match to all birth records by the Tennessee epidemiology staff funded by the Centers for Disease Control and Prevention, Early Hearing Detection and Intervention Tracking Surveillance and Integration (CDC EHDI TSI) grant. See Table A.

Table A

Meeting 1-3-6 Goals in Tennessee

| | 2008 (Jan.-Dec.) | 2009 (Jan.-Jun.) | State Goal | EDHI Goal |
|---|---|---|---|---|
| Total Hearing Screens | 93.9% | 97.1% | 95% | 100% |
| Before 1 month (of total screens) | 98.0% | 97.2% | | |
| Total Completed Follow-up Received | 68.9% | 83.2% | 75% | 100% |
| Before 3 months (of total FU) | 98.3% | 99.3% | | |
| Total Enrolled in Early Intervention | 21% | 14% | 50% | 100% |
| Before 6 months (of total EI) | 76.9% | 100% | | |

In July 2009, the Newborn Hearing Screening Program added an additional fulltime nurse to the central office staff to assist with follow-up on referred tests, high risk infants, and track infants diagnosed with hearing loss. The program now has two fulltime nurses and 0.75 FTE support staff in the central office located at the State Laboratory that conducts the metabolic testing. Additional follow-up activities are conducted by two part-time field nurse consultants (0.25 FTE), on a three month rotation alternating with birth defects registry activities. They are funded through the CDC EHDI TSI grant and are located in East and West Tennessee. Other program staff members are funded through two contracts. The University of Tennessee – Knoxville’s Center on Deafness employs an 0.75 FTE audiologist to provide consultation and training to hospitals, audiologists, medical providers, early intervention, and parent support consultants. Using the supplemental funds awarded in August 2009, an outreach audiologist (0.25 FTE) will be employed to implement phone consultation to hospitals in rural areas that do not have access to an audiologist. In addition, a deaf-educator (0.25 FTE) will be employed to serve as a family outreach coordinator. A second contract with the Tennessee Disability Coalition’s Family Voices program employs four part-time parents of children with hearing loss to provide outreach and one-on-one consultation to families of children with hearing loss. Supplemental grant funds will employ a part-time bilingual (Spanish) consultant to work with parents and the Hispanic Community. Newborn Hearing Screening continues to work closely with the Department of Education, Early Intervention System (TEIS), Individuals with Disabilities Act (IDEA) Part C program, to track infants in need of further hearing testing after a referred screen. By mandate, TEIS is to assist the program with follow-up activities. TEIS has a contract with the University of Tennessee Center on Deafness to fund a part-time TEIS consultant (Susie McCamy) and support staff to contact families for follow-up. Other central office staff members are provided by the CDC EHDI TSI contract. The CDC TSI grant project director and two epidemiologists are located downtown. The metabolic and hearing screening programs utilize the Natus-Neometrics data system. The system captures all screening and follow-up results, generates follow-up letters, and allows follow-up reports to be scanned into the infant's chart. See the position description for the four new positions, Attachment 1; the biographical data for the new central office nurse, Attachment 2; and the program Organizational Chart, Attachment 3.

Tennessee Newborn Hearing Program was approved to use CDC training funds to sponsor an eight state Southeast Regional EHDI conference in July 26-27, 2010 in Knoxville, Tennessee. Partners include NHS Program Coordinator, Audiology Consultant, TEIS Deaf Education Consultant, Family Voices Parent Consultants, TEIS, the University of Tennessee Center on Deafness, and Faye McCollsiter, NCHAM Regional Representative. Supplemental funds, in the amount of $150,000, were awarded August 24, 2009. The grant funds will be assigned to amend current contracts with the University of Tennessee Center on Deafness and the Tennessee Disability Coalition Family Voices program. Contractors currently provide consultant services by an audiologist and 4 parents to assist the hearing screening program with the development of program policy, training, education, and consultation to medical providers, audiologists, hospitals, early interventionists and families.

Goal 1: Increase from 93% to 95 % the percentage of infants, including home births, that receive a newborn hearing screening. Objective 1. By January 2010, increase from 59% to 70% the number of hospitals that provide hearing screens to at least 95 % of all births. Objective 2. By September 2009, provide training to implement the revised hospital guidelines to 25 hospitals.

