MATERNAL AND CHILD HEALTH DISCRETIONARY GRANT
PROJECT ABSTRACT
FOR FY 05

PROJECT: Universal Newborn Hearing Screening and Intervention

I. PROJECT IDENTIFIER INFORMATION

1. Project Title: Universal Newborn Hearing Screening and Intervention
2. Project Number: HRSA 05-090 CFDA 93.251
3. E-mail Address: Jacque.Cundall@state.tn.us

II. BUDGET

1. MCHB Grant Award	$150,000
2. Unobligated Balance	$150,000
3. Matching Funds	$N/A
4. Other Project Funds	$N/A
5. Total Project Funds	$150,000

III. TYPE OF SERVICES PROVIDED

- ☐ Direct Health Care Services
- ☐ Enabling Services
- ☒ Population based
- ☐ Infrastructure Building Services

IV. PROJECT DECRIPTION OR EXPERIENCE TO DATE

A. Project Description

1. Problem: Tennessee does not require hearing screening tests or reporting of diagnostic results to the Newborn Hearing Screening (NHS) program. Therefore, NHS has been unable to document the actual number of infants screened or diagnosed for hearing loss.
2. Goals and Objectives: The goal is to increase the percentage of infants documented to receive timely hearing screening, diagnostic assessment by appropriately trained providers, intervention services and family support services to 95% of the birth population, including home births.
   Objective 1: By June 30, 2005, provide training on hearing screening protocols to hospitals that report hearing screening on less than 90% of hospital births. Objective 2: By December 31, 2005, increase from 63% to 75%, the percentage of infants, including home births, that receive appropriate audiological assessment and are reported to the State. Objective 3: By March 31, 2006, medical home and specialty providers will report to the state a minimum 90% of infants in their practice that receive hearing follow-up or are identified with hearing loss. Objective 4: By March 31, 2006, provide a minimum of three regional trainings for early intervention services coordinator, parent advisors and care coordinators on home intervention practices for infants and children with hearing loss. Objective 5: By September 1, 2005, document the number of families of

infants/children identified with hearing loss that are linked to family support resources and have a medical home.

3. Activities undertaken to meet project goals: 1) Provide consultation and develop a corrective plan of action to hospitals that report hearing screening on less than 90% of the hospital births. 2) Distribute the revised Pediatric Audiologic Assessment and Amplification Guidelines to hearing providers. 3) Provide financial resources for 2-3 audiologists to attend an out-of-state pediatric audiology training sponsored by the National Resource Center on Universal Newborn Hearing Screening and Intervention. 3) Coordinate with the Tennessee Chapter of the American Academy of Pediatrics to promote participation in the American Academy of Pediatrics web based continuing medical education units on medical home and newborn hearing screening. 4) Collaborate with Tennessee Infant Parent Services to conduct statewide training on the revised SKI-HI curriculum for home intervention activities for infants 0-12 months with a hearing loss. 5) Contract with Family Voices to provide family to family support, family linking and outreach activities in three grand regions of the state. 6) Provide funds for individuals and families of children with hearing loss to participate in state and national meetings related to NHS. 7) Collaborate with Family Voices, to conduct a needs assessment and satisfaction survey for children with special health care needs to include families of infants and children with hearing loss. 7) Collaborate with Tennessee EHDI grant staff, Tennessee Genetics and Health Information Systems grant staff and Office of Policy, Planning and Assessment to integrate funds to expand the Neometrics data base.

4. Specify the primary Healthy People 2010 objectives (up to three) which this project addresses:
   a. HP Objective 16.23: Increase the proportion of Territories and States that have service systems for Children with Special Health Care Needs to 100%.
   b. HP Objective 28.11: (Developmental) Increase the proportion of newborns who are screened for hearing loss by 1 month of age, have audiologic evaluation by 3 months, and are enrolled appropriate intervention services by 6 months of age.
   c. HP Objective 28.13: (Developmental) Increase access by persons who have hearing impairments to hearing rehabilitation services and adaptive devices, including hearing aids, cochlear implants, or tactile or other assistive or augmentative devices.

