

Project Abstract

Section I – Project Identifier Information

Project Title: Universal Newborn Hearing Screening and Intervention

Project Number: HRSA 05-090, CFDA 93.251

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Section II - Budget MCHB Grant Award requested for grant period 4/1/05 – 3/31/08: \$450,000

Section III - Types of Service Provided

Direct Health Care, Population-Based, Infrastructure Building, and Enabling Services

Section IV – Program Description

1. If babies with hearing loss are not identified early, they will not develop language normally, will lag behind their peers in cognitive and social development, and will struggle in school and other areas of their lives. Birthing hospitals in Utah screen 98.5% of births, but too many babies are still not receiving adequate follow-up. Babies diagnosed with hearing loss are often not referred for early intervention and do not have access to a medical home and family support.
2. Goals of the project include:
 - Increasing the number of infants that receive evaluation before 3 months by:
 - Improving collaboration between screeners and hospitals.
 - Improve collaboration between E.I. programs and audiologists.
 - Linking infants to early intervention by 6 months by:
 - Providing workshops to update diagnostic technology and skills.
 - Develop and present AAP EHDI Chapter Champion presentation to professionals
 - Decreasing the number of infants lost to follow-up by:
 - Alerts to parents through Birth Certificate application process.
 - Increased documentation of referrals to audiology.
 - Improving linkage of infants with hearing loss to a medical home by:
 - Developing hearing screening module for Medical Home website.
 - Improve identification of infants with progressive and late onset hearing loss.
 - Evaluation of late-identified children through Parent Infant Program admissions.
3. Health People 2010 Goal: Measure number 12 is to monitor and report the “Percent of newborns who have been screened for hearing before hospital discharge”.
- 4-5. Collaborative partnerships, incorporation of best practices and lessons learned from other EHDI programs, and making use of statewide expertise and resources will guide the achievement of project goals and objectives. The project brings together the Utah Newborn Hearing Screening Advisory Committee (UNHS), NCHAM, the American Academy of Pediatrics (AAP) EHDI Chapter Champion, and various community partners to implement, evaluate, and monitor the effectiveness of strategies in creating sustainable systems change.
6. Monthly Hi*Track reports are used to monitor hearing screening and follow-up activities statewide. Quarterly Hi*Track and quality indicator reports will be used to evaluate state and local programs and to identify and respond quickly to specific needs in individual hospitals. CHARM reports, which include EHDI data integration components, will track progress and problems with data capture and data quality. The National Center for Hearing Assessment and Management (NCHAM) will be contracted to conduct an external evaluation of the project each year. The first year’s evaluation will investigate systematic ways of tracking children who have risk indicators for progressive or delayed late-onset loss every six months until three years of age. Results and recommendations will be reported to the UNHSI Advisory Committee, and findings will be used to plan and implement future activities to assure early identification of infants and children with progressive and late onset hearing loss.

Section V – Key Words Newborn Hearing Screening, Early Hearing Detection and Intervention, Genetic Screening, Medical Home.

Section VI - The purpose of the project is to refine and improve Utah’s UNHS Program. Challenges include accessibility to experienced audiological providers, understanding from the medical community, and reducing the numbers of children lost to follow-up. The activities discussed in this proposal rely on extensive collaboration with families, agencies, and providers.

PROJECT NARRATIVE

CHAPTER I. STATEWIDE POPULATION-BASED NEWBORN HEARING SCREENING AND INTERVENTION IMPLEMENTATION

1.1 PURPOSE OF PROJECT

When babies with hearing loss are identified early and provided with appropriate audiological, medical, and early intervention services, they develop language, cognitive, and social skills at a faster rate, and subsequently do better in school. Recognizing the importance of early identification of hearing loss, Utah has been a leader since the early 1970's in developing innovative strategies for early identification of congenital hearing loss.

From 1978 until 1993, the Utah Department of Health operated a birth certificate-based high-risk hearing screening program in which the risk factors for hearing loss recommended by the Joint Committee on Infant Hearing (JCIH 1972, 1982, 1990) were incorporated as a part of the legally required birth certificate. Parents of babies with identified risk factors were contacted by a computer-generated letter and invited to schedule a free hearing screening for their baby.

Although often cited as a model program, it was not without its problems. First, it was difficult to get parents to bring their babies back for diagnostic evaluations. Second, research in the 1980s showed that only about half of all children with congenital hearing loss had any of the JCIH risk factors. Consequently, in the early 1990s, the Utah Department of Health (UDOH) staff began exploring other options for early identifications of hearing loss.

As technological developments related to the measurement of otoacoustic emissions (OAE) or automated auditory brainstem response (AABR) made hospital-based universal newborn hearing screening feasible, Utah was one of the leaders in evaluating and implementing this new technology. The first universal newborn hearing screening (UNHS) program in Utah using OAE

was implemented in June, 1993, following the National Institutes of Health Consensus Development Conference, recommending that all babies be screened for hearing loss before leaving the hospital. By the end of 1996, approximately 70% of all Utah babies were born in hospitals with UNHS programs. In 1998, the Utah State legislature required all birthing facilities to have UNHS programs operational by July 1, 1999. The Hi*Track Tracking and Data management system developed at the National Center for Hearing Assessment and Management (NCHAM) has been used to register newborn hearing screening results and tracking efforts statewide since the mandate became effective. Hi*Track reports are also used to evaluate the effectiveness of individual hospital programs as well as the statewide program.

It is important to recognize, however, that hospital-based screening is only the first step in a process to identify babies with hearing loss and provide them and their families with timely and appropriate services. The goal of the Utah Newborn Hearing Screening Program (UNHS) is to make sure that all children with hearing loss acquire the language, communication, and cognitive skill necessary to reach their fullest potential. Unfortunately, many hospitals in Utah have struggled making these connections. For the benefits of universal newborn hearing screening to be available to babies and their families, screening must be appropriately coordinated and linked with diagnostic and early intervention services in a way that is family-centered and culturally competent. Throughout this proposal, the term "*Early Hearing Detection and Intervention Program*" (EHDI) will be used to refer to all components from hospital-based hearing screening, follow-up and tracking, diagnosis, and provision of medical, audiological, early intervention and educational services. It also includes the provision of culturally competent family support services and linking all children to a medical home. The purpose of this project is to refine the existing EHDI System in Utah in a way that ensures:

1. All newborns will be screened for hearing loss before 1 month of age, preferably before hospital discharge.
2. All infants who screen positive will have a diagnostic audiological evaluation before 3 months of age.
3. All infants identified with hearing loss will receive appropriate early intervention services before 6 months of age (medical, audiological, and early intervention).
4. All infants and children with late onset, progressive or acquired hearing loss will be identified at the earliest possible time.
5. All infants (and children) with hearing loss will have a medical home as defined by the American Academy of Pediatrics.
6. Utah will have a complete EHDI Tracking and Surveillance System that will minimize the number of children not screened or lost to follow-up.
7. Utah will have a comprehensive system that monitors and evaluates the progress towards the EHDI Goals and Objectives.