Hearing Screening: In 2008, 93.9% of the 90,885 live resident and non-resident births were screened for hearing; 6.1% did not receive a screen. The percentage of hearing screens increased to 97.1% for the first 6 months of 2009, with a decrease to 2.9% of infants not screened. In 2008, 95.9% of all infants with a metabolic screening also received a hearing screening. Of the 85,381 infants screened, 98% were screened prior to one month of age and 4.2% of infants reported had at least one risk indicator for hearing loss. In 2008, 5,504 infants did not receive a hearing screen: 86.6% had no report of screening, 10.3% did not receive a metabolic (blood spot screening), 1.3% refused testing, 3% transferred or were discharged, and 1.5% were unknown/error. In 2008, 572 (0.6%) of the births were home births and only 22% received a hearing screen. See Table B.

Table B

| Hearing Screening | 2008 (Jan.-Dec.) | | 2009 (Jan.-Jun.) | |
|---|---|---|---|---|
| Births (Resident and Non-Resident) | 90,885 | | 42,503 | |
| Hearing screens | 85,381 | 93.9% | 41,290 | 97.1% |
| No Screen | 5,504 | 6.1% | 1,213 | 2.9% |
| Hearing refers | 3,565 | 4.2% | 1,712 | 4.1% |
| Screened before 1 month | 83,632 | 98.0% | 40,147 | 97.2% |
| Risk Indicators (at least one) | | 2.4% | | 2.8% |

The percentage of hospitals that screened more than 95% increased from 59% (2008) to 65% (2009 Jan. - Jun.). 87% of hospitals screened more that 90% of all infants. The number of hospitals using ABR in the NICU population increased. The Tennessee Hospital Newborn Hearing Screening Guidelines were revised in June 2009 and distributed in August 2009 to all birthing hospitals/facilities and the two non-birthing children's hospitals. In addition, the "Newborn Hearing Screening Training Curriculum" DVD, developed by NCHAM, was also provided to each hospital. Ten hospitals have received an onsite visit by program staff at this time.

The revised Hospital Guidelines highlighted the following new practice recommendations: 1. Hearing screening is required prior to hospital discharge from the birth facility or prior to one month of age per Claire's Law. 2. Report final hearing results completed prior to discharge. 3. Obtain a signed, written, and witnessed statement from the parent or caregiver when a hearing screening is refused. 4. Report hearing results on the appropriate form within 2 weeks after the screen. (Daily reports are encouraged.). 5. If the infant "refers" – provide the family written hearing screening results and a written appointment to obtain further hearing testing as an outpatient at the birth facility or with an audiologist with pediatric experience and/or as designated by the primary care provider. 6. Transferred Infants: The hospital that discharges the infant to home is responsible for conducting the hearing screening prior to discharge.

An additional strategy to improve initial hearing screening and follow-up rate is to pilot an outreach audiologist to work with several hospitals in the West Tennessee area that do not have access to an audiologist for hospital consultation or for follow-up testing. A pilot will be conducted in the current year 2 with one part-time outreach audiologist to consult with hospital hearing screening staff by phone in regard to screening procedures, reporting results, and referral to pediatric hearing providers if an infant does not pass the hearing screen. In addition, the outreach audiologist will speak directly to families, before they leave the hospital, on infants that do not pass the hearing screen to provide education regarding the need for follow-up and to provide information on resources as needed. Pending the success of the pilot, an additional two part-time outreach audiologists will provide consultation to additional hospitals.

Monthly reports to hospitals with the names of infants not receiving a hearing screen were initially sent in September 2008 only to hospitals that requested the report. By February 2009, 29 hospitals received the report. In June 2009, the program began to send the report to all hospitals. This effort has increased the number, quality, and timeliness of reporting. Hospitals document information on each infant to report that the infant was screened, missed, transferred, expired, or is still in the Neonatal Intensive Care Unit (NICU) and fax the completed report to the Newborn

Hearing Program. The reports have decreased the number of NICU infants that had screening conducted prior to discharge but not reported.

Goal 2: Decrease from 33% to 25% the percentage of infants that do not receive follow-up testing after not passing the initial hearing screening. Objective 1. By January 2010, increase to 800 the number of hearing follow-ups submitted by medical home providers and to 1800 by audiology providers. Objective 2. By January 2010, increase from 3 to 8, the number of health departments that provide hearing screening and follow-up with non-English interpreter services.

