

PROJECT NARRATIVE

Background and Need

Universal Newborn Hearing Screening (UNHS) has been the standard of care in Washington State since 2005. The Department of Health (DOH) began collecting data on hearing screening rates in 1998 when only 3.8% of infants born in Washington received a hearing screen at birth. Data collected for 2006 show that approximately 97% of infants had at least one newborn hearing screen.

To help Washington hospitals manage their hearing screening data and provide follow-up services, the Washington State Early Hearing-loss Detection, Diagnosis, and Intervention (EHDDI) Program developed a tracking and surveillance system beginning in 2000. The system was developed with the national goals in mind: “ensure hearing screening for all newborns no later than one month of age, diagnostic audiologist evaluation no later than three months of age for those who do not pass the screening and enrollment in early intervention services no later than six months of age for those identified with hearing loss.” The system was also built to interact with the newborn blood spot program’s tracking and surveillance system. By joining the systems, we’re able to identify any child born in the state, those who may have missed any part of newborn screening, and the respective blood spot and hearing screening results of all infants.

Limelight Technologies, a software development company located in Tacoma, Washington, was contracted to develop the EHDDI tracking and surveillance system. The system was developed in two phases. Phase I allows for the collection of initial and rescreen results from hospitals via the newborn dried blood spot card (Appendix A). The

revised dried blood spot card includes mother and child demographic information as well as hearing screen results. This information is manually entered (i.e., data entry contract) then transferred into the EHDDI system nightly. These data are also cross-referenced with hospital birth roster information that is faxed weekly, to ensure unduplicated individual data. Infants who did not receive a hearing screen at birth, who did not pass their initial screen or rescreen, or who have risk factors for late onset hearing loss are identified by the EHDDI system and flagged for follow-up services. Follow-up actions that are triggered for EHDDI staff to complete include phone calls, letters or faxes, to hospitals or primary care providers. Please refer to Appendix B for the EHDDI Data Flow Chart.

Phase I was initiated in 2002 with 5 pilot hospitals. As of November 2006, all 69 of Washington's birthing hospitals have voluntary Universal Newborn Hearing Screening (UNHS) programs in place and all but the 3 military hospitals are reporting their screening data to the EHDDI program. The military hospitals do not receive their dried blood spot newborn screening through our laboratory; therefore, to date, including these infants in the EHDDI program has not been feasible. The increase in hospital births followed by DOH EHDDI program is presented in Appendix C.

Phase II is a secure web-based system where audiologists report diagnostic evaluation results and risk factor information to DOH using a secured network. These data are then linked back to the EHDDI system and the information collected through Phase I.

Over the past three years, the number of audiology clinics using the web application has increased from 8 to 14 clinics entering diagnostic results. With increased

audiologists' use of the web-based EHDDI system and their feedback, we've determined that a number of enhancements need to be made to the system to make it more functional and easier to use.

Data from the EHDDI tracking and surveillance system are also used as a tool for program evaluation and quality assurance. Data are used to assist hospital based UNHS efforts statewide by providing all hospitals with individualized regular reports regarding program performance and screeners' performance (Appendix D). This information is particularly important given the wide variety of UNHS program protocols in Washington State (i.e., the hearing screening may be performed using Evoked Otoacoustic Emissions (EOAE, OAE, TEOAE, DPOAE), Auditory Brainstem Response (ABR, AABR, BAER, ABAER), or a combination of both measures).

Data from the system can also be clinically important. Audiologists have the ability through the Phase II web application to generate a number of patient and facility related reports based on the information they have entered. Lastly, the EHDDI program staff routinely conducts internal evaluations to assess the effectiveness of the EHDDI system, the quality of our data collection methods, protocols, and procedures, and of course, whether we're meeting the national 1-3-6 goals.