The UDOH has developed a number of health-care information systems including systems for Newborn Screening (heelstick), Immunization, EHDI, Vital Statistics, Birth Defects, Early Intervention, and WIC. Each of these systems belongs to a corresponding health-care program, which is responsible for managing the individual program' data. In late 1999, the UDOH began the Child Health Advanced Records Management (CHARM) initiative to address the need for integrated child health information. The development of the CHARM data integration system is to create a virtual health profile for every child and to allow real-time data sharing across health care programs and partners. (See Data sharing agreement sample, Appendix D, Page 66) When it becomes fully operational, CHARM will provide immediate access to information that is

stored in the program specific databases to track and monitor screening results, immunization status, referrals, follow-ups, assessment, treatment and outcomes for children and their families. The linkage of the Hi*Track newborn hearing screening database to the CHARM network will reduce or avoid redundant data entry, improve data quality, decrease fragmented healthcare services, and increase the tracking ability of infants previously lost to follow-up.

National data indicate that nearly half of all newborns that do not pass hearing screening tests do not return for follow-up services (i.e. a hearing re-screening, audiometric evaluation, and medical diagnosis). The improvements to our Hi*Track and CHARM data surveillance and tracking systems, along with additional project activities, will help determine: why newborns do not return for additional testing; identify and target potential factors or barriers responsible for children that are lost to follow-up in EHDI programs; and develop successful strategies to reduce the number of children lost to follow-up.

1.2 NEEDS ASSESSMENT

The infrastructure for an effective EHDI system in Utah has been developed. Hospitals report that they are screening 98% of births, but comparisons to information on live births from the Department of Vital Statistics suggests under-reporting or duplicate reporting between hospital programs (such as not entering a baby missed at discharge, or reporting transfers in each hospital's Hi*Track database). Referral rates at time of discharge are still too high (approximately 7%, 2003) and it appears that a substantial number of babies who need follow-up diagnosis and enrollment in early intervention are not receiving these services in a timely way. A review of children referred to the Utah School for the Deaf (USDB) Parent Infant Program (PIP) from December, 2002 through June, 2004, indicates that the average age of referral is 9.25

months. Additionally, information is currently unavailable regarding how many infants are linked to a family-to-family support system.

The Utah Department of Health, Hearing, Speech, and Vision Services Program (HSVS), has contracted with NCHAM to assist Utah hospitals in implementing and refining UNHSI programs. NCHAM staff, in cooperation with Utah EHDI staff, have conducted workshops, held annual meetings for audiologists and (screening) program coordinators, and provided a toll-free telephone support line for people to ask questions. Collaboration has also continued on annual program evaluation measures suggesting where future effort is needed. From physician surveys completed in 2001 and early 2004, we have learned that only about 50% (of the physicians surveyed) think that hospitals are doing an effective job of educating them about hearing screening, and nearly half (48%) don't realize that babies under 6 months can be fit with hearing aids. Responses from a parent survey (2004) indicate that only about one-third (30%) remember being told why their child's hearing was being screened. Only 1 in 3 report being told where they could go for follow-up, and a significant number of families indicate they were confused by the information from the re-screening. Programmatically, only two-thirds of the hospital programs keep track of whether babies with hearing loss are enrolled in Early Intervention programs.

Healthy People 2010 identified early identification of hearing loss as one of the most significant preventable threats to people's health. Goal 28-11 from this national plan is to "Increase the proportion of newborns who are screened for hearing loss by age 1 month, have audiologic evaluation by age 3 months, and are enrolled in appropriate intervention services by age 6 months". Measure number 12 from the MCHB National Performance Measures is to monitor and report the "Percent of newborns who have been screened for hearing before hospital

discharge”. In 1998, the Utah State Legislature mandated newborn hearing screening of all live births in the state and a requirement to report the outcome of that screening to the Utah Department of Health. In 1999, the American Academy of Pediatrics endorsed the goal of universal detection of hearing loss in infants before 3 months of age.

Much progress has been made in the past several years and a solid foundation is in place currently for the development of an exemplary EHDI program in Utah. There is however, much that remains to be accomplished with respect to helping hospitals use the data management system more effectively, providing the appropriate training on screening techniques, completing data entry, assuring prompt referral and reporting from non-hospital screening and diagnostic sites.

1.3 DATA REQUIREMENTS

Utah’s Hi*Track EHDI Data Management system, along with data sharing enabled through CHARM, has the capability to collect all data elements listed in the guidance documents for this grant application, Goals for EHDI Programs, CDC 2004 draft, and Healthy People 2010 newborn hearing goals. Utah will also comply annually with the OMB approved MCHB National Performance Measures and Administrative Data Reporting as required for MCHB funded agencies and programs. The principal investigator will coordinate resources within Utah’s Children with Special Health Care Needs (CSHCN) Administration to complete these requirements.

Currently, only minimum data are required by Utah mandate and Administrative Rule, but additional reporting items are being reviewed nationally. Therefore, data element collection goals will be updated during each year of this grant project, and will reflect elements used for the CHARM data integration project, and national requirements. Hi*Track data provides excellent

information about the areas in which UNHS programs are doing well and where improvement is needed. On-going analysis of data collected, analysis of proposed data activities, and data integration linkages will help Utah meet the national goals and objectives.