Hearing Follow-up: Sixty-two infants were diagnosed with permanent hearing loss in 2008 and 24 infants by June 2009. Several new activities were initiated in 2009 to improve tracking of follow-up results. In 2008, 69% of the infants that did not pass the hearing screen had follow-up completed, 2.0% had pending results after at least one audiology evaluation, and 1.0% had a pending appointment to see an audiologist. The lost to follow-up rate was 31.1% in 2008 and was reduced to 16.8% in 2009 (Jan.-Jun.). See Table C.

Table C

| Follow-up Results Reported/Type of Hearing Loss | 2008 (Jan.-Dec.) | 2009 (Jan.-Jun.) |
|---|---:|---:|
| Referred for Hearing on Initial Screen | 3565 | 1712 |
| Sensorineural Hearing Loss | 49 | 16 |
| Conductive Hearing Loss | 3 | 0 |
| Mixed Hearing Loss | 3 | 1 |
| Auditory Neuropathy | 3 | 2 |
| Undetermined Hearing Loss | 4 | 5 |
| Total Permanent Hearing Loss | 62 | 24 |
| Fluctuating Hearing Loss | 20 | 16 |
| Within Normal Limits | 2374 | 1215 |
| | | |
| Total Completed Evaluation | 2456 (68.9%) | 1,424 (83.2%) |
| Completed before 3 months | 95% | 96.4% |
| Total Pending, Missed or No FU Received | 31.1% | 16.8% |

The number of follow-up evaluations reported by audiologists increased to 1,340, but not to the projected target of 1,800. The number of follow-up evaluations reported by medical providers increased to 503, but not to the projected target of 800. The name of the infant’s medical provider is reported by hospitals on the blood spot form. Some of the providers listed may be the NICU provider and the not the primary care provider/medical home provider. There are over 2,000 medical providers. When no follow-up is reported to the program by 6 weeks of age a letter of notification for follow-up is sent to Susie McCamy, TEIS (Part C) to contact the family. Letters to TEIS and medical providers were streamlined to reduce the detail of the results requested and has improved reporting.

Fran Myatt, R.N. and Joyce Sizemore, R.N., began in March 2009 to assist in newborn hearing follow-up activities. They are funded by the CDC EHDI grant. They are assigned follow-up activities to reduce the lost to follow-up rate on infants that have pending results after at least one audiology evaluation or have been reported to have an appointment with an audiologist. Follow-up reports are generated from the central office and staff contact families, audiologists, and medical providers to track status and assist in making appointments for follow-up if necessary.

They reduced the pending case load by 46%. The nurses work from the field and enter follow-up results directly into the Neometrics Hearing Summary data system. They are due to work with hearing in December 2009 to begin the next 3 month rotation. It is planned they will have access to the phone interpreting services for Spanish speaking families. If that is not possible, families will be referred to the hearing follow-up central office for contact.

Training activities to increase the retesting and reporting of hearing follow-up provided by Julie Beeler, Audiology Consultant, included the recruitment of a pediatric otolaryngologist/cochlear implant surgeon to fill a vacant seat on the Newborn Hearing Task Force; the distribution of the Tennessee Directory of Pediatric Hearing Providers and fielding of questions at an American Academy of Pediatrics training, entitled "Screening Tools And Referrals Training", for physicians in Knoxville; and submitted an article "Tennessee Newborn Hearing Screening Program Update" for the East Tennessee Medical News, an electronic newsletter for medical providers and submitted the same article to the Memphis and Nashville Medical News. She also submitted "Infant Hearing: Physicians are a Vital Part of 1-3-6" to the Tennessee Chapter of American Academy of Pediatrics Prevention and Intervention Newsletter and for Tennessee Academy of Family Physicians Quarterly Journal. Mrs. Beeler conducted in-service training related to newborn hearing to early intervention professionals in various settings: TEIS Eligibility Team Meeting; Local Interagency Collaborating Council; First Steps Preschool; TEIS Service Coordinator Meeting. In addition, consultation was provided to 5 hospitals regarding the purchase of new hearing screening equipment and other hospitals concerning reporting of follow-up. Julie Beeler attended training related to hearing at a Statewide Workshop sponsored by the Tennessee School for the Blind; the EHDI Investing in Family Support Conference in 2009; and presented a poster session on the role of the audiologist in EHDI at the Tennessee Association of Audiology and Speech Language Pathologists 2009 conference. The audiology consultant collaborated with the Friends of Tennessee Babies to restructure their hearing aid loaner bank and assist in a request to a private non-profit foundation for testing equipment.