Monitoring Whether Every Infant Receives a Hearing Screen (CY 2006)

In 2006, the EHDDI program followed approximately 80,600 births in Washington. This consisted of almost all births at the 66 civilian birthing hospitals, although one hospital was not reporting screening results until November 2006. The EHDDI program did not track the infants born outside of birthing hospitals (less than 1% of births; 1,937 infants), or births at the three military facilities (3,327 births) because

they do not use our state’s dried blood spot screening program, and hearing screen data are provided via the blood spot card. (Note: Within the three years of this proposal, the EHDDI program plans to develop a mechanism to include these infants’ data in the EHDDI tracking and surveillance system.)

The screening results reported to the EHDDI program for infants born in 2006 are shown in Table 1. A little over 95% of all infants received an initial hearing screen as reported by hearing screen data provided by hospital screeners. If no card was sent for an infant, the infant is listed on the “Possible No Test” report, sent by EHDDI program staff to hospital UNHS coordinators. This gives coordinators an opportunity to report a hearing screen that may have occurred but was not reported. If an infant is still shown to have missed their screen, EHDDI staff then contacts the infant’s Primary Care Provider (PCP) to recommend that the infant receive a hearing screen. In 2006, the EHDDI program determined that approximately 97% of infants received a newborn hearing screen, either before hospital discharge or as an outpatient. The average age at the initial hearing screen for all infants where the date of the initially screen was reported was approximately 3 days of age.

Table 1

Infant Hearing Screen Records 2006		
Infants with a Passing Initial Hearing Screen Record <i>(a)</i>	68,370	84.8%
Infants with a Referring Initial Hearing Screen Record <i>(a)</i>	8312	10.3%
Infants without Hearing Screen Records <i>(b)</i>	2815	3.5%
Parents refused <i>(c)</i>	1110	1.4%

Total Live Births (d)	80,607	100%
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- (a) *Hearing screen record was reported via the revised blood spot card*
- (b) *Infants without records were either missed or results were not reported*
- (c) *Parental refusal for hearing screening indicated on revised blood spot card*
- (d) *Total live births excludes infants who die, at or shortly after birth, at-home births, and births occurring at hospitals not participating in the EHDDI program*

Appropriate and Timely Screening Follow-up

Reported hearing screening results generate a series of actions to insure that timely follow-up care is provided. EHDDI program staff share hearing screen results and recommendations for additional hearing screening or evaluation with the infant’s primary care provider via letters, faxes, and phone calls.

Of the 2815 infants who missed their initial hearing screen at the hospital in calendar year 2006; 993 (35%) did not have a subsequent hearing screen result reported to the EHDDI program. While 993 infants account for only 3.5% of all births in the EHDDI system for 2006, the fact that 35% of those initially missed at the hospital *never* receive a hearing screen reveals the importance of screening prior to hospital discharge.

Of the 8312 infants who did not pass their initial hearing screen, 19% did not have additional screening results submitted to the EHDDI program. For the majority of these infants, (72%), the PCP shared with the infant’s parents the recommendation for the infant to receive an additional screen. For these infants, it’s not clear if the EHDDI program lacks further documentation (i.e., the re-screen results were not reported to the EHDDI program) or communication from the PCP alone is not sufficient for the recommended follow-up to occur. Developing and implementing strategies for hospital screeners that encourage and facilitate the process of parents/infants returning for a screen or re-screen may significantly decrease the number of infants lost to follow-up during the screening phase.

Appropriate and Timely Diagnostic Follow-up

As of February 2008; 693 infants born in 2006 were indicated as being referred for an audiologic evaluation. Diagnostic evaluation results were reported to the EHDDI system by 14 clinics using a secure web-based application, and 31 clinics faxed back diagnostic evaluation forms. A total of forty-five audiology clinics reported diagnostic evaluation results for infants born in Washington State in 2006. 68% of the infants evaluated were seen at one of the 20 audiology clinics that the Washington State EHDDI program recognizes as meeting best practices for audiologic assessment of newborns.

