

PROJECT NARRATIVE

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PROJECT NARRATIVE

INTRODUCTION

The primary purpose of this project is to fully enable the Idaho Early Hearing Detection and Intervention program, in conjunction with Idaho hospitals, out of hospital birthing facilities, physicians, audiologists, the State Part C Infant Toddler Program, and other healthcare providers, to reduce the number of infants lost to follow-up following a failed physiologic newborn hearing screening. Although the percent of infants receiving a newborn hearing screening in Idaho is well above the Joint Committee on Infant Hearing (JCIH) benchmark of 95 percent, the percent of newborns returning for an outpatient rescreen in 2006 fell short of the JCIH benchmark of at least 70 percent. The status of many infants – lost to follow-up or lost to documentation – is unknown. This is especially disconcerting as hearing loss can be invisible or difficult for the child's primary care provider to recognize until the child is well into early childhood.

Congenital hearing loss is one of the most prevalent birth defects. In fact, it is the number one birth defect. It is estimated that 2 to 3 infants are born with hearing loss per 1,000 live births. This estimate does not include those children who develop late onset or progressive hearing loss. The critical period for language learning and development is during the first 3 years of life when the brain is rapidly developing. Early identification of hearing loss is a critical factor in preventing language delays. Even hearing losses diagnosed as mild have been shown to negatively affect school success and psychosocial development.

The Idaho Early Hearing Detection and Intervention (EHDI) project, known as Idaho Sound Beginnings (ISB), began as a project under the Idaho Council for the Deaf and Hard of Hearing (Council). After many successful years, Idaho Sound Beginnings has moved under the oversight of The Idaho Department of Health and Welfare, Division of Family and Community Services, Infant Toddler Program. The Infant Toddler Program (Part C of IDEA) is currently the lead agency for Universal Newborn Hearing Screening and Intervention (UNHSI) in Idaho. The Idaho Infant Toddler Program has demonstrated a long term and active commitment to establishing and refining this system in Idaho. They support the work of UNHSI as led by the Council, dedicate staff to assist with ISB's follow-up efforts, serve on the ISB Advisory Committee, and attend the national EHDI conference as well as in-state EHDI training opportunities. Infant Toddler regional staff provide newborn hearing screening services for out-of-hospital births. Idaho Sound Beginnings promotes the use of these services through their health promotion outreach activities and supports the regional Infant Toddler staff by providing audiology training as requested.

The Council began discussions regarding universal newborn hearing screening with the state Part C agency, the Idaho Infant Toddler Program in the Department of Health and Welfare, Idaho School for the Deaf and the Blind (ISDB) and various stakeholders in 1995. This led to the formation of the Universal Newborn Hearing Screening Consortium (Consortium). The Consortium continues to provide guidance and assistance to the EHDI program through the cooperation of its various members who currently participate as members of the Idaho Sound Beginnings Advisory Committee. The newborn hearing screen program has seen tremendous success in initial newborn hearing screens being conducted state wide at birthing hospitals. This

has been achieved without state mandated legislation. The high initial screen rate has been achieved through the development and dissemination of educational, outreach and cultural sensitivity activities brought forth by ISB and stakeholders.

Idaho Sound Beginnings (ISB) has enjoyed success due primarily to the effectiveness of these collaborative efforts with other organizations in Idaho dedicated to ensuring all newborns receive hearing screening services before hospital discharge. The recent realignment of the EHDI program under the administration of the Idaho Part C program will further increase Idaho Sound Beginnings' capacity to pursue infants lost to follow-up and to obtain more accurate and detailed data with regard to infants with hearing loss.

Idaho Sound Beginnings Partners include:

- the Idaho Department of Health and Welfare, Bureau of Clinical and Preventive Services, Idaho's MCH Title V Agency;
- the Children's Special Health Program Manager, Idaho's Children with Special Health Care Needs program, also responsible for the newborn metabolic screening and genetics programs;
- the Idaho Chapter of the American Academy of Pediatrics;
- Idaho School for the Deaf and the Blind;
- Idaho Hands and Voices, a group modeled after Colorado's family support group, Hands and Voices;
- Idaho's Early Childhood Coordinating Council (EC3), charged with advising and assisting the Department of Health and Welfare and other agencies in implementation of all activities and early services for newborns and toddlers who have disabilities;
- Idaho Academy of Family Physicians;
- Idaho Hospital Association and all hospitals that provide birthing services in Idaho;
- Audiologists in Idaho; and
- Idaho Commission on Hispanic Affairs.
- Idaho Council for the Deaf and Hard of Hearing

The ISB Advisory Committee also includes a family physician, a neonatologist (the EHDI Chapter Champion), a representative of Idaho Hands & Voices, and a deaf adult.

The Bureau of Clinical and Preventive Services, Idaho's MCH Title V agency provides financial support to the EHDI program in a \$10,000 grant, renewable yearly, to be used to support ISB activities which further the MCH goals.

The Advisory Committee and other Consortium members provide a statewide network for information and data flow, disseminating UNHSI information to their members via their newsletters and websites-and providing ideas and feedback from their constituencies. Member organizations also regularly provide venues for educational presentations and other outreach opportunities with their members and with health care consumers.

Fourteen birthing hospitals in Idaho had implemented Universal Newborn Hearing Screening programs by 1999, due largely to the early efforts of the Consortium. In 2000, Idaho was awarded federal funding through a grant from HRSA to establish a formal UNHSI program (hereinafter referred to as EHDI) at the state level to identify and close the gaps in the system.

Idaho has achieved a 98% hearing screening rate without a statutory mandate by building this mass support and statewide system of collaboration.

Currently all 32 birthing hospitals voluntarily provide universal newborn hearing screening and submit data monthly to the State EHDI program (example of hospital MOA in Appendices); 31 use the Hi-Track data system and 1 hospital submits hard copy data. ISB disseminates information regarding newborn hearing screening to midwifery organizations throughout the state through the Idaho Perinatal Project. Lay midwives are not certified in Idaho. Many of them practice in more rural areas and they traditionally have not been open to the established health education community. The Perinatal Project has recently arranged with the Idaho lay midwives to provide regular distributions of educational health information and materials for them to distribute amongst their clients. ISB provides parent brochures, and other educational and promotional materials to be distributed as a recurring activity.

The Hi-Track software is used by the state EHDI program in Idaho and by 31 of the 32 birthing hospitals. Data from one hospital is submitted in hard copy. The number of newborns born, the number receiving hearing screens before hospital discharge, and the number of newborns for whom follow-up screening or diagnostic testing is indicated are reported. Performance reports for each hospital and the state are generated from Hi-Track at the state EHDI office. Hospitals receive quarterly feedback on their performance as measured against the JCIH benchmarks. Performance reports to hospitals contain suggestions for improving their hospital's performance depending on which benchmark(s) they are having difficulty achieving. Hospitals who exhibit continued difficulty reaching the benchmarks are scheduled for on-site training.

