Program Narrative

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INTRODUCTION

Over the past eight years, North Dakota (ND) has engaged in a wide range of activities to implement universal newborn hearing screening and subsequent referral, diagnosis, and intervention. These efforts have been supported with funding from both HRSA and the CDC and have been coordinated through local birthing hospitals, ND's American Academy of Audiologists (NDAAA), the North Dakota State School for the Deaf (NDSD), and the state's early intervention (Part C) program. Although ND has no statewide mandate for early hearing detection and intervention (EHDI), we have been successful at achieving 90% to 95% screening of newborns before the first month.

However, ND is failing to identify, refer, and treat the number of infants with hearing loss that would be expected based on our state demographics and expected incidence levels. State data and parent surveys indicate there are significant weaknesses in ND's capacity to follow-up, track, and refer infants with hearing loss to appropriate diagnostic, treatment, and family-support programs. ND will implement various strategies found effective through the National Initiative on Child Health Quality (NICHQ) learning collaborative to address these weaknesses and collect data on their effectiveness.

ND currently has two projects that support Early Hearing Detection and Intervention (EHDI) efforts. The ND First Sounds Project received initial funding from HRSA in April of 2000. At that time, emphasis was placed on universal newborn hearing screenings (UNHS), but not a great deal of attention was given to follow-up efforts. In July of 2005, ND received funding from CDC for Project Kaylyn to focus on follow-up issues. Since then, UNHS programs have evolved into EHDI; focusing on reducing loss to follow up after the screening process and early intervention for families with infants having suspected or confirmed hearing loss. Combined, both ND First Sounds and Project Kaylyn are referred to as the ND EHDI Program. For clarification, the term ND EHDI will be used throughout this proposal to indicate statewide EHDI efforts; answering to the national 1-3-6 message of screen before 1 month, diagnose before 3 months, and provide early intervention before 6 months of age.

This proposal requests funding for ND Hear Now, a program with a new title to reflect a focus on follow-up referral, diagnostic evaluation, and intervention. It will fall under the ND EHDI umbrella and will provide a more prescriptive message of early identification. The ND Hear Now program will provide training and technical assistance to hospitals, audiologists, child health professionals, and others in early intervention and family support programs on how to follow-up and work with families where infants have not passed the initial hearing screening. A statewide online database will be utilized to track infants from birth through diagnosis and intervention. In conjunction with our State EHDI Coordinator (located at the Department of Health), a statewide follow-up program will be implemented during the grant period and opportunities will be pursued for continuing follow-up efforts with other newborn screening programs.

NEEDS ASSESSMENT

Birth Statistics and Demographics

Despite previous efforts by professionals and families, ND has no mandate for early hearing screening for infants and young children. Further, the state legislature appears unlikely to provide directives for this in the future. Voluntary participation from ND's birthing facilities, early hearing professionals, and audiologists is vital in supporting ND's EHDI initiative. Other partnerships with Part C, Children Special Health Services (CSHS), Right Track, and the NDSD Parent Infant Program (PIP) will enhance the program's efforts to reduce the number of children lost to follow-up (LTFU).

ND has a total of 17 birthing facilities. Like many other Great Plains states, ND has few larger cities: Minot, Grand Forks, Bismarck, and Fargo. These cities are served by six comprehensive medical centers that account for over 80% of the state's births. The remainder of births occur in 11 other hospitals including one Indian Health Services (IHS) hospital which serves the Turtle Mountain Indian Reservation.

Vital Records indicated 9,875 births in 2006. Forty-eight of which were out-of hospital or home births. The number of live births entered into the statewide data system, OZ eSP, in 2006 was 8,222 (Attachment 2.1). The dissimilarity of birth numbers (15%) occurred due to incomplete data entry into OZ by North Dakota's largest birthing facility and an IHS hospital during that period. Since then, ND's birthing hospitals have improved data entry efforts. In 2007, missed data entry of births decreased to 5% when compared to Vital Records.

North Dakota had 1,527 (15%) non-resident births in 2006. The greatest numbers of non-resident births were from Minnesota (1,284 or 13%) followed by South Dakota (160 or 1.6%). Diversity by mother's race for 2006 births indicated 84% were white, 11% were Native American Indian, and the remaining 5 % were other races or unknown.

Screening and Diagnosis

Of the infants entered into OZ eSP, 97% had a birth screening conducted. While OZ eSP shows a commendable hearing screening rate, the missed entry of some births is still occurring thereby decreasing the actual state screening rate to 92% (when the birth number from Vital Records is used as the denominator). JCIH standards indicate a recommended benchmark of greater than 95%.

The ND EHDI program has a two part process for hearing screening: 1) initial screening prior to hospital discharge and 2) outpatient follow-up for those missing an initial screen and those discharged with a refer result. In 2006, 8,222 births were entered into the OZ system. Of those, 27 were designated as unavailable for screening leaving 8,195. At discharge, 874 referred and 313 missed indicating 14% who required follow-up and an 11% birth screening refer rate (Attachment 2.1).

ND is currently losing 54% of infants between hospital and outpatient screening. Of the 1,187 infants requiring outpatient follow-up, 547 (46%) returned. The vast majority of infants returning for outpatient follow-up (501) had been birth screen refers.

Of the 547 who returned for outpatient follow-up, 490 passed; leaving 57 refers or an outpatient referral rate of 10% (Attachment 2.2). In ND, 85% of missed birth screens do not return for outpatient follow-up and 43% of birth screen refers do not return for outpatient follow-up. This indicates a considerable need to educate families of the importance of screening prior to hospital discharge.

Outlier hospitals in North Dakota are those with a refer rate greater than the state's average birth screen refer rate of 11%. In 2006, 9 hospitals met this definition; three large birthing facilities and six smaller rural facilities (Attachment 2.3). The larger facilities typically have incurred a high staff turn over and have a large number of screeners. The smaller facilities have fewer births resulting in an inability to remain proficient with the screening process. Addressing these issues remains a significant challenge. Ongoing efforts continue to be provided through site visits by grant staff, screener training provided by audiologists, and ongoing communication with hospital staff.

An accurate number of infants LTFU between outpatient screening and audiological assessment/diagnosis is not available in the state database at this time due to limited data entry by audiologists. Some audiologists do not have access to OZ, some have access but require training, and some have indicated they simply do not have the time to enter data into the state database. However, available OZ data indicates that of the 547 infants who returned for an outpatient follow up, 61 (11%) required audiological assessment. Of those requiring audiological assessment, five have data entered for assessment leaving 56 infants, or 92% LTFU. The need for complete data entry in OZ by audiological providers is significant, as is the need for implementing an improved tracking mechanism for those providers who do not have access to the state database. Although previous efforts began to address this issue, the ND Hear Now program will increase its training to ND birthing hospitals and audiologists, and strengthen partnerships with early intervention and family support agencies.

Since 1998, ND has also collected hearing screening information via a paper survey conducted through the CSHS office. The 2005 survey indicated 28 infants (6.5%) were referred for diagnostic evaluation; however, only one infant was diagnosed with a hearing loss (Burns, 2006). This number is below the national incidence where three to four infants are expected to be diagnosed with hearing loss per 1,000 births.