In collaboration with the audiology center at Children's Hospital & Regional Medical Center (CHRMC), EHDDI program staff annually sends a survey to practicing audiologists within Washington. Based on survey responses, the clinics where the audiologists' practices are designated as meeting, or not, the state's recommended best practices for audiologic assessment of newborns. These best practices were last updated in 2007 (see Appendix E for audiology listings). While EHDDI program staff would prefer all infants were evaluated only by those meeting these best practices, because the state is so large and all of the facilities meeting best practices reside in urban areas, it is oftentimes not possible for a family to receive services at one of these audiologic sites. The EHDDI program staff welcomes whatever diagnostic information the other audiologic facilities can provide and continues to build pediatric audiology capacity around the state with local trainings, or scholarships to attend national trainings, for audiologists.

The available diagnostic outcomes for infants referred for audiologic evaluation are detailed in Table 2. Of concern, the EHDDI program did not receive diagnostic

results for ~24% of infants who were referred. The EHDDI program is currently performing a parent survey to identify barriers that families face when their infant is referred for an audiologic evaluation. Knowledge of these barriers will help EHDDI program staff strategize solutions to decrease the number of infants referred for diagnostic evaluations who fail to receive them.

Table 2

Diagnostic Outcomes for Infants Referred to Audiologists - 2006(a)		
Definition of Final Disposition	Number of Infants	Percent of Infants
Patient was found to have normal hearing	254	36.7%
Hearing loss was confirmed	196	28.3%
Outcome is unknown (b)	165	23.8%
Patient's evaluation was inconclusive	78	11.2%
TOTAL	693(c)	100%

- a) *Diagnostic outcomes were gathered through the web-based reporting system or a faxed diagnostic evaluation form*
- b) *Patient did not go to appointment, did not return for follow-up diagnostic appointment, or place of referral was not found by DOH*
- c) *Includes infants referred whom the DOH was tracking because of failed hearing screen(s) and infants DOH became aware of by being notified of audiologic evaluation by audiology clinic*

Assisting in Appropriate and Timely Entry into Early Intervention

Currently, the Washington EHDDI system does not consistently track infants diagnosed with hearing loss into early intervention services. The EHDDI program requests that audiologists report referrals made to early intervention in either the web application or a diagnostic evaluation form faxed to the program. As of February 2008, of the 196 infants born in 2006 and diagnosed with any type of hearing loss, 55 (28%) were reported as having been referred to early intervention. However, a study performed in

2006, counting the number of children with hearing loss of a given age receiving early intervention services during a specified timeframe (“kids count” model), suggested that this low figure is an artifact of reporting and not actual practice. The kids count study showed the majority of the expected number of infants with hearing loss enrolled in early intervention services although it also suggested that their entry did not occur until, on average, 218 days after birth (i.e., 7.3 months) which is greater than the established goal of early intervention by 6 months of age.

There are several needed modifications to the EHDDI web application that would make it more accessible and functional for audiologists to report referrals to early intervention. These changes to the web-based application, along with continued training of audiologists in using the EHDDI system, will likely increase the quality of data reported and the ability to capture more accurate data on referrals to early intervention. EHDDI staff also wishes to explore the possibility of a data sharing agreement or linkage with the Infant Toddler Early Intervention Program (ITEIP) database. The ITEIP is the state’s Part C program and is housed in a different state agency (Department of Social and Health Services). Nonetheless, EHDDI staff has worked closely with ITEIP staff over the years and both programs fully recognize potential benefits from such a data sharing capability.

Building the EHDDI system and program has required a great deal of collaborative relationships over the past several years. Currently there is no state legislation regarding UNHS in Washington so hospital based screening programs are entirely voluntary as is reporting of diagnostic information by audiologists. In October, 2001, the State Board of Health and DOH convened a newborn screening advisory group

to review the disorders included in the mandated newborn screening panel. Their work concluded in May, 2002 with a recommendation that the SBOH add, among others, newborn hearing screening. In October 2003, the SBOH decided to wait and determine whether UNHS could be achieved voluntarily. The SBOH made a commitment to continue to consider the issue and has asked the EHDDI program to report on the effectiveness of the voluntary approach each year since. While our data suggest that hearing screening indeed can occur voluntarily, there are other issues that the program continues to face including sustainability.

