

PROJECT NARRATIVE

INTRODUCTION

The goal of this initiative is to reduce the loss to follow-up (LTF-U) of infants who have not passed a physiologic newborn hearing screening (NBHS) examination prior to discharge from the newborn nursery by utilizing specifically targeted and measurable interventions. The purpose of this funding opportunity is to further focus efforts to improve the loss to follow-up / loss to documentation (LTF-U/D) by utilizing specific interventions such as quality improvement (QI) methodology to achieve measurable improvement in the number of infants who receive appropriate and timely follow-up.

Utah Early Hearing Detection and Intervention (EHDI) state goals align with that of the national goal of decreasing the number of infants who are LTF-U/D following a failed hearing screening by 5% each year of the grant.

Each year over 100 infants are born in Utah with a permanent hearing loss. This number compares with the national incidence rate of 1-3 infants in every 1,000 newborns having a hearing loss at birth. Hearing loss is one of the most frequently occurring birth defects and the consequences of permanent hearing loss can have long-term detrimental impact on all aspects of a child's development.

Prior to the implementation of universal screening, the average age at which hearing loss was identified in children was 18 months to 3 years of age (Commission on Education of the Deaf, 1988). Since the initiation of NBHS and EHDI programs, the average age of hearing loss identification has decreased to 2–3 months of age. (White, K. R. (2008). The current status of EHDI programs in the United States. *Mental Retardation and Developmental Disabilities Research Reviews*, 9(2), 70–88). There has been great success to date with NBHS, however, much work still needs to be done in reducing the loss to follow-up / documentation in EHDI programs across the nation.

The most recent published figures from the Centers for Disease Control EHDI Hearing Screening and Follow-up Survey (HSFS), 2011, estimates that for 50 states/territories reporting, 35.3% of the infants who did not pass screening through an EHDI Program are considered "lost to follow-up" or "lost to documentation". This is improved from 46.1% reported "lost" in 2007, yet these infants already failing initial screening have a higher risk of hearing loss and greater efforts need to be made to track and document their hearing status. And, of those infants who received a diagnosis of hearing loss (subsequent to the initial screening and follow-up), of the 77% who were referred for early intervention services, only 74% of those infants were *enrolled* in Early Intervention Programs. Clearly, we still have much work to do in reducing the numbers of infants lost to follow-up in the EHDI system.

The EHDI program in Utah mirrors what is happening at the national level. Virtually all (over 98% for 2012 occurrent births reported through the HI*TRACK database) of the newborns in Utah are screened for hearing loss. However, of those referred from the

initial hospital screenings 10% did not complete outpatient screening, and diagnostic results could only be documented for 67% (of those referred from screening programs) at the end of the calendar year. It appears that this group, which is at a higher risk for hearing loss by failing the first screen, is also at a higher risk of being lost to follow-up.

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. 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 benefits of early identification are only fully realized when a child who fails the initial hearing screen completes the necessary follow-up including re-screening, diagnosis, access to sound (appropriate amplification), and early intervention services. Additionally, this follow-up must be linked to the child's medical home for collaboration and reinforcement.

Although Utah EHDI has shown steady improvement, unfortunately, some hospital screening programs have struggled to make these connections. For the benefits of universal NBHS 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.

Goals developed for this project are consistent with the Healthy People 2020 Goals that seek to (1) increase the quality and years of a healthy life; and (2) eliminate our country's health disparities. Objective 28-11 is to "Increase the proportion of newborns who are screened for hearing loss by age 1 month, have an audiological evaluation by 3 months, and are enrolled in appropriate intervention by age 6 months". Goal 28-13 is to "Increase the proportion of persons with hearing impairments who have ever used a hearing aid or assistive listening device or who have cochlear implants". Additionally, Goal 16-23 (revised) is written to "Increase the proportion of children with special health care needs who receive their care in family-centered, comprehensive, and coordinated systems".

Measure 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". These national performance measures are at the core of the Utah EHDI Program.

Additionally, given the growing emphasis on understanding life course theory and its implications for maternal and child health, the goals of this project will also attempt to incorporate current life course concepts. NBHS programs are in a pivotal position to observe and participate in "factors that influence the capacity of individuals or populations to reach their full potential for health and well-being". The Utah EHDI team fully supports the concept that early experiences and events have a profound effect on an individual's future health and development, specifically, early identification of a

hearing loss, timely intervention services, and connection to a medical home and appropriate family involvement.

It is important to note that a significant change to Utah EHDI's program occurred on July 1, 2013. During the 2013 General Session of the Utah Legislature, House Bill 81 was passed and signed into law (UCA 26-10-10) (see Attachment 8). This law entitled, Cytomegalovirus (CMV) Public Education and Testing, included a mandate for testing all babies who fail two newborn hearing screenings for congenital cytomegalovirus prior to 21 days of age. This mandate necessitated a shift in Utah state NBHS protocols making the "1" in the national 1-3-6 CDC EHDI goals and Objective 28-11 of Healthy People 2020 Goals move up to two weeks. This change in our state NBHS protocols represents the subject of one of Utah EHDI's three presentations at the National EHDI Conference 2014 in Jacksonville, FL, entitled, "Mandated Congenital Cytomegalovirus Testing: The Utah EHDI Experience".

Over the last decade and a half, the Utah Department of Health (UDOH) has developed and deployed a number of electronic public health and health care information systems, including Early Hearing Detection and Intervention (EHDI), Newborn Blood Screening (Newborn-Lab Information Management System N-LIMS), Utah's Statewide Immunization Information System (USIIS), Vital Records, Women, Infant and Children (WIC), Baby Watch / Early Intervention (BW/EI), the Birth Defects Network and others. Each program is responsible for collecting and maintaining its own data and controlling the access policies for that data. Many of these programs are linked through the UDOH Child Health Advanced Records Management data integration system (CHARM).

CHARM's design uses a service-oriented architecture (SOA) called an arms-length information broker. The CHARM Server (Attachment 11) is a collection of independent services that include cross-program record matching, query processing, data cleaning, audit trail logging, and data synchronization. Participating programs may use any or all of these services. The CHARM service is an information broker, not a data repository; therefore, none of the CHARM services store program-specific operational data. When a program requests shared data for a child, it invokes CHARM's query processing service, which in turn locates the most reliable data source and retrieves the data in real-time. To do this, CHARM uses a distributed Master Person Index (MPI) that isolates and protects program-specific data structures and identifiers. Each program requests data from or provides data to the CHARM Server via a customized agent. The agents create a buffer zone between the programs and the CHARM Server, insulating them from changes to the CHARM system, differences in data structures and semantics, and potential security threats. The agents provide the "arms-length" aspect of this information broker architecture. The architecture also includes two supporting agents for each program service, an Alert Agent and a Sync Agent. A program's Alert Agent monitors the program's data for changes that might represent special conditions

such as “child needs hearing services follow up.” The Sync Agent, monitors program data for changes in demographic information that might be interesting to other programs. For example, if a child’s name changes, the Sync Agent will publish that change to any other program identified as wanting to be notified of name changes. In summary, the CHARM SOA is a collection of distinct components that supports program services and supports each programs’ stewardship of their data, and allows data-sharing invaluable in reducing LTF-U/D.

The UDOH continues to implement the Clinical Health Information Exchange (cHIE) statewide and incorporate many components of the existing CHARM system into it. The cHIE is part of a nationwide Health Information Exchange (HIE) initiative and is supported by all major health systems, providers, consumer organizations, public health and payers in Utah. The goal of the cHIE/CHARM collaboration is to make CHARM information (therefore EHDI information) more available to community physicians through integration with the Utah Health Information Network (UHIN). UHIN is the designated cHIE operational entity for the state of Utah, a coalition of health care providers, insurers and other interested parties, including State government.

One of the goals of this project will be to strengthen and expand our health information exchange and hearing screening data sharing ability statewide thereby providing another opportunity to reduce the number of children lost to follow-up as well as improving our overall newborn screening follow up activities.

The linkage of the EHDI database (HI*TRACK) to an expanding number of participating programs in the CHARM network has already reduced data entry, improved data quality, and increased the tracking ability of infants previously lost to follow-up. In addition, electronic data sharing of hearing screening results through the CHARM web interface with one pilot clinic, showed that duplication of hearing screening services/tests was reduced, changes to patient workflow were made, and effective data sharing helps expedite appropriate referrals/services.

