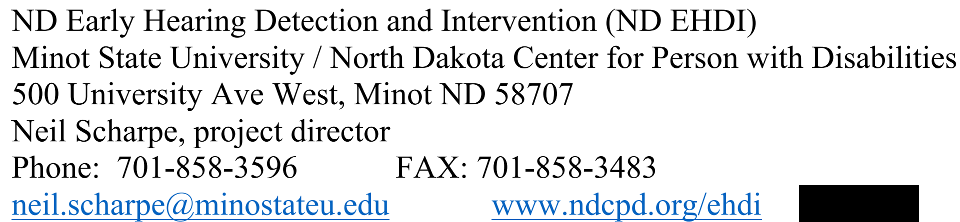
Abstract



ND Early Hearing Detection and Intervention (ND EHDI)
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Why would a parent not take their child back for a follow-up hearing screen after their infant has failed to pass on the birth screen?

This is the issue that continues to plague the North Dakota Early Hearing Detection and Intervention (ND EHDI) project. Is it distance? ND is a large state and distance and weather can be a factor for parents. Is it apathy? Hearing loss is the silent birth disorder and many parents are convinced that their baby hears. Is it fear and therefore they avoid the diagnosis? Whatever the reason it will be the ND EHDI primary focus for the next three years!

Using a quality improvement process that emphasizes small tests of change the ND EHDI Team will concentrate on building teams centered around each of the 13 birthing hospitals with a strong emphasis on parent involvement. These teams will focus on providing follow-up that is critical to child development.

In 2011, ND EHDI project reported a 66% loss to follow-up/loss to documentation (LTF/D) rate on our Center for Disease Control and Prevention (CDC) annual survey. This is a huge number, one no state would be proud of reporting. But when that percentage is broken down to the actual raw data it shows that we have made great strides in the delivery and recording data on infants born in ND.

While we have concentrated on identifying every child we have a number that are referred at birth whose parents for some reason do not bring back for an out-patient screen. With birth screen rates above 99% and a partnership with ND Vital Records that allows us to capture 100% of all occurrent births it is time to concentrate on bringing those babies who did not pass their birth screen back for follow-up.

ND is one of only a few states that does not mandate birth hearing screening, so the success we have had comes through much work on developing personal relationships with birthing hospitals, audiologists and parent groups. These relationships have paid great dividends in all areas of increasing the number of infants who have been identified with a permanent hearing loss.

Now is the time to use these relationships to go beyond screening and ensure that the reasons for the 66% LTF/D are identified, solutions proposed, quality improvement through small tests of change tried, procedures adapted as needed, successful procedures identified and passed on.

ND EHDI will reduce the percentage of LTF/D over the next three years to 40% with a plan to sustain those gains into the future.

INTRODUCTION

The North Dakota Early Hearing Detection and Intervention (ND EHDI) program originated in 2000. At that time, ND EHDI implemented an online data system, OZ eSP, from OZ Systems, Inc. In that first year, three infants were documented with a completed birth hearing screen. Despite the lack of a state mandate for screening or reporting for hearing healthcare, ND EHDI continued to see remarkable progress toward reducing Loss to Follow-up/Documentation (LTF/D). In 2012, North Dakota's 13 birthing facilities documented 11,681 births in OZ eSP with 11,481 (98.2%) of those infants having received a birth hearing screen.

The focus has been to develop partnerships with birthing hospitals, audiologists, early interventionists and family support programs. Soliciting their cooperation, ND EHDI became established and strengthened. ND EHDI utilizes the Joint Committee on Infant Hearing (JCIH) recommendations as the program's guide following the recommendation of screening all infants by one month of age, diagnosing hearing loss by three months of age and enrollment in early intervention services by six months of age. OZ eSP has proven instrumental in tracking North Dakota's (ND) birth population, providing a means to support follow-up and tracking program progress.

To illustrate progress, in 2000, ND EHDI's OZ eSP data indicated only 3 births, in 2005 that number increased to 7130 (74% of the occurrent birth population when compared to Vital Records). By 2007, ND EHDI reported 96% of all occurrent births and in 2011 the percentage had increased to 99.6% (10727 of the 10773 reported by Vital Records). ND EHDI's identifiable birth population has not only shown a population growth from 2000 to 2011 but also indicated nearly every child was being identified and screened.