There are 27 pediatric audiologists in ND. Previous ND EHDI efforts determined this number by mailing postcards annually to all board certified audiologists in the state. Audiologists were asked to indicate their geographical service area, update contact information, and verify that they are serving the pediatric population. The postcard was then sent back to the ND EHDI office resulting in a brochure that has been supplied to all facilities capable of birth and outpatient screenings, Right Track Coordinators, and PIP Coordinators. This brochure is supplied as Attachment 7.1.

Medical Home

Currently, the number of infants with a medical home is indicated in OZ eSP as those infants with a primary care physician listed as a professional contact. Medical home information is accessed through an export of OZ data. Data from 2006 indicate 2,285 (28%) have a medical home listed. Unfortunately, the medical home concept is not widely used in ND. Current procedures vary by facility and quite often the attending physician is listed on the newborn hearing screening; not the primary care physician (PCP). This is due to a variety of reasons (e.g., parents do not know or have a PCP, hospital policy, or the subsequent provider is unknown at the time of data entry). Focused training efforts to hospital staff will increase the percentage of infants having a PCP listed within OZ eSP.

Early Intervention and Family Support

The ND Hear Now program will continue to partner with ND's Right Track program to decrease the number of infants lost-to-follow-up (LTFU) between the hospital and outpatient screening. Program staff notify regional Right Track coordinators of infants leaving the hospital with a "refer" or "missed" result. This process was piloted in Regions II, III, and VI in 2006 and attained full implementation of all eight regions by year-end. Right Track coordinators provide support to families of newborns who refer on the newborn hearing screening, thus increasing the likelihood of returning for follow-up hearing screening.

The NDSD PIP will perform a similar function for families requiring an audiological assessment. PIP coordinators will receive notification of infants not passing the outpatient screening. PIP coordinators are then able to contact families encouraging them to attend an audiological assessment, and if possible, offer to attend the appointment with the family. PIP coordinators are highly qualified Teachers of the Deaf and can serve as a valuable resource to families about hearing assessment and management. PIP coordinators are respectful of family and cultural differences and will help families chose early intervention options in an unbiased way.

Although these efforts are a good first step in reducing LTFU, better mechanisms for contacting families and assisting them through the follow up, evaluation, and early intervention process will be explored and implemented. This will ensure that ND's infants with confirmed hearing loss and their families have a better opportunity to access family support information. The ND Hear Now program will maintain its relationship with pediatric audiologists, the Family to Family Network and ND Family Voices to ensure family support services are offered at the time of diagnosis.

Summary

ND is currently screening 92% of infants (when compared to Vital Records) and losing 54% of infants between hospital and outpatient screening. In ND, 85% of missed birth screens do not return for outpatient follow up and 43% of birth screen refers do not return for outpatient follow up. This indicates a considerable need to educate families of the importance of screening prior to hospital discharge.

Additionally, 92% of infants are LTFU between outpatient and audiologic assessment. The number of infants LTFU between diagnosis and entry into early intervention is unknown at this time. Those LTFU will be more accessible when hospitals, audiologists, and early intervention providers become more proficient with data entry.

The ND EHDI program is exclusively dependent on grant funds which are insufficient to provide OZ access for every screening, diagnostic and early intervention provider. Thus, a paper follow-up form will be implemented for non-OZ users to track screening, diagnostic, and early intervention services.

METHODOLOGY

Based on our needs, ND will employ a variety of strategies to promote, enhance, and sustain ND EHDI efforts. Some strategies continue proven methods from previous grant work and some are new strategies offered by the NICHQ learning collaborative. New strategies will initially be implemented in a small geographical region and its effectiveness will be assessed. If successful, these new strategies will be promoted and replicated throughout ND.

Goal 1: Assure that 98% of babies born in ND have their hearing screened before one month of age.

Objective 1.1 - All ND birthing hospitals will have access to the technical assistance, training, and program support necessary to provide hearing screening to every newborn and to implement appropriate follow-up and referral services.

Activity 1.1.1 – Renegotiate cooperative agreements between ND EHDI and the 17 participating birthing hospitals. Memoranda of Agreement (MOA) will be revised, updated, and mailed to each participating facility upon funding. Signatures from each birthing hospital, CSHS, the state Part C coordinator, and the project director will be obtained.

Activity 1.1.2 – Provide technical assistance and training to birthing hospital staff on how to implement ND Hear Now efforts. A checklist (Attachment 7.2) titled "The Hospital EHDI Assurance Report" (HEAR) will be utilized to identify the extent to which each hospital meets or exceeds EHDI policies, procedures, and protocols; public awareness; referral and follow-up; partnerships; and training and education. Standards were based on recommendations and guidelines provided by the National Center for Hearing Assessment and Management (NCHAM), Joint Committee on Infant Hearing (JCIH), CDC, and from the ND EHDI Advisory Group. In light of the recent 2007 JCIH Position Statement, there is a need to revise the HEAR document prior to hospital training. ND Hear Now staff will meet with Advisory Group members to modify the HEAR document and update ND's EHDI protocol. ND Hear Now staff will then provide hospital training on an individualized basis via phone, webcasts or face to face meetings.

ND Hear Now staff also plan to guest lecture to nursing students across ND. Based on a phone survey of parent's experience of hearing screenings (Attachment 7.3), it has become evident that ND nurses need additional training and information. This training would include: the definition of a screening, the technology used in gathering screen results, and how to deliver screening results to parents.

Activity 1.1.3 – Assure that birthing hospitals have access to online tracking software so they can provide follow-up for babies who have not been screened or who have not passed initial hearing screening. ND First Sounds and Project Kaylyn (ND EHDI) currently provide user license fees for each hospital to access OZ eSP. To date, all birthing hospitals are utilizing OZ eSP to document birth screening activity and have attained a 97% birth screening rate within OZ.

To address sustainability, ND Hear Now will provide 50 user licenses in Year 1; 35 user licenses in Year 2; and 20 user licenses in Year 3. This equates to all hospitals having grant-funded eSP access in Year 1. In Year 2, ND's eight largest hospitals will be requested to pay half of their access costs and in Year 3, all hospitals will be required to pay half of their access costs.

Activity 1.1.4 – Send follow-up letters to the parents of babies who require a follow-up hearing screening to remind them to schedule and attend a re-screening. ND Hear Now staff will generate weekly reports in OZ eSP to gather information on infants requiring a follow-up screening. Letters will be sent to guardians encouraging them to contact an outpatient screening provider, birth hospital or ND Hear Now program staff. Reminder postcards will then be sent 2-3 days after the letter in order to improve follow-up by parents. ND Hear Now staff will provide training to hospital personnel to decrease the number of infants LTFU.

Activity 1.1.5 – Provide birthing hospitals an annual progress report regarding their implementation of the ND EHDI protocol that can be used in their individual quality improvement activities. The HEAR document will be used as part of a quality monitoring process for hospitals. A baseline was established in September of 2006. Improvement results will be disseminated through the ND EHDI *CHIMES* newsletter quarterly. Consumer satisfaction data will also be gathered by ND Hear Now staff and included in an annual report. Each hospital administrator will receive an annual update detailing EHDI program adherence.

