

Project Title: Universal Newborn Hearing Screening and Intervention

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(1) Summary of the Overall Project Accomplishments (April, 2008 – December, 2008)

Newborn hearing screening is internationally recognized as an essential program for the identification of hearing loss in newborns. Left undetected, hearing impairment in infants can negatively impact speech and language acquisition, academic achievement, and social and emotional development. Texas mandated the Texas Early Hearing Detection and Intervention (TEHDI) Program in 1999 with full implementation in 2001. TEHDI is the State’s newborn hearing screening, tracking and intervention program and is currently being implemented in all obstetrically licensed birth facilities. Although 97 percent to 99 percent of the infants born in TEHDI certified facilities are screened for hearing loss, it is estimated that 40 percent of the 3-4 percent of infants referred for further testing from birth screenings are not known to receive follow-up care.

The purpose of this grant is to reduce this loss to follow up and to ensure all children who have hearing loss as newborn infants or young children are identified early and provided appropriate intervention services needed to prevent delays in communication and cognitive skill development. Many factors, such as lack of contact information, language and cultural barriers in communicating with the parents, and lack of data on child outcomes, influence follow-up rates. In this project, emphasis is being placed on identifying those factors that particularly influence the culturally diverse population of Texas. Funding for this project will facilitate efforts to enhance practices throughout the TEHDI system in order to reduce the number of infants and children lost to follow-up.

During the first year of the HRSA grant, DSHS started with the assessment of the screening and intervention process. For this, DSHS established a contract with a parental organization, Texas Hands and Voices, to assist with grant activities and to bring the parent perspective and experience to this grant initiative. The contractor has provided DSHS with a parent liaison to assess gaps and barriers to the entire TEDHI process and to develop and implement best practices protocol and educational material that incorporate cultural and linguistic competencies from a parent perspective. A parent survey has been developed, in collaboration with the stake holders, to assess parental needs/concerns in obtaining a diagnosis and accessing medical/ educational services emphasizing parent need and support. A provider survey, developed to assess the providers’ knowledge and concerns, is currently being tested by the stakeholders and will be distributed to providers by the end of January. These surveys will increase the parent /physician awareness/ training of medical community.

Additionally, DSHS is in the final phase of developing a contract with University of Texas at Austin to research and develop best practices. The contractor will advise on educational learning strategies and plan for developing culturally competent educational material. The Newborn

Hearing Screening (NBHS) Support Group is screening applications for the grant position of Education Coordinator to work on grant activities with the DSHS NBHS Support Group. Activities and the accomplishments of the first year of the grant will be presented in the EHDI conference at Dallas in March 2009.

Barriers to Progress: This is the first HRSA grant received in support of the NBHS TEHDI program. The NBHS Support Group has experienced delays related to the grant activities. It has required additional time to expand the infrastructure to accommodate the needs of this project such as developing a contract with University and other organizations. A new job description needed to be developed and passed through a multi layered process to include auditing. Also, an initial contract with a University responsible for developing the provider survey was deferred due to inactivity on the part of the contractor and a new contract was developed with a different University. However, these issues have been resolved and work on the project is in the full force.

(2) Project Accomplishments (April, 2008 – December, 2008)

DSHS established a contract with a parent organization, Texas Hands and Voices to secure a Parent Liaison (Family support coordinator) who has expertise in working with families of children with hearing loss (**for statement of work and timeline, see pages 10 - 12**). This organization in collaboration with the Texas Deaf and Hard of Hearing Leadership Council: Birth to Three (Leadership Council) developed a survey related to parent experiences with screening, referral and early intervention. The survey is being conducted as a part of a statewide initiative to improve follow-up rates from newborn hearing screening, diagnosis, and referral to early intervention services. The surveys are conducted either face to face during home visits, via material sent home with preschool students or online via Hands and Voices Texas Chapter's website (<http://www.txhandsandvoices.org>). To incorporate the needs of Spanish speaking population, the survey is made available both in English and Spanish.

Thus far 65 responses to the survey have been completed. The Leadership Council is in the process of compiling data from these surveys and analyzing. The responses on the survey will be used to assess parental needs/concerns in obtaining a diagnosis and accessing medical/educational services emphasizing parent need and support. Providing unbiased support to a parent, with a newly identified baby with a hearing loss, is key in helping get a family the resources they need as quickly as possible. The Parent liaison is also looking for parents of deaf or hard of hearing children that are interested in becoming involved in providing parent support. The specifics of the type of support needed are still being determined.