1.4 IDENTIFICATION OF TARGET POPULATION

The target population for this project is all babies born in Utah (occurent births) and their families. The latest report from the Utah Department of Health Center for Health Data (2003) showed that Utah had 49,975 resident births, of which 85% were Caucasian, 10% were Hispanic, 2.9% were Asian or Pacific Islander, 1.5% were American Indiana, and .6% were African-American. The land area of Utah is 82,168 square miles with the number of persons per square mile being 25.9 as compared to the average persons per square mile in the United States of 77. One in four Utahns live in a rural area (more than six but less than 100 persons per square mile) or frontier area (six or less persons per square mile). In addition, 20 of Utah's 29 counties are designated as Health Professional Shortage Areas and eleven counties are designated as Medically Underserved Areas. In these areas, access to health care and appropriate medical and audiological follow-up is difficult or impossible to obtain. Hearing screening is available at all birthing facilities statewide, but parents of babies who may be referred for additional screening or diagnostic follow-up, as well as families who are uninsured or underinsured, often face the challenge of locating scarce resources with limited availability of financial support. Utah also reports a significant number of home births that do not have immediate access to hearing screening, and some infants born in Utah's "border towns" may receive newborn hearing screening in Utah, and necessary follow-up in neighboring states (or the reverse). Although there is almost universal support for the concept of early identification of hearing loss, some of these issues highlight significant weaknesses in the current system. These weaknesses will be

addressed through a collaborative effort that involves a wide-range of agencies and groups, including, but not limited to, the Utah Baby Watch Early Intervention Program (BW/EI), the Parent/Infant Program (PIP) with the Utah State School for the Deaf, the Department of Health’s CSHCN Clinics, the Intermountain Pediatric Society, Primary Children’s Medical Center, the University of Utah Medical Center Department of Pediatrics, the Utah Chapter of Family Voices and NCHAM. (See Letters of Support, Appendix F, beginning page 72).

1.5 GOALS AND OBJECTIVES

The goal of this project is to refine and sustain the statewide population-based newborn hearing screening, identification, and intervention system(s) to assure appropriate and timely delivery of intervention services, and to assure quality developmental outcomes for infants identified with hearing loss. The over-arching goals and objectives to be completed by the end of this three-year grant period are listed in Table 1.

Table 1. Goals / Objectives
1. Ninety-eight point five percent (98.5%) of newborns will be screened for hearing loss before they leave the hospital. Increase screening and reporting of home births by 30%. <i>(MCH National Performance Measure 12)</i>
2. Infants who do not pass the initial screening will receive an appropriate evaluation before 3 months of age. <i>(MCH National Performance Measure 1)</i>
3. Infants identified with hearing loss will be linked to appropriate intervention by six months of age and receive appropriate health care and counseling. <i>(MCH National Performance Measure 1)</i>
4. Identification of high-risk medical factors will be established to identify and track infants and children who may be at-risk for late onset or progressive hearing loss.
5. All infants who fail the hearing screening will be connected to a Medical Home. <i>(MCH National Performance Measure 3)</i>

6. The percentage of infants who fail the initial screen and are lost to follow-up before they complete the diagnostic and evaluation process will be reduced by 30%.

7. The Utah EHDI database will be linked through the CHARM Data Integration System to other relevant public health databases including Vital Statistics, the Immunization Registry, the Birth Defects Network, Baby Watch/ Early Intervention, Newborn Screening (heelstick), and WIC to improve coordination of services, reduce the number of children lost to follow-up, and provide data for public health purposes. *(MCH National Performance Measure 1)*

1.6 PROJECT METHODOLOGY

A methodological approach that uses collaborative partnerships, incorporates best practices and lessons learned from other EHDI programs, and makes use of statewide expertise and resources will guide the achievement of project goals and objectives. The project brings together the Utah Newborn Hearing Screening Advisory Committee (UNHS), NCHAM, the American Academy of Pediatrics (AAP) EHDI Chapter Champion, and various community partners to implement, evaluate, and monitor the effectiveness of strategies in creating sustainable systems change. Specific project goals and objectives as well as strategies are listed a Logic Model (Table 2). By working to achieve the goals and objectives from a national, state, and community perspective, we will ensure that early identification and intervention for children with hearing loss becomes sustainable and the standard of care.

Using partnerships to implement the project strategies at every level provides an opportunity to embed the EHDI concept / philosophy into the infrastructure of numerous public and private agencies, thus increasing State capacity to provide services. The more the stakeholders are involved in each aspect of the “project”, the greater the sense of ownership of

the EHDI system statewide. With increased ownership comes a greater commitment to sustainability and a wide base of support.

1.6.1 Improving The Quality Of Existing UNHS Programs

All of Utah's birthing facilities, and Primary Children's Medical Center, (the intermountain pediatric hospital in Salt Lake City), have universal hearing screening programs, and all report data monthly to the State with the Hi*Track data management software. This system is able to provide excellent information regarding the status of each program, and indicates areas that need improvement. Some of this improvement happens, as stated before, simply as a result of generating Hi*Track reports each month at the State and local sites, and then working together to reconcile inconsistent, incomplete, and/or duplicate records. Additionally, a quarterly quality report is compiled by the State EHDI data specialist that records quality indicators, by site, that are not collected in Hi*Track. Timeliness of data transfers, unresolved data transfer issues, Hi*Track counts compared with Vital Records birth frequency counts, numbers of diagnostic referral forms received by the State for infants recommended for evaluation, and percent of Birth Record Numbers entered, are tracked along with Hi*Track reports of percent screened, percent passed as inpatient, and percent outpatient completions. Based on the summary of these quality indicators, State EHDI and NCHAM staff will provide on-site visits and targeted assistance to the least effective hospital programs. These quarterly reports are distributed to all newborn hearing screening program coordinators and the UNHSI Advisory Committee, and either entity may suggest/request training and technical assistance. During the first grant year we will improve the quality of existing programs by:

- Reducing hospital inpatient referral rates statewide to no more than 5.5% (with activities planned in Grant years 2-3 to improve that rate further to the national target rate of 4%).

Utah's refer rate is now at 7%, with the ten most effective hospitals averaging 98.1% passing, and the ten least effective hospitals far below the current 90% State standard at 75.9% passing.