Activity 1.1.6 - Work with the birthing hospitals to systematically track and follow-up on those newborns that leave the hospital without having received a newborn infant screening or who require an outpatient screen. Program staff will work closely with primary data entry personnel to assure all children born or transferred into a hospital are entered into OZ eSP. Program staff will also provide hospital training so that hospital staff can generate reports to track missed screens and provide necessary follow-up. Hospital staff will be encouraged to contact families and set appointments for follow-up activities. In addition, weekly reports will be generated by ND Hear Now staff to identify infants missing a birth screen result. Letters will be sent to guardians encouraging them to contact an appropriate outpatient provider or ND Hear Now staff. Program staff will provide a quarterly report to each hospital's primary OZ eSP data entry personnel,

department supervisor and hospital CEO/Administrator. Reports will include the number of total births entered into OZ, number having a completed birth screen, number having a missed screen, and number left in process. Hospitals will be reminded that they have the capability to track infants in OZ to identify those infants requiring follow-up.

In lieu of a newly developed ND EHDI screening protocol, ND Hear Now staff will implement specific strategies found to be effective in reducing families LTFU. Based on an informal parent survey, families in ND indicated that they were more apt to return for a follow-up appointment if it was made for them (Attachment 7.3). This was also found to be an effective strategy noted in the NICHQ learning collaborative. Program staff will study this strategy in Year 1 and assess the effectiveness of hospitals 1) making the follow-up appointment for the family and 2) making reminder calls before the appointment. In addition, effective strategies will be gathered by ND Hear Now staff via hospital phone calls and site visits. These strategies will be shared among hospital staff via an email list-serve. Recognition to hospital staff that employ effective strategies will also be given via our *CHIMES* newsletter.

Based on findings in Year 1 and from parent input, ND Hear Now staff will study other identified strategies in Years 2 & 3 as well. Various strategies will be implemented and their effectiveness will be analyzed. Successful strategies will be shared among hospital staff via an email list-serve and our *CHIMES* newsletter.

Activity 1.1.7 – Follow-up screen results will be completely documented in OZ eSP. ND birthing hospitals will be provided access and support to OZ eSP to ensure complete data entry of follow-up screenings, and referrals to audiologists and early intervention providers. Entities providing follow-up screens that do not have OZ eSP access will collect the information via a paper form (Attachment 7.4) and fax the information back to the ND Hear Now office so that ND Hear Now staff can a) confirm the accuracy of the data and b) enter the screening results into OZ eSP.

Objective 1.2 – Expectant parents, health care providers, policy makers, early intervention providers, and the general public will have an awareness of the importance and availability of ND EHDI.

Activity 1.2.1 – Provide print and video information to prenatal care providers so that it is available to expectant parents. ND Hear Now staff will review and revise their project brochures and fact sheets and update the Prenatal Care Provider mailing database. ND Hear Now staff will provide print information to prenatal care providers on a regular basis. All awareness materials will be made available in alternate formats upon request.

Activity 1.2.2 – Provide print and video information to child health care providers, including pediatricians, well baby clinics, and others about the importance of EHDI. Past ND EHDI promotional efforts have yielded numerous requests for restocking of ND EHDI brochures. Hospitals have indicated that the information is included in hospital packets provided to expectant and new parents. ND Hear Now will continue to provide print information to these providers on a regular basis. A mailing list will be updated annually to include ND pediatricians, child health care providers, well

baby clinics, and county health nurses. All awareness materials will be made available in alternate formats upon request.

Activity 1.2.3 – Modify public information print and video information so that it is available in alternative formats and multiple languages to meet the needs of people with disabilities and people from minority cultures. ND Hear Now staff will determine the cultural diversity across ND and identify any minority populations for which materials will need to be provided. Program staff will then distribute these materials in their alternative formats as needed.

Activity 1.2.4 - Increase ongoing education to the provider community to emphasize the importance of newborn hearing screening on all newborns prior to hospital discharge. In March of 2006, a new social marketing campaign was developed along with a variety of materials publicizing the nationally recognized 1-3-6 message supported by NCHAM, JCIH, and CDC. Program staff disseminated ND EHDI 1-3-6 materials to birthing hospitals, pediatricians, midwives, and OB/GYN offices. These materials included new brochures, fact sheets, hearing health bookmarks, clipboards, puzzles, stress cubes, post-it notes, window clings, and pens. The materials were intended to appeal to a variety of audiences within each clinic. These same materials have been disseminated during public reporting and awareness opportunities.

The ND Hear Now team will continue to be involved in educating the provider community by providing information through the *CHIMES* newsletter, presenting at the ND Speech, Hearing, and Language Association (NDSHLA) conference, presenting to nursing students, and by providing the opportunity to attend the National EHDI conference. In addition, past public service announcements have proven successful in generating public interest. ND Hear Now staff will continue the dissemination of promotional items and PSAs through radio. A competition among local university broadcasting students for the development of three 60-second radio PSAs with a $100 award will be held. The winning PSA will be distributed to AM and FM radio stations in ND and bordering communities.

Activity 1.2.5 – Provide a public reporting system that includes community, region, and state report cards on the status of EHDI efforts through project website and direct mailings to policy makers, service providers, and key project constituencies. The project website (www.ndcpd.org/ehdi), quarterly *CHIMES* newsletter, Advisory Group meetings, and the ND EHDI list-serve will all be used in the public reporting effort. Program staff will attend conferences and present information (via formal presentations or exhibits) to constituent groups such as policy makers, service providers, key partner agencies, parents, audiologists, and health care providers.

Activity 1.2.6 – Work with ND service clubs, such as Sertoma, in developing strategies to sustain EHDI efforts beyond the duration of the grant. ND Hear Now staff will present to service organizations to inform them of EHDI efforts and establish a support network. ND Hear Now staff will also invite a service club member to serve on our Advisory Group. This partnership will be increasingly important as screening equipment ages and external funding options are explored.

Activity 1.2.7 - Increase awareness among legislators of the importance of newborn hearing screening and educate them of the cost savings of timely screening, diagnosis and intervention of hearing loss. Also, ensure state legislators are aware of the non-guaranteed status of federal funding and explore options for state funds to sustain the ND EHDI Program. The ND Legislature meets every odd-numbered year. Program staff will develop and disseminate awareness materials to legislators; primarily in Year 1 while legislators are not in session. ND Hear Now staff plan to inform legislators about the project, the non-guaranteed status of federal funding, and stress the importance of sustaining this program through mandated screening.