On-site training was given at 8 hospitals in the first 9 months of 2007 with 3 more scheduled for 2007. Particular emphasis was placed on including regional early intervention staff and audiologists from the local areas to attend at each hospital. Representatives from Idaho Hands and Voices parent support group were also invited. They were each encouraged to explain their roles in EHDI to the hospital staff, thus increasing the staff's understanding and view of EHDI which will ultimately empower the parents to be advocates for their child's hearing health.

ISB designed a 5 part referral form used by all hospitals and birth facilities to record contact information for the family and the primary care provider (PCP), and to record the screening results and risk indicators for late-onset hearing loss. The parent's signature on the disclosure section allows the screening results to be shared with the audiologist, Idaho Sound Beginnings, Idaho Infant Toddler Program, Idaho School for the Deaf and the Blind, and Idaho Hands & Voices (parent support group). To reduce the number of infants lost to follow-up between the initial screen and the out-patient screen, the protocol for use of the referral form was amended to request the parent's signature and contact information before hospital discharge when a rescreening is indicated. This allows ISB to continue follow-up efforts if the infant does not return to the hospital for the rescreen. This small change in referral protocol resulted in a noticeable decrease in the number of infants lost at this stage. The Infant Toddler Program continues to work with ISB on tracking these "lost" infants and ensuring that they receive a rescreen, either at their birthing hospital or at their regional Infant Toddler Program Center.

Other strategies used that have proven effective in reducing loss to follow up have included; redesign of the brochure given to parents when their baby needs follow-up to include a place for writing follow-up appointment information in both English and Spanish; providing screening staff with a one page laminated “Did U Check” list that includes a concise hospital screening flow chart on one side, with a cheat sheet of “everything NHS personnel need to know” (including some ideas of what to say to parents). The “Did U Check” list was well received by the hospital staffs and has provided a way to carry over basic program knowledge to newer staff, and those who may do hearing screenings infrequently.

Various health promotional efforts have been undertaken including: public service radio announcements targeted at the areas of the State with significant Hispanic population and developed with the assistance of the Executive Director of the Idaho Hispanic Commission. A public service 30 second TV spot was developed using the resources and talents of a local school. This 30 second spot was distributed to all TV stations in the state.

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. Statewide professional education conferences have provided ISB with opportunities to educate medical personnel and raise their awareness of the importance of the 1-3-6 goals set by the Joint Commission on Infant Hearing (JCIH). ISB participates yearly in conferences sponsored by the Idaho Academy of Family Physicians, the Idaho Hospital Association, the Idaho Medical Association, and the Idaho Perinatal Project. This participation ranges from providing an educational vendor display and handouts to participants to sponsoring workshop sessions on issues of EHDI and early childhood hearing loss.

One successful means of educating early interventionists, childcare workers, and others involved with early childhood development has been through participation in the statewide “Early Years” conferences held every other year. At the 2006 conference, attended by over 400 providers and parents, ISB sponsored a track of well-attended sessions presented by national speakers, Paula Pittman, PhD, from the SKI-HI Institute and Arlene Stredler-Brown, CCC-SLP, CED from the Marion Downs Hearing Center at the University of Colorado.

In addition the EHDI Seminar and Roundtable is held every year as part of the Idaho Hospital Association 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. All EHDI stakeholders and Consortium members are invited to this IHA venue.

Idaho Department of Health and Welfare, Infant Toddler Program (DHW-ITP) is the lead agency for Idaho's (Part C) 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. 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.

DHW-ITP is responsible for maintaining an interagency data collection system that captures early intervention enrollment and service data required for management and reporting. DHW-ITP receives and enters all enrollment data and service updates through the use of a standard Infant Toddler Program Enrollment Form into this system, Data-Tot. Reports are routinely made available to regional programs and agency providers, the Early Childhood Coordinating Council, and the Regional Early Childhood Committees. A planned linkage of Hi-Track data with Data-Tot will expedite timely referral, follow-up, early intervention enrollment and feedback to Idaho Sound Beginnings to improve data accuracy.

The placement of Idaho Sound Beginnings under the lead of the Part C program provides the necessary infrastructure to support the goals of reducing loss to follow-up and providing culturally competent and family centered approaches to assure timely and ready access for all infants that need hearing screening, evaluation, and intervention.

NEEDS ASSESSMENT

Idaho has 44 counties divided among 7 regional districts. Districts 3 and 4 comprising the southwestern corner of the state accounted for 44 percent of the state's 23,064 births in 2005. According to the most recent census data available, The percentage of mothers of Hispanic origin rose to 15.2 percent in 2005. Two districts-District 3 and District 5-accounted for 58 percent of the 3,487 reported births of Hispanic origin.

The data and information used to assess the needs of the Idaho EHDI program (Idaho Sound Beginnings) statewide is collected from several sources. The Bureau of Health Policy and Vital Statistics, in the Idaho Department of Health and Welfare, provides data from state vital records and from the 2001 and 2004 Pregnancy Risk Assessment Tracking System (PRATS)* surveys of new mothers based upon the Center for Disease Control's (CDC) Pregnancy Risk Assessment Monitoring System (PRAMS). Hi-Track is a data system used by 31 of Idaho's 32 birthing hospitals to record, track, and report data monthly to Idaho Sound Beginnings (ISB). ISB analyzes the data and prepares quarterly and yearly performance reports of the State and individual hospital UNHS data. One limitation to using the PRATS and Vital Statistics data for comparisons to Hi-Track data is the inability to link this data to individual hospitals. Vital Statistics and PRATS data are available by Health District or county.

Statewide, 6 of the 44 counties accounted 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 costs, and often air travel is the most efficient way to reach the outlying areas, especially in the winter.

Travel distance and climate can affect the parent's ability to obtain timely follow-up as well as Idaho Sound Beginnings ability to provide trainings.

There are 32 birthing hospitals in Idaho. All voluntarily participate in Universal Newborn Hearing Screening. The type of screening equipment used, OAE or AABR, varies by hospital. On-site hospital trainings need to take each individual hospital's protocol and equipment into account. EHDI Consulting Pediatric Audiologists are required to have basic familiarity with all types of equipment used. Size of the individual hospitals and birth numbers vary widely. This affects training and follow-up needs. Most of the smaller hospitals are in rural areas. 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

32 hospitals in Idaho provide birthing services. The number of hospitals using AABR technology has been increasing. 17 hospitals use Otoacoustic Emissions (OAE) screening technology, and 15 hospitals now use Automated Auditory Brainstem Response (AABR) screening equipment for screening.

Currently 82% of Idaho hospital births occur in hospitals with AABR screening capability, this includes all of the hospitals with Newborn Intensive Care Units (NICUs).

UNHS in Idaho Hospitals	OAE screening technology	AABR screening technology	Total
Hospitals	17	15	32
Births	18%	82%	100%

Several hospitals have acquired the AABR equipment within the last year and are still adjusting to the new technology and protocol. On-site audiology trainings this past spring to several of these hospitals helped address some of their issues and increased their comfort level with the new equipment. Feedback during these meetings and afterwards was positive.