- A data study of Utah's 2 stage hospitals will be completed and the results distributed to all programs. Technical assistance will be provided to hospitals with 2 stage capability to expand the protocol to include all newborn nurseries. Two-stage hospital screening protocol will be promoted. Hospitals purchasing new equipment for their programs will be provided all supporting information to confirm the added benefits of the 2 stage protocol, and program cost and cost effectiveness information will be provided when available. Currently eleven hospital programs have equipment capable of incorporating a 2 stage protocol, but some use that protocol only in their NICUs. Comparative data for a rural Utah hospital serving a large Native American population with an average of 400 annual births shows a marked improvement in pass rates when a 2 stage protocol was implemented. The pass rate for 2002 births was only 86.8% as inpatient, with the coordinator reporting multiple TEOAE testing attempts prior to discharge. Intense efforts by the hospital, local BW/EI providers, the regional UDOH audiologist and State EHDI staff to track these babies returned only a 75% completion rate on re-screening. Since the 2 stage protocol was initiated in January of 2003, the pass rate increased to 99% (and continues to maintain at that level).
- Increase screening and reporting for home births by 30%. A reporting system for midwives who deliver outside of facilities will be studied and a timeline for development, approval and implementation will be completed. Use of national data, and collaboration

with EHDI partners will assist with this goal and activities. Currently only 9% of Utah's large cohort of home births are reported as screened in Hi*Track.

- Re-evaluate existing state protocols for screening, reporting, and follow-up activities. Minimum standards will be reviewed and updated to reflect national standards and Utah needs. The UNHSI Committee will be an integral part of this process, and will approve the updated standards.
- Develop a new quality indicator report for hospital-based outpatient screening. As inpatient referral rates improve fewer babies need outpatient screening. Hospital evaluation reports could reflect a declining percentage of outpatient screens completed, even though fewer babies are missed.

This grant project will provide the resources necessary to systematically help hospitals to achieve these goals. The project director will be assisted in these efforts by EHDI and HSVS staff, the UNHS Advisory Committee, and from the NCHAM.

- Workshops and tutorials will be provided through the annual state EHDI conference.
- Regional meetings will be specific to the needs of each area. The resources of this grant will also be held in each of five regions of the state, to provide training and technical assistance enable us to continue meetings on a regional basis, and enhance activities provided at the annual Utah EDHI Conference.
- State EHDI staff will continue to prepare and disseminate educational materials (in English and Spanish) for screening programs, physicians, and families; assist with the improvements to and the implementation of the Hi*Track data tracking system and CHARM Data Integration system; and continue educational assistance and support to hospital programs.

Success with these goals and activities will also help reduce the amount of extra time needed to track babies through the screening process. Available tracking resources at the hospital and State levels can then focus time and efforts in tracking missed and lost babies and in following those babies needing diagnostic evaluation and intervention services.

1.6.2 Increasing the Number of Infants that Receive an Evaluation Before 3 Months

When an infant fails inpatient screening the baby is greater risk for hearing loss as well as being lost to follow-up. During this grant period we will expand current protocols and initiate activities to help expedite and improve the process:

- To reduce the number of infants lost to follow-up, (in pre-selected hospitals, based on performance criteria) a partnership will be established between the hospital screening program and the BW/EI program to have a Parent Advisor (PA) contact the family. The PA will reinforce the importance of completing follow-up screening and/or diagnostic testing. Specifically, when an infant does not pass inpatient screening the hospital screener will approach the family to schedule a follow-up appointment. At that time a Follow-up Form (see Appendix A, Page 60) will be completed and signed by the parent(s) indicating their approval to be contacted by a representative of PIP. The completed form will be faxed to the PIP office where a local Parent Advisor will be assigned. The PA will then contact the parent (usually by phone) to discuss any related concerns about the screening and reinforce the need to return for the follow-up appointment. The PA makes notes on the form, which is then faxed back to the screening facility prior to the appointment date. If the appointment is not kept, the process is

repeated. If the infant requires diagnostic testing, essentially the same format is followed with the family and the pediatric audiologist.

- The collaboration (and family support) with early intervention (PIP) will be continued throughout the diagnostic audiology process, and the connection to a medical home.

Preliminary pilot testing in 3 hospitals has revealed minimal increase in time involvement for both the hospital screeners and parent advisors, increased parent satisfaction by “having someone else be concerned about the baby’s welfare”, and improved coordination between hospitals and EI personnel. The UDOH has developed guidelines for diagnostic audiological evaluations and has recently updated, published, and distributed a “self-selected” list of pediatric Audiology providers throughout the state. In Utah, as in most states, there is not general agreement as to what constitutes a qualified pediatric audiologist.

- Through the Utah Consortium of Pediatric Audiologists (UCOPA) list-serve and the UNHSI Advisory Committee, Utah will begin to address the potential creation of uniform standards in screening, diagnostic testing, training, and experience.

1.6.3 Linking Infants with Hearing Loss to Early Intervention by 6 Months

Although in Utah there are well-established procedures for referring babies diagnosed with a hearing loss to BW/EI, (and the link to services through PIP) many medical practitioners and audiologists, who should make the connection to early intervention, often do not have the knowledge, expertise, or experience necessary to deal with these complex issues. Many parents with a newly identified baby are still not receiving adequate multidisciplinary assistance through the existing mechanisms. Providing appropriate services to infants and young children is a complex task. In a recent study conducted by NCHAM as a component of a Utah program evaluation, physicians caring for young children were asked to whom they would refer a

newborn patient diagnosed with a hearing loss. Although 94% said they would refer to an otolaryngologist, only 21.6% and 38.2% said they would refer to an ophthalmologist and a geneticist, respectively. Other physician studies have also suggested a clear need for a better understanding of the issues involved in making appropriate referrals and providing appropriate treatment for infants and children with hearing loss.

Although an excellent working relationship currently exists between the EHDI Program and BW/EI, improvements can still be made. The activities in this section will focus on providing training and education to allied professionals to increase the linkage to early intervention services, including:

- Collaboration with the AAP EHDI Chapter Champion for Utah, Dr. David Boettger. A presentation will be developed as an inservice and training tool for audiologists. This presentation will focus on the role of the physician in the EHDI process, making appropriate and timely referrals, and using the medical home to provide quality hearing health care. This presentation will be previewed and evaluated by the UNHSI Advisory Committee and a selected medical practice. This presentation may also be developed as a CD presentation and then distributed throughout the state.
- Updating diagnostic protocols. With over 98% of infants born in Utah being screened for hearing loss, a need exists for audiologists to be using current diagnostic protocols. To bring them up-to-date, two workshops will be held for developing, enhancing and reinforcing diagnostic skills, applying timely referral linkage, and appropriate hearing aid management for infants.
- An informal “pediatric audiologist” certification program will be evaluated for Utah based the American Academy of Audiology (AAA) guidelines for Pediatric Audiologists.