Activity 1.2.8 – Educate birthing hospital administrators and management staff on how OZ can be used as a program management and quality improvement tool. ND Hear Now staff will meet with hospital staff and demonstrate how OZ eSP can be utilized to generate reports and compare report results to established quality improvement indicators (i.e., HEAR document). ND Hear Now staff will also provide hospital administrators with an annual progress report detailing adherence to EHDI protocols and timelines. Within this report, hospitals will view their individual performance compared to state averages. ND Hear Now staff will provide a great deal of communication with hospital administrators, department managers, and primary OZ eSP data entry personnel to encourage complete and timely OZ eSP data entry. Barriers to this effort will be discussed on an individual basis and effective strategies will be shared.

Objective 1.3 – The ND Hear Now program will provide Right Track coordinators with the technical assistance, training, and program support necessary to provide appropriate follow-up and referral services.

Activity 1.3.1 – Provide technical assistance and training to ND Right Track staff on how to implement ND EHDI efforts. ND Hear Now staff will conduct regular trainings during existing statewide Right Track meetings. These meetings are delivered via a Polycom system and include Right Track and Part C personnel. Training topics will include: ND EHDI protocol, scripts when talking to parents, data tracking forms, and a referral list of pediatric audiologists and PIP professionals.

Activity 1.3.2 – The ND Hear Now program will ensure that families of children requiring a follow-up screening will be contacted by the ND Right Track program to encourage attendance, offer support and resources, and record results of the conversation. Previous ND EHDI staff have met with the State Right Track Coordinator to enlist program participation with this activity. The State Right Track Coordinator has indicated that this activity is within their program's Scope of Service (Attachment 7.5) and has agreed to carry out the activity on behalf of the ND EHDI program. Right Track staff will receive a list from the ND Hear Now office of those children requiring follow-up screening or risk factor monitoring. Right Track staff is to consider this list as an official referral to their program and contact the family via phone. Right Track providers will offer services to the family at no cost, including a developmental screening, and encourage the family to return to their local facility for a second hearing screening. Right Track providers will have a script available from the ND Hear Now office on how to talk to families about their child's hearing screening management and also a list of available facilities conducting outpatient screenings. Right Track providers will also track any

screening information provided from the family via the ND EHDI Follow-up and Intervention Form (Attachment 7.4) and fax this information to a secured ND Hear Now office. They will also encourage the family to see an audiologist if they are requiring an evaluation. In the event that parents refuse to return for a second screening, Right Track providers will ask for the reason and record this information so that the ND Hear Now office can analyze these reasons and study trends of refusal ultimately increasing ND's awareness of the LTFU population.

Activity 1.3.3 – Provide the ND Right Track program a quarterly progress report regarding their implementation of the ND EHDI protocol that can be used in their individual quality improvement activities. ND Hear Now staff will generate a report indicating the percentage of contacts to families compared to the number of referrals given by ND Hear Now staff. This information will be provided at a regional level and copies will be provided to the State Right Track Coordinator.

Goal 2: ND babies not passing initial screenings will receive an audiological evaluation by 3 months of age.

Objective 2.1 – Information about babies who have not passed initial screening will be shared among families, health care professionals and early intervention providers.

Activity 2.1.1 – The ND Hear Now program will ensure that families of children requiring an audiological evaluation will be contacted by the Parent Infant Program to encourage attendance, offer support, and serve as a liaison between the medical community and early intervention. Previous ND EHDI staff met twice with the State PIP Coordinator and has enlisted program participation in carrying out this activity. Guidelines were established during these meetings and agreed upon by all involved. PIP staff will receive a list from the ND Hear Now office of those children requiring audiological evaluations or risk factor monitoring. PIP staff is to consider this list as an official referral to their program and contact the family via phone. PIP staff will encourage the family to see an audiologist and provide a list of ND's pediatric audiologists (Attachment 7.1). PIP staff are highly qualified teachers of the deaf and can speak knowledgably about the upcoming audiological evaluation, intervention options, and available Part C services. They are respectful of family and cultural differences and serve as a neutral yet expert source of support. PIP services are of no cost to the family. Information will be gathered via the PIP survey (Attachment 7.6) to track the number of attempts made to the family, the result of the audiological evaluation, and the early intervention options chosen by the family.

Activity 2.1.2 – Conduct an EHDI referral and follow-up summit involving Part C Disability Services, Right Track, Early Head Start, NDSD PIP, Family Support agencies (Family Voices and Family to Family Network), Public Health Home Visiting Program, Hospitals, Tribal Health Coordinators, American Academy of Pediatrics (AAP), ND American Academy of Audiologists (NDAAA), and local/regional early intervention programs. ND Hear Now staff will conduct a full day summit meeting involving all partner agencies with a vested interest in children and families who may have hearing loss. Our purpose will be to review existing state EHDI guidelines and make any necessary revisions. Changes made to existing protocols and guidelines will be a crucial

precursor to the development of training and public awareness materials. A cooperative agreement will also be drafted at this time to foster a more seamless system of screening, diagnostic, and intervention activities.

Activity 2.1.3 – Conduct an ND EHDI Advisory Group meeting at least three times per year. The ND EHDI Advisory Group serves in an advisory capacity and includes all stakeholders in the newborn hearing screening and intervention system. Members include hospital screeners, audiologists, tribal representative, a pediatrician (AAP State Chapter Champion), early intervention providers, family support providers, and parents of children with hearing loss. ND Hear Now staff will establish timelines for meetings and publish the meeting dates and locations in advance. At least one meeting per year will be conducted face to face and the remaining will be conducted electronically. The purpose of these meetings is to present marketing information, identify program gaps and discuss how these gaps might be addressed.

Activity 2.1.4 – Develop and implement interagency data sharing agreements and procedures. Our State EHDI Coordinator has recently moved from the Department of Human Services to the Department of Health. This move precipitates the need to revise existing data sharing agreements to reflect this change in office. A draft of the agreement will be created during the ND EHDI referral and follow-up summit and finalized during our first Advisory Group meeting. The ND Attorneys General Office has released a statement regarding HIPAA compliance and EHDI data release from CSHS to other agencies (Mullen, 2005) and will be referenced as needed.

Activity 2.1.5 – Explore opportunities to develop streamlined or mandated reporting requirements in conjunction with the state's newborn screening program. CSHS is housed in the Department of Health and is involved with a number of state level committees, some of which could offer a route to develop a more streamlined reporting system. Various opportunities will be explored including: increasing the newborn screening fees (a successful endeavor in MN), leveraging legislative support and funding of an ND EHDI program or database linking with Vital Statistics Birth Record and Metabolic Screening. Currently the metabolic screening data is linked to the Birth Record at the state level. Efforts will be made to network with other states using OZ to see if they link with other newborn screening or birth record databases. Starting in 2006, the results of the infant's hearing screening prior to hospital discharge are included on the electronic birth certificate.

Objective 2.2 – ND will have a HIPAA-compliant online tracking system available for health care and early intervention service providers to track babies who require follow-up and audiological assessment.