Participating programs currently integrated through CHARM include:

- Vital Records
Vital Records high risk information and death alerts available to NBHS program in HI*TRACK.
- NBHS (HI*TRACK)
NBHS alerts received by Birth Certificate clerks (OLIVER/CHARM Birth Certificate Project)
- Immunization Information System (USIIS)
Newborn Hearing Screening results/alerts available in the Utah Statewide Immunization Information System (USIIS) for all Intermountain Health Care (IHC) users that have access to USIIS. Expanding this to all non-IHC providers statewide.
- Newborn Screening (heel stick) information available in HI*TRACK for the

NBHS Program

- Baby Watch/Early Intervention Part C (BTOTS)
NBHS results and Immunization history available to Early Intervention providers.

- Most conclusive NBHS results available to Fostering Healthy Children (FHC)

Utah's Central EHDI database is currently running HI*TRACK 4.5.6 with the most recent update in February 2013. All 43 Utah hospitals report to Utah EHDI through HI*TRACK; thirty hospitals use Web-enabled HI*TRACK. Version 4.5.7 of HI*TRACK will be available in early 2014 to address updates to the CDC HSFS reporting categories/fields prior to the CDC EHDI deadline for 2012 data. Tracking and reporting capabilities have been increased to better focus on national Healthy People objectives and on national EHDI recommendations for 1-3-6 timelines. The National Center for Hearing Assessment and Management (NCHAM) HI*TRACK programmers are currently working on a special module for CMV test reporting for Utah EHDI (this, too, will be presented at National EHDI 2014 in a presentation entitled, "Addition of Congenital Cytomegalovirus Testing Data Management to an EHDI Data System").

Early Intervention reporting fields/formats were revised in HI*TRACK and now include first and latest EI referral date information. Program language, data fields, and tracking options were aligned with current EI database (BTOTS) options. Account security enhancements were added that allow stricter account security and now meet Utah IS (Information System) Risk Assessment recommendations. HI*TRACK enhancements also expanded the linkage capabilities to other service systems that are following children through the CHARM data integration system. The updated HI*TRACK system also supports the HL7 2.x messaging standards rapidly approaching in our cHIE (Health Information Exchange) development and transmits a subset of hearing screening information for other systems to receive.

Additional updates to HI*TRACK are being developed for the next budget year by our contractor, NCHAM, and will include:

- Complete redesign of User Interface
- Person-specific Logins (for individual physicians and audiologists)
- Automated Letters grouped by physician (to be emailed or faxed as physician batches)
- Additional Letter merge fields (audiologist and physician address)
- Refined User Access Right controls
- Revised 64-bit web server compatibility
- Web-Farm server capability
- Support for larger text fonts
- Screener Profile Report enhancements
- Additional support for tablet users
- Additional improvements based on user feedback

The Utah EHDI Program adheres to the goals and objectives established nationally for Early Hearing Detection and Intervention Programs, the 2007 Joint Committee on Infant Hearing Position Statement and its 2013 Supplement for guidance in the project.

The overarching goal of the EHDI Program is to improve the health and quality of life of children with hearing loss and their families by reducing the number of infants who are lost to follow-up or documentation after failure to pass NBHS (including those who may have missed a physiologic hearing screening at birth for any number of reasons).

The Utah EHDI Program will accomplish its goals by developing a sustainable statewide system through carrying out the following activities:

- Screen all newborns at birth or before one month of age, and as of July 1, 2013 before 2 weeks of age to allow for mandated testing for congenital CMV if test criteria is met (failing two hearing screenings before 14 days or failing an initial screening at or after 14 days of age).
- Collect screening results, demographic and medical home data on the approximately 53,000 infants born in the state each year.
- Perform direct outreach to the approximately 1,200 to 1,300 families whose newborn does not pass a NBHS to ensure appropriate follow-up.
- Document that hearing loss is either ruled out or confirmed in infants who do not pass their NBHS before they are three months of age.
- For infants diagnosed with a hearing loss, assist the family with enrollment into an appropriate early intervention program as early as possible or before the infant reaches six months of age.
- Assist families in obtaining parent to parent support and provide a Parent Notebook to all families of children diagnosed with hearing loss.
- Assist families who may not have appropriate resources to obtain state-of-the-art amplification. One of the ways this will be accomplished is through the Children's Hearing Aid Pilot Program (CHAPP) (referenced in Attachment 7).
- Conduct on-going analysis of programs, projects and data systems to determine barriers to follow-up and disparities to receiving care (needs and gaps) which will lead our Quality Improvement (QI) efforts in reducing loss to follow-up / documentation that will be the focus of this funding opportunity.
- Utilizing the Utah Newborn Hearing Screening Advisory Committee (NBHSAC) with the addition of a new QI expert to guide our efforts in order to maximize our effectiveness at reducing LTF-U/D and assist in QI projects. This committee meets quarterly with mandated and consultant specialties represented and will be utilized as Utah's "QI Committee" Stakeholder team. (See methodology section and Attachment 9.)

By initiating a number of new activities focused on QI, this grant project's goal is to significantly reduce LTF-U statewide. This funding opportunity will continue our

successful efforts to screen children for hearing loss, provide outreach to families whose newborn does not pass a hearing screening or misses a screening, support families throughout the screening process and provide parent to parent support after diagnosis. The HI*TRACK data management system will continue to be used to collect the data necessary to evaluate the success of the QI initiatives carried out by this project.

The target population includes all children born in Utah, including those born in hospitals, free-standing birthing centers, those born at home, as well as those babies who are residents of Utah, but born in another state (border babies) and those babies shown as born in Utah but move to another state. With this project, EHDI staff will continue work with neighboring states so that babies born in Utah who reside or move to another state get connected to their state's NBHS program.

The EHDI Team is committed to providing quality care to all families. That commitment to quality includes assuring access to services for all families – regardless of their financial situation. This project will provide high quality information, services and materials delivered by competent providers to all families that shows respect to the diversity and cultural richness of populations served and will accommodate their language needs. The goals of this project will include families as partners in decision making at all levels, including QI. The Utah EHDI staff will determine families' level of satisfaction with services, strive to ensure that infants and young children with hearing loss receive ongoing care within a medical home, and conduct outreach efforts to advertise the availability of UDOH's charitable hearing aid programs to assist in the achievement of the JCIH 2007 goal of amplification within one month of hearing loss diagnosis.

NEEDS ASSESSMENT

The target population for this project is all live births in Utah (and their families). The most recent published report from the Utah Department of Health's Center for Health Data (Utah's Vital Statistics: Births and Deaths, 2012), showed that Utah had 51,439 live resident births, of which 78.4% were Caucasian, 14.7% were Hispanic, 3.6% were Asian or Pacific Islander, 1.2% were American Indians, and 1.0% were African-American. Additionally, 1.1% of the birth certificates were marked "other" or left blank. The land area of Utah is 84,897 square miles with the number of persons per square mile being averaged at 33.6 as compared to the average persons per square mile in the United States, 82.7. 95% of the state's land mass is considered rural or frontier. Resident births for 2012 show that 82.1% of births occurred in urban areas, 17.3% of newborns were born in rural areas (more than six but less than 100 persons per square mile) and 2.7% were born in a frontier area (six or less persons per square mile). In addition, 28 of Utah's 29 counties are designated as Health Professional Shortage Areas and twenty-two counties are designated as Medically Underserved Areas. In these areas, access to health care and appropriate medical and audiological follow-up

is difficult, at best, or impossible to obtain. In the recently released 2013 Annual Report of America's Health Rankings®, although Utah is the 6th healthiest state in our nation, one of our biggest health challenges is the limited availability of primary care physicians.

Universal newborn hearing screening is done at all 43 birthing hospitals, as well as the intermountain region's pediatric specialty hospital, Primary Children's Hospital (PCH) in Salt Lake City. Utah also has twelve small free-standing birth centers that provide NBHS services. All hospitals report hearing screening data weekly to the State (Utah Department of Health) with the HI*TRACK data management and tracking software. Approximately 1.3% of Utah newborns are out-of hospital births. The latest complete year (2012) of hearing screening data (see Attachment 6, HI*TRACK Flow Chart Report 2012) show that 98.7% of occurrent (52,518 occurrent births reported by Vital Records, 52,402 babies reported in HI*TRACK) births received hearing screening (inpatient and outpatient screenings). Of those screened and reported in HI*TRACK, 95.2% passed the initial screening and another 3.4% of total babies screened passed the outpatient screening or rescreening (documenting pass results for 98.6% of babies screened). Current tracking data shows that 465 infants have no definitive hearing diagnosis following failed initial and/or follow-up screening or results have not yet been documented in HI*TRACK; 213 of those babies did not return following the initial failed inpatient screening. 557 babies were never screened due to infant deaths, parent refusal, and unknown reasons. Of those, 288 are home births that may not have had immediate access to hearing screening or hearing screening was not reported to state EHDI. There are 116 babies counted by Vital Records not reported in HI*TRACK due to program contractor changes – the old hospital newborn hearing contractor is responsible for reporting, but can no longer access hospital records, and the new contractor cannot access information prior to their contract. These 2012 babies are truly lost to the HI*TRACK system.