- A Parent / Community Partner Task Force will review current hearing aid reimbursement options locally and nationally. Most insurers do not provide good coverage for hearing aids for infants and toddlers. In conjunction with the UNHS Advisory Committee and HSTS, the Task Force will develop recommendations (from advocacy through legislative mandates for insurance companies) to help families with this issue.

1.6.4 Early Identification of Infants and Children with Progressive and Late Onset Hearing Loss

The Joint Committee on Infant Hearing (JCIH, 2000) recommends monitoring any infant *with risk indicators* for progressive or delayed-onset hearing loss every six months until three years of age. Although this recommendation appears logical, little is known about the costs or benefits of implementing such a recommendation. With this grant we are proposing a study to investigate the newborn hearing screening status of children who are identified late. It could be valuable to know whether these children passed their newborn screening and likely had late-onset hearing loss (in which case, we would need to find more systematic ways of tracking children who have risk indicators for late-onset loss – see activities in 1.6.6) or whether these children failed the newborn hearing screening and did not return for a diagnostic evaluation until they were older. In the latter case we may want to follow-up with families to determine if there are useful methods that would have increased the probability of the families obtaining services earlier.

- This project will be accomplished through a collaborative study with NCHAM, the Utah School for the Deaf, and the UDOH CHARM Data integration program by: 1) reviewing the USDB rosters to identify “late-onset” referrals to their program; 2) matching these

names to the Hi*Track database to determine newborn screening status; 3) analyzing the data; and 4) interviewing parents for health and family history information.

1.6.5 Infants with a Hearing Loss will have a Medical Home

The Maternal and Child Health Bureau and the AAP advocate that all children should have a Medical Home. Hearing loss is estimated to affect approximately 3 children in a thousand. Rapid changes in identification technology, early intervention, and amplification are taking place at an astounding pace. It is unrealistic to expect that all physicians will remain well-informed about all issues in what may constitute a very limited number of the families in their practice. In a medical home, the pediatric health care professionals and parents act as partners to identify and access all the medical and non- medical services needed to help children and their families achieve their maximum potential. The Utah Collaborative Medical Home Project has created a “MedHome Portal” (website) designed to be a source of specialized information for physicians, teachers, and parents to help them in caring for children with special health care needs.

- Through the Utah Medical Home website we will develop a learning module about newborn hearing screening that provides links to pediatric audiologists and connections to early intervention.
- Through the CHARM data integration system, we will determine the feasibility of designing a query that identifies designation of “medical home” or primary care physician from immunization records on infants diagnosed with hearing loss.
- In order to further obtain a better indication of the number of hearing impaired children that have a Medical Home, we will request from the Parent Infant Program (PIP) the

number of infants enrolled in PIP that have a reported Medical Home on their program admission documents.

- Grant activities will include training that assists PAs in the PIP program to encourage parents to choose a “Medical Home ” practitioner for their hearing impaired infant.
- The Utah Intermountain Pediatric Association EHDI Chapter Champion will attend the AAP training course.
- The Chapter Champion will be involved in physician education through grand rounds presentations, local seminars, and childhood/pediatric conferences.

Every child should have a primary health care provider who knows that child individually, cares about him or her, is aware of his or her medical needs, and is capable of providing culturally sensitive and appropriate medical services. The concept of medical home is a little difficult to define in operational terms, and we are still a long way from achieving the goal that every child has a medical home in Utah.

1.6.6 Decrease the Number of Infants and Children lost to Follow-up

A high percentage of babies who need an audiological diagnostic evaluation require intense efforts to complete follow-up. Even with additional effort many are still lost to follow-up. Utah Newborn hearing screening staff in all hospitals should complete a standard form for babies who do not pass the hearing screen (.8% for 2003 births). This “Referral for Diagnostics” form contains contact information about the baby, the primary care physician, and the audiologist the parent has chosen for the evaluation. These forms provide valuable tracking information, yet we can only document this referral information on 60% of babies recommended for diagnostic follow-up. During the first grant year we will:

- Increase documentation of referral to pediatric audiology to 75% compliance following

failed outpatient testing. A goal of 90% compliance is planned for grant years 2-3. The use of NCR forms will be expanded and activities which have been successful in other state EHDI programs will be evaluated. State EHDI staff will report significant findings and improvement quarterly to hospital programs and the UNHS Advisory Committee.

- A “targeted case management” protocol will be developed for use with Home Health nurses that identifies infants who missed initial newborn hearing screening.
- New linkages with the CHARM data integration system will help provide additional opportunities for tracking children previously lost to follow-up through 1) access to other public health data bases, 2) access to system-wide “address cleaning” software, and 3) a unique birth identification number.
- With this grant we are proposing a “Proof of Concept” study to use the Birth Record Number (BRN) and the CHARM technical infrastructure to alert parents who order birth certificates for infants needing follow-up on failed hearing screening results.

Attempting to conduct public health outreach to parents obtaining their child’s birth certificate is an unexplored program area, so we propose a relatively limited exercise that will provide a test of the usefulness of this concept. Preliminary review has already demonstrated that in Utah about 40 % of children obtain a birth certificate before their 2nd birthday, so we have some evidence that the opportunity exists to reach a substantial number of potentially at-risk, lost-to-follow-up children using this method. A growing number of parents use a web-based birth certificate ordering application to obtain their child’s birth certificate, and provide an e-mail address for the Department of Health, Office of Vital Records, to contact them. This project will entail matching the parents who are ordering birth certificates with the Hearing, Speech, and

Vision Services' (EHDI) lost-to-follow-up cases. A positive match will result in an e-mail to the parents regarding the need for follow-up on their child's positive hearing screening result.

Obviously, there are many details to work out in the implementation of this project, including case selection, content of alert messages, and measurement of success. We will document our planning and development of these elements, as well as the demographic characteristics of children reached through this test. Parents' reaction to this form of outreach will also be of interest, and might reveal public concerns over the use of integrated child health information systems that will be important to consider in the development of applications for these systems. We will also continue our collaboration with the CDC's Loss to Follow-up study.