To date, 15 county health departments in the East Tennessee Health Region Knoxville provide hearing screening utilizing the Children's Special Services audiologist. The audiologist travels to each of the counties and provides hearing screening an diagnostic follow-up. The CSS program the West Tennessee Health Region discontinued their on-site audiology clinic in 2009. The West Tennessee School for the Deaf is one of only 3 audiology providers in the 19 counties. Supplemental HRSA funds will be used to purchase hand held hearing screening equipment that can be used in county health departments, the home and by midwives. The first three-four pieces of equipment will be purchased as soon as the amended contract for UT Knoxville is complete.

The NHS program has collaborated for a number of years with the University of Tennessee grant for Health Information Technology, directed by geneticist Carmen Lozzio, MD. The pilot program developed a statewide electronic child health profile that was planned to enable medical providers and audiologists to access and report data toward the goals of reducing lost to follow-up on children with special health care needs, including hearing loss. The data system was programmed to track the long term progress and developmental skills of children with hearing loss. The Department of Health did not renew the agreement to continue collaboration with the project in August 2009, pending approval by a newly re-organized review committee.

Reports were developed by the epidemiologists to track the number of infants screened, referred, and enrolled in follow-up by each of the 2,000 medical providers and 76 hearing providers. The audiology report tracks the number of infants, number of visits, and method of testing by each of the providers. The reports enable the program to track the most utilized centers and identify programs not serving this population or possibly not reporting follow-up. Reports will be shared with the hearing centers.

Goal 3: Expand the family support network of parent to parent links and deaf mentor volunteers. Objective 1. By January 2010, increase from 1% to 10% the percentage of children with hearing loss that are referred to the Newborn Hearing Parent Consultants. Objective 2. By September 2009, incorporate parent consent on the TEIS Part C IFSP form to improve release of information to the EHDI program on infants and toddlers with hearing loss.

Early Intervention: Follow-up services by the Department of Education, Early Intervention System (TEIS), Part C program were reorganized in March 2009 to centralize follow-up activities from the nine district offices to one location at the Center on Deafness. TEIS contracts with a deaf educator and a support staff to conduct calls to track infants in need of further testing or at risk for hearing loss. Of the 2,088 infants referred to TEIS for follow-up in 2008, 67% had follow-up completed. From January to June 2009, the percentage increased to 71%. The centralized TEIS follow-up program spends quality time tracking infants by calling parents, medical providers, and audiologists. When an infant is diagnosed with a hearing loss, the NHS program sends a letter of referral to the TEIS district, TEIS central follow-up staff, and to the CSS Title V regional program near the parent’s home.

Obtaining detailed data of enrollment into Part C and non-Part C early intervention services continues to be a challenge after a referral for hearing loss. Some of the nine TEIS districts have implemented the procedure to obtain a request to release hearing information to the EHDI program and to the Family Voices Newborn Hearing Parent Consultants when they make the initial intake home visit to the family. This continues to be a challenge to implement. Tennessee Newborn Hearing staff serve on a CDC EHDI committee to address the development of a standardized “Part C Release Form” to be utilized by all state programs. The new nurse in the NHS office will track all infants diagnosed with hearing loss to assess early intervention activities. See Table F.

Family Support: Family Voices consultants and other parents are collaborating with the National Hands and Voices group to explore the possibility of beginning a chapter in Tennessee. In addition, a new Family Support Group was held 10-24-09 in Memphis. It was sponsored by Vocational Rehabilitation and held at Deaf Connect. The goal of this group is to connect parents of the deaf and hard of hearing. The “Families Learning About Support Hear” parent support group continues to provide meetings with speakers in the Knoxville area. The Newborn Hearing Program is collaborating with Hands and Voices to conduct a “Guide by Your Side” training to develop a network of mentors for families of the deaf and hard of hearing. Training may occur prior to the Southeast Regional EHDI meeting to be held in Knoxville, July 26-27, 2010. Parent Consultants have begun attending local/regional Part C TEIS interagency coordinating councils to increase awareness of the family support network to TEIS district service coordinators and to the local programs and agencies working with children. Central office staff attended the