Over the years, partnerships have expanded to include Vital Records, a Division of the ND Heath Department. Today, with the use of Vital Records information, ND EHDI is able to identify every child born in ND, a critical element to tracking hearing health and identifying loss to follow up. Additionally, all birthing hospitals in ND have signed a memorandum of agreement indicating participation with ND EHDI and pledging to enter complete, timely data into OZ eSP. This partnership allows ND EHDI to state that 99% of all infants birthed in ND receive a hearing screen prior to discharge.

Over the 13 year history of the ND EHDI program, the number of birthing hospitals in North Dakota has dramatically declined from 23 to 12 facilities. The loss of birthing facilities has led to increased distance between the remaining facilities and an increased distance traveled by families. Infants discharged with a missed or referred birth hearing screen are generally rescreened within two weeks at their birth hospital or by the hospital's audiology staff. While birth screen missed and referred rates in ND are typically acceptable, there are population pockets with unacceptably high rates. Additionally, it has been noted that once an infant has a documented missed birth hearing screen or does not have a scheduled outpatient appointment prior to discharge, the likelihood of the infant returning for follow-up is lowered. Moreover, ND's rural topography may negatively influence rescreen rates as parents are reluctant to travel not only the distance but are influenced by wintery road conditions.

In ND, the pediatric audiology professionals completing diagnostics are located in the four largest cities in central and eastern ND. Infants referred on an outpatient screen generally have to travel to one of these locations to have diagnostics completed. Once again, ND's rural topography may play a role in whether they return for audiological follow-up with additional factors including lack of concern or budgetary constraints.

ND EHDI has partnered with several early intervention programs to support follow-up efforts beyond hospital doors. These partnerships have provided a venue for additional parental education on the importance of hearing care and support complete, timely follow-up. ND EHDI will continue to work with ND's early intervention programs, support their efforts, strengthen their ability to educate parents and increase their competency in preforming free in-home hearing screens.

This proposal will incorporate the knowledge gained over the past 13 years as well as the skills and techniques learned through the National Initiative for Children's Healthcare Quality (NICHQ) learning collaborative to reduce the overall LTF/D rate in North Dakota by at least 5% yearly. ND EHDI's strategy will incorporate the development of *working communities of practice* built around the birthing hospital, the utilization of *small tests of change* and the subsequent *spread of positive outcomes* throughout the state as the focus for reducing LTF/D. The 2011 CDC EHDI Hearing Screening and Follow-up Survey (HSFS) indicated North Dakota's LTF/D was 66.2%. With that in mind, *ND EHDI's goal will be to reduce the LTF/D percentage as reported by the CDC from 66.2% in 2011 to 40% by March 31, 2017.*

Aim Statement:
The ND EHDI program will maintain, strengthen and enhance current program efforts by working with communities of practice throughout North Dakota by utilizing quality improvement methodology to achieve a 5% per year reduction in the LTF/D and develop a plan for program sustainability by April 2017.

ND EHDI has broken hearing care into stages including; 1) complete documentation of the occurrent birth population, 2) birth hearing screening, 3) outpatient hearing screening, 4) audiological assessment/intervention, and 5) early intervention support. It should be noted that because North Dakota's birth population is completely identifiable, ND EHDI focuses on each infant at their stage in the follow-up process. Data indicates and identifies each stage in the follow-up process as having its own LTF/D pockets of concern. These concerns will be the focus during the upcoming grant cycle.

To achieve the overall goal of a 5% annual reduction in LTF/D there is an aim statement for each stage. These aims are proposed to address areas of concern and will be markers for the NICHQ's Plan Do Study Act (PDSA) cycles.

Aim Statement 1: By April 1, 2017, ND EHDI will utilize the Quality Improvement concept in collaboration with partners to document final hearing screening outcomes for 99% of all ND occurrent births at each level of the screening process.
Objectives will include the capture of missing documentation of birth hearing screens from the home birth population which will be addressed by revitalizing efforts in working with North

Dakota's midwifery community. Additional concerns to be addressed will include two birth hospitals with known high LTF/D rates at the birth screen level; the largest target identified as outpatient screen LTF/D which may utilize a proven strategy of outpatient appointments scheduling prior to discharge; and an initiative to strengthen an early intervention program called Right Track to increase competency in performing in-home hearing screens and decrease the number of infants deemed lost to follow-up. Finally, ND EHDI will also pursue outpatient screening result documentation for the non-resident infant population birthed in ND.

