

“Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening”  
Competitive Supplemental Application 93.251

**PROJECT NARRATIVE**

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## INTRODUCTION

The primary purpose of this initiative is to support the efforts of the Idaho Early Hearing Detection and Intervention program (EHDI), in conjunction with Idaho hospitals, out of hospital birthing facilities, physicians, audiologists, the Part C Infant Toddler Program (ITP), and other healthcare providers, to reduce the number of infants lost to follow-up following a failed physiologic newborn hearing screening.

The Idaho EHDI system functions as a collaborative, voluntary effort to provide the recommended “Standard of Care.” The EHDI program provides the supportive infrastructure for the providers of this standard of care. With limited staffing capacity, program activities have primarily focused on supporting hospital staff with screening and referral activities, and promoting the provision of timely and appropriate services through educational outreach activities for audiologists, early interventionists, and medical personnel.

Currently all 32 birthing hospitals voluntarily provide UNHS and submit hearing screening data monthly to the State EHDI program- Idaho Sound Beginnings (ISB). Thirty use the Hi-Track data system and 2 hospitals submit hard copy data. ISB has disseminated information regarding the importance and availability of newborn hearing screening at regional Infant Toddler Program offices to midwifery organizations throughout the state through a collaborative effort with the Idaho Perinatal Project.

Idaho Sound Beginnings (ISB) collected data on approximately 96 percent of Idaho births in 2008 (based on a comparison of EHDI program data to preliminary aggregate birth data from Vital Records). All 32 Idaho birth hospitals voluntarily screen infants for hearing loss, and only 5 hospitals’ initial screening rates in 2008 were below the 95 percent benchmark set by the JCIH. Statewide, over 98 percent of infants born in hospitals received at least an initial screening in 2008.

This supplemental MCH grant funding will be applied to several key projects directly aimed at the ‘system gaps’ where babies are missed or lost in Idaho (see Needs Assessment), and will be primarily measured by an increase in both the number of infants achieving the 1-3-6 benchmarks and the number early identified with hearing loss.

EHDI tracking and surveillance systems are needed in order to effectively track and document the status of every child identified through a screening program, and to identify those who need follow-up, or those who may be at risk of being ‘lost.’ A well planned, integrated system is also critical for identifying the ‘system gaps’ in service provision, and planning for process improvements.

Centers for Disease Control (CDC) funds have also been applied for and, if granted, will be used upgrade the data tracking system to a web-based system and to increase the capacity of the program to accurately collect and analyze data. Proposed CDC project activities will increase the timeliness with which the state receives infant hearing screening data and is able to begin follow-up and tracking activities, as well as provide feedback reports to hospitals and screening sites. A data linkage with birth records data will provide the information needed to determine where the largest clusters of out-of-hospitals births are occurring and help identify any demographic and geographic factors that are influencing loss to follow-up numbers.

This information, along with hospital survey information will be used to identify the initial areas to be targeted in year one for supplemental MCH activities. The following chart shows a

comparison of Idaho program strengths and weaknesses. Several of these challenges, were primarily targeted in the CDC grant, including those concerning reporting of only aggregate data, late or incomplete data, and incomplete diagnostic and early intervention data.(\*), and are mentioned here due to the overlapping nature of the goals, objectives, and often activities between available EHDI funding sources.

Program Strengths
<ul style="list-style-type: none"> <li>• All birthing hospitals voluntarily participate in UNHS</li> <li>• UNHS endorsed by Idaho Hospital Association as “Standard of Care”</li> <li>• Over 98% of babies born in Idaho hospitals had their hearing screened in 2008</li> <li>• Hospital participation and support for hearing screening is high</li> </ul>
<ul style="list-style-type: none"> <li>• Out-of-hospital births are able to receive hearing screens at their regional Part C office</li> <li>• 30 hospitals use Hi-Track system and voluntarily report data</li> </ul>
<ul style="list-style-type: none"> <li>• Approximately 34 babies have been early identified with hearing loss each year since 2002</li> <li>• All babies identified with hearing loss, including mild and unilateral losses are eligible for and referred to the Part C program</li> <li>• The Part C program has agreed to involve development of a linkage with EHDI data in the second phase of their web based data system roll out</li> </ul>
<ul style="list-style-type: none"> <li>• All audiologists included in the EHDI listing voluntarily completed the 2008 survey of statewide pediatric audiology services</li> <li>• Several Idaho audiologists have attended pediatric audiology training each year that it has been offered by the National Center for Hearing Assessment and Management (NCHAM)</li> <li>• Most audiologists send testing results to the EHDI program in hard copy form</li> </ul>
<ul style="list-style-type: none"> <li>• Dedicated staff and the support of stakeholders</li> <li>• Support of Advisory Committee</li> <li>• Strong partnership with Idaho School for the Deaf and Blind outreach services</li> </ul>