Approximately 34% of the OAE screened hospital births occur in areas with high percentages of Hispanic births. Since the OAE technology relies on outpatient rescreens, this increases the need to target these areas with culturally competent educational materials and new strategies focused on increasing health literacy and timely follow-up.

In 2005, approximately 3 percent (629) of Idaho's resident births occurred in a non-hospital setting. Most of the out-of-hospital births occurred at home (343) or in freestanding birthing center (285).

Total Live Births	Hospital	Freestanding Birth Center	Home	Unknown
23,064	22,429	285	343	6

Vital Statistics 2005

Physicians or Certified Nurse Midwives were listed as attendants in 98 percent of births in 2005. The other attendants listed include Nurse, Naturopath, Lay Midwife, Other, and Not Stated. These alternative birth attendants are frequently “outside” of the traditional medical system and therefore require different promotional techniques and educational materials to engage their support and participation in EHDI.

Births by Lay Practitioners	Naturopath	Lay Midwife	Other	Not Stated
520	26	406	74	14

Vital Statistics 2005

A change made to the birth certificate in 2004 enables hospitals to indicate if a newborn has failed the hearing screen before hospital discharge. This data is currently not linked with demographic information nor reviewed consistently. [Data may be underreported because the test may not have been completed before the birth certificate was filed.]The first results reported by Vital Statistics showed that “failed newborn hearing test” (860) was the 3rd most common abnormal condition reported on the 2005 birth certificate. 2005 data also show that although 3.9 percent of births reported a failed newborn hearing test, the percentage rose to 6.5 percent in the Hispanic population. Further information is needed which can only be gathered by linking ISB program data and Vital Statistics birth data. This has been determined to be a feasible project and will help to identify demographic information regarding these infants along with uncovering possible data collection disparities that may need attention.

The Pregnancy Risk Assessment Tracking System (PRATS) is a survey of Idaho resident mothers aged 18 years or older who had a live birth in Idaho. NHS data obtained from the 2004 survey show that mothers’ awareness of their baby receiving a hearing screening increased 22.8 percent (from 74.5 percent to 91.5 percent) from the level reported in the 2001 survey. “Results of Further Testing by Health District for 2001-2004” show that the percentage of babies who failed the first hearing testing and did not receive further testing varies by Health District from a low of 3.5 to a high of 10.3 in the Health District with the highest proportion of Hispanic mothers. Overall, the PRATS survey found that 15.2 percent of babies were not tested at all or did not receive further testing after failing the initial newborn hearing screening.

Due to the efforts of Idaho’s EHDI project, 98 percent of newborns born in hospitals received hearing screening before discharge. Of those, the percent referred for outpatient rescreening decreased to 7 percent for 2006. Although the statewide average screening rate was 98 percent, among individual hospitals this varied from a low of 81 percent to a high of 99+ percent. One of the lowest screening hospitals has since ceased providing birthing services.

Hi-Track data for 2006 shows that of the 330 infants who missed an initial hearing screening, 61 percent did not return to the hospital for the screening and only 67 percent of infants needing to return for a rescreen received one. In addition, only 4 percent of infants needing diagnostics are listed as “Follow up Discontinued” or lost, 58 percent (744) are listed as “Normal Hearing,” 33 percent as needing “Medical Follow up,” and 3 percent with “Hearing Loss.”

Number of infants “lost to hospital follow up” (including those discharged without an initial screen, and those who fail to return for rescreening)	660
Number lost to audiologic diagnostics	55
Number lost to documentation of diagnostic follow-up results (may or may not have received further testing recommended)	474

All infants identified with a hearing loss, or failing to return for an outpatient rescreen, are referred to the Infant Toddler (Part C) program following the ISB referral form protocol. Linking the infants diagnosed with hearing loss reported in the Hi-Track database with the children enrolled in Part C has been more difficult due to the previous placement of the EHDI program under the Council for the Deaf and Hard of Hearing.

This is the target population for the EHDI-Upgrade (EHDI-*Up*) proposal.

The new placement of the EHDI program, under the coordination of the Idaho Infant Toddler Program (Part C) will allow better integration and sharing of data. The EHDI program will be able to access follow-up information for infants entered into the Infant Toddler database, Data Tot. Data integration will be accomplished manually between the databases until a new Part C database, better equipped to handle the increasing load of information, will be able to electronically integrate with the UNHSI Hi-Track database. The ISB Data Manager presented information on the Hi-Track database to the Part C database business requirement planning committee and will continue to provide information as needed to ensure that the new database is able to assimilate the Hi-Track data and provide alerts for children needing follow-up. The ISB Program will continue to work with the Part C Program Manager to ensure that UNHSI follow-up reporting requirements are also provided for in the database design.

The Idaho Infant Toddler Program and the Idaho School for the Deaf and the Blind (ISDB) engage in a renewable memorandum of understanding (see Appendices) outlining their shared commitment and individual roles and responsibilities in providing services to birth to 3 year old children with vision loss and/or hearing loss. The main purposes of this agreement are to: clarify the process and protocols for coordination of services, assure efficiencies and compliance with IDEA and Idaho’s Early Intervention Act; minimize delays or gaps in service; and assure that procedural safeguards are met and services are delivered in a timely way at no cost to families. As part of the alignment with Infant Toddler Program, Idaho Sound Beginnings is included under these provisions and will benefit from inter-agency trainings, information and data sharing and support.

Idaho Sound Beginnings (ISB) was instrumental in the formation of Idaho Hands & Voices, providing in-kind administrative support and support for travel and training. Idaho Hands & Voices was the first statewide Hands & Voices chapter established and was modeled on the original Colorado Hands & Voices parent-to-parent support group. Two of the founding members of the Idaho chapter were members of the ISB Advisory Committee. This relationship continues with one of the Hands & Voices leaders continuing to serve on the ISB Advisory

Committee. ISB has continued to provide financial support for statewide training efforts and for a Hands & Voices parent consultant to travel to the National EHDI Conference.

ISB conducted a survey of Idaho audiologists to assess their willingness and ability to provide services to infants and the pediatric population. The results of this survey were used to develop an audiology resource directory for hospitals and providers. The approximately 30 responding audiologists were separated into two categories on the list – Limited or Comprehensive- according to their capacity to provide the necessary testing for infants and young children. The reference also contains an outline of the recommended protocol for comprehensive infant audiologic testing to assist providers with choosing an audiologist.

Since this original survey was completed, the field of pediatric audiology has evolved significantly. In response to this, ISB provided scholarships for 11 audiologists to attend various sessions of the NCHAM Pediatric Audiology trainings from 2004 through 2006, and for 4 audiologists to participate in the “Genetics of Childhood Hearing Loss” online training offered in 2007. Two of the audiologists who participated in the pediatric audiology training workshops are professors of audiology at Idaho State University (ISU) and are integral in the development of the curriculum as well as in the operation of the ISU audiology clinic.

Due to the training provided, there are now some audiologists in the Southeastern and Northeastern areas of the State with pediatric audiology training. There remains a complete lack of comprehensive pediatric audiology services available in 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 new survey of pediatric audiologists is planned for spring 2008 based on the latest JCIH recommendations. This survey will also act as an evaluation tool to determine not only the services and testing equipment available in each area, but also 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. An evaluation of cultural competency issues such as the language services available and the availability of a private room for interpretation services will be included.