The Parent liaison meets with the other stakeholders to discuss a possible alignment of HRSA grant activities with other state funding for the family support coordination and the possible pilot sites in Texas. The Parent liaison also attends meetings to collect information towards developing the action plan to support the HRSA grant and the related goal. Some of the meetings attended by the Parent liaison are:

CDC monthly conference call for collaboration on Communication Options for families with a child that has hearing loss. Since many states are involved in this monthly call and many members are involved in their state EHDI team, it provides a chance to learn and share ideas with other EHDI teams.

Leadership Council meeting in Dallas, TX to discuss the problems faced and possible ways to improve outcomes.

Parent Involvement and Family Support Committee (PIFS), a subcommittee of the Leadership Council, to discuss if a formal model of Parent/Family Support (Guide by Your Side) implemented in other states, would be a good fit for the goals of the present HRSA grant.

In addition to the parent survey, a provider survey is being developed by the Leadership Council. This survey will assess provider knowledge and gaps/barriers across the TEDHI continuum, in addition to looking at early childhood hearing loss and state and local resources. The survey draft is available at http://www.surveymonkey.com/s.aspx?sm=jzi3v5ilpgeDbEKROJ9_2bug_3d_3d

The survey is currently being tested by the stakeholders. It will be ready for distribution to providers by the end of January. The result of the survey will be used in making recommendations to TEHDI policies and protocols and in the development of educational materials and the training curriculum. The following lists some sample survey questions:

- Does this hospital use a systematic procedure to determine whether newborns have a hearing loss?
- At approximately what month and year did this hospital begin doing universal newborn hearing screening?
- Does your professional practice/facility provide interpreting services?
- Do you and your staff at your professional practice/facility utilize interpreters with patients?
- For the babies who DO NOT PASS the FIRST-STAGE SCREEN before they are discharged from the hospital, do you try to screen them again after discharge in the SECOND-STAGE-SCREEN before they are referred for diagnostic evaluation?
- WHO responds to the questions and concerns of the families as they go through the hearing screening procedures with their babies?
- For babies who DO NOT PASS the hospital newborn hearing screening test, what are families told about their OPTIONS for obtaining an outpatient hearing screening test?
- Contract questions.

The information gathered from provider/parent survey outcome data will be used in the development of culturally and linguistically appropriate educational/training material for a pilot tool kit as well as in the design and evaluation of focus groups that are planned.

DSHS is in the process of finalizing a contract with University of Texas at Austin. The contractor will assist with the research and evaluation components of the grant (**for statement of work and timeline, see pages 13 - 15**). The Contractor will assess the current TEHDI system to identify gaps and barriers in the newborn screening and intervention service delivery system at the 1-3-6 month stages that may contribute to loss to follow-up. Assessment of the TEHDI program protocol and materials will also include conducting at least two focus groups for the purpose of determining cultural competence of the program, specifically pertaining to the Spanish-speaking population. The contractor will determine best practices to ensure a seamless continuum of care.

The Newborn Screening Support Group Manager is currently screening applications for the position of the grant Education Coordinator. A large number of applications have been received and interviews will be conducted within the month of January. The Education Coordinator will

be responsible for overseeing the assessment of current TEHDI practices at each stage of the early hearing and intervention process, and the research of best practices in the delivery of culturally and linguistically appropriate TEHDI intervention protocols and training materials. The Education Coordinator will work closely with the Parent Liaison for the development of policy and protocols, resource materials (printed and website), mentoring and advocacy opportunities, and interaction with the Deaf and Hard of Hearing community.

The results of activities performed since the award of HRSA grant will be presented at the upcoming EHDI conference at Dallas during March, 2009. The conference is a platform by which key members of the TEHDI process network with others at both the state and national level (**for abstracts, see page 16**).

Year One Goals and Objectives

Goal 1: Assess the current TEDHI system to identify gaps and barriers in the newborn screening and intervention service delivery system at the 1-3-6 month stages that may contribute to loss to follow-up, and determine current best practices to ensure a seamless continuum of care.

Objectives: By the end of year one, the TEHDI Project will:

1. Produce a report of recommendations, solutions, and successful and innovative strategies that will reduce loss to follow-up rates in Texas.

DSHS collaborates with a group of stakeholders that form the Texas Deaf and Hard of Hearing Leadership Council. Parents, educators, medical service providers and administrators, Deaf and Hard of Hearing community members, community partners and multiple state agencies meet to address obstacles to providing each Texas child the best possible outcome as related to hearing loss. There are regular meetings held by the Leadership Council. Also, The Leadership Council has formed several sub-committee work groups to make recommendations to increase awareness among families and professionals about the importance of newborn hearing screening and early intervention. The Leadership Council is conducting a survey to assess provider knowledge and gaps/barriers across the TEDHI continuum, emphasizing parent need and support, looking at early childhood hearing loss, state and local resources, and parental needs/concerns in obtaining a diagnosis and accessing medical/educational services. The Project is coordinating with the Leadership Council on this activity, incorporating recommendations as a result of the survey for TEHDI policies and protocols.