The HI*TRACK data and tracking system lists a medical provider entered in only 40% of hearing screening records for 2012 births. Currently, there is no way to confirm that the provider listed in the child's hearing screening record is indeed the child's Medical Home, or if it is simply the provider (on call) who evaluated the baby in the newborn nursery. Beginning July 1, 2013, Utah law (26-10-10) requires referral for CMV PCR testing following two failed hearing screenings. Efforts to link babies to a medical home and then have access to accurate information about that medical home is essential to assure referral for the appropriate testing within 21 days of age. During the upcoming grant project, HI*TRACK programmers will develop a tracking module specific to CMV to more accurately report the correct primary care provider, referral for CMV testing, CMV timelines and results. This NCHAM data project will be the subject of one of Utah EHDI's presentations at the National EHDI Conference 2014 entitled, "Addition of Congenital Cytomegalovirus Testing Data Management to an EHDI Data System".

Developing and sustaining family-to family support is a focus area of intervention activities in Utah. The Parent Infant Program (PIP), the Early Intervention Program that provides services through the Utah Schools for the Deaf (USDB), is represented on Utah's NBHSAC (see Attachment 9, Utah NBHS Advisory Committee), and collaborates with Utah's EHDI program, early intervention services, and parents. With the addition of their new Deaf PIP Director, their family friendly focus has expanded to include much sought after and newly hired deaf ASL mentors as well as a plan to trial a Guide By Your Side program. Referral information is shared between State EHDI and PIP, yet the recently CDC-required IFSP dates are not currently shared. A plan is in development to obtain that information. At present, every other month, state EHDI receives new enrollment or change in status information from USDB PIP. Utah's EHDI program partners with and supports the AG Bell-Utah Chapter activities providing family-to-family support, which has just been re-invigorated with the hiring of a new executive director. Currently, the Utah EHDI Program does not document the number of families involved in or who have access to family-to-family type support but feels this is an essential part of the EHDI process, and would like to propose this as a future research project.

Although there is almost universal support for the concept of early identification of hearing loss throughout Utah, many important challenges still remain. Specifically, infants who do not receive appropriate follow-up after failing the initial newborn screen, and infants who don't receive a timely diagnosis after failing a second screen highlight weaknesses in our current system. Infants diagnosed with a hearing loss not receiving timely and appropriate intervention services (including the connection to a medical home), are always a priority, however, achievement of the "6" of CDC's 1-3-6 EHDI goals has shown significant improvement during the current grant period in Utah. 2011 CDC Data shows that LTF-U/D is 12.5% in Utah compared to the national average of 26%. Utah data reported to the CDC in 2011 also highlight our areas in greatest need of improvement: 31.5% of infants in Utah not passing inpatient NBHS did not receive outpatient NBHS (compared to a national LTF-U/D of 12.1%) and 55.2% of infants in Utah had no diagnosis following failed NBHS (compared to a national LTF-U/D of 35.3%).

Results of the most recent (December 2013) EHDI survey obtained from key stakeholders in Utah revealed that many challenges and barriers to effective follow-up exist in our state. The survey was distributed to all Hospital NBHS Coordinators, Supervising Audiologists and Homebirth/Birth Center Midwives. Six questions were asked: 1) What do you feel contributes the most to LTF-U between a failed first newborn hearing screen (typically inpatient) and completing a second screen (typically outpatient), 2) What do you feel contributes the most to LTF-U between a failed second screen and completion of a diagnostic evaluation, 3) What do you feel contributes the most to an eligible child not enrolling in early intervention, 4) What problems / comments

/ feedback have you encountered from stakeholders re: the mandated CMV testing, 5) What contributes the most to loss to documentation, 6) If a magic wand could be waved, what has the most potential to decrease your program's LTF-U.

Most programs feel that LTF-U between the first refer and a second screen is due mainly to lack of parental interest and education, as well as difficulty for some to get back to the hospital for the rescreen, especially with certain demographics. It was noted that transportation, job and child care, as well as the language barrier can make it difficult to get parents to return. There were multiple facilities that said that lack of rides/gas money is an issue. There are also those parents who see that baby responds to sound so they don't think there is a problem or need to return. One response from a traveling audiologist (USDB) reported that even with an appointment scheduled for her to come to the families house to screen, they are often not even home at the scheduled appointment time.

For LTF-U between the second refer and a diagnostic exam, parental compliance is again a major issue. Since there are fewer facilities to go to for diagnostics, it is harder for families to get to these appointments, and many are concerned about the expense. Many of these families do not have the resources or a large enough concern to follow through with a diagnostic appointment. There are also a few smaller hospitals that pride themselves in the fact that once they have a second refer, they send them straight to an audiologist and have no families that have been lost to follow-up. The last concern mentioned is that NICU babies who have other health issues sometimes have a major lag in time to diagnostics and this is an issue that needs to be addressed. As part of new CDC reporting guidelines, optional fields have been added to report infants who were in a NICU for more than 30 continuous days. While this does not directly address the lag in time to diagnostics for NICU babies, it will assist in reporting and validating data.

While all children with a hearing loss are (or should be) referred to Early Intervention, it has been found that not all families enroll in the program. Most of the responses to this issue is that families don't seem to have the time (because they have other kids, work, etc.) or they don't understand the importance and impact to their child. Three responses showed that there seems to be a gap in knowledge where diagnosing audiologists are not making a referral to PIP so the family does not know that resource is available. One response noted that PIP does not follow through once the referral has been made, which is the first time we have received such feedback.

Since Utah's CMV testing mandate has been implemented the most common note from screening programs and audiologists is the lack of awareness of the PCP, those who have outdated knowledge of CMV and have an unwillingness to proceed with testing, some who are unaware of their role in the process and how to go about the testing (create a standing order), and others who are completely on board. Many programs have not heard any feedback from PCP's yet. One audiologist has even gone

to the effort of sending a packet with the fax form with information (from the state site) on CMV, the flow chart, information on how to collect samples and what labs can process them. This particular audiologist feels that it is a lot more work for the Audiologist to carry this out and that this effort is totally separate than their contracted jobs of overseeing the hearing screening portion.

When asked what contributes the most to loss to documentation, answers ranged from the screener knowing they forget to enter follow up results, babies being lost when they are transferred, other professionals not being educated on reporting requirements, to the possibility of data dropping when transfers were made to the state. One audiologist commented that there needs to be more communication in the audiology community; there are many times that the child has been seen but not reported.

Those magical wands, they would be used to create more time to work on LTF-U, solve parent socioeconomic issues, help parents to understand the ramifications of hearing loss and increase their commitment to complete follow-up, give rural hospitals ABR screening equipment, allow screeners to go to the families homes or for pediatricians to complete the screening.

The survey responses, analysis of HI*TRACK data, and anecdotal information obtained via formal and informal means elucidate the following pervasive barriers to 100% successful completion of 1 (Utah: ½ or 14 days) -3-6 EHDI Goals:

- A shortage of audiology services in rural areas – specifically, those trained to work with newborns and infants.
- Lack of access; both geographical and economical.
- Inadequate or misinformed educational counseling on the importance of NBHS and the importance of follow-up.
- Lack of adequate private insurance or personal funds to cover the full cost of diagnosis, amplification, and other intervention services.
- Healthcare providers are not always aware of all the programs available to support families or how to guide them through the follow-up process.
- Physician knowledge and attitudes regarding hearing loss are improving but the “wait and see” approach is still pervasive.
- A general lack of understanding among parents regarding hearing screening, hearing loss, the importance of follow-up, and early intervention.
- Language barriers for Hispanic populations still exist—hearing professionals lack the educational resources and interpreter services to adequately care for this growing population.

This information will be interwoven throughout the activities and strategies of this project. Reducing LTF-U for infants failing to pass NBHS will be addressed through QI activities as a collaborative effort involving a wide-range of agencies and groups. This project brings together the Utah NBHSAC aka the “QI Committee”, the National Center

for Hearing Assessment and Management (NCHAM), the American Academy of Pediatrics (AAP) EHDI Chapter Champion, the Utah Department of Health (UDOH), the Utah Baby Watch Early Intervention Program (BW/EI) and the USDB Parent/Infant Program (PIP), the Utah Department of Health's Children with Special Health Care Needs (CSHCN) Clinics, Child Health Advanced Records Management Project (CHARM), Utah Regional Leadership in Neurodevelopmental Disabilities Program (URLEND), Primary Children's Hospital (previously known as Primary Children's Medical Center), the University of Utah Medical Center Department of Pediatrics (UPIQ), the Utah Chapter of Family Voices, and various community partners to implement, evaluate, and monitor the effectiveness of these strategies in creating sustainable systems change. (See Attachment 10, Letters of Support.)