5. Coordination: The Newborn Hearing Screening Program (NHS) is located in the Tennessee Department of Health, Women's Health and Genetics Section (MCH Title V). Partners within the Department of Health include The Genetics Program, Newborn Metabolic Screening, Children's Special Services, the Perinatal Advisory Committee, the Early Hearing Detection and Intervention (EHDI) grant staff and regional and local health departments. The Department of Education, Tennessee Early Intervention System (Part C), and Tennessee Infant Parent Services provide outreach for infants in need of further hearing testing. Both programs provide in-home early intervention services to infants with hearing loss

and other developmental disabilities. Family Voices-Tennessee, provides advocacy by and for families of children with special needs. Family Voices will provide family support, links to families, fiscal support to assure families can participate in hearing related training and policy development for newborn hearing loss. They will provide expertise in conducting a need assessment and a family satisfaction survey. The University of Tennessee-Knoxville Center on Deafness, will provide contract services for an audiology consultant and to assist in the implementation of training activities for the program.

6. Evaluation: The Newborn Screening Neometrics data system serves as the primary data collection and reporting mechanism for hearing screening. The system has the ability to create reports (crystal reports) as needed. Evaluation of system effectiveness and quality of client outcomes will be measured using the program objectives and the Healthy People 2010 Performance Measures. A logic model will be developed to assist the program to better identify data needs to provide evidence of best practice to assure optimal client outcomes.

V. KEY WORDS

Hearing Screening, Hearing Loss, Newborn Screening, Title V Programs, Audiology, Interagency Cooperation, Data Systems, Family Support Programs

VI. ANNOTATION: Tennessee will increase the documented percentage of infants that obtain an initial hearing screening and if indicated, complete audiologic assessment and are enrolled in intervention services. Activities will focus on educating hospital hearing screening programs, medical home providers, audiologists and other hearing providers of the benefits of reporting to the State program. Reporting ensures the family the opportunity to communicate with the Tennessee Early Intervention System to promote a team effort to have the infant complete additional testing and enroll in appropriate intervention programs to promote better communication outcomes.

PROGRAM NARRATIVE

PURPOSE OF THE PROJECT

The Tennessee Department of Health, Newborn Hearing Screening (NHS) successfully established a coordinated statewide system of newborn hearing screening, assessment and intervention and served an estimated 97% of the birth population in 2003. This was accomplished without a state mandate to require screening. The Newborn Hearing Screening program utilized the Neometrics patient tracking and follow-up system already established by the Newborn Metabolic Screening Program. The hearing component was added at little cost. Medical home providers and parents of infants that do not pass the initial hospital hearing screening receive letters reminding them to obtain further hearing testing. When an infant does not have follow-up results reported to the NHS program within six weeks of the parent letter, the program sends a Child Find letter of notification to the Tennessee Department of Education, Individuals with Disabilities Act (IDEA) Part C, Tennessee Early Intervention System (TEIS). The notification requests TEIS to contact the family, determine if testing was completed, and to offer assistance to coordinate further testing if indicated. If the TEIS contact attempt is unsuccessful, the Tennessee Infant Parent Services Program (TIPS) is contacted and a home visit is attempted to locate and advise the family of the need for further testing. The follow-up rate increased from 25% to 63% after July 2003 when notification of TEIS/TIPS was initiated. Children identified with a hearing loss may then be enrolled in the TEIS and TIPS programs for service coordination and home habilitation.

The problem with the current program relates to not having a mandate to require hearing screening and reporting screening and/or diagnostic results to the NHS program. In 2003, 86 of 91 birthing hospitals conducted hearing screening; however, only 82 hospitals reported results to the NHS Program. Thirty of the 82 reporting hospitals reported screening results on less than 80% of their birth population (Appendix A, Table 1 and 2). Therefore, NHS has been unable to document the actual number of infants screened or diagnosed for hearing loss. There is a need to improve reporting of these activities. In January 2004, a requirement was added to the Genetic

Rules and Regulations for hospitals to report hearing screening results on the newborn metabolic bloodspot form that is sent to the State Laboratory for testing on all babies.

The current grant application will enable the Newborn Hearing Screening Program to implement strategies to ensure that hearing screening and diagnostic results on all infants who are screened are reported so that NHS can assist families of infants that do not pass the initial hearing screening to collaborate with their medical home and receive audiologic diagnostic evaluation by a capable professional prior to 3 months of age. Better reporting will enable NHS to identify populations at risk for late onset hearing loss. The grant will enable NHS to provide resources and technical assistance to expand family support systems for families of children identified with a hearing loss.