Aim Statement 2: By April 2017, ND EHDI will decrease the number of infants LTF/D by 5% annually at the audiological diagnostic level before three months of age.
While ND has only a few audiologists performing infant hearing diagnostic evaluations, all are not documenting results in OZ eSP or via the ND EHDI Online Reporting Form or Fax-Back Form. Ongoing efforts to capture this information use small tests of change and the influence of other audiologists. Additionally, ND EHDI will also pursue diagnostic outcomes from bordering states for the non-resident population birthed in ND who received assessments/diagnoses in their home state.

Aim Statement 3: By 2017, 100% of ND infants identified with a diagnosed permanent hearing loss will have documented Part C status by six months of age.
If national statistics for the incidence of congenital hearing loss hold true for ND, there should be approximately 30 infants diagnosed each year. This is a number that can be easily documented if ND EHDI can capture the enrollment from Part C and/or the Parent Infant Program (PIP) operated by the ND School for the Deaf. To date, the Health Insurance Portability and Accountability Act (HIPAA) and the Family Educational Rights and Privacy Act (FERPA) have been obstacles to openly sharing eligibility/enrollment status by these programs. Solutions such as using parental consent forms and the possibility of a memorandum of agreement with Part C will be utilized.

Aim Statement 4: Utilizing ND EHDI partnerships, collaborate to identify a means of sustaining ND EHDI beyond federal funding.
The ND Legislature has not initiated new mandates to hospitals and has taken an even more stringent approach to funding new mandates. Substantial revenue from the ND energy boom may be an opportunity to revisit legislative mandates for ND EHDI screening and reporting. Also, restructuring the ND EHDI Advisory Board may lead to a stronger voice for infant hearing healthcare.

In 2007, the CDC EDHI HSFS indicated North Dakota's LTF/D was at 80.9%. While ND EHDI has shown yearly improvements with 2011 survey report now indicating a 66.2% LFT/D, work still needs to be done. However, it is important to note that while this percentage is high, the denominator utilized to derive the CDC LTF/D rate has also decreased over 50% (from 470 infants in 2007 to 266 infants in 2011). This indicates that while the percentage LTF/D remains elevated above the acceptable limit of 35%, the number of infants who failed or did not receive a screening has been reduced. ND EHDI will work to maintain current program rates, elicit program sustainability by increasing hospital responsibility for their individual hearing care program and implement NICHQ process to address areas of identified need.

NEEDS ASSESSMENT

ND's 2010 population was 672,591. Frequently recognized as one of the most rural states, ND has 37 of its 53 counties designated as frontier counties. This designation is given to those areas with a population density of less than 7 people per square mile. In fact, ND's overall population density is only 9.9 people per square mile, making beneficiary contact, advertising, and conducting educational events in these rural areas challenging.

Although ND citizens are still predominantly white, our population is becoming increasingly diverse. The 2010 census data show 90% white, 5.4% American Indian or Alaska Native, 2.0% Hispanic or Latino, 1.8% two or more races, and 1.2% African American. Our racial diversity is increasing at a rate much faster than the rest of the US, American Indians, the state's largest racial minority, increased by 17%. Over 800 refugees settled in eastern ND in the past two years with the largest groups being Bhutanese and Iraqis. Additional refugees come from Somalia, Eritrea, Sudan, DR Congo and Liberia.

The ND EHDI program has been in operation since 2000. The program has progressed over the years from Universal Newborn Hearing Screening (UNHS) into Early Hearing Detection and Intervention (EHDI). The focus of decreasing loss to follow up/loss to documentation (LTF/D) is continually being addressed by working with hearing healthcare partners. However, there is an additional need to address program specific targeted populations to provide measurable improvements in follow-up, documentation and timeliness leading to subsequent reduction in the overall LTF/D rate.

The target population are defined by the 2011 CDC Hearing Screening and Follow-up Survey (HSFS) as infants whose parents were contacted but unresponsive, infants whose parents were unable to be contacted and infants falling into the category of unknown. The total target population in ND was 176 in 2011. This total divided by the total number of infants who did not pass or receive a hearing screen (266) results in the 66.2% LTF/D reported in the CDC HSFS. Through collaborative efforts and excellent cooperation from North Dakota's hearing care partners, ND EHDI has been able to reduce the denominator to 266 from the 407 denominator in 2007. The focus of this proposal will be to utilize Quality Improvement strategies to achieve the aim of reducing not only the percentage of LTF/D but specifically the number of infants who are represented in that percentage.