Much progress has been made in the past several years and a solid foundation is in place currently for the development and continuation of an exemplary, sustainable EHDI program in Utah. There is however, much that remains to be accomplished with respect to hospitals having access to and inputting all necessary demographic fields in Hi*Track to allow for a match with Vital Records, screeners imparting the necessary urgency to families of timely follow-up, using 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.

Although the HI*TRACK system provides fields for maternal race, ethnicity, and education, hospitals have been inconsistent in entering that information since state law does not require it be reported to state EHDI. The linkage between Vital Statistics and the EHDI program, which has been accomplished through CHARM, will enable the EHDI program to report all of the necessary data on matched records on the CDC EHDI Hearing Screening and Follow-up Survey.

Successful EHDI programs depend on accurate tracking and follow-up. All babies referred from NBHS programs must receive appropriate and timely diagnostic, audiological, medical, and early intervention services. Utah has successfully reached the benchmark of screening 98% or greater since 2002, due in part to our data management and tracking system. There have been continual challenges, though, in assuring timely completion (prior to 3 months of age) of a diagnostic evaluation.

Effective tracking of infants from screening through diagnosis and then to early intervention remains the most essential task. Utah's EHDI data system (HI*TRACK) tracks approximately 53,000 infants born each year. The HI*TRACK system, developed by NCHAM, has fields for over 200 variables related to demographic, medical, and contact information about the baby and mother, results of screening and diagnostic measures, and status relative to diagnosis and intervention. An electronic interface connects HI*TRACK to the Electronic Birth Certificate to match and upload demographic information required by the 2012 CDC EHDI Hearing Screening and Follow-up Survey (HSFS), and provide viewing access to potential high-risk issues for

each birth (from the birth certificate worksheet). The HI*TRACK system is backed-up daily to ensure that information is not lost. All birthing centers and hospitals report individual screening results to the UDOH weekly. On a monthly basis, HI*TRACK tracking reports are generated at State EHDI and used to monitor hearing screening and follow-up activities statewide; these analyses are ongoing and continuous. The monthly reports are then distributed to each NBHS program statewide listing those infants on whom we have not yet received information or are LTF-U. Our Quarterly Quality Indicator reports are used to evaluate state and local programs and to identify and respond as quickly as possible to specific needs in individual hospitals and screening programs.

Analyses of data from Utah's EHDI tracking system highlight a number of challenges to reduce LTF-U and meet the timelines for diagnosis and referral to intervention programs. As previously mentioned twenty-eight of Utah's 29 counties are designated as Health Professional Shortage Areas, and 22 counties are designated as Medically Underserved Areas. In these areas, access to health care and appropriate medical and audiological follow-up is difficult and/or impossible to obtain. Parents of babies who are 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 financial support.

All birthing facilities are required to report weekly to the State EHDI Program on all births (through direct upload to the State database through web-enabled HI*TRACK or through encrypted electronic transfer files). Midwives in attendance at homebirths or deliveries at free-standing birth centers are also required to report to State EHDI. This is still done through hard-copy screening forms faxed, mailed or sent by secure email at the time of the screening, with a summary report of their births due to State EHDI by the 10th of each month. Babies and results are added to the HI*TRACK system manually by EHDI staff. Additionally, anyone who conducts a procedure necessary to complete an infant's hearing screening or audiological diagnostic assessment (audiologists or physicians) is required to report the results to State EHDI. In spite of this rule, an additional challenge has been educating and reminding health care providers to report current information regarding the hearing status of children referred to them from hearing screening programs. Many hours are currently spent by EHDI staff procuring the information and reports that should be reported immediately (and without request) to the State EHDI office. QI initiatives for reporting data and decreasing LTD are planned for this grant.

Quarterly, data from the EHDI tracking and surveillance system is summarized and reported to the state NBHSAC. This report includes information for each birthing facility: percent of infants screened, referred, and evaluated; babies referred for diagnostic evaluation; and status/outcome of audiological testing, including confirmed hearing loss and LTF-U rates. EHDI data from HI*TRACK is also used to make hospital-by-hospital

analyses and to identify problem areas with regard to infants not screened (i.e. refused, lost, missed, broken appointment, etc.) and the timeliness of the diagnostic process (such as needing a diagnostic auditory brainstem response (ABR) test, medical follow-up, risk monitoring, etc.) However, it is clear that even though screening is happening for almost all births, additional activities are still necessary to identify babies with hearing loss and provide them and their families' timely and appropriate services.

The need for privacy, confidentiality and security policies in Utah's Newborn Screening Programs and the subsequent short and long-term follow-up remains a significant priority. Sharing of NBHS results is common and necessary for effective and timely management. Secure communication is critical to the patient-family/physician/audiologist relationship, contributing to the quality of care and improved health outcomes. The integration of the newborn screening results data (heel stick and hearing) with the Utah cHIE (clinical Health Information Exchange) virtual health record, presents unique challenges with respect to appropriate sharing and transmission of results. Private and secure solutions are needed to facilitate electronic reporting or web access to screening results by the parents and/or parent-authorized health care providers. Utah law allows the UDOH to disclose NBHS results for treatment purposes. As Utah moves to provide accessible newborn screening results and related data through the cHIE and the CHARM system, it is important for health care providers, the patient-family and others involved in reporting, to better understand the application of privacy and security laws. Gaining this understanding will enable the appropriate sharing and exchange of newborn screening results. In addition, addressing privacy/security concerns and/or policy gaps, can alleviate barriers to the effective and timely exchange of newborn screening and follow-up information. Since effective EHDI programs must share information and one of the best ways to share information with appropriate providers is through electronic communication, this project will not only address data sharing opportunities, but will continue to concentrate on any issues related to privacy and confidentiality of shared child/family information.

METHODOLOGY

A methodological approach that uses collaborative partnerships, incorporates best practices, utilizes lessons learned from other EHDI programs, and takes advantage of national and statewide expertise and resources will guide the achievement of project goals and objectives. Implicit in each individual goal of this project is the overarching goal to screen all babies for hearing loss before 14 days so that CMV testing can be done prior to 21 days of age if needed, complete a diagnosis for those who fail the screening before three months and provide appropriate early intervention services, including amplification, before six months.

As aforementioned, Utah has been a solid performer in the achievement of screening infants prior to one month of age (>98% screening rate since 2002), and has shown significant improvement in referring and enrolling eligible children into early intervention prior to six months (52.6% of eligible children were enrolled by six months of age for 2009 births; 65.5% were enrolled by 6 months for 2011 births according to published CDC HSFS data: <http://www.cdc.gov/ncbddd/hearingloss/ehdi-data.html>).

Diagnosis prior to three months of age continues to be a challenge; 57.1% of 2009 births failing two hearing screenings had completed diagnosis by 3 months of age, with 56.7% of 2011 births completed by 3 months. This area requires more directed efforts in reducing loss to follow-up / documentation.

Utah has a well-established NBHSAC that meets quarterly. (Attachment 9). This committee will share in the responsibility to monitor the progress of this project. 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. The more the stakeholders are involved in each aspect of the “project”, the greater the sense of ownership of the EHDI system statewide. With a broader ownership comes a greater commitment to sustainability and a wider base of support.

To accomplish the stated purpose of this funding opportunity, Utah EHDI will be transforming our NBHSAC with a reinvigorated focus on QI. As can be seen in Attachment 9, our current committee represents a wide array of EHDI stakeholders: managing audiologists from large birthing centers, the rehabilitation director from Primary Children’s Hospital, National Center for Hearing Assessment Management (NCHAM) (both the director and EHDI project coordinator), representatives from early intervention (both state Baby Watch and USDB PIP), out of hospital births (we added a midwife chapter champion during the current grant year), neonatology, family physicians, pediatricians, otolaryngology, health insurance industry, Utah Hospital Association, public health nursing, parents of a hearing impaired child (consumer representatives), and a state Medicaid representative as part of the UDOH Children’s Health Improvement Collaborative. In addition, we have included a new member starting in 2014 that is an expert on quality improvement. This new member is the Senior Program Manager of the Children’s Healthcare Improvement Collaboration (CHIC) and the Utah Pediatric Partnership to Improve Healthcare Quality (UPIQ). This committee is also comprised of all Utah EHDI team members: our EHDI Director, Follow-Up Coordinator, Data Coordinator, Audiology Coordinator and our three Ehdi-ologists (audiologists). This committee will meet quarterly: in February, May, August and November. In addition to these full-committee quarterly meetings, the Utah EHDI team will meet on a weekly basis and will devote a portion of each week to our PDSA cycles / quality improvement activities.