Funding for the development of the system was provided by the Centers for Disease Control and Prevention, (CDC) from 200- 2005. In 2003, the program requested general fund state dollars from the legislature and were given \$125,000 per year. This past legislative session, the legislature was again asked to support the EHDDI program and an additional \$325,000 annually was granted signifying the legislative intent that DOH will continue the EHDDI program even without a legislative mandate for newborn hearing screening.

Work Plan

Overarching goal: To develop and enhance the EHDDI tracking and surveillance system to increase the capacity of the program to collect and evaluate accurate data throughout the EHDDI process.

Goal 1: Enhance the EHDDI tracking and surveillance system to improve the collection of data and minimize infants lost to follow-up.

Objective 1.1 By December 31, 2008, identify and contract with an IT vendor to improve and update Phase I of the EHDDI surveillance system to track hearing screening results and generate hospital quality assurance reports.

Objective 1.2 By December 31, 2008, identify and contract with an IT vendor to enhance the web-based audiology reporting system (Phase II), based on feedback from audiologists and current information technology standards.

Objective 1.3 By December 31, 2010, develop a process to include within the EHDDI tracking and surveillance system, infants who are born outside of hospitals and at military facilities.

Goal 2: Increase the reporting and accuracy of data by collaborating with birthing facilities, diagnostic centers, Part C, and other early intervention services.

Objective 2.1 By December 31, 2009, in collaboration with the Newborn Screening Program, and with input from birthing hospitals, review the revised blood spot/hearing screening cards and, as needed, make changes.

Objective 2.2 See Objective 1.1

Objective 2.3 By March 1, 2010, develop a mechanism for linking with or sharing Department of Social and Health Services (DSHS) Infant Toddler Early Intervention Program (ITEIP) data to monitor whether infants with hearing loss are entering early intervention services by 6 months of age.

Goal 3: Improve mechanisms to identify and collect standardized data on unduplicated individual infants and children with late onset or progressive hearing loss.

Objective 3.1 By December 31, 2009, continue to work with audiologists on using the web-based application to report information from diagnostic evaluations and to explore their willingness to enter data on all children evaluated up to five years of age.

Objective 3.2 By December 31, 2009, work with audiologists to enter in Phase II risk factor(s) for late onset hearing loss for all infants evaluated for hearing loss.

Goal 4: Develop an analytic plan to address loss to follow-up rates including, but not limited to, differences between variables such as birthing facilities, false positive rates, demographic differences and geographic location.

Objective 4.1 By January 1, 2009, analyze data, by geography, race, and other variables of interest, to determine loss to follow-up rates after an initial failed hearing screen performed before hospital discharge.

Objective 4.2 By January 1, 2009, analyze data, by geography, race, and other variables of interest, to determine loss to follow-up rates after referral for diagnostic evaluation.

Objective 4.3 By June 30, 2009, with input from stakeholders, use findings from data analysis in Objective 4.1 and 4.2 to strategize methods to reduce loss to follow-up rates after one failed hearing screen and referral to audiologist.

Objective 4.4 By June 30, 2009, implement at least one strategy for each stage of loss to follow-up (after initial failed hearing screen and after referral for diagnostic evaluation).

Goal 5: Develop a quality assurance and improvement plan to monitor the accuracy and quality of data reported to the EHDDI program.

Objective 5.1 By August 31, 2008, continue to disseminate monthly reports to birthing hospitals that provide information on screening statistics of individual hospital screeners

and aggregate hospital data on the quality of hearing screening information being reported.

Objective 5.2 By August 31, 2008, on a monthly basis monitor hospital screening statistics and contact Children's Hospital and Regional Medical Center (CHRMC) trainers to suggest site visit training or other intervention for hospitals with referral rates above 10%.

Objective 5.3 By August 31, 2008, continue to disseminate weekly a report to birthing hospitals that list infants who did not receive a hearing screen before hospital discharge.

Objective 5.4 By August 31, 2008, continue to disseminate monthly reports to birthing hospitals that list infants who did not pass their initial newborn hearing screen and have no record of a subsequent hearing screen.