NEEDS ASSESSMENT

The Tennessee Department of Health, Newborn Hearing Screening (NHS) has been unable to document the actual number of infants screened or diagnosed for hearing loss, therefore there is a need to improve reporting of these activities. This indicates a need to assess communication between the NHS program, providers and parents.

In 2003, Tennessee had 84,015 total births but hearing results were reported on only 44,155 infants (53% of the births). The data that follows is based on the 53% reported. Of the 44,155 infants reported, 1,218 (2.8%) did not pass the initial hearing screening and 99.9% received the screening prior to one month of age. Initial follow-up was completed on 796 of the 1,218 infants in need of further testing (Appendix A, Table 3). Follow-up screening or diagnostic assessment was reported on the 796 infants by the following providers: TEIS/TIPS (350), audiologists (200), medical home (110), hospitals (58), otolaryngologists (32), parent (15), CSS (4). Ninety-eight (98%) infants had a medical home. Infants were evaluated by audiologist (252), medical home (127), hospital (214), and otolaryngologists (41). Eighty-six (86) infants received follow-up prior to the national goal of three months of age and 50% of that number received follow-up prior to one month of age. However, 82 infants received follow-up from 4-6 months and 12 infants were not seen until 6-12 months of age. Results of the follow-up: Normal limits (571), pending (88), high risk (22) parent refused F/U (9), lost to follow-up after initial contact (71). Based on national statistics of infant hearing loss of 3:1000, an estimated 248 infants should be identified from the total Tennessee birth population. However, only 8 infants diagnosed with hearing loss and enrolled in early intervention were reported to the program. Tennessee 2003 data demonstrated a critical need to improve reporting from hospital hearing screening, medical home, and from diagnostic providers. Hearing follow-up rates increased from 24% to 96% in the first three months after TEIS notification was implement in July 2003 (Appendix A, Table 4 and 5). Infants reported to NHS benefit from having increased support offered by the Tennessee Early Intervention System to understand the importance of follow-up, locating a capable provider, enrolling in a system of care if indicated and providing coordination of care based on family needs, such as travel to keep appointments. Tennessee birthing hospitals may choose the physiologic hearing screening test method used by their facility. Test methods utilized by the 86 screening hospitals included 55% automated auditory brainstem response (ABR), 38% otoacoustic emission (OAE), and 7% combination ABR/OAE.

In March 2004, the NHS updated the Pediatric Hearing Screening, Audiological Diagnostic, and Early Intervention Provider list and distributed copies to hospitals, medical home providers, early intervention providers and hearing providers. The pediatric provider list includes 66 hearing screening and audiological assessment providers by region, type of testing available, professional staff and insurance accepted. In addition, 44 hearing aid providers, 22 cochlear implant providers, over 200 Tennessee Early Intervention System service coordinators and Tennessee Infant Parent Services parent advisors and 18 other early intervention/habilitation providers are listed by region. Children's Special Services (CSS) has over 60 care coordinators to provide medical follow-up for children who financially qualify for the program. Pediatric hearing guidelines instruct providers to educate families on all communication options. The pediatric provider list will be reassessed in 2005 in regard to service availability, staff capability and accessibility.

The existing newborn screening Neometrics system needs to have data fields expanded to capture newborn hearing follow-up data to better evaluate outcomes. At this time follow-up information is reported in narrative form. To monitor follow-up results and outcome data the

EHDI staff created a temporary computer “Access Program” data base. Patient profile data are being developed by the staff of the Tennessee Plan for Integration of Genetics and Health Information Systems - Tennessee Child Health Profiles (UT Knoxville Genetic Center, Health Resources and Services Administration grant). The child profile will contain newborn metabolic/genetic/hearing screening and follow-up results. It will allow viewing access on individual clients by designated medical providers. It is intended that this will improve provider follow-up of infants who have not completed confirmatory testing for referred conditions. A voice response system for providers to access newborn screening results is currently under development and is to be operational in 2005.