## NEEDS ASSESSMENT

Although the percent of infants receiving a newborn hearing screening in Idaho is above the 95 percent benchmark of the Joint Committee on Infant Hearing (JCIH), the percent of newborns who failed to return for an outpatient rescreen in 2008 averaged 30 percent. Of the total number of babies reported as needing an outpatient screen, 23 percent were babies who referred on their initial inpatient screen, but 74 percent were babies who did not receive any hearing screening before hospital discharge (‘missed’ babies). Of 800 reported out-of-hospital births in 2008, only 24 documented hearing screenings were reported to Idaho Sound Beginnings (ISB).

Program Barriers/Weaknesses
<ul style="list-style-type: none"> <li>• Screening is voluntary</li> <li>• 3.3% of babies are born out-of-hospital</li> <li>• Rate of completion of outpatient rescreens varies widely by hospital</li> <li>• Support and time for hospital follow-up on babies needing rescreens is limited</li> <li>• Time for state staff to devote to supporting hospital efforts on follow-up is limited</li> </ul>

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- Dependence on midwives to provide information and brochures to parents of babies born out-of-hospital has been mildly successful.
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- Reporting is voluntary
  - 2 hospitals report aggregate data (CDC\*)
  - Reporting of screenings for out-of-hospital births is incomplete
  - Data may not be complete (hospitals may not be including all babies such as transfers or deceased. (CDC\*))
  - Outpatient rescreen data is not reported consistently
  - Late submission of data impedes the state program’s efforts to provide timely feedback to hospital programs and alert them to babies who are at risk of being ‘lost’ and to assist with follow-up and quality improvement efforts. (CDC\*)
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- Based on national statistics, the same number of babies may not have been early identified each year in Idaho
  - Late and missing data hinders timely tracking and surveillance activities (CDC\*)
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- There is currently no way for the EHDI program to quickly and efficiently refer babies to the Part C early intervention program (CDC\*)
  - Information on IFSP enrollment and services provided is difficult and time consuming to obtain (CDC\*)
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- Comprehensive diagnostic services are not readily accessible in all areas of the state
  - Results of audiologic evaluations are not always reported on the EHDI program form and data elements are often missing
  - Results are often unclear as to how or if mild and minimal losses are being properly addressed by the audiologist and the parents.
  - Audiology office diagnostic protocols and protocols for follow-up for children “at risk” for late-onset or progressive hearing loss vary.
  - Information on follow-up audiology appointments, or later appointments for children with risk factors is often missing
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(CDC\* - these barriers, primarily dealing with data reporting and lost to documentation verification are addressed more fully in the recently submitted CDC funding request)

Idaho is a largely rural state. It’s 44 counties are divided among 7 regional districts. Districts 3 and 4 comprise most of the southwestern corner of the state and account for 44 percent of the state’s births. Statewide, 6 of the 44 counties account for 63% of the births demonstrating the extreme rural nature of the state with the majority of the population clustered in a few locales. The geographic features of the state and its remote and mountainous terrain adds to travel and training costs. Often air travel is the most efficient way to reach outlying areas, especially in the winter.

Idaho’s percentage of mothers of Hispanic origin has risen to over 15 percent. Two districts- Districts 3 and 5-account for 58 percent of the over 3500 reported births of Hispanic origin. Size of individual hospitals and birth numbers vary widely affecting training and follow-up needs. The following chart shows the birth distribution and varying size of Idaho’s 32 birth hospitals.