Activity 2.2.1 – Continue providing outpatient screeners and audiologists access to the eSP software by OZ systems. Historically, the ND EHDI office has paid OZ Systems for 50 eSP user license fees; ensuring each birthing facility and select providers have software access. The OZ eSP system meets HIPAA security standards through its encryption transmission protocol and its use of secure data storage servers. This information has been supplied to each of the hospital's Information Technology department in order to satisfy administrative concerns. To address sustainability, ND

Hear Now will provide 50 user licenses in Year 1; 35 user licenses in Year 2; and 20 user licenses in Year 3. This equates to all hospitals having grant-funded eSP access in Year 1. In Year 2, ND's eight largest hospitals will be required to pay half their access costs and in Year 3, all hospitals will be required to pay half their access costs. It is felt that there will be more accountability and a sense of ownership if providers are partially paying for OZ eSP access. Current cost incurred is about $350 per user per year.

Activity 2.2.2 – Audiological evaluation results will be completely documented in OZ eSP. ND birthing hospitals and select audiologists are provided access and support to OZ eSP to ensure complete data entry of audiological evaluations and referrals to early intervention providers as necessary. Entities providing audiological evaluations that do not have OZ eSP access will collect the information via a paper form and fax the information back to a secured ND Hear Now office so that ND Hear Now staff can a) confirm the accuracy of the data and b) enter the evaluation results into OZ eSP.

Activity 2.2.3 - Provide training and technical assistance to health care providers, audiologists, and other interventionists about how to access and use the data tracking system to provide follow-up for babies who have not passed initial screenings. ND Hear Now staff will provide technical assistance to each hospital, audiology clinic, or early intervention program in the use of the data tracking system for follow-up activities. Training opportunities for ND Hear Now staff, hospitals, birthing clinics, pediatricians, audiologists, and early intervention case managers will occur regularly. Each facility will be contacted quarterly in order to determine training needs. ND Hear Now staff will increase their ability to provide training by participating in training sessions with OZ, attending the National EHDI conference, and continuing involvement in various training opportunities offered through national organizations (e.g., NCHAM, HRSA).

Activity 2.2.4 – Using data from the statewide tracking system, develop hospital and regional progress reports describing the number of babies who do not pass the initial screening that are re-screened and appropriately referred. ND has made significant strides since 2005 in the completeness of data within OZ eSP. The combination of OZ eSP data and the HEAR document will provide each facility information about EHDI program adherence for use as a quality monitor. State and anonymous facility comparisons will be shared with facilities and state partners through direct mailings and the *CHIMES* newsletter.

Activity 2.2.5 – Communicate with Border States (MN, SD, and MT) to develop data sharing agreements to track newborns that move out of state, ND residents who are born out of state, or for non-resident births. Program staff attended the Minnesota Border Baby conference in March of 2006 and participated in subsequent teleconferences with Minnesota and South Dakota. ND Hear Now staff will continue to correspond with Border States to develop data sharing agreements via phone conferences and face-to-face meetings at the National EHDI Conference.

Goal 3: ND babies with confirmed hearing loss will receive early intervention services by 6 months of age.

Objective 3.1 – ND audiologists will have the training and expertise to provide appropriate diagnostic services, intervention, and referral.

Activity 3.1.1 – Provide training opportunities for ND hearing health professionals and audiologists in early hearing detection, intervention, follow-up, and referral. ND Hear Now staff will support attendance to the National EHDI conference by Advisory Group members; which include representation from hearing health professionals and audiologists. ND Hear Now staff will also actively seek other training venues for hearing health professionals and audiologists to attend. Presentations and print materials will be developed and disseminated through the *CHIMES* newsletter, Advisory Group meetings, and through electronic means (e.g., ND EHDI website, NCHAM website).

Activity 3.1.2 – Audiological intervention services will be completely documented in OZ eSP. Early intervention services in this activity are referring to necessary audiological intervention (which may include diagnostic testing, hearing aids or cochlear implants). Select audiologists will be provided access and support to OZ eSP to ensure complete data entry of audiological evaluations and referrals to early intervention providers (i.e., Part C) as necessary. Entities providing audiological evaluations that do not have OZ eSP access will record information via a paper form and fax the information back to a secured ND Hear Now office so that ND Hear Now staff can a) confirm the accuracy of the data and b) enter the early intervention service into OZ eSP.

Objective 3.2 – ND Part C providers will follow-up with babies who are potentially eligible for early intervention services.

Activity 3.2.1 - The ND Hear Now program will ensure that families of children potentially eligible for Part C services will be contacted by Part C staff to offer services. ND Hear Now staff will meet with Part C staff to establish a referral protocol. It is anticipated that Part C staff will receive a list from the ND Hear Now office of those children with confirmed hearing loss. Part C staff are to consider this list as an official referral to their program and contact the family via phone. Part C staff will offer the family a developmental evaluation; possibly leading to enrollment and the development of an Individualized Family Service Plan (IFSP). Part C staff are respectful of family and cultural differences and serve as a neutral yet expert source of support. They are knowledgeable of various family support groups and provide services that are family-friendly. Part C services are of no cost to the family; and eligible families automatically qualify for Medicaid services in ND. Program staff will hold meetings with Part C staff to develop procedures to share information. Data to be collected by Part C staff would include: the number of referred families contacted by Part C staff, reasons (if any) of refusal of services, the number of referred families not found eligible for Part C services, and the number and age of children with hearing loss who have a signed IFSP.

Goal 4: North Dakota will have a comprehensive evaluation program to document the impact of the ND EHDI program.

Objective 4.1 – ND Hear Now staff will implement formative and summative evaluation systems.

Activity 4.1.1 – Design and implement an ongoing formative evaluation system to monitor project implementation. The Workplan provided in this proposal will be used to monitor program progress and be reviewed during weekly staff meetings to manage staff assignments, document outcomes, and make changes in the use of program resources.

Activity 4.1.2 – Design and implement a summative evaluation system to monitor project implementation. The program director will prepare required MCHB outcome reports at six month intervals and annually. Formative data gathered in Activity 4.1.1 will be used to prepare summative project data. In addition, ND Hear Now staff will use surveys to collect data from parents and providers to illustrate the impact of this project. Combined formative and summative data reports will be used to prepare a final project report.

Objective 4.2 - ND will provide performance data on the impact of EHDI on ND's infants and families.

Activity 4.2.1 – Use OZ eSP to collect data on newborn hearing screenings, referrals, and early intervention services. Program staff will prepare monthly status reports using eSP software to report newborn screenings, referrals, and early intervention services. Status reports will be used to prepare state, regional, and hospital progress reports. Reports will compare hospitals anonymously to the state average and will be disseminated to hospitals and state partners showing ND EHDI participation, compliance, and improvement.

Activity 4.2.2 – Compile statewide data on HRSA data requirements. ND Hear Now staff will adhere to reporting requirements administered by MCHB and follow suggested timelines.

Activity 4.2.3 – Report statewide and HRSA data. ND Hear Now staff will report program data to partner agencies, legislators, and the general public through a variety of medium including the *CHIMES* newsletter, mailed fact sheets, PSA's, our program website, and official electronic reporting forms.

WORK PLAN

Goals, Objectives, and Activities with Staff Assignments, Anticipated Timelines, and Expected Outcomes or Products.