ISB will continue to invite audiologists to attend, or assist with, UNHS hospital trainings in their regions as a means to increase their knowledge of UNHSI and enable them to network with their local hospital staff and develop into a source of information and regional support for hospital staff. Trainings specifically for audiologists are needed and will be designed by ISB’s Consulting Pediatric Audiologist. Initial training for the Northern Idaho area will be planned to coordinate with ISB’s annual Idaho Hospital Association workshop which will be held in Coeur d’Alene in 2008. This change of venue (to North Idaho) provides an opportunity to combine the regular yearly meeting with regional audiology and hospital trainings.

Hi-Track data reports are generated as needed for each individual hospital and for the state EHDI program. These reports are used to provide feedback every quarter to the hospitals on their performance, and include a comparison to the overall statewide performance. Each hospital’s performance is plotted against the JCIH benchmarks for screening and follow-up for

comparison. These performance reports often are the first indicator that a hospital may be having problems. Occasionally these problems have turned out to be small glitches in the data entry or data transfer systems that are easily corrected by phone or email communications either with the ISB data manager, or with support staff at the National Center for Hearing Assessment and Management (NCHAM). Continuing difficulty of a hospital to attain the JCIH benchmarks signals the need for further investigation of the problem by state EHDI program staff, which may lead to on-site training, or may be remedied by a review and suggested change of hospital procedure.

EHDI participants assemble every year for the annual roundtable and seminar. This day long meeting provides the opportunity for ISB program staff to survey a mixed gathering of EHDI service providers and users, including screeners, nurses, early interventionists, audiologists, parents, and others, on current issues of concern. The most recent survey revealed several common areas of concern/barriers among all groups. The major concerns expressed included:

- Staff turnover and resistance to ensuring that NHS protocol is implemented

- The medical community is not completely committed to the program and does not always support their efforts at trying to ensure follow-up and provide timely and appropriate services, and

- Communication between players often breaks down.

Approaches suggested included:

- More education on UNHSI for all primary care providers.

- Increasing outreach and educational efforts especially for family physicians that provide the medical home for the majority of Idaho children and may not be as familiar with the “Medical Home” concept as pediatricians.

- Educating medical front office staff since they are often responsible for communications

- Providing physicians with a flow chart/checklist for the Idaho services for children with hearing loss in Idaho.

METHODOLOGY

The 3 year Idaho EHDI-*Up* initiative combines the use of methods that have proven effective to reduce the number of infants lost to follow-up after failure to pass newborn hearing screening, in conjunction with the implementation of new strategies proposed by the NICHQ learning collaborative and by Idaho EHDI stakeholders. The work plan makes use of the increased opportunities for tracking and follow-up activities provided by alignment with Idaho’s Infant Toddler Program, including the linkage of data systems.

Idaho Sound Beginnings (ISB) will continue and further refine current strategic activities to sustain and improve the high level of initial hospital hearing screening, including strategies to increase the number of out-of-hospital births who receive hearing screening within 30 days of birth. Activities, such as targeted site visits, hospital and regional trainings, health promotional and “Did U Check” promotions, and education of medical providers will continue with the added inclusion of, and emphasis on, the implementation of multiple new strategies.

Idaho Sound Beginnings will continue to collaborate with stakeholders and the Advisory Committee to identify gaps in the Idaho EHDI system of care and to develop strategies to address these gaps. Follow-up processes will be refined and educational efforts expanded to identify and close the gaps in order to provide a more seamless system of newborn hearing screening and intervention.

Findings from a survey of EHDI stakeholders taken at the October 2007 statewide conference will further guide the strategies to be implemented through EHDI-*UP* to address the priority needs of reducing loss to follow-up and engaging Idaho's minority population.

Under the leadership of the Infant Toddler Program, new strategies will also be implemented and newly available evaluation opportunities will be utilized. As part of the Family and Community Services Division and the Infant Toddler Program, ISB will have increased access to data and data analysis services for process evaluation. Idaho Sound Beginnings staff will have the opportunity to provide input on data and reporting needs to the design team for the new Infant Toddler early intervention tracking system which is in the beginning development stage. The new system design will allow Hi-Track data on infants with hearing loss to be linked with the state early intervention database and alerts to be made to statewide early intervention programs about incoming referrals for audiological and other testing. Further analysis and planning will be completed between ISB and the Infant Toddler research analysts to determine the extent to which further data needs can be addressed.

ISB will utilize the resources of the Bureau of Health Policy and Vital Statistics to provide an analysis of Hi-Track data. This one-time authorized linkage of databases will provide demographic information and analysis by Idaho Health District and by county, in order to facilitate comparative analysis and evaluation and determine if there are factors affecting return for follow-up rates that can be used to determine the need for specific targeted regional strategies.

The Idaho Immunization Program is located in the Bureau of Clinical and Preventive Services, Idaho Department of Health and Welfare, Division of Health. This program provided the lead in Idaho to address the rate of childhood immunizations in the state. In this role, they increased the education levels of physicians and other health providers across Idaho. Immunization program staff are supportive of efforts to meet with ISB staff in order to provide health program planning and consultation. The Immunization program provides Immunization Records to all hospitals that are given to parents for their infants, upon discharge. Both programs will explore the possibility of adding information related to the newborn hearing screening on this card, which should be kept as permanent records for immunization purposes.

Universal newborn hearing screening in Idaho has become the norm for hospital births. Successful strategies such as: on-site and regional trainings; use of ISB referral form; provision of scholarships for audiologists; use of quarterly hospital reports for feedback and monitoring; educational efforts aimed at the medical home; collaboration with state agencies, universities, and programs that provide early childhood services; health promotions, parent education and

outreach efforts; and utilization of the support and feedback of the ISB Advisory Committee, will be continued, expanded, and refined.

Cultural competency efforts will be increased. Efforts will include inclusion of a cultural competency awareness segment in future workshops for health and early childhood professionals. This training segment was developed by the Project Consultant and tested at the Fall 2007 annual roundtable with statewide Consortium members. It received high evaluation ratings from members of both populations, medical and early interventions providers. EHDI Materials specially designed for the Hispanic population will be distributed to all hospitals, health clinics, and early intervention program. Links to bilingual EHDI information will be submitted to the websites of Idaho medical associations and the Early Childhood Information Clearinghouse Spanish site. These resources will include materials developed by the Centers for Disease Control, such as the “Guia para familias de ninos con perdida auditiva,” as well as materials developed by Idaho Sound Beginnings (ISB) with the assistance of the Idaho Hispanic Commission and the Community Council of Idaho (formerly the Idaho Migrant Council). The Community Council of Idaho has newly agreed to assist with the design of health promotional efforts for their population.