Statewide Interagency Coordination Council. Three parents, two audiologists and a deaf educator for Part C TEIS attended the 2009 Investing in Family Support Conference. Scholarships were provided to 2 attendees. Jacque Cundall and Rebecca Walls conducted a presentation on EHDI and the need for volunteer mentors to the Nashville Hearing Loss Association.A five page family satisfaction survey was developed by Family Voices and hearing team members to assess ease and quality of access to diagnostic and early intervention services for infants and toddlers with hearing loss. To date over 300 surveys have been distributed through audiology offices, schools and day care centers with deaf and hard of hearing children. The first group of surveys was due September 30, 2009. Results have not been compiled at this time. Additional surveys will be distributed.

Family Voices and hearing team members completed the revision of the parent support materials. A three-ring notebook entitled “Staying on Track with Your Child Who Has Hearing Loss” is being distributed to families through hearing providers, parent consultants, and early intervention programs. A training video clip for providers on how to use the manual is available at http://tnnewbornhearinginfo.shutterfly.com . The notebook is colorful and easy to read. There are letters from parents, resources for state and local services, facts and tools on development, and a place to keep the child’s appointments and records. This will be available on the state web site and the NCHAM be site. In addition, the CDC brochures developed to be used as a checklist of questions to providers (early intervention, medical professionals, speech/language pathologists, audiologists, genetics and ear, nose and throat doctors) and the NCHAM hearing loss brochure will be included.

Goal 4: Reduce the barriers to access hearing follow-up due to lack of cultural and linguistic appropriate materials and competent health care providers. Objective 1. By September 2009, distribute a list of hearing providers that have access to interpreter services for non-English-speaking families.

A survey was conducted in May 2009 to assess interpreters and materials available in Spanish by the pediatric audiology/otolaryngology providers. Of the providers, 18 (28%) provided interpreters through staff or language line services; 21 (33%) had materials in Spanish and other languages. The information was included in the Tennessee Directory of Pediatric Hearing Providers available to hospitals, medical providers and early intervention providers. Julie Beeler, Audiology Consultant, contacted Hispanic radio stations to request airing the Spanish public service announcement (PSA) developed by CDC. She collaborated with Children’s Hospital in Knoxville to disseminate the Spanish-version of Newborn Screening materials to the Hispanic population at the Hola Festival in Knoxville in September. Julie also collaborated with the Disability Pathfinder program to disseminate the Spanish-version of Newborn Hearing Screening materials to the Hispanic population at the Hispanic Community Conference at Knoxville’s Cherokee Health Systems in April 2009.

A statement in Spanish was included in the “No Hearing” letter advising parents to contact Jacque Cundall for further information regarding their infant’s hearing. The response to the letters was immediate. Many families reported passing the hearing screen before discharge, others were given the phone number for a pediatric audiologist in their area. The telephone interpreting service was used for Spanish speaking families to direct them to an audiologist with

Spanish interpreting services. The supplemental HRSA funds have been directed through program contractors to purchase language line services for the audiology consultants, family outreach consultant and parent consultants. In addition, funds have been directed to hire a Spanish bilingual hearing family support consultant who will assist the program in contacting Spanish speaking families, assisting audiology providers to improve access to interpreter services, and working with the Hispanic Community. Amended contracts for these additions have been submitted for approval through the State process and it is projected they will be completed in January 2010.

Goal 5: Improve data collection and evaluation of services utilizing strategies outlined in the TN CDC EHDI grant for tracking, surveillance and integration. Objective 1. By June 2009, develop reports for the expanded Neometrics newborn screening follow-up screen. Objective 2. By December 2009, implement tracking and follow-up procedures of missed and high risk infants by the field nurse consultants provided by the CDC grant.