Activity	Lead Staff	Timeline	Outcomes and Progress Indicators
GOAL 1: Assure that 98% of babies born in ND have their hearing screened before one month of age.			
Objective 1.1 - All ND birthing hospitals will have access to the technical assistance, training, and program support necessary to provide hearing screening to every newborn and to implement appropriate follow-up and referral services.			
Activity 1.1.1 – Renegotiate cooperative agreements between ND EHDI and the 17 participating birthing hospitals.	PD	Q1 – Q4	Memoranda of agreement from 17 birthing hospitals.
Activity 1.1.2 – Provide technical assistance and training to birthing hospital staff on how to implement ND Hear Now efforts.	TC	Q1 – Q12	Report of training and technical assistance events.
Activity 1.1.3 – Assure that birthing hospitals have access to online tracking software so they can provide follow-up for babies who have not been screened or who have not passed initial hearing screening.	DC	Q1 – Q12	Monthly reports from eSP on hospital utilization.
Activity 1.1.4 – Send follow-up letters to the parents of babies who require a follow-up hearing screening to remind them to schedule and attend a re-screening.	DC	Q1 – Q12	Copies of follow-up letters; percent of babies re-screened at the outpatient level.
Activity 1.1.5 – Provide birthing hospitals an annual progress report regarding their implementation of the ND EHDI protocol that can be used in their individual quality improvement activities.	DC	Q1 – Q12	Copies of annual report.
Activity 1.1.6 - Work with the birthing hospitals to systematically track and follow-up on those newborns that leave the hospital without having received a newborn infant screening or who require an outpatient screen.	DC/TC	Q1 – Q12	Percent of babies re-screened at the outpatient level.
Activity 1.1.7 – Follow-up screen results will be completely documented in OZ eSP.	DC	Q1 – Q12	Percent of hospitals completely entering outpatient screen in OZ eSP.
Objective 1.2 – Expectant parents, health care providers, policy makers, early intervention providers, and the general public will			

Activity	Lead Staff	Timeline	Outcomes and Progress Indicators
have an awareness of the importance and availability of ND EHDI.			
Activity 1.2.1 – Provide print and video information to prenatal care providers so that it is available to expectant parents.	MC	Q1 – Q12	List of items distributed and list of locations where information is placed.
Activity 1.2.2 – Provide print and video information to child health care providers, including pediatricians, well baby clinics, and others about the importance of EHDI.	MC	Q1 – Q12	List of items distributed and list of locations where placed.
Activity 1.2.3. – Modify public information print and video information so that it is available in alternative formats and multiple languages to meet the needs of people with disabilities and people from minority cultures.	MC	Q1 – Q12	Copies of items translated into French and Spanish.
Activity 1.2.4 – Increase ongoing education to the provider community to emphasize the importance of newborn hearing screening on all newborns prior to hospital discharge.	MC/TC	Q1 – Q12	Copies of awareness materials and list of locations where they were used.
Activity 1.2.5 – Provide a public reporting system that includes community, region, and state report cards on the status of EHDI efforts through project website and direct mailings to policy makers, service providers, and key project constituencies.	PD	Q1 – Q4	Copies of reports. Archives of informational products. Mailing list.
Activity 1.2.6 – Work with ND service clubs, such as Sertoma, in developing strategies to sustain EHDI efforts beyond the duration of the grant.	PD/SC	Q1 – Q12	List of presentations made.
Activity 1.2.7 - Increase awareness among legislators of the importance of newborn hearing screening and educate them of the cost savings of timely screening, diagnosis and intervention of hearing loss. Also, ensure state legislators are aware of the non-guaranteed status of federal funding and explore options for state funds to sustain the ND EHDI Program.	PD	Q1 – Q4	Copies of educational materials and a list of locations where they were used.
Activity 1.2.8 - Educate birthing hospital administrators and management staff on how OZ can be used as a program management and quality	DC/TC	Q1 – Q12	Copies of hospital mailings.

Activity	Lead Staff	Timeline	Outcomes and Progress Indicators
improvement tool.			
Objective 1.3 – The ND Hear Now program will provide Right Track coordinators with the technical assistance, training, and program support necessary to provide appropriate follow-up and referral services.			
Activity 1.3.1 – Provide technical assistance and training to ND Right Track staff on how to implement ND EHDI efforts.	TC	Q1 – Q12	Report of training and technical assistance events.
Activity 1.3.2 – The ND Hear Now program will ensure that families of children requiring a follow-up screening will be contacted by the ND Right Track program to encourage attendance, offer support and resources, and record results of the conversation.	TC	Q1 – Q12	Report on Right Track contacts to families.
Activity 1.3.3 – Provide the ND Right Track program a quarterly progress report regarding their implementation of the ND EHDI protocol that can be used in their individual quality improvement activities.	DC/TC	Q1 – Q12	Copies of Right Track report card.
GOAL 2: ND babies not passing initial screenings will receive an audiological evaluation by 3 months of age.			
Objective 2.1 – Information about babies who have not passed initial screening will be shared among families, health care professionals and early intervention providers.			
Activity 2.1.1 – The ND Hear Now program will ensure that families of children requiring an audiological evaluation will be contacted by the Parent Infant Program to encourage attendance, offer support, and serve as a liaison between the medical community and early intervention.	TC	Q1 – Q12	Report on PIP contacts to families.
Activity 2.1.2 - Conduct an EHDI referral and follow-up summit involving Part C Disability Services, Right Track, Early Head Start, PIP from North Dakota School for the Deaf (NDSD), Family Support (Family Voices and Family to Family Network), Public Health Home Visiting Program, Hospitals, Tribal Health Coordinators, American Academy of Pediatrics (AAP), ND Academy of Audiologists (NDAA), and local/regional early intervention programs.	PD	Q1	Agenda from summit and list of participants.
Activity 2.1.3 – Conduct an ND EHDI Advisory Group meeting at least	PD	Q1 – Q12	Agenda and minutes from

Activity	Lead Staff	Timeline	Outcomes and Progress Indicators
three times per year.			Advisory Group meetings.
Activity 2.1.4 – Develop and implement interagency data sharing agreements and procedures.	SC	Q5 – Q8	Copies of interagency data sharing agreements.
Activity 2.1.5 – Explore opportunities to develop streamlined or mandated reporting requirements in conjunction with the state's newborn screening program.	SC	Q1 – Q4	List of meetings with metabolic screening task force and joint initiatives.
Objective 2.2 – ND will have a HIPAA-compliant online tracking system available for health care and early intervention service providers to track babies who require follow-up and audiological assessment.			
Activity 2.2.1 – Continue providing outpatient screeners and audiologists access to the eSP software by OZ systems.	DC	Q1 – Q12	Annual data utilization reports for eSP.
Activity 2.2.2 – Audiological evaluation results will be completely documented in OZ eSP.	DC/TC	Q1 – Q12	Monthly report of data entry at the audiological level.
Activity 2.2.3 – Provide training and technical assistance to health care providers, audiologists, and other interventionists about how to access and use the data tracking system to provide follow-up for babies who have not passed initial screenings.	TC	Q1 – Q12	Report of training and technical assistance activities.
Activity 2.2.4 – Using data from the statewide tracking system, develop hospital and regional progress reports describing the number of babies who do not pass the initial screening that are re-screened and appropriately referred.	DC	Q1 – Q12	Copies of report cards.
Activity 2.2.5 – Communicate with Border States (MN, SD, and MT) to develop data sharing agreements to track newborns that move out of state, ND residents who are born out of state, or for non-resident births.	PD/SC	Q5 – Q8	Data sharing discussion and ultimately an agreement among border states.
GOAL 3: ND babies with confirmed hearing loss will begin early intervention services by 6 months of age.			
Objective 3.1 ND audiologists will have the training and expertise to provide appropriate diagnostic services, intervention, and referral.			
Activity 3.1.1 – Provide training opportunities for ND hearing health	TC	Q1 – Q12	Revised protocol.