2. Update TEHDI newborn screening and intervention protocols.

DSHS has contracted with University of Texas at Austin to review the existing protocols as posted on the program website, program educational materials, TEHDI protocol, Texas Health Steps Newborn Hearing Online Provider module, and materials of partner agencies. These materials will be evaluated against national standards and by February 28, 2009, the contractor will make recommendations for updating the protocols.

3. Incorporate cultural and linguistically appropriate procedures into the newly revised policies and procedures.

The contract with the University of Texas at Austin will conduct two focus groups to assess the effectiveness of educational materials by Spanish-speaking end-users. Also, the parent liaison contractor will identify the most effective/preferred models, for conveying protocol/educational

information to TEHDI professionals, through research and survey. These activities will be completed by March, 2009.

Goal 2: Enhance current educational and training materials to reflect the language needs and cultural diversity of the Texas population.

Objectives: By the end of year one, the TEHDI Project will:

1. Create a tool kit to be used by Newborn Hearing screeners, public health educators, parents, primary care providers and specialists, social workers, and early intervention specialists.

Over the years, in collaboration with Leadership Council and Early Childhood Intervention, a number of educational material have been developed that can be included in the tool kit. Currently, Leadership Council is focused on establishing a family support model, increasing physician awareness and support, and simplifying follow-up reporting for audiologists. The group seeks to develop statewide standard procedures newborn hearing screener training, hospital follow-up activities, and provider communications to parents. Meeting the needs of Spanish speakers is an underlying theme in accomplishing these goals. A prototype tool kit compiled by several sub-committees of the council will soon be completed. Also, our project contract from the University of Texas at Austin will review already available educational material and make recommendations to standardize the tool kit.

2. Design a strategy for the dissemination of educational information outlined in the curriculum and a method for utilizing the tool kit.

The parent liaison contractor will review TEHDI protocols/educational materials as they relate to cultural and linguistic competency in general, and to Spanish speaking populations specifically.

3. Produce or identify an existing parent guide or fact sheet that targets the Spanish speaking population based on results of surveys, focus groups, and identified best practices.
4. Combine and refine current TEHDI process curriculum addressing each stage in the early hearing and intervention continuum, and develop a component targeting the Texas Spanish speaking population that will include emphasis on cultural and linguistic appropriateness.

As information at all stages of the TEDHI process will be communicated to the family in a culturally sensitive and understandable format, the Project will contract with a Cultural Competency expert to review TEDHI protocols from screening through intervention. The Consultant will provide expertise to the Project regarding training activities and educational materials/curriculum to improve TEHDI follow-up outcomes for the targeted Spanish speaking population. The Communication Unit of the Center for Consumer and External Affairs of DSHS provides technical assistance to the programs in the area of communications plan development and public-awareness campaign coordination. Their services will be utilized in selecting the Cultural Competency expert.

Findings from the needs assessment will be incorporated into the Texas model, in order to decrease the number of infants and children lost to follow-up at all the stages of early hearing detection and intervention process. Following this, the project will pilot test the Texas model to include assessment of program sustainability. Findings from the pilot test will be used to produce a finished model for replication across the State in the third year of the grant. The population to be served includes all families of infants and children with hearing loss, with emphasis on the families who face potential barriers due to cultural diversity.

Year Two Goals and Objectives

Goal 1: Training and education on the TEHDI process will be piloted.

Objectives: By the end of year two, the TEHDI Project will:

1. Complete tool kit and training curriculum.
2. Prepare 15 TEHDI leaders in the use of the tool kit.
3. Pilot test the tool kit in the two areas selected in year one; and conduct 20 workshops in each area.

Goal 2: Assist providers in the delivery of services which are culturally and linguistically appropriate for the Spanish speaking population they serve.