Target Populations

Occurrent Birth Capture

ND EHDI is documenting 100% of North Dakota's occurrent live birth population. (Attachment 6.1: ND EHDI Occurrent/Birth Screen Data). In 2012, the ND EHDI IS grant (Centers for Disease Control funded) acquired a Data Use Agreement with Vital Records which included patient identifiable information for all births and allowed for identification of the missed hospital entries and home birth population previously unidentified. The data are also a useful tool for deduplication of OZ eSP data to ensure accuracy and an indication of OZ eSP data entry training needs (Attachment 6.1: ND EHDI Occurrent/Birth Screen Data).

- *This indicates a strong need to maintain a current Data Use Agreement with Vital Records.*

Home Births
Home births comprise a high percentage (86% and 83% in 2012 and 2013) of infants with a missed birth screen and subsequent documented LTF/D at the outpatient level (Attachment 6.1: ND EHDI Outpatient Screen Data). ND's home birth population has more than doubled since 2008. Vital Records data from 2008 indicated 44 home births. This number has shown incremental yearly increases now indicating 91 home births in 2012. (Attachment 6.1: ND EHDI Occurrent/Birth Screen Data). While this population is now identifiable through the Data Use Agreement with Vital Records, the agreement has a limitation which does not allow ND EHDI to apply the information to pursue hearing care follow-up.

- *The growing home birth population in ND highlights the need to revitalize and heighten efforts to establish a relationship with the midwifery population to decrease LTF/D of missed home birth hearing screens, birth hearing screen documentation and follow-up.*

Birth Hearing Screen Level (Hospital Births)

Lack of State Mandate for Hearing Screening and Reporting
ND EHDI's current birth screening rates in OZ eSP indicate a 98% and 99% completion prior to discharge with greater than 95% completed prior to 30 days of age (Attachment 6.1: ND EHDI Occurrent/Birth Screen Data). Due to the lack of a state mandate for birth hearing screening/reporting, ND EHDI implemented Memoranda of Agreements (MOAs) with all birthing facilities indicating participation and expectations.

- *There is a need to continue to keep hospital MOAs in an active status.*

The MOAs have proven to be an effective indicator of hospital support and vestment indicated via their high rate and percentage of birth screen completion.

Oil Country
In western ND, a significant change has occurred due to oil and gas exploration. North Dakota is now the second largest oil producer among 50 states (USA Today[1]). According to the census bureau, North Dakota has been the fastest growing state in the country for the past 3 years (Marketwatch.com[2]). The oil boom has affected the people of North Dakota in many ways, including putting a huge strain on 4 of the 12 birthing hospitals. The increase in population has decreased the state's unemployment rate to the lowest in the nation at 3.1% (US Bureau of Labor Statistics[3]), causing hospital staff shortages. We are seeing increased number of births and a work force that is decreasing. High wages in the oil industry have caused hospitals to operate with less people and/or change their practices. For example, one hospital in the heart of oil country (Mercy Hospital, Williston, ND) opened an out-patient birthing clinic where the mother and infant are discharged within 24 hours if there are no complications. Completing a successful birth screen in that environment was next to impossible with many of these babies referring

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[1] http://www.usatoday.com/story/money/business/2013/06/15/states-with-the-fastest-growing-economies/2416239/
[2] http://blogs.marketwatch.com/energy-ticker/2013/06/06/north-dakota-fastest-growing-state-thanks-to-oil-boom/
[3] http://usnews.nbcnews.com/_news/2012/12/20/16046374-north-dakota-is-fastest-growing-state-thanks-to-oil-boom?lite

(33% in 2012 and 39% in 2013). To complicate the situation further, the unit was opened without having a screener in place to complete newborn hearing screening. This has led to a high rate of missed birth hearing screens and delayed entry for birth screen results if a screen was completed. To complicate the problem further, many of these babies went home to places that were 60-90 miles from the hospital decreasing follow-up rescreening due to distance. Additionally, due to the rapid population increase, housing was limited or non-existent. Families lived in campers, moved often, and did not report back to have their infants rescreened.

- *ND EHDI has identified the western part of ND as a high priority target population to decrease LTF/D.*

At present, Mercy Hospital in western ND will be targeted as a location for Quality Improvement measures to reduce the number of missed and/or delayed documented birth screen outcomes and reduce the birth screen refer rate.