Utah participated in the National Initiative for Children’s Healthcare Quality

(NICHQ) Newborn Hearing Screening Learning Collaborative in 2008. A NICHQ EHDI interdisciplinary team was developed and participated in collaborative discussions, projects and meetings. The emphasis was on implementing small tests of change to improve the follow-up from screening and diagnosis. These change cycles, referred to as Plan, Do, Study, Act (PDSAs), provide the opportunity to investigate changes that resulted in successful outcomes. During this NICHQ collaborative, Utah EHDI projects included an exhaustive manual chart review of every current child in foster care in Utah “Fostering Healthy Children”, a beta test with several hospital screening programs to request two points of contact for all babies, development of a parent roadmap for families that fail NBHS, a midwife home birth screening trial, and a project that tracked how long it took families to get scheduled for a diagnostic audiology appointment at the regional children’s hospital. (This information gathered from the last project was instrumental in providing documentation that allowed the hospital to purchase additional diagnostic equipment and shorten wait times for families). Our previous HRSA funding has supported the successful implementation of a number of NICHQ quality improvement strategies, including adding hearing screening results to records of all children under the age of three in foster care, purchasing equipment for midwives to screen babies, developing a script for the screener’s message to families, a beta test with using fax-back forms between screeners and physicians, attempting to document every infant’s primary care provider, identifying a second point of contact for the family, making a rescreening and/or audiology appointment before the family leaves the birthing center or hospital, telephone reminders for appointments, scheduling two audiology appointments two weeks apart at hospital discharge (which was met with some resistance), streamlining the EI referral process (the Audiologist is charged with the referral to PIP; in addition, Utah EHDI makes a secondary referral when the diagnosis is completed in HI*TRACK and Parent Notebook is sent to family), and creating a parent roadmap.

At the 2013 Annual Utah EHDI Conference, all attendees (Screening Coordinators and/or Audiology Coordinators) were surveyed to determine which NICHQ initiatives they still utilize in their hospital screening programs. Of the eight initiatives on the survey, five are still being used by over half of the respondents. 90% of the screening programs verify the PCP of the infant prior to discharge if the infant does not pass the hearing screening, one facility has not had a baby refer and 2 facilities recommend that the family seek a provider, but do not verify. Half of the programs make a confirmatory call to the PCP on a baby who refers, but it should be noted that in the follow-up question of how many notified the PCP by phone or fax within 2 business days, all but two hospitals confirmed that they do this. Over half of the programs are collecting a second point of contact, but during the next grant year every program will be required to collect 2 points of contact. This extra contact should help reduce LTF-U. In recent months, the State EHDI program has been examining the success of using fax back

forms from the hospital program to state EHDI to report a refer on the first screen. For this survey, more than half of the programs reported that they are utilizing this, but State EHDI reports that only 3 hospitals consistently send the fax back form requested for this initiative. Since hospital programs are already contacting the family to remind them of the follow-up appointment record on the fax back form, the work is being duplicated by the program and state EHDI. Because of this, we are re-evaluating this initiative. All but two hospitals make a follow-up appointment at the time of refer; there is one hospital that has a general recommendation for parents to come back in two weeks. Half of programs report that they document race/ethnicity. Most of those who do not report this, responded on the survey that they did not know they needed to document this information. The last initiative on the survey was distribution of the Parent Roadmap at time of initial refer. Again, half of the programs reported that they do distribute the Roadmap.

The main methodology for achievement of Utah's EHDI goal to reduce LTF-U/D by 5 % each year of this new grant cycle will be through the utilization of the PDSA model as the framework in developing, testing and implementing changes for improvement in Utah's EHDI System. Specifically, we will implement small tests of change to evaluate the change strategies that we have identified through our Needs Assessment. These change strategies will involve implementing PDSA cycles to decide what changes lead to improvement to guide our process of goal / aim achievement. Data obtained from these small, focused tests, will be analyzed both in terms of process measures and outcome measures. Successful changes, i.e. those that lead to improvement, will then be implemented on a larger scale with the ultimate goal of spreading successful changes throughout our whole EHDI system. We anticipate that the PDSA cycles planned for the first grant year, will guide our aims for the following year, and success will be shown through the data we report to the CDC.

Although this funding is specifically for targeted intervention for reducing LTF-U/D utilizing QI methodology, the following goals and objectives for Utah EHDI are always present:

- Sustain the success of Utah's NBHS programs by formalizing and standardizing the most efficient and effective methods to track infants throughout the NBHS process
- Create opportunities for new and increased collaborative relationships. The proposed project will build upon our existing long-time partnerships, while at the same time supporting the expansion of new and renewed relationships that will include local health departments, Early Head Start, OBGYN, Family Practice and ENT physicians, Title V Programs such as Women, Infants & Children (WIC), and the Office of Home Visiting (OHV).
- Improve the quality of the EHDI data to ensure better data sharing and follow-up capability for all infants who fail newborn hearing screening

- Assure that children who fail the hearing screening will receive follow-up diagnostic services and access to early intervention in a timely manner
- Evaluate and update the existing (individual) hospital and birthing center protocols and script for screening, information and referral, and reporting results to families on a continual basis
- Provide screening services for newborns through CSHCN itinerant clinics
- Increase parent support statewide for families who have children who are deaf or hard of hearing and increase families' awareness of family support organizations
- Provide opportunities for professionals working with young children with hearing loss to increase their capacity to provide age appropriate services. Medical Home and clinical decision support is imperative to assure high quality care and coordination of care for infants and children diagnosed with hearing loss. However, the expertise of primary care clinicians, appropriate infant and pediatric audiology skills and training and coordination of care across providers and access to resources and support for parents is often suboptimal, especially in rural Utah. The Utah EHDI team believes that it is part of our responsibility to provide mentoring, training, and educational opportunities for the many EHDI stakeholders across the state. Their knowledge and skills help assure the sustainability of NBHS in Utah.
- Assure that all EHDI focused educational materials are culturally sensitive and accessible to non-English speakers. UDOH's CHSS program and CSHCN bureau has a dedicated Spanish-speaking social worker of Latino background who acts as a liaison between our programs and Latino families, providing interpreting for spoken communication and translation of all our program forms and brochures into Spanish. He also assures cultural competence by providing assistance and insight on the Utah Latino culture to our providers.

The following section explains the specific quality improvement aims and strategies that will be utilized during this first grant year.

WORK PLAN

The proposed work plan for the first grant year will consist of five aims which are all underneath the umbrella of the overall project goal of decreasing LTF-U/D (as reported through the CDC annual EHDI survey) by 5% in the state of Utah. As with all state EHDI activities, care will be taken to improve communication and foster healthy relationships across our culturally diverse population. As previously noted, Utah has a functioning statewide EHDI Tracking and Surveillance System (HI*TRACK).

Additionally, the CHARM data integration project is continuing to integrate this system with other appropriate state databases and service systems. Having the infrastructure of these systems in place enhances Utah's ability to meet the goals of this project and the

state EHDI Program. Accomplishing our goals will require the active participation of many stakeholders.

The following section describes the aims of the first grant year and their proposed PDSA activities, delineating the specific need behind the aim chosen and the methodology chosen.

Need (Aim 1-2) : For 513 children referred for diagnostics in 2012, 25% received diagnostic testing by 3 months with the average age of diagnosis at 1 month; 27% received diagnostics late with the average age of diagnosis being 7 months; and 48% are overdue with no confirmed diagnosis. Of the 248 children who are overdue for diagnostics we know that a number of them have received a diagnostic evaluation but have not had a confirmed diagnosis due to middle ear fluid; while others have not received a diagnostic exam. For this grant year we will investigate two aspects of the delay in confirmation of hearing. One is the delay from the 2nd refer to the diagnostic appointment (Aim 1) and one is the delay once the infant has entered the diagnostic process to receiving a confirmed hearing status (Aim 2).

Aim Statement #1: By March 31, 2015, Utah EHDI will reduce the average time from 2nd failed screening to diagnostic evaluation by one month (with the project goal to achieve the “diagnosis before 3 months” goal to comply with the CDC 1-3-6 guidelines by the end of this funding cycle).

Plan: Review program summaries for each Utah hospital. Determine which hospitals do not schedule a diagnostic appointment at the time of 2nd refer.

Do: Choose 2 hospitals that do not schedule a diagnostic appointment at the time of 2nd refer. For the next 5 refers at each chosen hospital, the screener will schedule an appointment with a diagnosing audiologist (chosen by the family) while the family is there.