Family Voices of Tennessee is an advocacy program operated by families and for families of children with all disabilities. Family Voices-TN program will conduct a needs assessment and satisfaction survey in collaboration with Vanderbilt School of Nursing, the Family Voices Advisory Board, Children’s Special Services, Newborn Hearing Screening, Tennessee Early Intervention System, and Tennessee Voices for Children (advocacy for children with mental health issues). The evaluation tool will be distributed to families of children with special health care needs to obtain family responses regarding timeliness of service, provider communication, referral to appropriate services, family participation in decision making of the child care, difficulty in locating and scheduling provider services, and more. Items related to hearing loss are included in the survey. Results of the survey will be distributed to all programs that work with children with special health care needs.

DATA REQUIREMENTS

The Newborn Hearing Screening Program (NHS) will provide data as required by the 1) Health Resources and Services Administration (HRSA) grant; 2) HRSA funded National Center for Hearing Assessment and Management; 3) Centers for Disease Control and Prevention (CDC) Early Hearing Detection and Intervention (EHDI) grant; 4) the Directors of Speech and Hearing in Public State Health and Welfare Agencies (DSHPSHWA); and 5) Healthy People 2010 Objectives and Performance Measures.

Current data capabilities for reporting include the number of live births, number of infants screened prior to discharge, the number of infants suspected of a hearing loss with an audiologic diagnosis by 3 months of age, and the number infants diagnosed with a hearing loss enrolled in a program of intervention before 6 months of age. In addition, the number of infants with a medical home and the number of infants linked to a family to family support system will be reported. Data is available by sex, race, ethnicity, age, date of birth, city, county, region of the state, hospital medical record number, hospital of birth, mother's name, mother's social security number, gestational age, test results and other information.

In 2003, Tennessee had 84,015 total births but hearing results were reported on only 44,155 infants (53% of the births). The data that follows is based on the 53% reported. Of the 44,155 infants reported, 1,218 (2.8%) did not pass the initial hearing screening and 86% received further testing prior to 3 months of age. Based on national statistics of infant hearing loss of 3:1000, an estimated 248 infants should be identified from the total birth population. However, only 8 infants reported to NHS were identified with hearing loss and enrolled in early intervention prior to 6 months of age.

Other data to be reported will include individual program goals and objectives and data on a number of the Healthy People 2010 Performance Measures (Appendix G). The Tennessee MCH Block Grant report submitted in July 2004, reported a percentage of 88% out of the goal 98% on Performance Measure # 12 "Percentage of infants who have been screened for hearing before hospital discharge". Methods to collect data for the seven newly required performance measures will be developed and reported on designated forms.

IDENTIFICATION OF TARGET POPULATON

All infants born in Tennessee are considered the target population for receiving hearing screening prior to hospital discharge or prior to one month of age. Infants that do not pass the initial screening are to receive audiological assessment prior to 3 months of age and infants found to have hearing loss are to receive intervention/habilitation prior to 6 months of age.

Medical home providers and medical specialty providers (obstetrics, otolaryngology, genetics) will be targeted to receive hearing related materials developed by NHS and by the American Academy of Pediatrics. NHS will promote the availability of the AAP on-line continuing medical education programs related to medical home and hearing screening and follow-up. Training opportunities will be made available to audiologists to increase evaluation and habilitation skills with the birth to 5 year pediatric population. Audiologists will receive training to implement the Tennessee Pediatric Audiologic Assessment and Amplification Guidelines (Revised October 2004).

Early intervention providers will receive training on the new SKI-HI curriculum for home visit habilitation. Training covers amplification, cochlear implants, early communication, play, sensory integration and natural routines, language and literacy for infants 0-12 months. Information will be provided to audiologists and medical providers on the benefits of SKI-HI activities to supplement center-based habilitation practices.

Families of infants and children identified with hearing loss will be targeted to receive Parent Packets that provide state and national resources and materials on all aspects of dealing with hearing loss. Packets will be reviewed with families and distributed by audiologists, early intervention providers and parent support programs. The Newborn Hearing Screening and Newborn Metabolic Screening programs will develop improved methods to communicate the need for genetic, metabolic and hearing screening follow-up and related information for families of limited English proficiency.

GOALS AND OBJECTIVES

The goal of the Newborn Hearing Screening program during the April 1, 2005 to March 31, 2006 grant period is to increase the percentage of infants documented to receive timely hearing screening, diagnostic assessment by appropriately trained providers, intervention services and family support services to 95% of the birth population, including home births.