The Early Hearing Detection and Intervention (EHDI) Tracking, Surveillance and Integration grant from the Centers for Disease Control and Prevention (CDC) is administered through the Office of Policy Planning and Assessment. The program works in collaboration with the EHDI newborn hearing follow-up program (HRSA grant). Yinmei Li and Fenyuan Xiao, epidemiologists, provided by the CDC EHDI grant, submitted their first report February 2009 for National 2007 EHDI Hearing Summary Data. This was the first year infants were matched to individual birth records and not just reported as summaries of totals between birth data and hearing/metabolic data. Monthly reports are generated to match births to the Neometrics Newborn Metabolic/Hearing Screening data system to identify infants that did not received a blood spot or hearing screen. Other reports have been used as quality improvement tools to evaluate the accuracy of data entered into the Neometrics “Hearing Summary” data screen. Examples include identifying infants with a date and method of hearing screen but no results, dates of screening that were prior to the date of birth, and infants that had results reported in one ear only. Steps were initiated to correct the inaccurate data, retrain data entry staff, and alert hospital staff of the need to review forms for accuracy. Reports were developed following the time line as planned. Additional reports have been developed with statistical precision that the program was unable to do in the past.

The program is tracking Home Birth, African American, and Hispanic populations to identify disparities in screening, diagnostic follow-up, and early intervention activities. There was a greater percentage of screening and follow-up from 2008 to 2009 in the African American population than in the general population. This may be contributed to the improved reporting by the hospitals in Memphis with a higher percentage of African American births. See Table G.

Table G

| African American | 2008 (Jan.-Dec.) | | 2009 (Jan.-Jun.) | |
|---|---|---|---|---|
| | All | African Amer* | All | African Amer* |
| Births (Resident and Non-Resident) | 90,885 | 20.4% | 42,503 | 20.6% |
| Hearing screens | 93.9% | 94.8% | 97.1% | 97.2% |
| No Screen | 6.1% | 5.2% | 2.9% | 2.8% |
| Hearing refers | 4.2% | 3.3% | 4.1% | 3.6 |
| Risk Indicators (at least one) | 2.5% | 3.7% | 2.8% | 4.3% |

| | | | | |
|---|---|---|---|---|
| Return for follow-up after initial screen | 72% | 77% | 88%. | 90.8% |
| Hearing Loss | 95 | 16 | 42 | 4 |
| Hearing Loss Incidence per 1000 | 1.05 | 0.86 | 0.99 | 0.99 |
| *Maternal Race | | | | |

The home birth population had a much lower rate of hearing screens (22%) in 2008, but a 100% rate of follow-up after a referred screen. One activity that increased the number of home birth infants with a hearing screen was to send letters to each family advising of the need for hearing screening. Midwives are aware of the mandate to have a hearing screen (Claire's Law), and have increased referrals to pediatric hearing providers. The hand held hearing screening equipment to be purchased will be made available to midwives on a check out basis and will be placed in county heath departments with a large population of home births. See Table H.

Table H

| Home Births | 2008 (Jan.-Dec.) | | 2009 (Jan.-Jun.) | |
|---|---|---|---|---|
| | All | Home Birth | All | Home Birth |
| Births (Resident and Non-Resident) | 90,885 | 0.63% | 42,503 | 0.71% |
| Hearing screens | 93.9% | 22% | 97.1% | 27.9% |
| No Screen | 6.1% | 88% | 2.9% | 72.1% |
| Hearing refers | 4.2% | 4.8% | 4.1% | 4.8% |
| Risk Indicators (at least one) | 2.5% | 12.7% | 2.8% | 3.6% |
| Return for follow-up after initial refer | 72% | 100% | 88% | 75% |
| Hearing Loss | 95 | 0 | 42 | 0 |
| Hearing Loss Incidence per 1000 | 1.05 | 0 | 0.99 | 0 |

Activities to reduce missing initial hearing results are conducted by Jacque Cundall, RN and Rebecca Walls, RN from the central office. In May 2009, the program began sending letters to all families (not just home births) that did not have hearing results reported. A statement in Spanish was included in the "No Hearing" letter advising them to contact Jacque Cundall for further information regarding their infant's hearing. The response to the letters was immediate. Many families reported passing the hearing screen before discharge, others were given the phone number for a pediatric audiologist in their area. The telephone interpreting service was used for Spanish speaking families to direct them to an audiologist with Spanish interpreting services.

The following section will discuss the progress of the additional goals and objectives proposed in the supplemental HRSA funds approved in August 2009. Supplemental Goal 1: By August 31, 2010, decrease from 4.8% to 3.0% the percentage of infants that do not have a documented initial hearing screening by one month of age. Objective 1. By March 31, 2010, begin a 4 county pilot program in a rural audiologic underserved area of the state to provide additional phone support to the families prior to discharge for infants with hearing referred results on the initial hearing screen to be measured by quarterly hospital "no hearing screen" reports and lost to follow-up reports for hospitals in pilot counties. Objective 2. By December 1, 2009, collaborate with the 19 county health departments in West Tennessee Region to provide hearing screenings by CSS staff in the health department or in the home.