Goal 6: Develop an evaluation plan to monitor progress toward meeting program goals and objectives and to assess the timeliness, completeness, and success of the EHDDI system.

Objective 6.1 By December 2008, train EHDDI staff in developing a program evaluation plan using the CDC evaluation framework.

Objective 6.2 By December 2009, develop an evaluation plan using the CDC evaluation framework to assess the EHDDI tracking and surveillance system and program goals.

Collaborative Efforts

As described in the background section of this proposal, the efforts to support and sustain the EHDDI program and tracking and surveillance system in Washington require many collaborative relationships. Below are some of the groups with whom DOH

EHDDI staff routinely work and who are involved in addressing early hearing screening, evaluation and intervention services.

Washington State Birthing Hospitals

UNHS programs are located within individual birthing hospitals. As of 2006, all Washington birthing hospitals had voluntarily implemented UNHS programs. Hospital staff are responsible for nearly all aspects of UNHS program development and maintenance. This includes:

- determining their screening protocol from options shared by DOH.
- determining procedures.
- training screening staff.
- recording and reporting results.
- financing the program.
- obtaining and caring for screening equipment.
- communicating with parents, DOH and care providers.

All but the three military hospital UNHS programs are coordinating efforts with DOH to collect and report hearing screen results. Military hospitals (approximately 3000 births) in Washington use Oregon's newborn screening laboratory for their dried blood spot screening, therefore coordination between military hospitals and the EHDDI program has not been feasible.

Washington State Hospital Association

The Washington State Hospital Association (WSHA) provides leadership, advocacy, and support to Washington hospitals. The WSHA played a critical role in encouraging hospitals to establish their voluntary UNHS programs.

Children's Hospital and Regional Medical Center (CHRMC)

The EHDDI program contracts with CHRMC audiologists and staff to provide on-going technical assistance to hospital based UNHS programs. CHRMC makes periodic site visits to hospitals, conducts annual UNHS manager trainings, and works with EHDDI staff to develop and distribute professional and parent educational materials.

Audiology Clinics

Audiologists provide the critical step of identifying infants who are deaf or hard of hearing by performing diagnostic evaluations on infants who do not pass their hearing screen. Audiologists also assist in reviewing proper protocols in hearing screening and diagnostic evaluation. These are outlined in Appendix E. Finally, audiologists work with the EHDDI program to collect and report diagnostic results through the secure web-based extension of the EHDDI tracking and surveillance system.

Primary Care Providers

The EHDDI system includes a directory of all pediatric facilities and providers. This enables us to more easily provide follow-up services when required. PCPs also routinely contact the EHDDI program to provide additional information (e.g., infant referred to audiologist, infant has moved out of state, etc.) or to request hearing test results on file. Focus group data collected from this stakeholder population in 2005, indicates that the information DOH is providing to PCPs and the timing of this information is appropriate for them to meet the needs of their patients.

Newborn Screening Program

A close collaboration exists between the EHDDI program and the Newborn Screening program. Hospitals report hearing screening results via the dried blood spot

newborn screening card. Also, patient demographic information and hospital birth roster data from the Newborn Screening program's data system populate the EHDDI tracking and surveillance system.

Infant Toddler Early Intervention Program (ITEIP)

Currently, the EHDDI program works with ITEIP to promote newborn hearing screening and follow-up in the community and among ITEIP's Family Resource Coordinators to improve coordination of services. However, in this proposal we plan to explore the possibility of linking with or sharing ITEIP data to better monitor whether infants with hearing loss are entering early intervention by six months of age.

Division of Information and Resource Management

DIRM staff provides cross-agency technical support as well as establishes information technology standards for the agency. For this project, DIRM staff is again committed to working to identify an IT vendor to improve and update the surveillance system and to explore the feasibility, constraints, and costs and benefits of linking with or sharing ITEIP data.

MCH Assessment Section

The EHDDI program is collaborating with the Maternal and Child Health (MCH) Assessment Section, located in the Office of MCH, on a project to better understand barriers to obtaining follow-up services after a failed newborn hearing screen in Washington State. The EHDDI program expects that this work will result in the development and implementation of new strategies to overcome these barriers. Epidemiologists within MCH Assessment will continue to provide technical assistance and support to the EHDDI program.