The NHS program plans to continue contract services with the University of Tennessee – Knoxville, Center on Deafness in the amount of $80,000 to provide a 0.5 FTE audiology consultant and to organize regional and statewide trainings, develop and print hearing related educational materials (Appendix D). NHS will change the contract scope of service with Family Voices from supporting one 0.5 FTE parent consultant to providing funds to be distributed through the three regional Family to Family Health Resources Center (F2F) staff as well as to individual families of children with hearing loss (Appendix D). The regional F2F staff are better located to assist families with local hearing resources and links to families. The following objectives and activities are designed to address the goal by providing training to all providers regarding the benefits to their clients in utilizing the medical home to coordinate services and to become familiar with the services other agencies and providers to improve referrals that will benefit the infant and family. Training will be provided to increase the number of pediatric audiologists and to increase the hearing related habilitation skills of early intervention staff. Families will be active in provider training activities. In addition, direct family to family support services will be incorporated into the Family to Family Health Information Center program.

Additional goals for the second and third year of the grant when data reporting is improved will focus on measuring child outcomes, adequacy and effectiveness of intervention services.

Objective 1) By June 30, 2005, provide training on hearing screening protocols to hospitals that report hearing screening on less than 90% of the hospital birth population.
Activity a) Evaluate the Neometric report of individual hospitals quarterly to assess the percentage of hearing screens reported to metabolic screens. If the percent of hearing screenings to births is less than 90%, contact the hospital NHS contact person to determine strategy to improve reporting.
Activity b) Provide training and education materials to hospital hearing coordinators and nurses on the revised Newborn Screening blood spot form. The new section on the form will require the reporting of risk factors for progressive hearing loss (Appendix A). Reporting of risk factors will enable the NHS program to track and monitor infants every 6 months through the first three years of life.

Objective 2) By December 31, 2005, increase from 63% to 75% the number of infants, including home births, that receive appropriate audiological evaluation and have findings reported to NHS.
Activity a) Distribute the Pediatric Audiologic Assessment and Amplification Guidelines to hearing providers by mail and e-mail. Hearing providers are to include identified pediatric audiologists, all licensed Tennessee audiologists, medical specialty otolaryngologists, early intervention providers and the schools of audiology.
Activity b) Provide financial resources for 2-3 audiologists to attend an out-of–state pediatric audiology training sponsored by the National Resource Center on Universal Newborn Hearing Screening and Intervention.
Activity c) Coordinate training opportunities for audiologists with the state university-based audiology programs in the three grand regions of the state.

Objective 3) By March 31, 2006, medical home providers and medical specialty providers (obstetrics, otolaryngology, genetics) will report that 80% of the number of infants in their practice are referred for or have obtained appropriate diagnostic evaluation, medical evaluation and early intervention services.
Activity a) Distribute Tennessee infant hearing screening and follow-up data to medical providers listed in the Neometrics data base every 6 months.
Activity b) Coordinate with the Tennessee Chapter of the American Academy of Pediatrics, Universal Newborn Hearing Chapter Champion and the National Center for Hearing Assessment and Management the promotion of the availability of American Academy of Pediatrics web based continuing medical education units on medical home and on infant hearing screening.
Activity c) Conduct presentations for medical and medical residency groups on the benefits of early hearing screening and methods of audiological evaluation, communication options, specific intervention/habilitation and the need to recognize the importance of the family and the need to involve the family in the infant's plan of care.

Objective 4) By March 31, 2006, provide a minimum of three regional trainings for early intervention service coordinators, parent advisors and care coordinators on home intervention practices for infants and children with hearing loss.

Activity a) Tennessee Infant Parent Services (TIPS) Regional Lead Teachers will conduct statewide training on the updated SKI-HI curriculum for home intervention activities for infants 0-12 months identified with a hearing loss.
Activity b) Provide training on the revised TEIS Filemaker-Pro computer program as it applies to documentation of hearing screening follow-up.