American Indian/Reservation:
ND has four Indian Reservations with the Turtle Mountain Indian Reservation still maintaining a birthing hospital, Quentin Burdick Memorial Hospital. This facility has an excessive refer rate approaching 40% and a missed birth screen rate of 12% (24 of 197 births) (Attachment 6.1: ND EHDI Occurrent/Birth Screen Data). Additionally, OZ eSP data indicates many of these infants do not return for outpatient screening. The development of a Quality Improvement team built around this facility which includes hospital staff, administrators, parents, and home visiting programs may be a means of changing this trend.

- *There is a definite need to identify strategies to reduce the birth screen refer rate found at the Quentin Burdick Memorial Hospital located on the Turtle Mountain Indian Reservation as it will greatly reduce the number of infants requiring an outpatient screen and thus reduce LTF/D.*

Early Intervention at the Birth Screen Level (Right Track Program/Tribal Tracking)
ND EHDI collaborates with several early intervention programs to offer support throughout the hearing care process. In ND, early intervention support is offered to families at hospital discharge if the infant has a missed or referred birth hearing screen. This level of early intervention is offered by a program called Right Track, a free program offered through the North Dakota Department of Human Services. Right Track providers offer family support/education stressing importance of hearing care follow-up and can also provide free in-home hearing screens and/or support to attain an outpatient provider follow-up appointment(s). Tribal Tracking is a free program located on each of the four tribal communities offering the same supports to tribal members. Referrals to the Right Track and the Tribal Tracking program are made directly in OZ eSP at the time of need (generally discharge). Currently, ND EHDI staff are initiating the majority of these referrals, however hospital staff have the ability to initiate the referral process. Hospital provided referrals to Right Track/Tribal Tracking at discharge would definitely increase the timeliness of early intervention referral receipt as opposed to ND EHDI staff initiation of referral. Additionally, it moves hospitals one step closer to becoming sustainable in providing complete hearing care for the future.

- *There is a need to make hospitals responsible to initiate early intervention referrals to Right Track/Tribal Tracking at hospital discharge for infants requiring outpatient follow-up.*

Outpatient Hearing Screen Level
Current OZ data indicates the LTF/D at the outpatient screen level to be at 26% and 29% in 2012 and 2013, respectively, with 73% (2013) completing the outpatient screening within the 30 day recommended timeline (Attachment 6.2: ND EHDI Outpatient Screen Data). Outpatient LTF/D has been identified to be comprised of four distinct hearing outcomes including infants with a "missed" or "referred" birth screen outcome who do not return for outpatient screening, those considered to be "lost contact" at the outpatient level and non-residents birthed in North Dakota.

Missed Birth Screen: LTF/D at Outpatient Screen Level
Home births comprise a high percentage (86% and 83% in 2012 and 2013) of infants with a missed birth screen and documented as LTF/D at the outpatient level (Attachment 6.2: ND EHDI Outpatient Screen Data).This population is being address within the "Home Birth" section above.

Referred Birth Screen: LTD/F at Outpatient Screen Level
Infants with a birth screen outcome resulting in a referral, who do not complete the required outpatient follow-up, make up the largest population of outpatient screen level LTF/D (147 infants (65%) and 104 (67%) in years 2012 and 2013 respectively) (Attachment 6.2: ND EHDI Outpatient Screen Data). One large identified area with a high LTF/D rate is western ND. Due to the oil boom and population influx, hospitals do not have the time or staffing to provide outpatient rescreens for their infants discharged with a missed or referred birth hearing screen. Out of area audiologists are traveling to these areas attempting to provide outpatient rescreens, however the increased road/travel time has decreased the number of infants they can see in their home office and satellite site.

- *There is an enormous need to decrease LTF/D within the population that does not complete the required outpatient follow-up.*

Lost Contact
The current number of infants indicated as Lost Contact within the OZ eSP system has been relatively small with 29 infants being reported in 2012 and 14 in the first 6 months of 2013. The "lost contact" population is currently being monitored for trends. Should an upward trend be identified, ND EHDI will develop a Quality Improvement team to determine the cause and address the issue via Quality Improvement methods.

- *Additionally, there is a need to ensure outpatient providers who do not have OZ eSP access are knowledgeable in ND EHDI reporting methods (ND EHDI online reporting form and faxback form). While this population may be smaller in number, they are non-the-less important to reducing LTF/D.*

Border Babies
Of North Dakota's birth population, non-resident infants constitute a relatively large population (15% or 1689 of 11533 in 2012). ND EHDI has identified that of non-residents discharged with a birth screen outcome of refer or missed a greater than 30% are considered as LTF/D as they do not have outpatient follow-up screen documentation (Attachment 6.2: ND EHDI Outpatient Screen Data).