Study: The hospital coordinator will track those families to see if they kept the diagnostic appointment and report back to State EHDI.

Act: If these appointments were kept, do another PDSA with more families, eventually spreading to more hospitals. If those diagnostic appointments were not met, re-evaluate the process.

Methodology for Aim 1: Review program summaries for each hospital in the state of Utah. Determine the process each hospital takes after the child refers on the 2nd screen. Choose two hospitals that do not schedule a diagnostic exam for the patient at the time of refer. Contact the hospital coordinator of each of these hospitals. For the next five patients that refer the 2nd screen, the screener will call to make an appointment with a diagnosing audiologist before the family leaves the office (the diagnosing audiologist will be chosen by the family, using the State’s Guide to Pediatric Audiologists booklet or EHDI PALS). This initial test will be done with hospitals that have diagnosing facilities nearby, with spread to hospitals in rural areas with fewer diagnostic sites available once

feedback has been received on this project. The screener will review how many of these patients kept their diagnostic appointment. The same two hospitals will then complete the same process with ten patients. Data will be collected for how many patients kept appointments for diagnostic exams. Once data is collected, this will be spread to include more hospitals and more patients. If this is successful, new protocols will be created for hospital screening programs to require a diagnostic exam be scheduled for every 2nd refer.

Aim Statement #2a: By March 31, 2015 we will reduce the number of infants who go beyond three months between failed screening and follow-up due to middle ear issues by 5% by working with ENTs to re-evaluate follow-up protocol.

Plan: Complete a data review to find out how many of the 248 children from 2012 who are overdue for diagnosis have had an initial diagnostic evaluation. Of those children, determine how many were referred to ENT due to middle ear issues, and which ENTs are referred to most often.

Do: Choose the two ENTs who receive the most follow-up referrals. Create a survey for the ENTs to evaluate their protocol when a child is referred to them after failing NBHS. Call ENT office and complete survey.

Study: Evaluate the results of the survey from the ENT. Determine what changes can be made to decrease the time in follow-up for children who have middle ear issues.

Act: Edit and update the survey based on responses to the questions, repeat this survey with two more ENTs in order to get more input. Schedule a time to meet with the ENT group to discuss ideas and educate re: timely diagnosis and reporting to state EHDI to decrease the time in follow-up based on replies to the survey.

Methodology for Aim 2a: Review Hi*Track data to determine how many children are “in process” with an incomplete diagnostic exam. For all children that are “in process” review diagnostic reports to determine how many of those children have been referred to an ENT due to middle ear issues. In the reports, record which ENTs children are referred to most often. Choose two ENTs that audiologists refer to most often. With input from the EHDI team and the NBHSAC, create a survey to be given to the ENTs. Complete the survey with the ENTs over the phone. Evaluate the results of the survey, revise and repeat with two more ENTs. Review results with the EHDI team and NBHSAC to determine if there are new protocols that can be proposed to the ENTs. Given the success of the survey, revise as necessary and repeat with more ENTs until enough useful information is received to make a change to protocols. Once protocols are revised with ENTs, success can be measured by the decrease in number of children who stay “in process” with no confirmed hearing diagnosis.

Aim Statement #2b: By March 31, 2015 we will increase the number of infants who receive confirmation of normal sensorineural function, despite middle ear involvement,

via bone conduction (BC) auditory brainstem response (ABR) testing prior to 3 months by 5 %.

Plan: Select one pediatric audiologist in the state that has BC ABR testing capability, expertise and sees a consistent number of babies every week. In the presence of abnormal middle ear function, BC ABR testing will be routinely done at all diagnostic evaluations in order to determine sensorineural function so that a confirmed diagnosis can be garnered.

Do: For two weeks the audiologist will perform BC ABR testing on any child he/she sees with abnormal middle ear function.

Study: Determine the feasibility of routinely performing BC ABR to ascertain sensorineural function. If so, calculate the decrease in time between failed second screen and confirmed diagnosis.

Act: If successful, expand this testing concept to other audiologists to include in their routine testing protocol.

Methodology for Aim 2b: Select a pediatric audiologist that has BC ABR testing capabilities. Schedule a meeting with this audiologist to request their support. For the next two weeks, the audiologist will perform BC ABR on any infant with abnormal middle ear function. Determine how many of those infants received a confirmed diagnosis after BC ABR. Based on the success of the previous steps, increase the trial period with this audiologist to one month. Review data of the past month's results to determine if there is a decrease in the time between failed 2nd screen and confirmed diagnosis. Based on findings, spread to additional audiologists with a longer trial period. If successful, educate on a statewide basis the importance of BC ABR to reduce time to diagnosis.

Need (Aim 3): In 1998 the Utah legislature passed a law requiring that all hospitals in Utah birthing greater than 1500 births/year were to see that each infant was given a hearing screen prior to hospital discharge. In 1999 this same law required all birthing facilities, no matter how small, to meet the same requirement. All out of hospital births (OOHB) were also to have a hearing screening before 1 month of age. The OOHBs are, for the most part, attended by a midwife. Initial compliance to this mandate was positive for the hospitals and is currently at 99%. OOHB screening compliance was about 12% for being screened in 2007. In that year OOHB's became a priority and an effort was made to enlist the cooperation of midwives to screen infants. At initiation of the Home Birth Hearing Project in 2008, four otoacoustic emission (OAE) screening units were placed with cooperating midwives who had high birth numbers. Hearing screening percentages grew from 12% to 41% in the first year of the project. Midwives involved in the project were given training on the screening and reporting process. As of October 2013, there are a total number of 20 OAE units placed primarily with midwives who birth the most infants. There has continued to be a steady increase in screening percentage and we are currently (01/2013 to 06/2013) at 81% screened in

the OOHB population. There are 75 registered midwives throughout the state of Utah, 40 of them now having direct access to hearing screening equipment. If we could pair all midwives with access to equipment we could reduce the number of infants and increase percent screened to >86%.

Aim Statement #3: By March 31, 2015 reduce the number of infants born out of hospital who are not screened by 5%.

Plan: Regionalize state owned hearing screening equipment using cooperating midwife resources to improve distribution and availability to all midwives.

Do: Obtain a listing of all midwives in Utah and pair the “have equipment” midwives with those who “have not”. Enlist a midwife consultant to assist in identifying and resolving barriers.

Study: Monitor for increase of infants screened. Adjust as necessary.

Act: Maintain cooperative energies making adjustments as necessary to provide hearing screening access to attendees of Utah births.

Methodology for Aim 3: Update the MOU for midwives using state-issued equipment.

For all midwives in the state of Utah, identify those who have equipment (whether “state-issued” or “personal equipment”). Pair the midwives who have equipment with those that do not. Review pairings with Midwife Advisor to ensure successful teamwork and collaboration. Contact two midwives with equipment to review the MOU and discuss pairing/collaboration in other local midwives. Establish baseline of OOHB not screened. For one month, track how many births from the two midwife groupings were screened and determine if there was an increase in the screening rate. Coordinate with the Midwife Advisor and midwife groups to discuss needs and challenges of this goal. If successful, spread to regional and statewide levels.

Need (Aim 4): Utah is a state with many hospitals in rural (<1500 babies) and frontier (<150 babies) regions that are as far as 194 miles away from pediatric diagnostic services. It would seem that these facilities would have the most difficult time getting their babies back in for their second hearing screening or diagnostic evaluation; however, two hospitals with the highest LTF-U are 36 miles and 54 miles away from pediatric diagnostic services. One of the hospitals with the highest LTF-U rate has an in-house pediatric audiology team that can perform NBHS and complete diagnostic evaluations. An example of a targeted hospital would be Total babies screened (4234/4254); however, out of the 94 babies that did not pass, 82 babies still have no diagnosis or are lost-to-documentation.

Aim Statement #4: By 3/31/2015, decrease the LTF-U rate by 5% by providing targeted intervention: identify 3 hospitals’ needs and challenges, create site-specific EHDI goals, and implement tests of change using their own unique PDSA strategies.

Plan: Develop hospital report card and use to select three hospitals with the highest LTF-U rate.

Do: Coordinate with managing audiologist and coordinator to set site visit date. Meet with each hospital to review program summaries and write new goals specifically related to reducing LTF-U within their program. A change cycle will be implemented as appropriate.

Study: Hospital program will monitor timely completions of second screen and/or diagnosis.

Act: If successful, hospital program will implement this change in process and make it a permanent part of their protocol. The strategy will then be spread to other hospitals.