Objective 5) By September 1, 2005, document the number of families of infants/children identified with hearing loss that are linked to family support resources and have a medical home.
Activity a) Provide contract funds in the amount of $42,000 with Family Voices-TN to provide outreach to families of infants with hearing loss.
Activity b) Family Voices-TN contract funds will be available to families to participate in statewide training and planning programs and activities; daycare and travel will be provided. Two or three individuals will receive assistance to attend the annual newborn hearing grant meeting.
Activity c) Family Voices-TN contract funds will be utilized to conduct needs assessments and satisfaction surveys.
Activity d) The NHS and Family Vocies-TN will provide training to the statewide Family to Family Health Resource Center and Parents Encouraging Parents personnel on hearing resources, providers, communication choices, deaf community resources and links to other support systems for families of infants and children with hearing loss. Training is to be conducted by parents of infants and children with hearing loss.
Activity e) Consult with language professionals and parents who speak Spanish to translate a message to be placed on newborn hearing follow-up letters to parents. The message would briefly state the reason and need for follow-up and provide a phone number of an interpreter to assist the family.

Objective 6) By January 2006, expand the Newborn Screening Neometrics data elements to collect and report follow-up data through the Crystal Reports.
Activity a) Collaborate with the CDC EHDI grant staff and the Tennessee Plan for Integration of Genetics and Health Information Systems - Tennessee Child Health Profiles to provide funds to increase the Neometrics database.

Activity b) Collaborate with Neometrics and the Newborn Metabolic Screening program to expand the data capability to collect and report child profile outcome data. Provide a minimum $20,000 in funds to implement expansion.

PROJECT METHODOLOGY

The Neometrics Metabolic Screening Date System (MSDS) will be used as the primary data collection and reporting systems to monitor the number and result of hearing screenings, hospital referral rates, monitor dates and types of follow-up for infants referred and identified with risk factors for progressive hearing loss. The Neometrics Case Management System (CMS) generates follow-up letters to parents, medical providers, and TEIS service coordinators. Follow-up results are entered into the case management system. The system has the ability to create reports (Crystal Reports) as needed. Reports can be generated in an unlimited combination of data dependent upon the purpose of assessing client or population based results and services.

Tennessee Early Intervention System (TEIS) field staff reports hearing follow-up into the Department of Education Filemaker-Pro data base that it utilizes for children enrolled in TEIS, Part C. A hard copy is faxed to the NHS program. TEIS will provide NHS with quarterly reports of statewide and district activities. The planned data integration of TEIS data into the Department of Health system has been postponed due to changes in administration of the Office of Policy, Planning and Assessment. Population-based out-comes will be compared to expected National goals to enable the program to develop intermediate strategies and activities to improve future out-come.

Medical and audiology providers report diagnostic results and additional client referrals by fax on NHS forms. Data will be monitored to evaluate timeliness, appropriateness of testing, and appropriate referral to other providers/agencies. Future plans include web-based access by hospitals and medical providers to send follow-up results to the program.

A reporting system to collect the number and type of services provided to parents and families by the Family Voice’s Family to Family Resource Center and Parents Encouraging Parents programs will be developed to complement the current FV required reporting system. Data will be reported to NHS quarterly. Data will be evaluated to identified patterns and trends in family needs.

The newborn hearing screening program will develop and implement a logic model for each step of the screening, referral, diagnosis, intervention and family support process. The logic model will enable the program to better identify what information collected is necessary to evaluate systems outputs, individual outputs, and to provide evidence of best practice that assures high level individual client outcomes, not the level of the success regarding the system.

COLLABORATION AND COORDINATION

The Newborn Hearing Screening Program (NHS) is located in the Tennessee Department of Health, Women's Health and Genetics Section (MCH Title V). Partners within the Department of Health include Newborn Metabolic/Genetic Screening, Children's Special Services, the Perinatal Advisory Committee, and Early Hearing Detection and Intervention (EHDI) CDC grant staff. The EHDI grant is located in the Department of Health, Office of Policy, Planning and Assessment. The CDC grant focuses on data systems development and integration to other infant data bases such as electronic birth certificate. The above programs are located in the same building which enhances frequent and timely communication (Appendix E).

The program plans to continue a contract with the University of Tennessee-Knoxville, Center on Deafness to provide 0.5 FTE audiology consultant services as well as training and materials development. The current contract with Family Voices-TN and the Tennessee Disability Coalition provides 0.5 FTE parent consultant services and reimbursement for families to attend in-state and out-of-state hearing related programs. The Tennessee Early Intervention System (IDEA Part C) provides hearing follow-up through an agreement with the Tennessee Department of Education. Infants identified with hearing loss are enrolled in the TEIS and TIPS program and obtain consultation for developing Individual Family Services Plans. The Tennessee Early Intervention System collaborate with a number of departments and programs through a cooperative agreement initiated November 1, 2000 (Appendix D).