1.6.7 Improving the EHDI Data Management System

The Utah EHDI database will be linked through the CHARM Data Integration System to other relevant public health databases including Vital Statistics, the Immunization Registry, the Birth Defects Network, Baby Watch/ Early Intervention, Newborn Screening (heelstick), and WIC to improve coordination of services, reduce the number of children lost to follow-up, and provide data for public health purposes. All EHDI system improvement goals will be integrated with goals and objectives of CHARM. Current activities to improve the EHDI data management system have focused on training hospitals to use the Hi*Track Windows 3.5 data management system effectively. In collaboration with the NCHAM software developers and technical support staff, State EHDI staff has included training activities with all regional and statewide coordinator conferences. With approval of this grant application, appropriate support and training can be continued through a UDOH contract with NCHAM. HI*Track enhancements and upgrades will be developed, and technical assistance will be provided through a telephone helpline. These activities are crucial to program administration and improvement, as this is

Utah's avenue to provide appropriate services to newborns, to track infants and toddlers previously lost to follow-up, and to report on state and national performance measures. Utah's data integration efforts through the CHARM Project promoted the development of Hi*Track Web Enabled 4.0. Additional activities for this grant project include:

- Improved data quality and de-duplication efforts at the State and local level through collaborative activities with CHARM, including system-wide access to “address cleaning” software. State EHDI will coordinate with CHARM timelines and measure the effectiveness of this effort by comparing record matches among EHDI, Vital Records and Heelstick databases.
- Development of a timeline for converting the State Hi*Track data from the current HT WIN Version 3.5 to the Windows Client Hi*Track 4.0/Web Enabled 4.0. Current parallel database activities and testing should be complete by summer of 2005. Evaluation of that project will enable State EHDI staff to develop an appropriate timeline to fully convert the State EHDI system to the 4.0 version of the software.
- State EHDI and the NCHAM Hi*Track development team. will implement HT WEB 4.0 beta testing by a hospital program (yet to be determined) following the conversion of the State system. The State EHDI data specialist will work closely with the test site to compare and evaluate functionality, reporting and data/program quality at the local level.
- Develop a plan to utilize CHARM linkages to improve reporting of gender, race, ethnicity, etc, as required for MCHB funded programs. At the current time, these data elements are not collected on a consistent basis from hospital EHDI programs, nor is it required by Utah mandate.

Resources	Strategies	Outputs	Short and Long-Term goals and objectives	Impact
<ul style="list-style-type: none"> -Established hospital screening programs -State mandated requirements for NB screening -State Hearing, Speech and Vision leadership 	<ul style="list-style-type: none"> -2 stage screening study & education -State EHDI conference -Targeted training to hospitals -Midwife training & reporting -Update state protocols -Outpatient screening indicator -Develop education materials 	<ul style="list-style-type: none"> -Monthly hospital HiTrack reports. -Reports from mid-wives and birthing centers -New state protocols 	<ul style="list-style-type: none"> 98.5% of newborns will be screened for hearing loss before discharge -Increase screening and reporting for home births by 30% 	<ul style="list-style-type: none"> -Increased number of infants screened -Increased early identification of children with hearing loss - Improved speech-language, social outcomes
<ul style="list-style-type: none"> -Committed state E.I. programs -UCOPA list serve for pediatric audiologists -HSVS staff 	<ul style="list-style-type: none"> -Strengthen collaboration among hospital screeners, BW/EI and Audiologists -Training with screeners at E.I. sites -List Serve education 	<ul style="list-style-type: none"> -HiTrack Reports - # Referral tracking forms completed 	<ul style="list-style-type: none"> -Evaluation before 3 months of age for infants not passing first screen 	<ul style="list-style-type: none"> -Increased early identification of children with hearing loss. -Improved linkage to Early Intervention Programs
<ul style="list-style-type: none"> -Newborn Hearing Screening Advisory Committee -HSVS staff -UCOPA list-serve -AAP Chapter Champion 	<ul style="list-style-type: none"> -Improve H/A fitting protocols -Pediatric training to audiologists -Review Peds. Audiology certification -Training to MDs by AAP Chapter Champion -H/A reimbursement task force 	<ul style="list-style-type: none"> -Hospital reports -E.I. reports -Medical Home reports 	<ul style="list-style-type: none"> -Infants identified with hearing loss will receive appropriate E.I. services 	<ul style="list-style-type: none"> -Increased linkage at an earlier age to appropriate intervention services -Improved speech-language, social outcomes

Resources	Strategies	Outputs	Short and Long-Term Outcomes	Impact
-NCHAM -Parent Infant Program -HSVS staff -CHARM Data Integration Program	-Evaluation of late-identified kids through Parent Infant Program	-Birth certificate registration -NCHAM evaluation and report	-Early ID and referral of infants with late onset / progressive hearing loss -Early alerts to families needing diagnostic testing	-Earlier identification -Earlier links to E.I. programs -Improved speech-language, social outcomes
-Newborn Hearing Screening Advisory Committee -Utah Medical Home Project web site	-Develop hearing screening module for Medical Home web site -Feasibility study -Improved PIP linkages -Chapter Champion training and education	-Audiology referral list -Hits to Medical Home website -Grand Rounds presentations	-Infants who fail the hearing screening will be connected to a medical home.	-Coordinated services for families with children with identified hearing loss -Improved medical care
-UDOH home visit nurses -Newborn Hearing Screening Advisory Committee HSVS staff	-Improved documentation and referral -Targeted case mngt. -CHARM linkages -Proof of Concept study	-Monthly HiTrack reports -Home Health reports -CHARM data reports -Vital Records reports	-Decrease the number of infants (and children) lost to follow-up through improved tracking	-Improved identification of infants and children with hearing loss -Decreased number of kids lost to follow-up
-CHARM Data Integration system -Web-based HiTrack connection	-Phase II CHARM data integration -Web-based CHARM connection for providers -Web-based HiTrack reporting	-HiTrack reports -CHARM outcome and data integration reports	-Improved monitoring and evaluation of EHDI goals and objectives -Access to a real time Child Health Profile for Medical Home providers, primary care physicians, state service agencies, and families -Improved data quality	-Refine and improve the Statewide EHDI system -Additional information supplied to state Child Health Profile

1.7 COLLABORATION AND COORDINATION

Identifying infants with hearing loss, and providing appropriate services to them and their families, requires participation from many different stakeholders and disciplines. The essential components of this service system are already in place in Utah among state- and community-based agencies, health care providers, and private groups. In some cases, these groups serve a broader constituency, of which children with hearing loss are just one part. In other cases, their efforts are focused specifically on children with hearing loss.