- *There is a need to broaden efforts to ensure ND EHDI receives documentation of all non-resident outpatient hearing follow-up care.*

Early Intervention Outpatient Screen Support (Right Track Program/Tribal Tracking)
Right Track and Tribal Tracking providers offer family support/education stressing importance of hearing care follow-up and can also provide free in-home hearing screens and/or support to attain an outpatient provider follow-up appointment(s). Their ability to provide the free in-home hearing screens is an enormous benefit. Many families may not pursue outpatient follow-up due to lack of concern, budgetary constraints, distance, and/or travel conditions. However, many Right Track providers have indicated a reluctance to complete the Otoacoustic emissions (OAE) screenings because they do not feel proficient. Thus, Right Track/Tribal Tracking providers assist families in obtaining an outpatient screen at another outpatient screen location defeating the reason the family initiated early intervention services. Thus, families are still having to travel and often pay for a hearing rescreen at another outpatient provider location.

- *There is a need to increase Right Track/Tribal Tracking Provider OAE screening proficiency in performing in-home hearing screenings.*

Diagnostics Level
In 2012 the percentage of infants LTF/D between the outpatient screening and audiological assessment was 36%. In the first half of 2013 the LTF/D rate increased to 43% (Attachment 6.3: ND EHDI Audiology Data). ND EHDI has identified several issues believed to impact the high LTF/D rate at the diagnostic level in ND. These include lack of local diagnostic services for families, lack of documentation of assessment information by ND audiologists, and infants designated as lost contact and loss to documentation for non-resident infants receiving audiological services in their home state.

In North Dakota, pediatric diagnostic testing is only available at four sites located in central and eastern North Dakota leaving families in western ND traveling hundreds of miles for the nearest services (Attachment 6.4: North Dakota Birthing Facilities and Diagnostic Audiology Service Locations). Additionally, ND has an overall shortage of audiologists across the state. This shortage has forced many audiologists to travel to distant satellite clinics in an attempt to provide needed outpatient services. While they are providing a much needed service, the increased travel time has decreased the number of infants they can see and decreased time left for documentation to ND EHDI and/or collaboration with other audiologists throughout the state. Furthermore, many of the audiologists who do travel do not have diagnostic equipment at their satellite locations. On a statewide basis, ND EHDI has identified many infants are returning to an audiologist for evaluation however, the assessment results are not indicated in OZ eSP.

- *There is an overwhelming need to address the identified diagnostic issues.*

Finally, ND EHDI data also indicate a LTD of audiological outcomes from the non-resident population birthed in North Dakota.

- *This indicates a need to work with bordering states to ensure complete, accurate documentation of diagnostic evaluations performed out of state*.

This will be addressed in the Quality Improvement identified under Border Babies above.

Early Intervention Diagnostic Support (Parent Infant Program/Infant Development)
At the time of a diagnosed permanent hearing loss, Right Track staff provide referrals to two early intervention programs, the Parent Infant Program (PIP) and the Infant Development (Part C) program.

Parent Infant Program. The PIP is tied in directly with the North Dakota School for the Deaf (NDSD) and is a family centered, individualized program for infants and children ages birth to three and their family. The PIP is an Early Intervention home visiting program. They educate families on all options to encourage development of the child's listening skills, communication, language, and speech development through natural daily activities. They also provide support to families by attending diagnostic visits, as requested.

Infant Development. If a child is found to be eligible for the Infant Development Program services, infant and family will be offered a coach and consult model to assist the parents in enhancing overall development. This provides a connection between the Department of Human Services, Developmental Division which supports self-directed supports for travel/medical reimbursement options. Currently, ND EHDI does not have an agreement with the Infant Development Program to receive eligibility information. Thus, while it is known that Right Track makes the referral to Infant Development, Infant Development's enrollment/eligibility numbers attributed to hearing loss are unknown.

- *There is a distinct need for ND EHDI to obtain a Memorandum of Agreement with the Infant Development program for documentation of the number of infants enrolled in Part C as requested by the CDC HSFS.*

Conclusion

North Dakota's lack of mandated screening, rural topography, and increasing population has presented challenges for ND EHDI staff. Despite these challenges, ND has maintained a high birth screen rate and has gradually improved its overall loss to follow-up rates as reported through the CDC HSFS. In contrast, ND has recently experienced increases in home births and LTF/D at the outpatient and audiological levels. ND EHDI will incorporate Quality Improvement methodology revolving around each level within the hearing care process to decrease identified areas of greatest LTF/D.