Members of the Deaf Community and Parents of infants with hearing loss

The EHDDI program has always recognized members of the Deaf Community and parents of infants with hearing loss as valuable partners in developing best practices for screening and early intervention services. In addition, the EHDDI program helped to develop a birth-to-three track for an annual event for families with children who have hearing loss held by the Washington State Sensory Disabilities Services. This weekend camping adventure includes many opportunities for those with hearing loss and their families to meet, network, and learn from one another. In addition to developing the birth to three track, the EHDDI program also sponsors (i.e., pays for all expenses) for up to 8 families each year. In turn, we are greatly rewarded by these families as they oftentimes serve on “consumer panels” in educational offerings we host.

Program Capacity

The EHDDI program is part of the Genetic Services Section (GSS) within the Office of Maternal and Child Health (MCH), Division of Community and Family Health (CFH) in the Washington State Department of Health (DOH). The agency mission is to protect and improve the health of people in Washington State. One of the priority outcomes for MCH is the “quality screening, identification, intervention and care coordination,” and the GSS mission is to improve the health of people with, or at risk of, genetic disease or congenital abnormalities by:

- Serving as a resource for accurate, up-to-date information
- Promoting educational opportunities for health and social service providers
- Evaluating quality, trends, and access to services.

The MCH office is the Title V Agency in Washington State. MCH works to promote and develop an environment that supports the optimal health of all women of childbearing age, infants, children, adolescents, and their families. Programs within MCH include: the Genetic Services Section (GSS), Children with Special Health Care Needs (CSHCN), Child & Adolescent Health (CAH), Immunization Program CHILD Profile (IPCP), Maternal & Infant Health (MIH), and MCH Assessment.

The EHDDI program organizationally resides in MCH, the newborn screening (NBS) program resides in the Office of Newborn Screening, within the Division of Epidemiology, Health Statistics, and Public Health Laboratories. It has always been the intent of DOH to integrate the EHDDI program with the NBS program as much as possible, therefore, the EHDDI staff are co-located with the NBS follow-up staff at the public health laboratories in Shoreline, WA (just north of Seattle) - as opposed to most other MCH staff who are located in Olympia, and the section managers for each program interact on a weekly basis concerning space, staff and/or programmatic activities. (Refer to Appendix H for agency organizational charts.)

Reasons that the programs reside in different divisions include that hearing screening is voluntary in Washington, coupled with the NBS program's full plate in enacting multiple other changes that will expand the dried blood spot newborn screening program. It's anticipated that at some point, the two programs (NBS follow-up and EHDDI) will merge, but at present, the collaborative coordination of activities is preferable.

NBS leases their follow-up surveillance system through Neometrix, while a private vendor built the EHDDI tracking and surveillance system distinctly for

Washington State. The EHDDI system is intricately linked with the NBS system, whose infant demographic data populate the EHDDI system. There have been many discussions within the agency about pursuing a more elaborate integrated child health data system. To date, nothing beyond the planning stages for linking other systems, such as immunizations and vital statistics, has occurred.

Finally, while hearing screening currently is voluntary in Washington State, the GSS has been successful in two separate legislative sessions in securing state general funds to support the EHDDI program. The first occurred in 2005 when the program requested and received \$125,000 annually for EHDDI. In the most recent (2008) legislative session, staff requested and were awarded an additional \$325,000 annually. This demonstrated support clearly signifies that while voluntary in nature, the legislature expects and desires that DOH EHDDI staff continue to conduct and improve EHDDI services statewide.

Staffing and Management Plan

The GSS consists of 8.0 full-time equivalents (FTEs). GSS staff who will participate in this project include:

Program Manager/Principal Investigator, Debra Lochner Doyle, MS, CGC, who is responsible for all aspects of the sections activities as well as coordinating genetics and EHDDI related activities across the agency.