The proposed outreach audiologist and purchase of hearing screening equipment will be contracted through the Center on Deafness when the amended contracts are completed. Cost estimates for three-four pieces of hearing screening equipment are to be purchased first the year of the supplemental grant (Year 2 of the total grant award). Additional equipment may be purchased the following year. Equipment will be placed in areas with the most need including providing access to midwives for families with home births.

Supplemental Goal 2: By August 31, 2010, reduce the percentage of infants lost to follow-up after the initial hearing screen from 33% to 28%. Objective 1. By October 1, 2009, collaborate with Children's Special Services (CSS) when infants cannot be located for NHS follow up to provide additional family or medical home provider contact information.

The hearing program, located at the State's Laboratory, does not have access to the county health department Patient Tracking Billing Management Information System (PTBMIS) to track if families receive other health department services. The newborn hearing screening program and the Title V Children and Youth with Special Health Care Needs, known as Children's Special Services (CSS), revised the policy for collaboration and cooperation between the programs so that CSS regional staff now check PTBMIS and the TennCare eligibility system for new family addresses, phone numbers, and medical providers. The program met Objective 1, to implement the process by October 2009. Follow-up reports were sent to CSS of infants born in January 2009; a second report for February and March 2009 birth dates was sent in November. Preliminary data demonstrated less than 50% were found in the PTBMIS system and few had new phone numbers or addresses. We will continue to target all of the 2009 infants reported to the program as "unable to locate/contact" before they are counted as "lost to follow-up". The program will continue to try to obtain access to the PTBMIS system from the Laboratory so we can check infant addresses in a timely manner.

The blood spot form for newborn metabolic/hearing screening will be revised to collect an additional phone number for the family and indicate if the infant is in the Neonatal Intensive Care Unit (NICU). The hearing program has requested a revision to add a section of "Language Spoken in Home" and to change the wording in the hearing section from "discharged" to "transferred" and to add a category for "Remains in Hospital/ NICU" to improve reporting by the hospitals and documentation of why testing was not reported.

Supplemental Goal 3: By August 31, 2010, reduce the percentage of lost to follow-up in the Hispanic population from 30.89% to 20%. Objective1. By March 31, 2010, target counties with the highest Hispanic birth rates to provide additional linguistically appropriate education and support for hearing screening in those communities. Objective 2. By March 31, 2010, begin a promotional campaign to increase awareness of hearing screening in Tennessee to be measured by monitoring number of community campaigns and by quarterly reports on the lost to follow-up rate in the targeted Hispanic counties.

New reports were developed by the epidemiologists to extract screening and follow-up data by race and ethnicity. The percent of Hispanic infants not receiving a hearing screening decreased from 7.4% in 2008 to 3.6% in the first 6 months of 2009. The number of Hispanic infants that returned for hearing follow-up increased from 67% in 2008, to 79% in 2009 (Jan.-Jun.). See Table I.

Table I

| Home Births | 2008 (Jan.-Dec.) | | 2009 (Jan.-Jun.) | |
|---|---|---|---|---|
| | All | Home Birth | All | Home Birth |
| Births (Resident and Non-Resident) | 90,885 | 0.63% | 42,503 | 0.71% |
| Hearing screens | 93.9% | 22% | 97.1% | 27.9% |
| No Screen | 6.1% | 88% | 2.9% | 72.1% |
| Hearing refers | 4.2% | 4.8% | 4.1% | 4.8% |
| Risk Indicators (at least one) | 2.5% | 12.7% | 2.8% | 3.6% |
| Return for follow-up after initial refer | 72% | 100% | 88% | 75% |
| Hearing Loss | 95 | 0 | 42 | 0 |
| Hearing Loss Incidence per 1000 | 1.05 | 0 | 0.99 | 0 |

To increase follow-up by the Hispanic population a statement in Spanish advising parents that their infant was in need of hearing testing was inserted on all parent letters. Three types of letters sent to families include: 1) No hearing screening reported; 2) Need for follow-up testing; and 3) Letters for high risk follow-up. Families are instructed to contact Jacque Cundall for further information regarding their infant's hearing. The response to the letters was immediate. About three calls a day require the telephone interpreting service for Spanish speaking families. Families are directed to make an appointment with an audiologist that has Spanish interpreting services.