Educational efforts for primary care providers will be increased during this initiative, due in part to feedback from screening staff and early interventionists. ISB will continue to provide educational displays at prominent state medical association conferences and plans to provide support for nationally known medical experts and researchers in the field of EHDI and infant hearing loss to present at the Idaho Academy of Family Physicians Conference, the Idaho Association of Physicians Assistants, and at the Idaho Perinatal Project Conference. The executive directors of these associations have expressed interest in hosting these presenters and in working with Idaho Sound Beginnings to bring these national speakers to Idaho.

Educational outreach efforts will be expanded to include office staff and will include strategies to raise the level of communication between the hospital, primary care provider, specialists, and early interventionists. Obstetricians offices will also be included in outreach planning, since research confirms that parents who are informed about newborn hearing screening prior to the birth are more likely to follow-through. Dissemination of educational materials to midwives will continue through an agreement with the Idaho Perinatal Project.

Education on the importance of a “Medical Home” for children with hearing loss will be included as part of the educational outreach to primary care providers and others. This is an important element in the assurance of timely and effective early intervention services. A flow chart and checklist containing contact information for Idaho services for children with hearing loss will be designed in collaboration with stakeholders, and distributed to primary care providers and early childhood providers along with the AAP guidelines and recommendations.

Since physicians and health providers are overrun with information, all information will be provided in electronic format or on association websites. Information for hard copy dissemination will be provided in a simple easy to file format that can be readily accessed “Just in Time.” The ISB website is being redesigned and will be linked to all state stakeholder

websites, and will be easily accessible, heavily promoted, and provide a place for sharing of EHDI information for parents and professionals.

A cross section of all EHDI players, including hospital and screening personnel, and early intervention providers (generalists and hearing specialists), along with audiologists, parents and other interested parties were recently surveyed at the annual EHDI meeting. Participants were asked to rank the strategies found to be effective by the NICHQ learning collaborative to reduce loss to follow up, and to add their own suggestions.

Scripting the message to parents, making the appointments, using a fax back to the primary care provider, and obtaining consent for release of information were ranked the highest in importance for increasing follow up. Of these, scripting the message and making the appointments received high ratings for feasibility of implementation.

- 1. Scripting the message**- This has been widely promoted and encouraged at regional and statewide EHDI meetings. ISB staff has developed a “Did U ChecK” list, that is given to all hospitals to keep with their screening equipment. In addition to a reminder to provide parents with hearing milestones, brochures and a follow-up appointment when needed. It includes an audiologists’ guidance for delivering the follow-up message to parents in a way to encourage them to return or follow through. The message to be given to parents will be more tightly scripted and designed to increase parents’ understanding and fulfillment of follow through. The Community Council of Idaho will collaborate with designing and testing a culturally compliant version for Hispanic families. Efforts will also be expanded on increasing overall cultural awareness among screening personnel at regular regional and statewide trainings in order to ensure that the message of EHDI is delivered in the most culturally competence way.
- 2. Getting a second point of contact for families**- Hospitals will be encouraged to provide a second point of contact for families. In cases where contact is lost, the hospital will be contacted to research records for another point of contact. This will be accomplished through the addition of contract personnel time to contact hospital records departments for follow-up information.
- 3. Verifying the identity of the primary care provider (PCP) or clinic before the parents leave the hospital**- This information is a standard part of the 5-part ISB referral form. Hospital staff training has emphasized the importance of completing the referral form and obtaining the parents signature after the initial screen (before discharge) in order to ensure that the screening information can be shared with ISB for tracking and follow up in the event parents don’t return for the outpatient re-screening appointment. Increased emphasis through training and technical assistance will be placed on successfully securing this information.
- 4. Use of the Fax-back to alert the PCP of screening results and the need for prompt follow-up.** Hospitals have previously set their own protocol as to whether they use fax or regular mail to distribute the referral forms to ISB, the PCP, and the audiologist. Hospitals will be encouraged to use fax to send the referral form to the PCP. ISB will design and disseminate a fax cover sheet to be used with all hearing screening results to alert the PCP and medical office staff of the hearing screening results and provide them with clear instructions on hearing screening and diagnostic follow up. The cover sheet will also include contact information for the hospital and

ISB, along with instructions for the PCP office to redirect the referral to ISB if the child is not their patient.

5. Making the appointment for the family – ISB will increase efforts to encourage this among all hospitals. The “What do I do now” brochure, designed for use with infants needing follow-up was redesigned to include an area for the follow-up appointment to be written in. Promotional DUCK (Did U Check) magnets have been distributed to hospitals to use for reminding parents of their hospital rescreen appointments. These duck shaped magnets were designed with space for marking appointment information in permanent marker. Magnets will be distributed to hospitals for diagnostic appointment reminders, and will be distributed to audiologists for use as reminders for follow-up audiology appointments. Hospitals and others will be encouraged to implement the use of the magnets in their programs, and will be requested to report on their efforts to increase follow-up and return rates at the annual EHDI state conference. Hi-Track data will be used to evaluate referral follow-up and to target technical assistance where needed.

6. Use of the fax back between specialists, including the audiologist and PCP. Stakeholders and Advisory Committee members in medical and health fields will assess the feasibility and effectiveness of working to promote this strategy and address methods of promotion and implementation. If required a dedicated Fax line will be purchased to assure uninhibited access.

7. Obtain consent for release of information at first contact with Early Intervention so information can be entered into state database. Alignment of the Idaho EHDI program with the Idaho Infant Toddler Program will enable EHDI Hi-Track data to be linked to the Part C database, and will enable the EHDI staff to have access to Part C follow-up information, such as the number of infants with hearing loss who have IFSPs. Collaboration on the design of the new Part C database and EHDI requirements for follow-up information and reports will be completed in the first half of the 2008 grant year. The new database is projected to be ready for testing and evaluation late in 2008.

8. Use of volunteers for follow-up reminder calls. The use of hospital volunteers to assist hospitals with reminder calls will be promoted. Hospital EHDI coordinators will be encouraged to collaborate with their volunteer program. ISB will collaborate with an EHDI hospital program coordinator currently using volunteers for follow-up calls in order to develop a scope of work and script that could be adapted for use by any hospital. ISB will attend the annual state convention for volunteers, sponsored by the Idaho Hospital Association, to increase their understanding of EHDI and promote their participation.

9. Contracting with an experienced parent consultant to provide parent contact. The Idaho Sound Beginnings Project Consultant will work with the Idaho chapter of Hands & Voices parent-to-parent support group to develop a scope of work and script to be used by a parent consultant who will be trained to assist with follow-up and contact efforts for families who have proven resistant to previous follow-up and contact attempts.

10. Promoting use of the 2-1-1 Idaho CareLine number. Promotional and educational efforts will include promoting use of the CareLine for referral and follow-up information. Training of the CareLine staff will be continued to ensure that parents receive accurate referral information.