This project will focus on coordinating the efforts of these groups into an effective, statewide EHDI system. Although the number of collaborators will expand as the work of the grant continues, those thought to be most important at this time, (see Letters of Support, Appendix F), to participate in the project activities, are described below.

1.7.1 Baby Watch Early Intervention Program (BW/EI)

The Department of Health, CSHCN Bureau, is the lead agency in Utah for implementing statewide services for children with developmental delays and/or disabilities from birth to age 3, under the Individuals with Disabilities Education Act (1997), Part C. Although a much broader constituency of children is served, any child with a permanent hearing loss qualifies for the program. Services include multidisciplinary evaluation and assessment; service coordination among providers, coordinators, and agencies; provision of specialty and therapy services such as special instruction, nursing, physical therapy, speech therapy, family support; and other related services and strategies to build on family strengths and child potential. Audiology and speech/language pathology services may also be coordinated in local regions with HSVS and CSHCN staff. Recycled hearing aids are available through HSVS for financially eligible families.

1.7.2 Utah School for the Deaf (USDB), Parent/Infant Program (PIP)

A home-based program for parents of 0- to 3-year-old sensory-impaired children is provided through the Utah School for the Deaf, and a service contract with BW/EI. PIP services are based on the SKI*HI curriculum, which emphasizes develop of language, cognitive, and social skills using a systematic, behaviorally oriented curriculum. Parent advisors are available throughout the state to assist with the implementation of the program and participate with the BW/EI Program in developing an Individualized Family Service Program (IFSP) whenever a child is identified. This IFSP must be developed within 45 days of a referral being made to the Baby Watch program. Current collaborative planning efforts with USDB audiology and administrative personnel are geared to ensuring that children with hearing loss who live in rural and frontier areas will continue to have access to support services in accordance with their IFSP.

Parent Advisors will also become involved much earlier through current grant activities as we move forward in our effort to link the PA with the family beginning with the initial referral to additional screening or diagnostic testing.

1.7.3 Family Voices

Family Voices is a national grassroots network of families, friends, and advocates for health care services that are family-centered, community-based, comprehensive, coordinated and culturally competent for all children and youth with special health care needs. The organization promotes the inclusion of all families as decision makers at all levels of health care and supports essential partnerships between families and professionals. The Utah Family Voices Health Information Director is a member of the Core Council for the CHARM Data Integration Program, and the Family Advocate Coordinator for CSHCN and the Utah Medical Home Project. She has represented Utah EHDI at national and local conferences.

1.7.4 CSHCN Clinics

CSHCN provides multidisciplinary medical and developmental assessment services in clinics through the State. The Child Development Clinic serves children birth to 5 years of age who have developmental disabilities or chronic illness associated with developmental delay. Parent, family, and community education and involvement is emphasized, as is the importance of early identification diagnosis and treatment. The clinics do not provide routine medical care nor treat acute illnesses, but work closely with the clients' health care providers and the BW/EI Program. The Speciality Clinic Program is responsible for ensuring that children with special health care needs throughout the state, regardless of ability to pay, receive specialty health evaluations, diagnostic testing, follow-up care, and medical equipment. Genetics services provided by Specialty Clinics link closely with the EHDI program, and a study funded by CDC to offer services to infants identified with hearing loss through EHDI. Recent research shows that approximately half of all permanent hearing loss is genetic, and 80% of genetic hearing loss is non-syndromic and inherited in an autosomal recessive manner. Approximately 50% of childhood non-syndromic recessive hearing loss is caused by mutations in the connexin (cx26) gene (GJB2/DFNB1), making it the most common form of autosomal recessive non-syndromic hearing loss, with a carrier rate estimated to be as high as 2.8%. CSHCN Community-Based Services Clinics travel to rural areas to provide diagnostic and treatment services, and often helps families of children with hearing loss access other community agencies and resources in order to meet their child's non-medical needs, including educational, social, and mental health. HSVS providers are integral team members for all CSHCN clinics.

1.7.5 Intermountain Pediatric Society

The Utah Chapter of the American Academy of Pediatrics (AAP), the Intermountain Pediatric Society (IPS), and the Department of Health has collaborated closely over the last several years to promote the concept that all children should have a "medical home". We have also published numerous EHDI informational articles and documents through the monthly IPS newsletter. Our EHDI Chapter Champion, Dr. David Boettger, will be helping to develop and promote educational materials and presentations for area pediatricians. He also represents the IPS through his membership on the Newborn Hearing Screening Advisory Committee. The Executive Director of the Utah Department of Health (Scott D. Williams, M.D.), the Division Director for Community and Family Health Services (George W. Delavan, M.D.), and the Bureau Director for Children with Special Health Care Needs (Vera F. Tait, M.D.), are all members of the Intermountain Pediatric Society. Dr. Tait has also serves as the AAP, EHDI Task Force Chair and the Utah Department of Health designee to the Newborn Hearing Screening Advisory Committee.

1.7.6 National Center for Hearing Assessment and Management (NCHAM)

NCHAM has been very instrumental in Utah's implementation of hospital-based Universal Newborn Hearing Screening and state-based Early Hearing Detection and Intervention (EHDI) programs. NCHAM receives funding from federal, state, and private sources to conduct research, develop training materials, provide training and technical assistance, and disseminate information about early identification and management of hearing loss. Through this grant, the UDOH, PIP, and NCHAM will conduct a study to help determine late-onset high risk factor for hearing loss. This contract also secures coordinated training and technical support with the HiTrack data management system and program evaluation for the Utah EHDI Program. The

Director of NCHAM, Dr. Karl R. White, is a member of the Newborn Hearing Screening Advisory Committee.