Activity	Lead Staff	Timeline	Outcomes and Progress Indicators
professionals and audiologists in early hearing detection, intervention, follow-up, and referral.			Minutes of meetings.
Activity 3.1.2 – Audiological intervention services will be completely documented in OZ eSP.	DC	Q5 – Q12	Agenda and copies of training materials. Contract with ND representative to provide training.
Objective 3.2 – ND Part C providers will follow-up with babies who are potentially eligible for early intervention services.			
Activity 3.2.1 – The ND Hear Now program will ensure that families of children potentially eligible for Part C services will be contacted by Part C staff to offer services.	TC	Q5 – Q12	Report on Part C contacts to families.
GOAL 4: North Dakota will have a comprehensive evaluation program to document the impact of the ND EHDI program.			
Objective 4.1 – ND Hear Now staff will implement formative and summative evaluation systems.			
Activity 4.1.1 - Design and implement an ongoing formative evaluation system to monitor project implementation.	PD	Q1 – Q12	Evaluation materials and documents.
Activity 4.1.2 – Design and implement a summative evaluation system to monitor project implementation.	PD	Q1 – Q12	Evaluation materials and documents.
Objective 4.2 - ND will provide performance data on the impact of EHDI on ND's infants and families.			
Activity 4.2.1 – Use OZ eSP to collect data on newborn hearing screenings, referrals, and early intervention services.	DC	Q1 – Q12	Annual data utilization analysis.
Activity 4.2.2 – Compile statewide data on HRSA data requirements.	DC	Q1 – Q12	State report cards.
Activity 4.2.3 – Report statewide and HRSA data.	DC	Q1 – Q12	State report cards.

PD – Program Director (Wendy Thomas); SC – State EHDI Coordinator (Susan Burns); DC/TC – Data and Training Coordinator (Sue Routledge and Jerusha Olthoff); MC – Marketing Coordinator (Kimberly Witt)

Q1 – Q4 = Quarters in Year 1; Q5 – Q8 = Quarters in Year 2; Q9 – Q12 = Quarters in Year 3

RESOLUTION OF CHALLENGES

The ND EHDI program has been in operation since 2000. At that time, there was increased emphasis on universal newborn hearing screenings (UNHS), but not a great deal of attention was given to follow-up efforts. Since then, UNHS programs have evolved into EHDI; focusing on reducing loss to follow-up after the screening process and increasing early intervention services for families with infants having suspected or confirmed hearing loss. This change has brought about the need to enlist additional program partners including audiologists, child health care providers, and early interventionists. In order to follow an infant from birth through diagnosis and early intervention, a system bridging the medical and educational communities is required. Policies, procedures, and data sharing agreements between the medical and educational communities are essential.

Additionally, EHDI programs need to recognize that issues occurring at the hospital level cannot be ignored. Consistent staffing, current equipment, and knowledgeable personnel are critical in laying the foundation for a strong EHDI program.

The challenges listed below were the result of data analyses conducted in the Needs section of this proposal combined with a phone survey to parents conducted by grant staff in October of 2007 (Attachment 7.3). Survey participants were contacted by phone and asked a series of questions related to their hearing screening experience. Survey questions were modified from a survey form offered through the National Center for Hearing Assessment and Management (NCHAM). Participant names were pulled from OZ eSP to include those babies under one year of age; representing a wide geographical location and various stages of the hearing screening and assessment process.

<u>Birth & Outpatient Screening Challenges and Resolutions</u>

Challenge 1: *There is turnover of birth screening staff.*

Resolution 1a: Provide annual birth screening training by an audiologist or equipment representative. The purchase of training materials may be necessary to deliver the most current information and in a standardized format (Activity 1.1.2)

Resolution 1b: Make frequent contact with birth screen staff by ND Hear Now staff to deliver training and technical assistance (Activities 1.1.2, 1.1.5, 1.1.6)

Challenge 2: *Citizens are still not always aware of birth screenings and their importance.*

Resolution 2a: Conduct public awareness efforts targeting parents, legislators, health care providers and the general public (Activities 1.2.1, 1.2.2, 1.2.3, 1.2.4, 1.2.5, and 1.2.7)

Challenge 3: *Families are given inaccurate information about the screening process and next steps.*

Resolution 3a: Make frequent contact with birth screen staff to deliver training and technical assistance (Activities 1.1.2, 1.2.2) stressing the importance of talking to families about screening results and risk factor monitoring

Resolution 3b: Guest lecture to nursing students about the EHDI process and provide scripts of how to talk with families about screening results (Activity 1.1.2)

Challenge 4: *Not all families return for needed outpatient screenings.*

Resolution 4a: Utilize the Right Track program to encourage families to attend an outpatient screening (Activities 1.3.1, 1.3.2, and 1.3.3)

Resolution 4b: Collect information as to parent's reasons for not returning (Activity 1.3.2) and implement strategies to address those reasons

Challenge 5: *ND does not have a hearing screening mandate or external funding source for equipment purchases, database management, training, or awareness activities.*

Resolution 5a: Work with ND service clubs in developing strategies to sustain program activities beyond the duration of the grant (Activity 1.2.6)

Resolution 5b: Work with our State EHDI Coordinator to develop streamlined or mandated reporting requirements in conjunction with ND's newborn screening program (Activity 2.1.5)

<u>Audiological Assessment Challenges and Resolutions</u>

Challenge 6: *There are communication barriers between birth screen and follow-up providers.*

Resolution 6a: Develop interagency agreements and procedures through the ND EHDI referral and follow-up summit (Activity 2.1.2)

Resolution 6b: Conduct Advisory Group meetings face to face and electronically. Our electronic meetings will be held during winter months when travel is likely to be compromised by weather (Activity 2.1.3)

Challenge 7: *Not all families return for needed audiology assessments.*

Resolution 7a: Gather information from families as to why they are not returning (Activity 2.1.1)

Resolution 7b: Utilize the Parent Infant Program to encourage and offer support to families in returning to an audiologist (Activity 2.1.1)

Challenge 8: *Not all audiologists are entering results into OZ eSP.*

Resolution 8a: Provide training and technical assistance to those audiologists with OZ eSP access (Activities 2.2.1, 2.2.3)

Resolution 8b: Develop a paper tracking system to gather audiological results from those audiologists without OZ eSP access (Activity 2.2.2)