Through ND EHDI, staff will;

- *maintain a current Data Use Agreement with Vital Records.*
- *establish a relationship with the midwifery population to decrease LTF/D of missed home birth hearing screens, birth hearing screen documentation and follow-up.*
- *keep hospital MOAs in an active status.*
- *target high priority target population to decrease LTF/D.*
- *teach hospitals to be responsible to initiate early intervention referrals to Right Track/Tribal Tracking at hospital discharge for infants requiring outpatient follow-up.*
- *decrease LTF/D within the population that does not complete the required outpatient follow-up.*
- *ensure outpatient providers have OZ eSP access and are knowledgeable in ND EHDI reporting methods.*

- *ensure ND EHDI receives documentation of all non-resident outpatient hearing follow-up care.*
- *increase Right Track/Tribal Tracking Provider OAE screening proficiency in performing in-home hearing screenings.*
- *work with bordering states to ensure complete, accurate documentation of diagnostic evaluations performed out of state.*
- *obtain a Memorandum of Agreement with the Infant Development program for documentation of the number of infants enrolled in Part C as requested by the CDC HSFS.*

METHODOLOGY

Methods to address aims/needs

ND EHDI has proposed to reduce LTF/D by 5% annually over three years. In the past year ND EHDI participated in the NICHQ Collaborative that emphasized using quality improvement through small tests of change to make significant changes in LTF/D. ND EHDI will focus on soliciting teams that are willing to use the Quality Improvement (QI) techniques learned in the collaborative to address LTF/D at all three of the 1-3-6 stages. During the collaborative it was noted that beginning the QI approach is most successful when started with those who are willing participants. As noted in the needs section ND EHDI has a firm grasp on the issues that are causing our LTF/D. Efforts to reduce LTF/D will begin with those who have expressed an interest in working to improve outcomes for infants and whose participation is most likely to result in LTF/D reduction.

Each year ND EHDI will establish Community of Practice (CoP) teams based around each of the birthing hospitals. These teams, when fully functional, will include pediatricians, parents, obstetrics managers, audiologists, early interventionists, and other organization representatives as needed. These teams will have a ND EHDI staff person that will function as the coach and educator on QI techniques. A separate effort will be developed with at least one of the midwife programs to identify those barriers to hearing screening for infants born outside of the hospital setting. These teams of parents, midwifes and ND EHDI staff will allow QI teams to identify an individual aim statement and use PDSA cycles to identify barriers and solutions. The process will result in a set of procedures and a Tool Kit that can be used by providers at the 1-3-6 stages across the state.

The first three teams

Targeting hospitals with high LTF/D rates. There will be an emphasis to recruit teams from Mercy Hospital in Williston, ND (oil country) and with the Quentin Burdick Hospital on the Turtle Mountain Indian Reservation.

These two facilities have had significant issues with missed birth screens, high refer rates on birth screens, very high percentages of LTF/D on babies who were referred, and issues with timely entry of demographic data into the OZ data system. The QI teams approach utilizing small tests of change will result in measurable and meaningful reduction in LTF/D rates.

Developing an audiology community. Years ago, the audiology community of professionals in ND had a strong working group that met regularly for education and discussion of issues. Today there is no cohesive organization to discuss issues at the state level. This leaves a void when trying to initiate efforts of policy or practice because each practice has to be approached separately. ND EHDI initiatives of reporting and mandating hearing screening and intervention cannot be supported by an organization of audiologists but by individual professionals who do not carry the same weight. ND EHDI will work with several audiologists that participated in the NICHQ collaborative to establish an organizational structure that can represent the group on the ND EHDI Advisory Board.

Utilizing EHDI staff as coaches. DEHDI currently uses three staff as follow-up coordinators. This function, while being effective, has also shifted the focus of responsibility for assuring documentation away from those closest to the infant. Using the QI approach ND EHDI staff will shift their duties over the course of this project to being team developers, coaches, data reporting specialist, and disseminators of successful practice. NDCPD has staff with significant experience using PDSA cycles in medical settings. The ND EHDI staff will complete a series of in-house training sessions to ensure that the components of the QI approach are well understood and can be used as teams are identified.

QI teams will meet initially to develop an individualized aim statement. We will begin with a small team to address one specific issue. As small tests of change are tried and data are recorded the PDSA may be modified, expanded or discarded.