The Newborn Hearing Screening Task Force has over 20 active members. Representatives include nurses, neonatologists, pediatricians, hospital nurses, private practice audiologists, geneticists, speech/language pathologists, university based physicians, audiologists and nurses, professional organizations, individuals with hearing loss, and families of infants and children with hearing loss (Appendix F). The NHS Task Force serves as a subcommittee for the Tennessee Plan for Integration of Genetics and Health Information Systems - Tennessee Child Health Profiles (UT Knoxville Genetic Center HRSA grant). EHDI staff work in collaboration with the data systems for several related programs (vital records, electronic birth certificates, newborn blood spot screening, hearing screening, TennCare and the Tennessee Plan for Integration of Genetics and Health Information Systems) using the Neometrics data system. NHS training for audiologists will be coordinated with schools of audiology and the Tennessee Association of Audiology and Speech Language Pathology (TAASLP). The Tennessee American Academy of Pediatrics Hearing Screening Chapter Champion is an active participant in the NHS program. Other collaborations include TennCare, March of Dimes, HRSA grant programs for training, and Tennessee Deaf Blind Project.

ADMINISTRATION AND ORGANIZATION

The Newborn Hearing Screening program is located in the Tennessee Department of Health, Health Services Bureau, Women's Health and Genetics Section. In 2004, the Maternal and Child Health (MCH Title V) Section was reorganized into two distinct sections. The Women's Health and Genetic Section includes family planning, adolescent pregnancy, women's health, the genetics network, newborn metabolic screening and newborn hearing screening. Child and Adolescent Health programs and Children's Special Services are in the other section. another partner within the Department of Health is the Office of Policy Planning and Assessment (PPA). Health Statistics, Research, Birth Defects Registry, Vital Records, Cancer Surveillance, and Grants and Funded Projects are sections under the Office of PPA. The Early Hearing Detection and Intervention CDC grant staff are located in the Grants and Funded Projects section. Collaboration within the Office of PPA section enables data collection and integration to be coordinated among programs.

The Newborn Hearing Screening program has a full-time Public Health Nurse Consultant as program director and a fulltime Clerk 3. Both positions are funded with MCH Block Grant funds, not the HRSA funds. NHS staff work directly with the Newborn Genetic/Metabolic Screening (NBS) program and assist as needed. HRSA funds are utilized to contract with the University of Tennessee-Knoxville, Center on Deafness for 0.5 FTE audiology consultant. In the current HRSA grant, funds were utilized to contract with Family Voices – TN, at the Tennessee Disability Coalition for 0.5 FTE parent consultant. In this grant, funds will be allocated to provide partial support of the three state regional parent consultants in the Family to Family Resource Centers. Parent consultants are parents of special needs children and serve families of children with all disabilities. NHS partners with the EHDI (CDC) grant staff. The EDHI program funds two full-time positions for Project Coordinator and Data Manager. (Appendix B and C)

ORGANIZATIONAL EXPERIENCE, CAPACITY, AND AVAILABILITY OF RESOURCES

The Newborn Hearing Screening Program (NHS) has been successful in developing and maintaining strong partnerships within the Department of Health (TDH), Department of Education, Department of Human Services, Department of Mental Health and Developmental Disabilities, Mental Retardation and TennCare. Sharing of fiscal resources among departments is limited; however, in-kind sharing of staff has contributed to the extensive statewide network to assist children with special health care needs. The NHS Coordinator has experience as the director of the TDH Children's Special Services Program, Parent's Encouraging Parents Program, Genetics and Newborn Screening Program and Tennessee Technology Access Program. In addition, the NHS Coordinator served on a number of statewide and local agency boards and committees including Family Voices, Developmental Disabilities Council, Tennessee Technical Assistance and Resources for Enhancing Deaf/Blind Support, Part C State Interagency Coordinating Council (ICC), March of Dimes Program Committee, Vanderbilt Child Developmental Center, and the Vanderbilt HRSA grant for audiology training.