Supplemental Goal 4: By August 31, 2010, decrease the number of cases lost to follow up after at least one pending audiology evaluation from 4.3% to 3%. Objective 1. By October 31, 2009, distribute a monthly tracking report to the CDC EHDI follow-up nurses on infants listed with pending/incomplete diagnostic evaluations to be measured by monthly pending audiology reports. Objective 2. By November 2009, collaborate with pediatric audiology centers to provide parent incentives, such as diaper vouchers, taxi vouchers or children's books, to encourage parents to return for hearing follow-up.

The program had to revise Objective 1 from monthly follow-up reports to three month reports, due to the three month rotation of CDC EHDI nursing staff. The percentage of pending results for referred 2008 infants was 10%. The percentage increased to 30% for 2009 (Jan. to Jun.) due to the change in follow-up schedules for the CDC TSI nurse. No program calls for follow-up were completed on this group of infants since July 2009. Because follow-up time may extend to 3 months from birth many of the June infants were not due for return appointments before the nurses end the rotation. Nurses are to begin the next 3 month rotation to track infants in December 2009. In addition to schedule changes, staff time was reduced from 0.5FTE to 0.25FTE. The program had to revise Objective 2 due to the delay of approval of vendor contracts

Supplemental Goal 5: By December 31, 2009, increase the percentage of infants with hearing loss documented to be enrolled in early intervention from 25% to 50%. Objective 1. By March 31, 2010 provide education to TEIS on the current 2008 TEIS Newborn Hearing Guidelines that require TEIS to follow-up and report enrollment of infants with confirmed hearing loss to be measured by a quarterly report on the number of infants enrolled in early intervention.

A training power point presentation was developed to present to TEIS staff and was presented to TEIS administration. TEIS does not plan to utilize the "1-3-6 Early Intervention's Role in Hearing Loss". However, TEIS is in the process of developing their own training modules in collaboration with the School for Deaf. We will continue to collaborate to ensure National and State EHDI goals are incorporated into the training modules. The TEIS Hearing Follow-up consultant continues to be an active participant in all Newborn Hearing Screening Activities.

The following statements are included to address the weaknesses reported by the Objective Review Committee Summary Statement. The overall score was 90. Criterion 1 – Need: The program now has data to better assess the lost to follow-up race and by Hispanic ethnicity as demonstrated on pages 12-13 of this document. The data are also available for home births. Data will assist the program to place resources in targeted areas. We also have the ability to target populations by zip code. Criterion 2 – Response: Currently, not all health departments offer hearing screening or follow-up testing for infants. See page 6 of this document. Infants born in the home are currently referred to pediatric audiologists. Hearing screening equipment purchased by this grant will be available to midwives to use in the home. Equipment will also be placed in county health departments in the targeted areas with high lost to follow-up. See pages 10-11 of this document. Criterion 4 – Impact: It is not known if the additional positions of the outreach audiologist, bilingual parent consultant, and the deaf-educator will be fully sustainable with program funds. The purpose of our pilot project is to demonstrate the benefits of this type of service so hospitals will be likely to continue to collaborate with an audiologist as part of the hospital newborn hearing program. The use of the Deaf Educator is to demonstrate to the Tennessee Early Intervention System (TEIS) Part C program the necessity of rebuilding their infrastructure to replace the deaf/blind educators that were cut in 2007 when the program implemented changes. Currently, TEIS provides a staff person through a contract with the Center on Deafness to assist with newborn hearing follow-up. It is planned that Family Voices would continue services by a bilingual parent. Criterion 6 – Support Requested: The funding to increase access to infants born in the home is provided through the activities to place hearing screening equipment with midwives and in county health departments. There were no weakness addressed in Criterion 3 and 5.

The agencies and programs working with the Newborn Hearing Screening program and are committed to improve outcomes for children with hearing loss. For letters of commitment see Attachment 4. The Newborn Hearing Screening program has enthusiastic staff members that are dedicated to fulfilling the mission of the Early Hearing Detection and Intervention program and the Tennessee of Department of Health to achieve the 1-3-6 goals for newborn hearing screening, diagnostic evaluation, early intervention, and family support.