Methodology for Aim 4: Three community hospitals with the highest Lost-to-Follow-Up (LTF-U) rate will be targeted to assess where the breakdown between the first screening, second screening, and diagnostic evaluation are occurring. Our first PDSA cycle will begin with creating a hospital report card that includes the hospital's inpatient screening, outpatient screening and diagnostic completion before 3 months compared to the Utah average. Each hospital's program summary will be reviewed to ensure they are following JCIH recommendations and best practices. The hospital managing audiologist, coordinator, and State EHDI audiologist will meet in person to discuss the needs and challenges of their NBHS program. The end goal of the site visit will be for the audiologist and coordinator to create site-specific EHDI goals that target their specific needs/challenges, creating more buy-in of their NBHS program.

Need (Aim 5): EHDI materials available throughout the U.S. were reviewed by Utah EHDI staff, and it was discovered that limited prenatal information on NBHS for expectant mothers is available. Recent Utah public health initiative 26-10-10 requires babies' hearing to be rescreened before 14 days of age (following failed inpatient screening) in order to meet the mandated CMV screening requirement before 21 days of age. In an effort to inform expectant mothers about the importance of NBHS and CMV screening, when needed, a brochure was developed and printed during 2013, "Newborn Hearing Screening; What you need to know before you have your baby". In November 2013, all OBGYNs/midwives in the state were offered this brochure as part of their prenatal packet for all mothers. Brochures will be distributed starting January 2014 to those who requested them. A Spanish version will be available and distributed, also.

Aim Statement #5: By 3/31/2015, reduce screening LTF-U by 5% by evaluating the knowledge of expectant mothers of Newborn Hearing Screening and CMV, and providing education on the importance of the screening process.

Plan: Collaborate with the Utah Pregnancy Risk Line and University of Utah Maternal Fetal Medicine to distribute prenatal brochures about NBHS and CMV when expectant mothers call for information or come in for appointments.

Do: Develop an online survey in collaboration with Utah's Pregnancy Risk Line and University of Utah Maternal Fetal Medicine targeting expectant mother's knowledge of NBHS and CMV before and after receiving the educational brochure.

Study: Analyze completed surveys to evaluate pre- and post-brochure knowledge of NBHS and CMV.

ACT: Edit educational brochure, as needed, according to survey analysis and develop additional distribution processes according to feedback.

Methodology for Aim 5: Create survey of pre and post knowledge of NBHS.

Collaborate with Pregnancy Risk Line to offer NBHS brochure to expectant mothers. Evaluate survey results and make any needed changes to the survey process or brochure information and distribution. Collaborate with University of Utah Maternal Fetal Medicine (U of U MFM) to launch survey in their offices. Review legal processes for HIPAA to ensure the project will not violate protected health information. U of U MFM will distribute brochures to their patients with a link to the survey. Complete analysis of survey results and feedback. Make changes as needed to NBHS brochure and spread to other OBGYN clinics.

RESOLUTION OF CHALLENGES

Analyses of data from Utah's EHDl tracking system highlight a number of challenges to improve loss to follow-up and meeting the timelines for diagnosis and referral to intervention for infants with hearing loss. The concerted Quality Improvement efforts that will be the focus of this funding are expected to decrease Utah EHDl LTF-U by 5 % each year of the grant cycle. As with any test of change, some challenges could be encountered but our EHDl team has the support and skills to mitigate those that arise.

For example, with Aim Strategy #1, parents may still not keep the diagnostic appointment despite it being scheduled at the time of the second failed screening. In that instance, further small tests of change could be implemented, such as adding telephone reminder calls. If the no-show rate was still high, the EHDl team and NBHSAC could devise a survey that could be used with the delinquent parents to discover what barrier(s) they are facing in keeping the appointment.

With Aim Strategy #2, the ENT community may not be open to our survey and/or education. In that case, we could enlist one of our partners to intervene on our behalf. For example, we would enlist the help of our three immediately accessible physician partners (and members of our NBHSAC), i.e. the ENT, CSHCN Medical Director and the Utah EHDl AAP Chapter Champion to provide a bridge for our collaboration with the ENT community.

A possible challenge that could arise with Aim Strategy #3, is the logistics of sharing equipment amongst or between midwives that may be separate geographically. One potential solution would be to increase the motivation for NBHS through educational opportunities to highlight its importance, especially given the new cytomegalovirus testing law.

Lack of interest in help from state EHDI could be a barrier to the accomplishment of Aim Strategy #4. Submission of the poor Hospital Report Card to the hospital CEO could be one method to spark interest.

If there is a poor survey response rate for Aim Strategy #5, an incentive to complete the survey could be offered to increase parent interest and participation, e.g. free diapers.,

The majority of Utah EHDI team members have been with the state NBHS program for many years and as such, there is a long history of collaboration and partnership with stakeholders which has led to very good respectful working relationships. These will be called upon to assist with challenge resolution.

An excellent example of Utah EHDI enlisting the support of our stakeholders in our battle to reduce LTF-U has recently taken place. Key staff from Utah EHDI, USDB, BW/EI, NCHAM and Utah State University Sound Beginnings (an early education program that provides home and center-based services to children with hearing loss whose families want their children to learn to listen and talk) met at the 2013 National EHDI Meeting in Phoenix, Arizona. At that meeting, a great need to increase audiological access to infants in the many rural/frontier areas of Utah was identified.

Brainstorming took place and the group decided that they would like to closely collaborate to improve access to timely and appropriate services for children who are deaf/hard-of-hearing in the many remote parts of Utah. Karl White, PhD, the director of NCHAM and a strong member of our NBHSAC, spear-headed the effort to obtain funding for a coordinator to implement our plan. December, 2013 brought the good news that our newly formed “group” had received an Oberkötter Foundation grant that will allow the hiring of a part-time coordinator to implement our collaborative rural audiological evaluation program, and to evaluate and disseminate information about the results to other states.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

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 the current PDSA cycles, overall improvement to the EHDI system, and highlight the most successful strategies, as well as suggest change for improvement. Results and recommendations will be reported to the NBHS Advisory Committee, and findings will be used to plan and implement future activities to reduce LTF-U and assure early identification of infants and children with progressive and late onset hearing loss.

During the first year of the grant, the “UDOH appointed” NBHSAC will consist of 24 mandated members, consultants, and staff (Attachment 9) who represent families, audiology, early intervention, family practice physicians, pediatricians, otolaryngology,

health insurance companies and public health. The Committee Chair has agreed to include the evaluation of this project as a part of the Committee's agenda at each of their quarterly meetings. At the beginning of the project, a copy of the proposal will be sent to all Committee members, and a member of the EHDI Project Management Team will report at each Committee meeting on the progress made for relevant objectives.

This project is designed to enhance the effectiveness of short- and long-term follow-up of infants and reduce the number of infants who are lost to follow-up following a failed or missed hearing screening. Reports will be submitted to HRSA as routinely required to detail progress in achieving aims, effectiveness of the project, and effect of the project on participants.

In terms of technical support, NCHAM will be contracted to provide refinement and improvement of the State's Early Hearing Detection and Intervention (EHDI) HI*TRACK System. This will include assisting with quarterly EHDI Program meetings, maintaining a statewide EHDI database, and providing technical support and assistance to hospital-based NBHS programs. NCHAM also agrees to provide updated computer software and technical support to CHSS to maintain the EHDI Data Management and Tracking System (HI*TRACK) during the course of the project. Technical assistance (phone consultation, conference calls, and on-site support, technical reports) will be provided for Children's Hearing and Speech Services (CHSS) staff to assist them in using the software effectively. In addition, NCHAM agrees to respond to technical requests within 24 hours. Any upgraded HI*TRACK software will be installed and functional in all Utah hospitals during the current grant year, as appropriate. NCHAM agrees to facilitate technical needs and issues between our hospital HI*TRACK systems and our State HI*TRACK system. NCHAM will also provide all necessary data fields to be incorporated into their software that meet both CDC and HRSA reporting requirements for the State.

ORGANIZATIONAL INFORMATION

The Bureau of Children with Special Health Care Needs, located in the UDOH, Division of Family Health and Preparedness (FHP) will administer this grant. (See Organizational Chart, Attachment 5.) The Bureau is the state agency responsible for the administration of the CSHCN part of the Maternal and Child Health Block Grant and directly serves over 2500 children statewide. The Bureau's mission is to assure access to quality health care for Utah children and youth with special health care needs and their families. The Bureau's traditional direct service role has expanded over the past decade to include care coordination, systems development, medical home, access to health care, and promotion of cultural awareness and competency. In implementing this expanded role, the Bureau has worked in close partnership and through contractual agreements with the University of Utah, Division of Pediatrics, to bring specialty care to rural Utah. Additionally, the Bureau, Family Voices, Utah State University and the

Division of Pediatrics have worked collaboratively over the past several years to educate providers and build medical homes in Utah. In addition to the EHDI Program, the Bureau, (90 employees, [REDACTED],) is responsible for numerous programs including Newborn (heel stick) Screening; Technology Dependent Care Waiver; Medical Home; Fostering Healthy Children; Child Health Advanced Record Management; the State System Development Initiative, Multispeciality Clinics; Pregnancy Risk Line (now called MotherToBaby Utah); the Birth Defects and Genetics Program and Children's Hearing and Speech Services.