Births/year	25-135	200-700	1,000-2,000	5,100	
Number of Hospitals	13	9	9	1	32

Idaho hospitals are evenly split between the types of screening equipment used with 16 using OAE technology and 16 using AABR technology, although AABR equipment is now used to screen over 80 percent of state births. Most of the AABR hospitals complete the two stage screening before discharge and are referring directly to diagnostics.

This change in equipment and protocols over the last several years has led to a large decrease in the total number of babies lost at the outpatient rescreen stage, but continuous staff training and more immediate feedback is still needed to keep staff from occasionally attempting to schedule unnecessary outpatient rescreens, a large percentage of which result in ‘lost’ babies. The parents’ of ‘lost’ babies’ may have a diminished confidence in hearing screenings and equipment if several in-patient screens were already attempted making contact attempts more difficult. The use of ABR equipment is most effective at reducing lost to follow-up if it is combined with a strong training program and rapid feedback to hospital staff when the two stage in-patient protocol is not followed.

The majority of the OAE screened hospital births occur in more rural areas of the state. Since the OAE technology relies on outpatient rescreens this increases the susceptibility of infants in more rural areas to be lost to follow-up at the rescreen stage. These babies would benefit from more timely parent contact follow-up and education efforts.

**2008 Hearing Screening Data**

**Births reported**

Hi Track ‘individual’ data from 30 hospitals	21,750
Individual reports for screens done by Part C (home births)	24
Reported aggregate data from 2 hospitals	1,935
Total reported births from hearing screening	23,709

Vital Records 2008 births (not final data)\* = 24,600 (difference of approximately 891 births)

Summary:

1,935 reported births are not accompanied by individually identifiable data (not in Hi-Track)	Largest hospital reporting aggregate data will be upgraded to Hi-Track and provided with training. (*) A second hospital (240 births), is located at the Air Force base and has been willing to share aggregate data, but not to participate in electronic data sharing.
<b>800</b> unreported (in Hi-Track) out of hospital births. (2007 Vital Records) (Hearing screening data reported for only 24 births)	Efforts to increase screening and reporting of out of hospital births- outreach and education efforts with midwives will be expanded to lay midwives, and Part C staff will provide input on needed changes to tracking process, including responding to a request for the aggregate number of hearing screenings provided by their program, which may identify some ‘lost to documentation’ infants who did receive hearing screenings at Part C offices in 2008. The Part C program manager has endorsed reporting of all hearing screenings done by regional offices to the EHDI program and this will be incorporated into trainings. But, there still remains a large number of unscreened
Approximately <b>91</b> other births unaccounted for by EHDI program data	

	out of hospital births, and the number of out of hospital births has been increasing each year.
<b>181</b> babies in Hi-Track reported as never being screened (2008)  (does not include 9 refused)	Almost 2/3 probably “lost to follow-up”  Over 1/3 coded as “transferred out” (planned upgrades to the data system will aid in the reporting of transfers)  More timely receipt and analysis of hospital data is needed in order to provide more immediate feedback to hospitals in an effort to contact these families before they are ‘lost.’
<b>85</b> babies in Hi-Track reported as “not receiving evaluations”	Of these, 18 “refused diagnostics,” 48 are listed as “need to locate,” 17 were “discontinued” (indicating that many attempts were made to encourage follow-through) and 2 were deceased.
266 as “evaluation in process”	Further data analysis and tracking needed to determine exact status.
4 babies in Hi-Track reported as “enrolled in intervention”	All 35 babies with confirmed hearing loss were <u>referred</u> to the regional Part C program. Receiving confirmation of enrollment has required a manual request from ISB and time for individual follow-up. After the new Part C database has completed its piloting stage, the development of an electronic linkage between databases is scheduled for 2010.

## METHODOLOGY

Supplemental resources from this grant will be used to: increase the capacity of the state EHDI program to provide timely and efficient tracking and surveillance of referred babies, increase the statewide capacity to screen all babies, including out-of-hospital births, educate and support audiologists, physicians, early intervention providers, and families.

### *Hire support staff:*

A part time administrative assistant is needed to provide support to all grant activities including: assisting with parent and audiology contacts, mailings, correspondence, documentation of work plans and activities, advisory board meetings, preparation and documentation of scholarship applications, compilation of survey results, workshop and training planning and coordination, and other administrative support functions. This part time support is needed in order for the project coordinator, data manager, and consultant to be able to more adequately and efficiently oversee and implement other grant activities, and focus on tracking, follow-up, data analysis and parent contact.