The Newborn Metabolic Screening Program and follow-up system has demonstrated the effectiveness of the staffing component and of the Neometrics data system in providing timely and accurate methods for tracking follow-up, contacting providers and in updating the program as needed to meet new requirements. The system has the capacity to expand the hearing data base to include high risk factors for hearing loss, develop an audiology provider data base and develop child profiles that will allow web access by designated providers.

The Newborn Metabolic Screening, Children's Special Services, and the Part C Tennessee Early Intervention System are well established and institutionalized programs that are capable of continuing the hearing screening program after special funds are no longer available. HRSA grant funds have enabled the program to develop, print and distribute 4 newborn hearing screening brochures, 2 posters, and parent information packets. Funds were utilized to conduct needs assessments of birthing hospitals, audiologists, medical home providers, medical specialty providers, early intervention services and families to enable the program to determine activities to implement a statewide newborn hearing screening program. Protocols and guidelines on hospital hearing screening, audiological assessment, and early intervention follow-up were developed, printed and distributed. Several statewide and regional trainings for hospitals, audiologists, medical home providers, and early interventionists were conducted. In addition, trainings have been presented by displays, community fairs, web and satellite conferences to physicians, medical residents, nurses, TennCare Managed Care Directors and TennCare Early Periodic Screening Diagnosis and Treatment (EPSDT) coordinators. Newborn Hearing Screening Task Force members and special committees play an active role in program and policy development. Members include but are not limited to individuals and families of children with hearing loss, medical providers, medical specialty providers, early intervention services programs, Children's Special Services (CSS), audiologists, speech language/pathologists, nurses, educators, genetics providers, lay community representatives and professional organizations. The Newborn Hearing Screening Program, with the support of the Women's Health and the Newborn Metabolic program, is prepared to improve the quality of hearing screening, diagnosis and intervention for infants and children.

Tennessee Department of Health Appendix A

Newborn Hearing Screening
And
Tennessee Early Intervention System
Follow-up Partnership 2003

Table 4

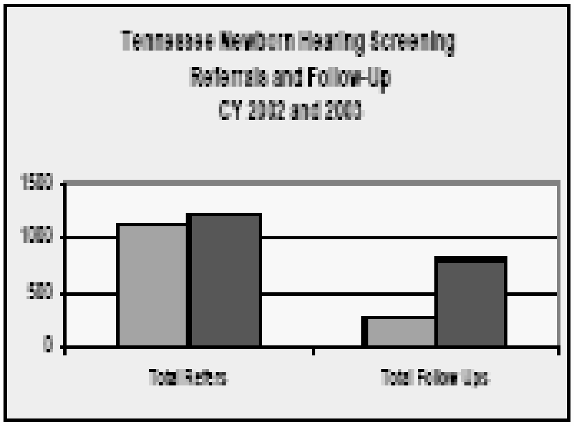
Partnership Success

- **Newborn Hearing Screening Follow-up**
- **TEIS follow-up began July 1, 2003**
- **Follow-up rates:**

	# Refer	# F/U	%F/U
2002 Jan.-Dec.	1,119	273	24.4%
2003* Jan.-June	504	213	42.3%
2003* July-Sept.	430	403	93.7%
2003 Jan.-Dec.	1,218	769	63%

* Preliminary Data

Table 5



Tennessee Birthing Hospitals and Hearing Screening Reporting

Table 1

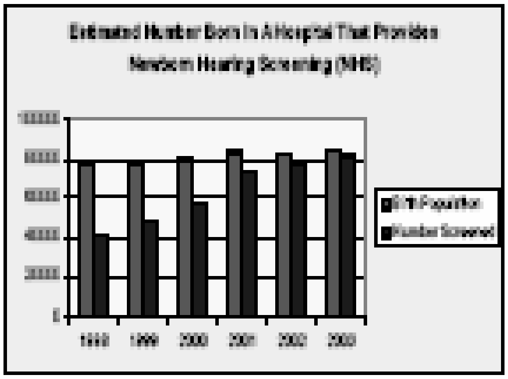


Table 2

Table 3

2003
Hearing Screening Data

Total Births	84,015 (85 Hosp.)
Hearing Reported	44,155 (73 Hosp.)
Refers	1,210 (02.8%)
Follow-up received	769 (63%)
High Risk	22 (2.9%)
Pending	88 (11.4%)
Hearing Loss	0