Health Services Consultant 4/ EHDDI Program Coordinator, (currently recruiting), who is responsible for negotiating and managing contracts, grant applications and updates, and facilitating communication among EHDDI contractors and stakeholders.

Health Services Consultant 3/ EHDDI Data Manager, Karin Neidt, MPH, who coordinates EHDDI follow-up, analyzes data, compiles and distributes data reports, manages data system updates, convenes weekly EHDDI team meetings, participates in hospital site visits as needed, and develops the annual report to the State Board of Health about progress and issues faced by the EHDDI program.

Health Services Consultant 1/ EHDDI Follow-up Staff, Caroline Maundu, who is responsible for the day-to-day follow-up actions (phone, fax, letters) triggered by the EHDDI tracking and surveillance system as well as data entry to the system as additional information is learned based on the actions taken

Health Services Consultant 1/ EHDDI Follow-up Staff, Martha Lucas, who is responsible for the day-to-day follow-up actions (phone, fax, letters) triggered by the EHDDI tracking and surveillance system as well as data entry to the system as additional information is learned based on the actions taken

Secretary Administrator, (currently recruiting), who is responsible for the day-to-day logistical operations and clerical support for all GSS staff.

Staff from the Grants Management Office further supports the GSS, and a Budget Program Specialist works with GSS staff to ensure all fiscal accounts are entered into the state fiscal monitoring system, and meets with program staff monthly to monitor the accounts. In addition, a warrants officer processes warrants authorized for payment by program staff and enters these payments into the fiscal monitoring system.

The GSS has a long track record of knowledge and experience in the planning, implementation, and evaluation of large-scale projects. GSS initiated its first statewide Genetic Needs Assessment in 1991. Since that initial effort, the GSS has undertaken

numerous other assessment and planning activities. Several examples further demonstrate GSS's ability to establish coordinated leadership. Each of these federally funded activities involved both quantitative as well as qualitative approaches that were (or are) coordinated, implemented, and evaluated:

- HRSA Special Projects of Regional & National Significance (SPRANS) entitled *Genetics Education Project for Primary Care Providers, "Genetics & Your Practice"* (1994 – 1998) (see publications at <http://mchneighborhood.ichp.edu/wagenetics/index.html>)
- HRSA Special Projects of Regional & National Significance (SPRANS) entitled *The Partner's Forum: A Washington State Model for Ensuring Access to Quality Genetic Services for Persons in Managed Care* (1997 – 2000) (see publication at <http://mchneighborhood.ichp.edu/wagenetics/index.html>)
- CDC State Capacity Project for Assessing & Preventing Secondary Conditions Associated with Disability and Promoting the Health of Persons with Disability (1991 – 2007) (see multiple publications at <http://mchneighborhood.ichp.edu/wagenetics/index.html>)
- CDC cooperative agreement entitled *Early Hearing Loss Detection, Diagnosis, and Intervention (EHDDI) Tracking & Surveillance System Development in Washington State*. (2000 – 2008)
- HRSA grant entitled *Early Hearing Loss Detection, Diagnosis, and Intervention (EHDDI) Implementation in Washington State*. (2001 – 2008)

- *HRSA grant entitled Genetic Services—Improving Health of Children: Implementation of the State Grants for the Integration of Programs and Their Information. (2002-2006)*

Evaluation Plan

In order to evaluate the effectiveness of these activities, process and outcome evaluations will be conducted. The process evaluation will consist of monitoring the extent to which activities are being done on time, their degree of completeness, and the quality of work performed. Team meetings between EHDDI, NBS, and DIRM will occur monthly to review the work plan for the necessary objectives and ensure that they are completed within the projected time frame. The outcome evaluation will consist of determining whether the activities undertaken have affected outcomes with regards to the goals stated in this proposal. It is our intent to actually develop a detailed EHDDI program evaluation plan using the CDC evaluation framework as one of our objectives. **Goal 6: Develop an evaluation plan to monitor progress toward meeting program goals and objectives and to assess the timeliness, completeness, and success of the EHDDI system.**