ISB has provided scholarships to audiologists from different areas in the state to attend the National Center for Hearing Assessment and Management pediatric audiology trainings. In return, these audiologists agree to provide training to other audiologists and hospitals as needed. This has been an effective means of leveraging program resources, continuing the education of audiologists involved in diagnosing hearing loss in infants, and supporting working relationships between those audiologists and other members of their communities. Continued audiology scholarships for advanced training will be incorporated for the term of the grant. The ISB program's consulting pediatric audiologist will develop and present smaller regional pediatric audiology trainings during this initiative, targeted at areas of shortage for pediatric audiology services and scheduled in conjunction with larger medical conferences to increase the capacity of the training provided and keep long distance travel to a minimum.

WORK PLAN

The EHDI-*Up* initiative will primarily focus on activities that have a high probability of being accepted and institutionalized into the state-wide EHDI system. Evaluation results from regional and site trainings, feedback on the feasibility of new strategies from the EHDI participants at the annual Roundtable, National study results, such as the NICHQ learning collaborative, and the expertise of the Idaho Sound Beginnings Advisory Committee members all contribute to program direction and focus.

Efforts for this three year initiative to reduce the number of infants lost to follow-up will depend on the continued collaborations and partnerships that have enable EHDI to succeed with out a mandate.

Strategies that have enabled ISB to reach the screening and follow-up levels already achieved will be continued and in many cases expanded over the three years. Evaluation of program data, by the Data Manager and Program Coordinator, will continue in order to assess areas and hospitals in need of training. All staff will participate in providing training and re-training throughout the three year initiative. The Program Consultant will assist the Coordinator with ISB newsletter production. The newsletter will be sent to all providers and participants quarterly as one means to promote and reinforce the use of new strategies. All staff will work on designing an informational fax back form in year one to be used by hospitals when faxing referrals to primary care providers to ensure that all pertinent information on procedure and follow-up is included, and that it is attention-catching. The Program Consultant will assist the Audiologist in scripting the message for delivery of newborn hearing screening results to parents.

Year one will focus on integration of Idaho Sound Beginnings into the Infant Toddler Program, including planning for data integration, which will begin in quarter one, with the first trials projected for quarter three. Training of early intervention outreach personnel in year one, and their inclusion in other regional and statewide trainings will help ensure that all regions of the state have outreach personnel educated in the fundamentals of EHDI procedure to assist with outreach and follow-up efforts. ISB will contract with an experienced parent consultant to assist

with parent follow-up efforts. The Program Consultant, who is also a parent of a child with hearing loss, will work with the Coordinator to ensure that all follow-up contact efforts are conducted in a supportive and culturally aware manner.

Promotional efforts for hospitals will continue around the use of DUCK magnets for follow-up appointment reminders, while adding in the recommendations of the NICHQ collaborative. Consistent promotional efforts and education of the medical providers, who support the nursing staff will be continued and increased and will include newsletter articles, website reminders and links, presentations by early childhood and EHDI professionals, mailings, and the continual reminders on the fax cover letter.

Development of a new Idaho Sound Beginnings website, integrated with the Infant Toddler program will begin in year one. Efforts in year one will also focus on audiology assessment and pediatric audiology training. Two major medical conventions are scheduled for North Idaho late in year one providing an opportunity for combined audiology and medical presentations.

Years one and three include the state-wide "Early Years" Conference for early childhood providers. Idaho Sound Beginnings sponsored two national speakers on early childhood hearing loss at the 2006 conference and will continue to support the conference with state and national speakers as a way to reach these providers.

Year two will include support of national presenters at state medical provider conferences for the Idaho Academy of Family Physicians, and the Idaho Perinatal Project. Executive Directors of both organizations are willing to include a national speaker on issues of EHDI.

Independent evaluation activities will begin in year one. An evaluation sub-committee will be convened by the contracted evaluator and a design plan will be developed.

Evaluation activities will continue in year two with finalizing the design and measurement strategies and beginning implementation of surveys and other data collection mechanisms. Final evaluation activities in year three will complete the implementation strategies and data and trend analysis activities resulting in the production of a report of program performance.

RESOLUTION OF CHALLENGES

To date, a significant barrier to program activities has been the limitation in staff time. Staff have focused work efforts on the key activities necessary to support the EHDI program goals and have achieved a 98 percent screening rate for hospital births, and a 67% return for out-patient follow-up rate. Activities for this EHD-*Up* initiative will focus on reducing the percent lost to follow-up, at each stage, screening, follow-up, and intervention; and increasing the number of newborns screened for hearing loss to 100 percent for hospital births and increasing the screening participation of out of hospital births and identifying more accurate data for these. This barrier has been addressed with the expansion of the Program Coordinator position to a full-time position and the addition of a contract with a trained parent support consultant to assist with contacting parents to encourage follow-through. Temporary office help to assist with data collection and integration will be added using funds from the MCH Block Grant provided through a Memorandum of Agreement with Idaho's Title V Program.

In addition, ISB has undergone major recent changes. ISB has physically and administratively moved from the Idaho Council for the Deaf and Hard of Hearing to the Idaho Infant Toddler Program. ISB has also encountered staffing changes with the addition of a new Program consultant. Integration with the Idaho Infant Toddler Program will enable the EHDI program to more fully utilize the capacity and resources available through the Part C program. The program oversight and guidance provided by the Part C Coordinator and Principal Investigator for the EHDI grant will further strengthen the EHDI program.

A consistent source of follow-up data has been a program challenge. Linkage of the Hi-Track data with the state early intervention database will address this issue. Involvement of the EHDI program in the design stages of the new Part C database will allow for EHDI follow-up and reporting data needs to be written into the system from the start.

Geographical barriers are many in Idaho. Idaho is primarily a rural state with a large proportion of small hospitals and outlying community health clinics. On-site training has been found to be crucial to hospital and professional acceptance of EHDI goals. In addition to increasing the amount allocated for program travel expenses, ISB will use the network of regional outreach personnel in the Infant Toddler Program to assist with outreach in outlying areas. Regional staff will be included in all statewide and regional trainings, including hospital trainings in their regions to ensure that they are well-grounded in the goals and protocols of EHDI and are familiar with their local birthing hospital staff. 2008 trainings will be targeted at the North Idaho region. Trainings trips will be combined with trips for medical association presentations to ensure the best use of time and funds.

Due in part to turnover, hospital staff may not all demonstrate continuous and strident commitment to screening. Including other disciplines in site trainings will give hospital staff an opportunity to interface with the interdisciplinary team associated with EHDI. This will lead to increased buy in and emphasize the importance of the screenings they are doing. Redesigning the quarterly hospital reports to accurately reflect relationships with similar sized hospitals will more easily allow comparisons to be made in order to increase compliance and decrease loss to follow up. Encouraging those hospitals who utilize ABRs to complete the two-stage screening

before discharge will also significantly decrease the loss to follow up by decreasing the number of infants who need to return to the hospital for a second screen (the point with the largest number lost to follow-up)

Staff turnover is a continuing problem, in hospitals, medical professions, audiology, and in early intervention. ISB will continue to address this with focused outreach, including regional and site trainings, quarterly newsletter updates and reminders, and providing an EHDI program presence at conferences statewide. The use of the Did U Check? (DUCK) logo, program materials, and display will further strengthen the message of EHDI statewide.