CSHCN also collaborates with the University of Utah, Division of Pediatrics and Utah State University in the Utah Regional Leadership Education in Neurodevelopmental Disabilities (URLEND) Program which provides leadership opportunities for students and professionals from a variety of health related disciplines to increase their knowledge and skills in providing services and supports to children with neurodevelopmental disabilities. The Project Director, Stephanie McVicar, AuD., CCC-A, for this funding opportunity is the Audiology Faculty for URLEND, as well as the mentor in charge of the Infant and Pediatric Audiology (IPA) supplemental grant to LEND. Both the LEND and IPA grants are through the Maternal and Child Health Bureau. The Bureau also supports the Utah Family Voices (UFV) Director as a CSHCN staff member. As CSHCN staff, the UFV Director is involved in Bureau, Division and Department level consultation and family support activities. Administrators at UDOH have committed appropriate space and equipment to support the functions of the project. UFV has recently formed a family support center in CSHCN's home clinic site in Salt Lake City.

Technical support services will still be contracted through the National Center for Hearing Assessment and Management (NCHAM) at Utah State University. NCHAM and the Utah Department of Health have established on-going collaboration and research activities for several years. The lead agency, Children's Hearing and Speech Services has demonstrated the leadership and expertise necessary to complete the goals of this grant.

Dr. McVicar, project director, has been involved in early identification and management of hearing loss for many years. As a licensed audiologist with over 23 years of pediatric experience and a member of Utah EHDI for the past 7 years, she is particularly well informed about issues related to early hearing detection and intervention and quality improvement.

Part of this project will focus on the technical aspects of refining the existing EHDI system with particular emphasis on reducing the number of infants lost to follow-up or documentation by utilizing quality improvement methodology. Inherent in this initiative is the automatic inclusion of a focus on the relational and "political" aspects of creating improved system changes. The various groups who have agreed to support the EHDI system are listed below:

- National Center for Hearing Assessment and Management (NCHAM)

- Utah School for the Deaf and Blind Audiology Services and Parent-Infant Program
- American Academy of Pediatrics EHDI Chapter Champion
- The Utah Collaborative Medical Home Project / Pediatric Partnership to Improve Healthcare Quality (UPIQ)
- Primary Children’s Hospital
- Utah Family Voices
- Baby Watch / Early Intervention
- Fostering Healthy Children
- Newborn Screening (heel stick) Program
- CSHCN Clinics
- CHARM (Child Health Advanced Records Management Project)
- Bureau of Vital Records(Center for Health Data and Informatics)
- Office of Home Visiting

CHSS will help coordinate the efforts of these groups into an effective, statewide EHDI system. The number of collaborators may change as the work of the program continues, but these are the current most intimately involved collaborating groups. (See Attachment 10, Letters of Support.) A thumbnail sketch of project collaborators is included in the table below.

National Center for Hearing Assessment and Management (NCHAM): NCHAM has been very instrumental in Utah’s implementation of hospital-based Universal Newborn Health Screening and State-based Early Hearing Detection and Intervention 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. There is collaboration around training and technical support to the HI*TRACK data management system, tele-intervention and program evaluation for the Utah EHDI program. Director of NCHAM, Dr. Karl While, is a member of the Utah NBHSAC.

Utah School for the Deaf (USDB): The home-based Parent-Infant Program (PIP) for parents of 0-3 year-old sensory impaired children is provided by USDB through a service contract with Baby Watch/Early Intervention (BW/EI). PIP services emphasize development of language, cognitive skills, and social skills using a systematic, behaviorally oriented curriculum. Parent advisors are available throughout the state to assist the BW/EI Program in developing an Individualized Family Service Program (IFSP) whenever a child is identified. The IFSP must be developed within 45 days of a referral being made to the BW/EI 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 and NBHS needs. Parent Advisors (PA) are also involved through current efforts to link the PA with the family starting with the initial referral for additional screening or diagnostic testing.

The Utah Chapter of the American Academy of Pediatrics (AAP): The Utah AAP and the UDOH have collaborated closely to promote the concept that all children should have a “medical home.” We have also published numerous EHDI informational articles and documents through their monthly newsletter, *The Changing Times*. These articles and periodic email blasts to their membership play an important role in our communication with the Utah medical community. Our EHDI Chapter Champion, Dr. Katie Jolma, is a key consultant in the development and promotion of EHDI and CMV educational materials and presentations for area pediatricians. She also represents the Chapter through her membership on the NBHSAC.

The Utah Collaborative Medical Project: As with hearing loss, most chronic and complex conditions in children are uncommon. Their cumulative prevalence, however, is significant. The Medical Home portal (website) offers information, tools and resources for Primary Care Physicians to enhance their ability to care for children with special health care needs and to provide a Medical Home for all of their patients. Utah EHDI has been instrumental in reviewing and providing updated information for their portal, and will continue to do so throughout this grant period. During this past year, a new Newborn Hearing Screening Module was developed that provides useful information to practitioners and about newborn screening programs, follow-up, testing referral, and “next steps” for families.

Primary Children’s Hospital (PCH): PCH is Utah’s and its surrounding states’ 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.

Utah Family Voices (UFV): UFV collaborates with national Family Voices chapters and coordinators throughout the states, especially Region 8 (UT, CO, WY, MT, SD and ND) with communications occurring primarily through monthly conference calls. The volunteer director for UFV serves on the national Family Voices Board of Directors as well as the national Family-to-Family Health Information Centers Advisory Committee. Participation on these two committees provides an avenue for state and regional issues to reach a national level as well as a vehicle to gather information from national and regional entities to bring back to Utah families and communities. The Utah Director has represented Utah EHDI at national and local conferences and has been a staunch supporter of family-to-family support for our program and CSHCN bureau.

Baby Watch Early Intervention (BW/EI): Although still in our UDOH Family Health and Preparedness Division, BW/EI is under the Bureau of Child Development now. BW/EI is the lead agency in Utah for implementing statewide services for children with developmental delays and/or disabilities from birth through age 3, under the Individuals with disabilities 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 multi-disciplinary 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 CHSS and CSHCN staff. The Office of Home Visiting is part of this program's organization.

CSHCN Clinics: CSHCN provides multidisciplinary medical and developmental services in clinics throughout 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 do they treat acute illnesses. They work closely with the clients' health care providers and the BW/EI Program. The Specialty Services Physical and Occupational Therapy 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 the Specialty Clinics link closely with the EHDI program, and offer services to infants identified with hearing loss through EHDI. CSHCN Community-based Service Clinics travel to rural areas to provide diagnostic and treatment services, and often help families of children with hearing loss access other community resources in order to meet their child's needs, including education, social and mental health. CHSS providers are integral team members for all CSHCN clinics.

Office of Vital Records: In the past, not all live births were being included in the database reported to the EHDI management system. CHARM's goal is to develop a unique identifier for all Utah newborns using the Birth Record Number from the Newborn (Heel Stick) test kit. Success was achieved among three mandated newborn databases: Vital Records, EHDI, and Newborn (heel stick) Screening with consistent propagation and matching of the BRN "linking" those three databases. This success has created avenues for more effective tracking and will help reduce infants LTF-U.

Child Health Advanced Records Management Project (CHARM): CHARM is the technical data integration initiative through the Utah Department of Health that

integrates child health-related programs and systems. CHARM creates a virtual health profile for every child in Utah and allows real-time data sharing across health care programs and partners. It currently links Vital Records (birth and death certificate information, plus adoptions and name changes), the Utah Immunization Information System (USIIS), and EHDI HI*TRACK (the NBHS database). The second phase currently in implementation will add links to Newborn Screening (heel stick), BW/EI (BTOTS), and the Birth Defects Network. Each participating program maintains its own database and controls what data is shared with whom.

Utah Regional Leadership in Neurodevelopmental Disabilities Program (URLEND)

The Utah Regional LEND, or URLEND, is a LEND program that covers five states: Utah, Idaho, Montana, Wyoming and North Dakota. It uses state-of-the-art technology to connect the groups. Professionals are trained to move beyond discipline boundaries to provide optimal services to child and adolescents with special health care needs. Because families are essential to well-being, this program emphasizes the role of family-centered care. Two of Utah EHDI's team members are previous URLEND IPA (Infant-Pediatric Audiology) leadership trainees.