### *Contract for development of new website:*

An EHDI website will be developed through an outside contract and will be hosted on the Health and Welfare website. This website is sorely needed as a means of providing up to date information for parents and providers. The previous website was connected to the Council for the Deaf and was dismantled several years ago and staff had not had the resources to complete a

new one. Early intervention staff, audiologists, hospitals, and physicians will be able to quickly access and download forms, guidelines and other information.

The main website will be hosted on the secure Health and Welfare site, which will also host the upgraded web-based Hi-Track database. This will provide an easy and convenient way for screeners and audiologists to look up information or send messages to the EHDI staff while they are working on their data.

*Develop other more interactive web presence such as a Facebook page:*

Since the Health and Welfare system is a very secure site, perfect for database hosting, an interactive parent friendly webpage will also be developed on a site such as Facebook. The current education and parent consultant will develop and maintain this site. The initial focus of the site will be for parent education. It will include videos and allow for parent to parent contact. The newly redesigned ISB referral form includes not only a request for a second contact number, but also an email address for contacting. The parent consultant will also be working with Idaho Hands and Voices on collaborative ideas for using the Facebook site for parent interactions.

*Target hospitals with equipment difficulties with incentive grants to upgrade equipment:*

Based on the results of needs assessments conducted by ISB, there are several hospitals who are in need of equipment upgrading. Several smaller ones have been increasingly relying on loaner equipment from the ISB office in order to continue screening while their equipment is out for frequent repairs. Some have been told by the manufacturer that their equipment is “obsolete.” These smaller hospitals lack the capacity to purchase new equipment, especially since due to their low birth numbers, the costs of screening would never be recovered. One large hospital is using equipment that is not approved by the JCIH, and has consistently reported an extremely low referral rate in relation to the number of births.

A few larger hospitals are struggling with older OAEs. Upgrading just a few of these larger hospitals to ABR would decrease their time burden due to providing outpatient rescreens and greatly decrease their need for hand entering hearing screening data into the tracking system. This would have a positive effect on the timeliness with which they would be able to send data to the state, as well as eliminate their babies ‘lost to rescreen.’

Another large hospital uses ABR for screening, but a substantial segment of their births occur not on the birthing unit, but in a separate birthing facility located a block away. These babies are told to ‘stop by’ the nursery for hearing screening when they return for their follow-up visit. This two part system results in a higher number of ‘lost’ babies. This facility would benefit from having an OAE on site at the birthing facility to perform the first stage of screening, then referring babies on for a second stage ABR at the hospital if needed.

Incentive grants will be offered to hospitals to be used for equipment upgrades and replacement. It is expected that due to the variability of equipment costs and hospital needs that the grant process will be competitive and that there will be a range of amounts offered based on the hospital’s demonstrated need for a certain type of equipment. Amount funded is not expected to exceed 50% of the purchase price of the equipment.

*Target midwives and Community Health Centers with training and grants to purchase OAE screening equipment:*

Approximately 800 out-of-hospital births occur each year and despite educational outreach efforts to certified midwives and the availability of free OAE hearing screenings at regional Infant Toddler (Part C) offices, there was reported data for only 24 hearing screenings performed at regional Part C offices in 2008, a small improvement. Final aggregate data reports from regional offices may show more babies were screened, but this still remains the largest segment of unscreened births. Over 50% of these babies are delivered by certified nurse midwives and the majority of these occur in 4 or 5 birthing centers around the state. These centers will be offered training in hearing screening and the opportunity to submit a request for funding for the purchase of OAE screeners.

Due to recent legislation, all midwives are now required to be licensed. This will enable the provision of direct outreach to this often hard to contact segment of the home birth providers.

Idaho's 12 Community Health Centers serve a large portion of the uninsured and underinsured population. Results of a planned data linkage and analysis with birth records will be used to target several of these health centers, and identify areas of greatest need. These centers will also be offered training and the opportunity to submit a request for funding for the purchase of screening equipment. These centers are in an excellent position to provide screenings for home births, and also to offer rescreens when needed.