Staff resistance may be encountered to using a scripted message for parents. Trainings will include promotion for the message, along with assessment of staff attitudes and compliance issues. Staff will be assessed for their input into the final messages to assure that they are in agreement and will be more compliant with the procedure.

Getting a second point of contact will require extra effort on the part of hospital staff. In addition to emphasizing the importance of this in trainings and in the newsletter, ISB staff will begin to send referral copies for 'lost' babies back to the EHDI coordinator to emphasize the importance of this procedure.

The use of hospital volunteers for reminder calls may not work at all hospitals due to confidentiality reasons. This will require individual research and consultation with each hospital program coordinator before implementation.

Hospital staff training has consistently emphasized the importance of completing the referral form in its entirety, including the identity of the primary care provider. Hospitals have previously set their own protocols as to whether referral copies are sent by mail or fax. To ensure that they are sent by fax, ISB will include this information in trainings and promotions, as well as design and distribute a fax cover sheet to be included for faxing results to the PCP.

Outreach personnel will be a resource to the EHDI staff in identifying alternate birthing sites and providers in their regions. ISB will continue to rely on a collaborative relationship with the Idaho Perinatal Project for outreach to, education of and distribution of materials to midwives.

Provider shortages have been a challenge for ISB. The majority of regions in Idaho contain medical provider shortage areas and this is also true for the audiology profession. ISB will continue to research training opportunities in pediatric audiology, including the NCHAM workshops in pediatric audiology, and provide scholarships to audiologists. In addition, ISB will work with the EHDI consulting audiologist and professors of audiology at Idaho State University to develop a basic training in pediatric audiology that can be presented in regional trainings. Prior to designing the training, state audiologists will be re-surveyed to assess their knowledge base and interest in pediatric audiology. The provision of scholarships for national trainings in pediatric audiology is dependent on the future availability of this training through NCHAM or another accredited agency. Audiology training activities will be targeted to areas of provider shortage in year one. Subsequent trainings will be statewide in scope.

Quarterly newsletters will have cultural competency sections with pointers designed by ISB in conjunction with the Community council of Idaho (formerly the Idaho Migrant Council). These will be implemented when dealing with cross-cultural situations. Assessment of these implemented ideas will be assessed at follow-up in-services and conversations with testers, charge nurses, etc. Cultural competency awareness training has been designed and will be included in all future ISB trainings. Staff and other professionals will be provided with, and encouraged to read, the English translation of the Spanish “Guia para familias de ninos con perdida auditiva,” (guide for parents) in order to increase awareness of the effect that culture has on health literacy.

The lack of a legislative mandate has not proven to be a major impediment to the success of the EHDI program in Idaho. In evaluating the benefits and costs of screening by mandate, the outcome has consistently been that the benefits of voluntary participation have been excellent. Should the political climate change in Idaho, ISB will engage stakeholders and legislative advisers to develop strategies and anticipate legislative impediments. Alignment with the Part C program will bring ISB closer to sustainability.

Although barriers exist in fully implementing the newborn hearing screening and intervention program, numerous thoughtful and innovative solutions have been implemented to overcome the initial barriers, and more strategies await implementation, and final assessment. Idaho Sound Beginnings is excited to commence this new challenge of decreasing loss to follow-up.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

The Infant Toddler Program collaborated with the Council for the Deaf and Hard of Hearing in the establishment of Idaho’s Universal Newborn Hearing Screening Consortium in 1995 and has sustained continuous involvement as a key partner in the support of early hearing detection and intervention. The current Part C Coordinator, Mary Jones, has served as Idaho’s Infant Toddler Program (Part C) Coordinator and Program Manager for 17 years, providing administrative management for early intervention services to infants, toddlers and their families. The Infant Toddler Program is the current applicant agency for the grant, and Ms. Jones is the Principal Investigator, providing oversight of the EHDI program and ensuring it’s full integration into the Part C program.

The Idaho Sound Beginnings Advisory Committee continues the role of guidance and support initiated by the Universal Newborn Hearing Screening Consortium to the EHDI program. Members of the ISB Advisory Committee are:

Sherry Iverson, RN, Executive Director, Idaho Chapter AAP, and Idaho Perinatal Project;
 Carolee Eslinger, Program Specialist, Idaho Infant Toddler Program;
 Toni Pugmire, Director of Education, Idaho Hospital Association;
 Bob Seeheusen, CEO, Idaho Medical Association;

Janet Stout, Director of Outreach, Idaho School for the Deaf and the Blind;
 Mitch Scoggins, Program Specialist, Division of Health, Bureau of Clinical and Preventative Services, Children's Special Health Program;
 Pawel Zieba, M.D., Neonatologist, St. Luke's Regional Children's Hospital, EHDI Chapter Champion;
 David Ballance, M.D., Family Physician, Member Idaho Academy of Family Physicians;
 Susie Jones, parent of a child with hearing loss, Speech Language Pathologist Director of Idaho Hands & Voices;
 Cindy Schreiner, Representative of the Council for the Deaf and Hard of Hearing;
 Debbie Baerlocher, AuD, Clinic Manager, Hearing and Balance Centers at the Elks, EHDI Consulting Pediatric Audiologist for Idaho Sound Beginnings.

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.

In addition to the Principal Investigator, who will provide program oversight, ISB staff includes a Program Coordinator, Data Manager, Program Consultant, and Consulting Doctor of Pediatric Audiology. The Program Coordinator for the EHDI-*Up* initiative, Cynthia Carlin, has been with Idaho Sound Beginnings since 2001 and has served as the assistant program coordinator for three years. Janette Lytle has been the data and referral specialist for 6 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 two years, and is experienced in Pediatric Audiology and the requirements of EHDI. Andrea Amestoy, RN, is a newer addition to the EHDI staff, serving 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 9 month old baby, early identified, with moderate hearing loss.

A Memorandum of Agreement (MOA) is in effect between Idaho Sound Beginnings and the Idaho Title V Program (Appendices) granting ISB funding for projects related to MCH program goals. 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. (Appendices)

The Idaho Immunization Program is located in the Bureau of Clinical and Preventive Services, Idaho Department of Health and Welfare, Division of Health. Immunization program staff are supportive of efforts to meet with ISB staff in order to provide health program planning expert consultation and explore the possibility of adding information related to the newborn hearing screening on this card.

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 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. (Plans for EHDI-*Up* include an updating of the Guidelines to reflect the results of current research, including the JCIH 2007 recommendations, and the results of a survey of hospitals as to its ease of use.)
- Brochures: “What do I do Now?” and “Hearing Screening for ALL Idaho Babies.” (Available in English and Spanish. Distributed to all hospitals and regions.)
- Quarterly newsletters
- Special Issue newsletter for Early Intervention Providers
- Special Issue newsletter for Medical Providers
- Radio PSA (Spanish)
- Television PSA spot (30 second)

Materials produced by Idaho Sound Beginnings have centered around the “Did U ChecK ?” - Newborn Hearing Screening (DUCK) Logo and include: pins, pens, badge holders for nurses and medical professionals, notepads, and Duck magnets. The program logo is used on all promotional displays and program materials and has become instantly recognizable to a large segment of the population of health professionals in Idaho dealing with early childhood care. EHDI-*Up* will continue to promote recognition of the logo as one means to increase program recognition and acceptance both across the boundaries of provider agencies and with the target population of families of newborns.