1.7.7 Child Health Advanced Records Management (CHARM) Project

CHARM is the data integration initiative through the Utah Department of Health that will integrate child health related programs and systems. The charter is to create a virtual health profile for every child and to allow real-time data sharing across healthcare programs and partners. This project is initially linking Vital Records (birth and death certificates), the Utah Immunization Program, and EHDI (the Newborn Hearing Screening Database). Phase II will link the databases from Newborn Screening (Heelstick), Baby Watch/ Early Intervention, and the Birth Defects Network. Each participating program maintain their own database and controls what data is shared and with whom. Additional data linkages will enable more accurate tracking of adoptions and babies with name changes.

1.7.8 Department of Vital Statistics

One of the weaknesses identified during the initial needs assessment was the fact that not all live births were being included in the database reported to the stated EHDI management system. The Newborn CHARM (N-CHARM) project's goal was to develop a unique identifier for all Utah newborns using the Birth Record Number from the Newborn (Heelstick) test kit. Success was achieved among three mandated newborn databases, Vital Statistics, EHDI, and Heelstick screening, with consistent propagation and matching of the BRN "linking" the three databases. Propagation (of the BRN) has increased from 85% to 95.2% of birth certificates and from 70% to 94% of hearing screening records, with a three-way match of 93% (as of January 2004). This success has created avenues for more effective tracking and will help reduce infants lost to follow-up.

1.7.9.Primary Children’s Medical Center

Primary Children’s Medical Center is Utah’s only tertiary care hospital for children. As such they are the designated referral hospital for a very high percentage of newborns with birth complications, genetic disorders, and a myriad of other issues potentially linked to hearing loss (and other disorders). Support through their hospital based and community audiology programs is extremely important in linking families to appropriate medical services, family-to-family support, and infants who could potentially be lost to follow-up.

1.7.10 The Utah Collaborative Medical Home Project

As is the case with hearing loss, most chronic and complex conditions in children are uncommon. Their cumulative prevalence however is significant (studies in the U.S. find 13-18% of children have special health care needs). The Medical Home portal (website) is offering information, tools, and resources for Primary Care Physicians to enhance their ability to care for Children with Special Health Care Needs (CSHCN) and to provide a Medical Home for all of their patients. Earlier collaborations with the Medical Home Project have resulted in an educational “module” about hearing loss. This module provides reliable, relevant information, tools, and resources to aid in the care of children with hearing disorders. Activities associated with this grant will design a “Newborn Hearing Screening Module” that will provide information to practitioners (and others) useful information about newborn screening programs, follow-up testing, how and when and who to refer to, and “next steps” for the families.

1.8 ADMINISTRATION AND ORGANIZATION

The organizational structure showing the organizations within the Department of Health that are relevant to this proposal are shown on Appendix E. The Principal Investigator for the project will be Richard S. Harward, M.S., a licensed pediatric audiologist who directs the

Hearing, Speech, and Vision Services (HSVS) Program for the Utah Department of Health. Other staff on the project will report directly to Mr. Harward, as shown. Technical support services as well as a research project will be contracted through the National Center for Hearing Assessment and Management (NCHAM) at Utah State University. NCHAM staff have worked closely with HSVS for the last 10 years.

1.9 ORGANIZATION EXPERIENCE, AND CAPACITY AND AVAILABLE RESOURCES

The Utah Department of Health is the designated state agency for Title V funding. The Department of Health houses the divisions of Health Care Financing, Community and Family Health Services, and Rural and Primary Care. Within the Division of Community and Family Health Services are the Bureaus of Maternal and Child Health and Children with Special Health Care Needs. The Lead Agency, Hearing, Speech, and Vision Services (within the CSHCN Bureau) has demonstrated the leadership and expertise necessary to complete the goals of this grant.

CSHCN houses ten programs that include interdisciplinary clinics, administrative case management, birth defects surveillance, early intervention, newborn blood screening, *early hearing detection and intervention*, and the technology dependant waiver. The UDOH and CSHCN have been involved in many federal and state systems-change initiatives. Hearing, Speech, and Vision Services (HSVS) at the is responsible for providing state-wide screening, diagnosis, consultation, and education in pediatric hearing, speech, and vision disorders. The mission of HSVS is to assure optimal hearing, speech, language, and vision in Utah children through a collaborative, statewide system of prevention, early identification, and care coordination. HSVS maintains clinical facilities in five geographically distributed locations

within the state, all of which are staffed by licensed and certified speech-language pathologists and/or audiologists. Services are also provided in many rural areas of the state through Child Development Clinics held in cooperation with local Health Departments. Once a problem is identified by HSVS, children are referred to appropriate local resources for continued management.

The project director for this grant, Richard S. Harward, has been involved in early identification and management of hearing loss for many years. He is a licensed audiologist with over 20 years of pediatric experience and is the parent of a child (now a young adult) with a profound hearing loss. Because of his personal and professional experiences, he is particularly well-informed about issues related to early hearing detection and intervention and family support. He is currently the Program Director of Hearing, Speech, and Vision Services. He holds adjunct faculty appointments at the University of Utah Department of Pediatrics, School of Medicine and at Utah State University, Center for Persons with Disabilities.

As a part of the 1998 legislation requiring all Utah hospitals to do universal newborn hearing screening, a state newborn hearing advisory committee was created. This committee consists of 11 mandated representatives appointed by the governor, and additional consultants and staff approved by the Committee membership, as listed in Appendix A. These members represent families, audiology, early intervention, family practice physicians, pediatricians, neonatology, health insurance companies, public health, and parents. The committee is responsible for advising the Department of Health on all aspects of early hearing detection and intervention.

1.10 PLAN FOR EVALUATION

Monthly Hi*Track reports are used to monitor hearing screening and follow-up activities statewide. Quarterly Hi*Track and quality indicator reports will be used to evaluate state and local programs and to identify and respond quickly to specific needs in individual hospitals. CHARM reports, which include EHDI data integration components, will track progress and problems with data capture and data quality. Each grant strategy item will be monitored according to the methods listed in Table 3.

The National Center for Hearing Assessment and Management (NCHAM) will be contracted to conduct an external evaluation of the project each year. The first year's evaluation will investigate systematic ways of tracking children who have risk indicators for progressive or delayed late-onset loss every six months until three years of age. Results and recommendations will be reported to the UNHSI Advisory Committee, and findings will be used to plan and implement future activities to assure early identification of infants and children with progressive and late onset hearing loss.