All funding of screening equipment will be accompanied by Memorandums of Agreement to ensure facility commitment to maintaining a hearing screening program, using the ISB referral process, and reporting screening results to Idaho Sound Beginnings.

*Sponsor national pediatric audiology presenter at Idaho Speech and Hearing Association (ISHA), and*

*Provide audiologists with partial scholarships to attend pediatric audiology training:*

Idaho Sound Beginnings (ISB) has supported audiologists attendance at national training whenever training has been offered in an attempt to increase the knowledge base of audiologists. Due to the training provided, there are now a few audiologists in the Southeastern and Northeastern corners of the State with specialized pediatric audiology training. There remains a complete lack of comprehensive pediatric audiology services available within Northern Idaho. This forces families to choose between out of state providers, who are unwilling to accept Idaho Medicaid payments, or an extremely long journey to the Southwestern, more populated, section of the state. A 2008 survey of pediatric audiologists was used to assess, and raise, the level of awareness of audiologists of the requisites for infant and pediatric testing. Results will be used to plan and design training for those audiologists.

The Idaho Speech and Hearing Association (ISHA) is sponsoring a full day training session with Jay Hall, a nationally recognized audiology trainer, during their fall 2009 conference. In addition to assisting by supporting this presenter, ISB will provide small scholarships to audiologists to encourage their attendance at this one day training as well as a workshop on the second day of the conference which will be designed by the ISB consulting audiologist based on the areas of need identified in the 2008 survey results as well as an analysis of diagnostic testing reports sent

by individual audiologists to the ISB office. One physician, who has been recently identified as providing ABRs for hearing screenings in a neurology setting (N. Idaho) will also be invited to participate in the audiology training.

*Provide follow-up audiology mentoring via the web:*

This training opportunity at the ISHA conference will provide the opportunity for ISB to outreach to Idaho audiologists. ISB will support the consulting audiologist in offering follow-up mentoring via the web to assist audiologists with their pediatric audiology skills. A social networking/training site for Idaho pediatric audiologists will be developed in year two if there is enough interest.

The two audiologists who were scheduled to attend the cancelled 2009 Arizona audiology training with ISB scholarships will be again offered support for training when it is scheduled. Supplemental funds will also allow the program to support several additional audiologists to attend.

*Increase quality of pediatric audiology services in N. Idaho:*

The Northern Idaho region lacks comprehensive pediatric audiology services, mainly due to the lack of diagnostic ABR equipment. The provision of funds to support the purchase of diagnostic equipment in year two will help close this gap. The consulting audiologist will perform an informal assessment of the capacity and interest of audiologists' in this area to devote the time to training necessary to provide qualified pediatric audiology services. Completion of national training and follow-up mentoring will be a requirement of any funding awards for diagnostic equipment.

*Strengthen educational outreach efforts for physicians:*

Medical providers are often unaware of the importance of their role in the EHDI system of care. Physicians have admitted that they believed that hearing screening was handled by the hospitals and had little to do with them until they were presented with return for follow-up statistics. ISB proposed to sponsor a national speaker on EHDI for the spring or fall 2010 conference of the Idaho Academy of Family Physicians. This is a group that provides care to more of Idaho's babies than pediatricians do. The executive director of the IAFP has been agreeable to our proposal of support.

The directors of both the family physicians and pediatrics groups will enable a direct link from their websites to our new EHDI site, greatly enlarging our medical community training and education radius.

*Provide scholarships for hospital coordinators, screeners, early interventionists to attend IHA:*

The EHDI Seminar and Roundtable is held every year as part of the Idaho Hospital Association (IHA) annual conference. This yearly event provides the opportunity for all participants to network and brainstorm new ideas and map out strategies to ensure continued success for newborn hearing screening, diagnosis and intervention. It also provides the opportunity for ISB to announce new procedures, new grant opportunities, or new upgrades to the tracking system. ISB will support travel each year to this conference for at least one staff member from each hospital. EHDI program coordinators will be encouraged to attend. Yearly attendance at this

conference has been a main support for collaboration among all players and in the past, travel scholarships were supported with funding no longer available from Idaho's MCH Block Grant.