Traditional program evaluation methods will be continued throughout the EHDI-*Up* initiative. Analysis of program data will be completed quarterly and compared to previous data. Individual hospital data will be analyzed for any changes and/or issues that need to be addressed. Evaluations will be completed by participants for all training components of the program. Results will be used to implement adjustments to the trainings.

Integration of Idaho Sound Beginnings into the Infant Toddler Program, will provide ISB with access to Division of Family and Community Services (FACS) research analysts to perform expert program data analysis. Data analysis will provide increased evaluation capacity to study trends of performance and measure the impact of specific outreach, screening, or intervention strategies.

An independent evaluation will be conducted of the Idaho EHDI-*Up* initiative. Idaho Sound Beginnings will contract with an experienced program evaluator and professor of early childhood development, Carrie Mori, PhD, OTR/L, BCP. Dr. Mori has agreed to design and conduct an independent evaluation of the 3 year EHDI-*Up* initiative. She is an Assistant Professor of Early Childhood Education/ Early Childhood Special Education at Boise State University. Dr. Mori participated in the initial development of the Universal Newborn Hearing Screening Program and served as primary support and outreach coordinator in her early membership with the Consortium.

Dr. Mori's experience in program evaluation has included local, community, and statewide projects including assisting the Idaho Infant Toddler Program in an assessment of inter-rater reliability for the OSEP Child Outcome Measurement System (2006-2007). She has participated in statewide projects to develop interagency and intra-agency programs for children and their families, e.g., Hilton Special Quest Head Start project (2004-2007), and the Idaho Association for the Education of Young Children Quality Rating System (2006).

Design and development planning for year one will include, review of data, development of surveys, identification of key performance indicators (including the JCIH benchmarks), determining measurement strategies and a time line. Surveys of parents and professionals will be included in data collection.

The following steps will be taken to design and implement evaluation of the EDHI-*Up* project:

Year 1 – Convene an Evaluation Subcommittee of the ISB Advisory Committee. The Evaluation Subcommittee will prepare an evaluation plan to : 1) identify priority indicators to be used to measure the outcome of the grant activities, including the JCIH benchmarks, 2) design measurement criteria and methods to assess the performance of ISB in achieving the objectives of the project, and 3) design and develop tools to conduct the evaluation, set a schedule for implementation of the evaluation.

The Evaluation Subcommittee will be chaired by Dr. Carrie Mori and will be made up of lead EHDI stakeholder representatives from the ISB Advisory Committee. They will meet at least three times during year one to finalize evaluation methods, strategies and tools.

Year 2 – Implement the evaluation according to the schedule recommended by the Evaluation Committee. The evaluation strategies will be implemented including necessary surveys; data analysis of hearing screening by each hospital, birthing facility and known midwife; and process evaluation of planned ISB program activities. Upon request by the Evaluation Subcommittee, ISB personnel will gather and provide to the committee any required data and information to be used in the evaluation, Infant Toddler Program Research Analyst,

Senior will prepare any necessary data analysis beyond the routine performance reports prepared by ISB on a quarterly basis.

Year 2 evaluation techniques will include steps to assure accurate and reliable data. This will include steps to evaluate data collection and submission processes to verify valid and reliable data.

Year 3—Continue implementation of evaluation techniques as outlined in the Year 1 Evaluation Plan. The Evaluation Committee with ISB and Infant Toddler Program staff support will complete collection and analysis of any required evaluation data and will develop a final report regarding the outcomes of the EHDI-*Up* project as compared with the proposed grant activities and timelines in the work plan. The Evaluation Report will be available to ISB and Infant Toddler Program personnel and to the ISB Advisory Committee prior to the close of the three year project.

Year two activities will encompass the implementation of surveys and other data collection mechanisms. Analysis of data will begin in year two with final data analysis, including trend analysis to be completed in year three.

ORGANIZATIONAL INFORMATION

The Idaho Infant Toddler Program (Part C) is the applicant agency for the EHDI-*Up* initiative. The Infant Toddler Program, partnered with the Council for the Deaf in the establishment of Idaho's Universal Newborn Hearing Screening Consortium in 1995. Mary Jones has served as Idaho's Infant Toddler Program (Part C) Coordinator for 17 years, providing administrative management for early intervention services to infants, toddlers and their families. She is the principal investigator for the EHDI-*Up* initiative, devoting 10% of her time to the oversight of the EHDI program.

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. As of 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).

The plans to move the EHDI program under the administration of the Part C program have been discussed for several years. Release of information to the Infant Toddler program was written into the ISB referral form from the beginning of the program in an effort to increase the success of the EHDI program. Collaboration was increased with the agreement for Infant Toddler personnel to provide contact and follow-up services in their individual regions.

“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.” (Idaho Infant Toddler Program/ISDB Interagency Agreement, February, 2007)

Program Components include:

- Public Awareness and Community Education Campaigns;
- Child Find — identification of children who would benefit from services;
- Evaluation and Assessment — activities to determine a child's current developmental status;
- Individualized Family Service Planning — a plan that addresses the child's and family’s unique needs;
- Early Intervention Services — therapeutic and support services provided in a "natural setting" such as the home or a childcare center;
- Service Coordination — activities which ensure needed services are available, accessible, and cost-effective;
- Procedural Safeguards — parent’s rights which guarantee timeliness and confidentiality;
- Transition Planning — procedures to help families access appropriate services when a child leaves the Infant Toddler Program;
- Personnel Training and Standards — assurance that providers are qualified and receive appropriate and adequate training;
- Program Self-Assessment — quality assurance and monitoring activities; and
- Data Collection and Evaluation — development and maintenance of a database that tracks the number of children served, services delivered, and other demographic information required for planning and reporting purposes

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 Idaho Infant Toddler Program and the Idaho School for the Deaf and the Blind participate in an interagency agreement. The purposes of this agreement are to:

- Work together to serve and support birth to three-year-old children with hearing loss and/or vision loss and their families.
- Understand each agency's roles and responsibilities, including financial obligations.
- Clarify the process and protocols to coordinate services and assure efficiencies and compliance with the provisions of IDEA and Idaho Code Chapter 16, Title 1, Idaho's Early Intervention Act.
- Minimize delays or gaps in service.
- Assure that procedural safeguards are met and services are delivered in a timely way at no cost to families.

The EHDI-*Up* initiative integrates seamlessly into the Division of Family and Community Services, Infant Toddler Program's mission and scope of work. Activities to increase follow-up will be enhanced due to the increased capacity of the statewide Part C program. Communication and training opportunities with regional outreach personnel will be increased, and program protocols will be streamlined and integrated throughout both programs. ISB will have increased access to follow-up data and data analysis services through the Division of FACS, and Hi-Track data will be linked with the new Part C early intervention database.