Early Intervention Challenges and Resolutions

Challenge 9: *Early Intervention providers (e.g., Part C) aren't getting referrals from audiologists and other health professionals.*

Resolution 9a: Provide training to audiologists and other health professionals about available early intervention services in ND (Activity 3.1.1)

Challenge 10: *Early Intervention services are not documented in OZ eSP.*

Resolution 10a: Provide training and technical assistance to those Part C staff with OZ eSP access (Activity 3.1.2)

Resolution 10b: Develop a paper tracking system to gather Part C or early intervention services for those providers without OZ eSP access (Activity 3.1.2)

EVALUATION AND TECHNICAL SUPPORT CAPACITY

Collaboration and Coordination

The ND EHDI program is a collaborative effort between the North Dakota Center for Persons with Disabilities (NDCPD) at Minot State University (MSU), and CSHS of the ND Department of Health. A cooperative agreement between NDCPD and CSHS has been in place with the original UNHS grant proposal in 2000 and continues to form the foundation for the ND EHDI program.

A letter of agreement and support from the Director of CSHS is included in Attachment 5. Concentrated effort has been placed in developing and encouraging participation from all ND birthing hospitals, NDSD PIP, ND Right Track, IHS, family support programs, and early intervention programs. A listing of the agencies with which the project has acquired support is included in Attachment 7.

Program staff will be employees of MSU and their job performance will be managed consistent with MSU's human resource policies. Additionally, Susan D. Burns

will continue to serve as State Implementation Coordinator. Ms. Burns is an employee of the ND CSHS program in the ND Department of Health. Her continued participation with project activities will help ensure close collaboration between the project, CSHS, and the ND Title V program.

The interests of health care providers, practicing audiologists, early intervention programs (including Part C), family support organizations, and others will be integrated into this project's activities through the Advisory Group. This committee will meet three times per year to review project accomplishments, identify opportunities for leveraging additional resources, and troubleshoot barriers to effective follow-up. The program's organizational chart is in Attachment 6. A list of those who are currently serving on the Advisory Group is included in Appendix 7.7.

Administration and Organization

Ms. Wendy Thomas, MS will serve as the ND Hear Now Program Director. Ms. Thomas is responsible for overseeing all project activities, managing the project's budget, reporting progress, and collaborating with other EHDI partners. Ms. Thomas currently serves as a Training Coordinator for Project Kaylyn. She also works for a local Part C agency; providing early intervention services to children with disabilities ages birth to three. Ms. Thomas is a MSU Special Education Adjunct Faculty member and has been teaching special education courses since 2001.

Ms. Susan D. Burns, BS will serve as the ND Hear Now State Implementation Coordinator. Ms. Burns is an employee of ND CSHS (Title V agency for Children with Special Health Care Needs) and will help coordinate ND EHDI program activities at the state level. Ms. Burns serves as the Title V State EHDI contact and is responsible for reporting to MCHB regarding state and federal performance measures. Ms. Burns serves on eighteen state level committees including the state Genetics Committee, Early Childhood Comprehensive Systems, Family Voices, Medicaid Policy, March of Dimes, and State Birth Review Committee.

Ms. Sue Routledge, BS and Ms. Jerusha Olthoff will serve as the ND Hear Now Data & Training Coordinators. Both are currently serving as Data Coordinators for Project Kaylyn and the ND First Sounds 2 Project and have extensive knowledge of the OZ eSP database, are in constant contact with hospital staff, and have participated in training sessions via hospital site visits.

Ms. Kimberly Witt, MS will serve as the ND Hear Now Program Marketing Coordinator. Ms. Witt is currently the Principal Investigator for the ND First Sounds 2 Project and has her master's degree in Management. She has successfully implemented an EHDI social marketing campaign in ND and has extensive knowledge of marketing techniques to promote the EHDI message.

ND Hear Now staff will report to the Program Director, as illustrated in the Organizational Chart in Attachment 6. Vitae for program staff are included in Attachment 4.

Program staff will meet weekly to review progress of specific activities and note the achievement of project objectives and goals. A running list of grant activities will be included on the weekly meeting agendas and progress will be noted in the meeting minutes. Program staff will utilize Sharepoint3 to share documents, announce upcoming events, and maintain a calendar of activities. The ND EHDI State Coordinator, Susan Burns, will also participate in the weekly meetings through teleconference technology.

Monthly progress reports will be generated indicating hospital screening and data entry performance and shared with ND Hear Now staff. Quarterly reports will be disseminated to program partners detailing state performance of EHDI efforts.

NDCPD's grant management protocol is founded on participatory management and research. This protocol provides for interaction among staff and project partners to engage in problem solving, provide one another technical assistance and advice, and create opportunities for collaboration and expansion.

The ND EHDI Advisory Group will meet at least three times per year. The Advisory Group is made up of representatives from a variety of organizations providing services to infants with hearing loss and their parents. The Advisory Group will work with program staff to review progress and identify barriers to achieving program objectives and goals. Attachment 7.7 provides a list of the people who served on the 2007 ND EHDI Advisory Group and their affiliation.

Based on formative and summative measures, an annual report will be generated to evaluate the impact of the ND Hear Now program. Data will be gathered from the OZ eSP database, feedback from training events, results from the HEAR document, and input from parents through a phone-based interview.

ORGANIZATIONAL INFORMATION

Organization Experience, Capacity, and Available Resources

NDCPD, a Minot State University Center of Excellence, will serve as lead agency and fiscal agent for the ND Hear Now program. NDCPD is a member of the Association of University Centers on Disabilities and is part of a national network of university research and service centers engaged in a wide range of grant funded activities serving the disability community. These activities include research, teaching, community services, systems change activities, and technical assistance to service agencies and state programs. The mission of NDCPD is "to provide leadership and innovation that advances the state-of-the-art and empower people with disabilities to challenge expectations, achieve personal goals and be included in all aspects of community life."

NDCPD is located at MSU which has 58 undergraduate and 10 graduate degree programs serving nearly 4,000 students. NDCPD has access to all university computing

services, library, online instructional resources, and media facilities including satellite downlinks, Internet connections, and an interactive video studio for distance communications. NDCPD also has extensive website development and support resources through its design lab. These resources are used to carry out project activities.

NDCPD has successfully developed a wide range of programs serving the needs of people with disabilities. In 2006-07, NDCPD provided services to over 1,500 persons with disabilities and their families and produced over 40 publications. Training and technical assistance was provided to over 18,000 people working with and for persons with disabilities. NDCPD's operating budget, combined across 45 different grants and contracts, is over $6 million per year.

NDCPD has served as lead agency and fiscal agent for the original First Sounds Project and facilitates a wide range of EHDI activities. During the past seven years, NDCPD has carried out collaborative activities to enhance EHDI in ND. In addition, NDCPD hosts statewide collaborative conferences for families and professionals. Many of its projects involve early intervention and work with family support programs. These projects, funded through other agencies, create opportunities for the ND EHDI program to gain increased access to and contact with family support groups throughout the state.