*Awards for best hospital and audiology programs:*

Certificates of achievement for quality services will be awarded to hospitals at the end of each program year. Criteria for evaluation will include completeness, timeliness, and accuracy of data received and results of a survey of parents as to the message received from hospital staff regarding the screening results. Parent survey content will include: Were they given clear directions? Did they know what to do? Did they understand why it was important? And, how did this information influence their follow-up actions?

Certificate/posters will also be presented to audiologists who have completed training in pediatrics and satisfactorily achieve the JCIH recommendations for diagnostic follow-up. The certificates will be more like posters with the ISB "Did U ChecK"(DUCK) theme and background in order to draw attention to the pediatric service provision.

*Develop, purchase and distribute educational, promotional, and training materials:*

Screener training CDs will be purchased and distributed to all screening programs, including Part C regions and other participating screening sites.

The newer parent education brochures have been well received and widely distributed due in part to a collaborative distribution plan in conjunction with the Idaho Metabolic Screening. These need to be reprinted, and will continue to be distributed to all programs, including childbirth educators, midwives, and the WIC programs in all health districts.

Inserts with Idaho specific information and contacts will be created and included in copies of the new "Communicate with your child" that will be distributed to parents and providers.

Since the lack of clear specific instruction on what needs to happen next and why is a large negative factor influencing follow-through both by parents and professionals, other educational materials will be purchased or developed to encourage follow-through. These will include handout/reminders for nurses and screeners, such as the AG Bell Hospital Staff Checklist: "Help Parents Understand Early Hearing Detection and Intervention," and educational information on minimal hearing loss for audiologists and others to distribute to parents.

Educational materials for physicians will include information on the effects of minimal and mild hearing loss and emphasis on the imperative for completion of the initial infant hearing screening and follow-up process, as well as continuous audiologic monitoring.

Idaho Sound Beginnings will continue to develop educational and promotional plans and materials using the Did U ChecK (DUCK) theme, which is widely recognized and makes program materials easy for staff to identify. In addition, new efforts will involve expanding the focus on promoting early brain growth and the importance of stimulation. This topic has been used frequently in staff program trainings and is now included in many of the print materials developed for parents of newly identified children with hearing loss.

The PSA already developed and distributed by Idaho Sound Beginnings shows a baby in a crib watching his mother speaking baby talk, but from the baby's vantage point the speech sounds are not clear. This PSA will be reformatted with a catchy introduction on brain development/feeding baby's brain and the early learning window and will be placed on the new website as well as sent to the physicians websites and distributed to parents, audiologists, and others.

Hopefully, beginning with the new introduction, parents sense of denial will be weakened and they will be more likely to follow-through with testing. This material could also be converted into a printed form for distribution.

Spanish interpreter services will be contracted for on an as needed basis for translations. A bilingual parent will be contracted with on an as needed basis to assist the parent consultant with follow-up efforts.

## **RESOLUTION OF CHALLENGES**

The largest barrier to program activities has been the limitation in staff time. Staff have focused work efforts on the key activities necessary to support the program goals and have achieved a 98 percent screening rate for hospital births, and an almost 70% return for out-patient follow-up rate. The current Idaho system is limited by staff and capacity and has been able to maintain these outcomes, but not improve beyond them.

The second largest barrier has been keeping all screening programs up and running efficiently. The addition of loaner screening equipment and equipment grants will address this barrier.

Misperceptions about hearing loss and especially hearing loss and infants need to be addressed before messages can be heard by parents and providers alike. Promotional and educational plans will address these misperceptions by emphasizing brain development and language as well as hearing loss.

Funding for overall system evaluation and data tracking systems enhancements, including upgrading to a web-based system and providing extra support for hospital staff and audiologists to participate in data system training has been applied for from the CDC. These enhancements will enable the Idaho program to better identify and address system gaps where babies are lost to screening, follow-up, and documentation.

Increasing the timeliness and accuracy of outcome data will lead to improved planning for future needs, such as program integration or legislation, as well as an increase in timeliness of feedback to hospitals and other providers which will aid follow-up and documentation efforts.