The plan would broaden current program evaluation efforts that primarily use the EHDDI data to answer whether or not the program is meeting the “1-3-6 goals.” By expanding these efforts, we hope to include other program areas such as does the program meet the needs/expectations of all stakeholder groups, and/or is it cost effective and efficient? A timeline for this plan development follows:

By: September 2008	Engage stakeholders
September 2008	Describe the program Describe goals and objectives (including need, activities, resources, outputs and expected short term and long term outcomes) Develop logic model

October 2008	Focus evaluation Identify purpose of evaluation, key questions, how results will be used Identify evaluation type and design
January 2009 (ongoing)	Gather credible evidence Identify indicators, data sources/ methods Manage logistics of data collection
April 2009	Justify Conclusions Analyze and Synthesize findings. Interpret Findings Present Results Make recommendations
May 2009	Ensure use and share lessons learned Share findings Identify lessons learned/ obtain feedback Document how evaluation used

Until the full plan is developed it is difficult to know what outcome measures should be included. However, some intermediate outcome measures to evaluate the impact of the activities proposed in this proposal include the following:

Goal 1: Enhance the EHDDI tracking and surveillance system to improve the collection of data and minimize infants lost to follow-up.

Obj. 1.3 ... develop a process to include within the EHDDI tracking and surveillance system, infants who are born outside of hospitals and at military facilities.

Evaluation. Collect baseline data of current home/military births within EHDDI system; compile data on a quarterly basis and by March 2011 compare.

Goal 2. Increase the reporting and accuracy of data by collaborating with birthing facilities, diagnostic centers, Part C, and other early intervention services.

Obj. 2.3 ... develop a mechanism for linking with or sharing Department of Social and Health Services (DSHS) Infant Toddler Early Intervention Program (ITEIP) data to monitor whether infants with hearing loss are entering early intervention services by 6 months of age.

Evaluation. Use ITEIP data merged with EHDDI data to determine if infants with hearing loss are enrolled in early intervention by 6 months of age.

Goal 3: Improve mechanisms to identify and collect standardized data on unduplicated individual infants and children with late onset or progressive hearing loss.

Obj. 3.2 ... work with audiologists to enter in Phase II risk factor(s) for late onset hearing loss for all infants evaluated for hearing loss.

Evaluation. Compile baseline data of risk factor information of infants in Phase II, compile same data quarterly and compare.

Goal 4.: Develop an analytic plan to address loss to follow-up rates including, but not limited to, differences between variables such as birthing facilities, false positive rates, demographic differences and geographic location.

All Objectives. Evaluation: The EHDDI program is collaborating with the Maternal and Child Health Assessment Section to evaluate the results of a parent survey, currently underway. The survey targets parents of children referred to diagnostic audiology, whether they received these services or not, to ask what barriers they encountered in obtaining audiology services in Washington. The data from the confidential portion of the birth certificate for these infants are also being analyzed to determine if there are any identifiable risk factors that may suggest one is less likely to pursue referral recommendations (e.g., marital status, level of education, zip code, etc.) Results of this evaluation study are expected by July 2008 and will be used to determine future strategies for addressing the needs to begin September 2008. A reduction in loss to follow-up rates after implementing the new strategies will indicate their effectiveness.

Goal 5: Develop a quality assurance and improvement plan to monitor the accuracy and quality of data reported to the EHDDI program.

Obj. 5.2 ... on a monthly basis monitor hospital screening statistics and contact Children's Hospital and Regional Medical Center (CHRMC) trainers to suggest site visit training or other intervention for hospitals with referral rates above 10%.

Evaluation: On a monthly basis, the EHDDI program monitors for each birthing hospital the a) percent of infants screened, b) percent of infants who did not pass their initial hearing screen, and c) percent of parents who refused newborn hearing screening. Hospitals struggling (i.e., less than 95%, more than 10%, and greater than 2% respectively) in any of the above areas will be contacted to address the specific challenge. EHDDI program or contracted staff will provide a training visit and/or suggest strategies to improve their screening practices. Effectiveness will be based on improved rates for the formerly deficient measure.