Objective: By the end of year two, the TEHDI Project will:

1. Improve provider awareness of cultural diversity as indicated in the evaluation tool.

Methodology for Year Two

The Project will target two pilot sites for comparison, which will be selected based on either rural and urban populations or an urban area with a large population. The sites selected will have a large Spanish speaking population to test the efficacy of the newly revised TEDHI protocols. The Project will work in partnership with the birth facilities, medical home, audiologists, early intervention specialists, and other stakeholders to employ the protocols. The project will enter into a contract with a marketing consultant to direct the design, copy and printing of educational materials, parent guides, fliers, evaluation forms and certificates, researched and developed in year one of the project. Through a series of workshops, a team consisting of the Education Coordinator, Parent Liaison, an audiologist specialist, an early intervention specialist, and other stakeholders will apply the educational awareness strategies developed in year one to providers in the service delivery of TEHDI at the pilot sites. Strategies will include:

- Collecting baseline data for Project outcomes in development of tool kit;
- Implementing best practices in cultural and linguistically appropriate service delivery;
- Developing interventions that build on strengths, informed choices and cultural beliefs of population served;
- Utilizing updated brochures and website;
- Training on awareness and importance of “read only” physician look-up; and
- Emphasizing the importance of ensuring follow-up for newborns.

Collaboration and partnerships developed in year one will continue, and additional collaborations will be developed, as the key to the success of the Project is the fostering and collaboration with TEHDI stakeholders. Per recommendations from the Joint Committee on Infant Hearing, TEDHI will seek out partners in genetics, ophthalmology, developmental pediatrics, service coordination, supportive family education and counseling.

(4) Technical Assistance Needs:

The project currently is in the assessment phase. There are a number of factors that may contribute to whether the parents of an infant seek follow-up care for their newborns with

negative hearing screening results. One such factor is lack of awareness about the seriousness of the problem and lifelong effects of infant and childhood hearing loss. Informed parents are more likely to seek follow-up care. Once the assessments are made and gaps/barriers identified, we might need assistance from National Center for Hearing Assessment and Management (NCHAM), for implementing the recommendations.

(5) Description of linkages:

The TEHDI Program operates within the Division for Family and Community Health Services. Other closely related programs within this division include: Children with Special Health Care Needs; Early and Periodic Screening, Diagnosis and Treatment Program, known in Texas as Texas Health Steps; WIC Nutrition Services; Case Management; Title V; and Newborn Screening. These programs share common goals and principles that often result in collaborative projects. For example, TEHDI staff is currently working with the Medical Home Workgroup, comprised of individuals from each of these programs, as well as representatives of the state agencies, health care providers, family advocacy groups, family members, training and technical assistance providers, and other stakeholders. Workgroups such as this come together under a common goal, which ultimately benefits the target populations, e.g., families, providers, and health care facilities. Shared goals and principles among division programs include:

- To provide family-centered, community-based strategies for improving the quality of life for children and their families;
- To promote cultural competency in agency leadership and staff;
- To research, assess, and evaluate program strategies and materials to effectively reach diverse populations;
- To provide health education and community outreach in a culturally and linguistically appropriate manner;
- To reduce health disparities among Texans; and
- To serve as a major information and referral resource in order to link families with the services they need.

The continued support of and collaboration with division programs adds to the project team workforce. Additionally, DSHS offers support to the TEHDI Education Project through its language services program, Contract Development and Support Branch, Quality Monitoring Branch, and Division for Regional and Local Health Services.

DSHS collaborates with numerous public and private agencies to ensure access to quality health and human services. TEHDI collaborating agencies include:

- Early Childhood Intervention, a division of the Department of Assistive and Rehabilitative Services (DARS);
- Office for Deaf and Hard of Hearing Services, part of the DARS Division for Rehabilitative Services;
- Texas Education Agency;
- Deaf and Hard of Hearing Leadership Council;

- Texas Parent To Parent;
- Texas Hands & Voices; and
- Early Hearing Detection and Intervention (EHDI) State Champion

DSHS has been awarded \$175,000 for each of the three years for a grant titled, “Early Hearing Detection and Intervention, Tracking, Surveillance and Integration” from the CDC. With this grant, Texas has taken the initial steps towards developing an integration and data sharing concept beginning with the Texas EHDI program. In this way the state can begin the process of using one program as a cross-check to monitor service quality in other programs to assist in ensuring all infants receive screening and follow-up, to minimize duplicative data entry by hospital staff and DSHS staff, reduce redundant communication and to break down information “silos” that contribute to disjointed care for the child and the family. The focus of this grant is on:

1. Analysis of the entire TEHDI process, particularly as it relates to improving our data management system and protocols for reporting data;
2. Enhancing the capacity of TEHDI to accurately report the status of every birth in Texas, including those exempted from the Texas hearing screening program;
3. Taking action steps toward developing plans for data sharing/integration opportunities with other newborn data bases; and,
4. Implementation of enhancements to our current data management system as needed.