Barriers may be encountered with full linkage of NHS data with birth records. Preliminary contacts with Vital Statistics show a willingness to analyze the NHS data against birth records, but the extent of the analysis and the information able to be obtained has yet to be determined. For these MCH grant program activities, learning the demographics of out of hospital births will be the minimum needed in order to begin targeting geographic areas for implementation of new screening sites, and this level of analysis from Vital Statistics has been determined to be attainable.

Data analysis may lead to the identification of the need for more targeted promotions and information for specific Hispanic areas. This would be easily addressed by increasing the amount and type of Spanish materials available and targeting these areas for adding screening equipment in an easily accessible area (possibly a community health center in the area.).

## **EVALUATION AND TECHNICAL SUPPORT CAPACITY**

Recent and ongoing evaluation activities have included:

A Survey of Pediatric Audiologists (November 2008)- this survey was designed by the consulting audiologist and coordinator and distributed to the Idaho pediatric audiology network as well as other audiologists. All audiologists that were members of the pediatric audiology network completed and returned the survey except one. Several new audiologists were also found and completed and returned the survey expressing an interest in training.

Quarterly and year end data reports are prepared for each hospital.

Currently the program is working to provide more immediate feedback to hospitals by using a part time temporary worker to notify hospitals at least quarterly of their individual 'outstanding' babies who are still reported as needing a screen and also those still needing diagnostics.

2008 year end reports were also prepared for audiologists showing their 'outstanding' babies-babies who were referred to their clinic but for whom the EHDI program never received testing information.

As a result of the audiology survey results and the provision of this year end report, the EHDI program has since begun monthly reminder emails and calls to each audiology clinic concerning their 'outstanding' babies.

In addition to quarterly and yearly data monitoring and analysis of Hi-Track reported data, an analysis of EHDI data to birth records will be done at the beginning of the project period and again at the end of the project. This comparison of year end data from pre-project period to post-project will confirm that the objectives have resulted in an overall decrease to loss to follow-up over pre-project numbers, especially for out-of-hospital births.

Other evaluation methods used will include questionnaires and phone interviews to collect information from parents, hospital and audiologists, at the end of the first year and again at the end of the project period.

#### Staffing

ISB staff includes a Program Coordinator, Data Manager, Program Consultant, and Consulting Doctor of Pediatric Audiology. Temporary help is also used on an intermittent basis to provide support for data entry. (Job descriptions and biographical sketches are attached)

The Program Coordinator, Cynthia Carlin, has been with Idaho Sound Beginnings since 2001 and served as the assistant program coordinator for three years prior to becoming the program coordinator in 2007.

Janette Lytle has been the data and referral specialist for 8 years and also provides hospital staff training on the Hi-track software and the ISB referral form.

Debbie Baerlocher, has provided Consulting Audiology services for the EHDI program for three years, and is experienced in Pediatric Audiology and the requirements of EHDI.

Andrea Amestoy, RN, serves as a Program Consultant in the areas of medical education and procedure, cultural awareness, parent support issues, training and development. Ms. Amestoy brings a unique perspective to the program resulting from her combined experiences as a NICU nurse and pre-natal educator, and as the parent of a toddler who was early identified, with moderate hearing loss.

Other programs and associations who provide technical support include, but are not limited to: Idaho Hospital Association – provides the venue for EHDI annual stakeholder meeting; Idaho Perinatal Project – provides educational access to physicians, nurses, midwives and other groups, and supports presentations on EHDI topics to members at their annual conference; Idaho Medical Association, Idaho Academy of Family Physicians, Idaho Association of Physician's Assistants, and Idaho Nurses Association – provide CEU accreditation, presentation opportunities, and access to membership through their websites and newsletters. Idaho School

for the Deaf and Blind (ISDB) provides support on issues of early childhood hearing loss, interventions, and communication methods, and collaborates with ISB in providing specialized early intervention training to early intervention generalists and health professionals, and Idaho Hands & Voices works with ISB to ensure that parents receive support from experienced parent consultants in a timely and appropriate manner.

A variety of materials have been developed and will continue to support the successful implementation of newborn hearing screening. Publications and products of Idaho Sound Beginnings include:

- “Help and Hope – Family Resource Guide,” Connecting Families to Resources for Infants and Young Children Who are Deaf or Hard of Hearing. Issued in 2003, updated and reissued in 2005. (Currently being revised to increase its accessibility and usefulness to family members and other users.)
- “Guidelines for Early Hearing Detection and Intervention,” A resource guide for all Idaho EHDI participants. Issued and distributed to all hospitals and participants beginning Fall of 2004.
- Brochures: “What do I do Now?” and “Hearing Screening for ALL Idaho Babies.” Newer version is bilingual
- Newsletter for Early Intervention Providers
- Newsletter for Medical Providers
- Radio PSA (Spanish)
- Television PSA spot (30 second)
- “Babies can’t tell us if they can’t hear” poster (English and Spanish)
- “DUCK” badge holders for nurses
- “DUCK” soft squeaker promotional toys
- “DUCK” badge holders for providers

## **ORGANIZATION**

ISB has enjoyed success due in part to the effectiveness of collaborative efforts with other organizations in Idaho dedicated to ensuring all newborns receive hearing screening services before hospital discharge. On September 1, 2007, the Idaho Sound Beginnings program was transferred from the Council for the Deaf and Hard of Hearing (Council) to the Infant Toddler Program (Part C).

“Idaho Department of Health and Welfare, Infant Toddler Program (DHW-ITP) is the lead agency for Idaho's Early Intervention System for infants and toddlers with developmental delays or disabilities or those with conditions that have a high probability of resulting in a developmental delay. As lead agency, DHW-ITP has the responsibility to assure that each eligible infant and toddler receives needed early intervention services. This delivery of services is accomplished through multiple agencies who share the responsibility for serving infants and toddlers, but the Department is the payer of last resort for any service that is not available or covered through other federal, state, or local programs.

The Department is responsible for the statewide delivery of early intervention services in accordance with IDEA, Part C, and Idaho Code--Chapter 16, Title 1, Idaho's Early Intervention Act. The Act directs child find, public awareness, evaluations, IFSP development, procedural safeguards, data collection, service coordination, interagency agreements, the Early Childhood Coordinating Council, Regional Early Childhood Committees, assignment of fiscal responsibility and monitoring supervision. The Department of Health and Welfare Infant Toddler Program (DHW-ITP) also provides or contracts for the provision of direct early intervention services." As part of Idaho Infant Toddler Program, ISB is included in the MOA between Infant Toddler Program and Idaho School for the Deaf and the Blind.  
(Idaho Infant Toddler Program/ISDB Interagency Agreement, February, 2008)

There are two ways a child, newborn to age three, can be eligible for services through the Infant Toddler Program. A child will be eligible if he or she has a developmental delay or an established condition that has a high probability of resulting in developmental delay. The criteria for service eligibility for children with hearing loss (in one or both ears at one or more of the following frequencies – 500 Hz, 1000 Hz, and 40000 Hz) ranges from: Mild hearing loss – 20-40 dB HL through Profound hearing loss – 91 or greater dB HL. Chronic Otitis Media, chronic allergies, and/or eardrum perforations that result in temporary or fluctuating hearing loss and may impair listening skills, language development, or articulation are also criteria for services.  
(Idaho Infant Toddler Program, Interim Implementation Manual, June 2007, Appendix D-6)

The Idaho Infant Toddler Program is part of the Department of Health and Welfare (DHW), Division of Family and Community Services (FACS). FACS is also the administrative home for child welfare services and developmental disability services. Other programs under the administration of the Infant Toddler Program are: The Head Start Collaboration Office and the Early Care & Learning Initiative, supported by the MCH ECCS grant. (An organizational chart is included in the Appendices)

The ISB Advisory Committee meets quarterly to review and assess EHDI program goals and accomplishments; to provide professional insight, information, and guidance; to provide opportunities for collaborative activities; to support ISB training and outreach activities through the provision of access to membership for outreach and/or provision of venue support. Members of the Committee also research current recommendations for EHDI and advise ISB on strategies for implementation.

The ITP (Part C) will be piloting their new web-based data system in the Fall of 2009. The Part C program is ready to begin planning for data linkage with the EHDI database as a second stage enhancement to their system development. The IT developers of the new ITP-Web will be available and included in any upgrades made to the Hi-Track system if CDC funding is awarded, in order to ensure compatibility.