How Will QI Strategies Be Used?
ND EHDI staff will use the tools made available through the NICHQ Collaborative as a basis for developing aim statements for each team and also for documenting results of small tests of change. The ND EHDI staff member will coach each team through the process with the goal of each team functioning independently after one year.

EHDI staff will help establish teams in regions throughout the state, starting with three teams and adding teams throughout the grant period. It is important that teams maintain autonomy and decision-making authority. The small tests of change need to relate to things teams view as important problems and include strategies that teams believe will work. EHDI staff will not develop plans and give them to the QI teams, rather teams will develop their own small tests of change.

QI teams will, however, use the same process. QI process will the following steps: 1) identification of the aim; 2) description of the problem; 3) a goal for what they would like to see happen instead of the problem; 4) a change-strategy that will be used; 5) a simple data collection system that will identify progress; 6) current data regarding the problem; 7) system for collecting data during the small test of change; 8) OZ data review comparing LTF/D rates before and after the strategy was implemented; 9) a brief statement about what was learned by the QI team; and 10) how the strategy will or will not be used from now on. These steps will remain consistent for every team.

Measurement of success will be monitored at the implementation level by using summary sheets to identify whether teams used the process correctly and successfully. The quality, or fidelity, of using the system will be measured by using the summary sheets to ensure that each step was implemented correctly. This allows EHDI staff to implement training on how to use the process without interfering with QI team autonomy about the topics and strategies used in the small tests of change.

EHDI staff will also use run charts to document data. As each test is expanded, the results can also be monitored through the OZ system. QI Teams will be trained to pull data results directly from OZ to identify areas that need improvement and monitor efforts of change.

As needed, the efforts of each of the QI Team will be guided by the development of their individual aim statement which should be focused on data captured by the OZ system. Strategies that might be tried could be those identified by previous teams such as; 1) documenting the primary care physician, 2) documenting two points of contact, 3)setting up appointments prior to discharge, 4) appointment reminder calls, 5) obtaining parental consent for information exchange, 6) scripting messages, 7) or they may find ideas that are unique to their environment.

As teams discover successful strategies they will be encouraged to include them on a statewide ND EHDI electronic bulletin board that can be accessed through the ND EHDI website. ND EHDI will use list serves and newsletters to inform our partners of progress and successful strategies. The Advisory Board will also be apprised of team efforts through email and regular meetings.

ND EHDI Advisory Board

ND EHDI will appoint an advisory board that will be comprised of stakeholders who can advise project staff regarding the successful implementation of its work plan. The current advisory board is not functioning in that capacity. Restructuring the board with written guidelines, duties and establishing membership that represents the partners in the EHDI program will allow the ND EHDI program to move to sustainability. Partners will be asked to review, modify and adopt the new guidelines and duties. Membership will be established and work groups will be formed to address identified needs.

WORK PLAN

Aim Statement 1: ***By April 1, 2017, ND EHDI will utilize the Quality Improvement concept in collaboration with partners to document final hearing screening outcomes for 99% of all ND occurrent births at each level of the screening process.***

ND EHDI has been fortunate that even though North Dakota's birth hospitals are not mandated to provide birth hearing screens or report the screening outcomes, they have implemented hearing screening as a standard of care and have proven quite proficient in documenting live births and hearing screening results to ND EHDI on a voluntary basis. ND EHDI will continue to ensure Memoranda of Agreements (MOAs) remain in active status with all birthing hospitals as the MOA indicates hospital participation and expectations. Current OZ eSP data indicates North Dakota's birthing hospitals have a 98% and 99% completion of birth screens reported in 2012

and 2013 respectively and are completing greater than 95% of screens within 30 days (Attachment 6.1: ND EHDI Occurrent/Birth Screen Data). Additionally, ND EHDI staff will continue to support hospital efforts and monitor their progress; however ND EHDI follow-up coordinators will transition tracking and data management methods to individual hospital hearing care programs to promote self-reliance and sustainability.

Objective 1.1 – Document 100% of ND occurrent births in the OZ eSP system.

Activity 1.1.1 – Continue to enhance data fields received from Vital Records (VR) and its integration into the OZ eSP data system. ND EHDI will continue to ensure accuracy and completeness of OZ eSP data utilizing Vital Records information as a denominator and pursuing additional EHDI data field requirements from Vital Records as needed.

Activity 1.1.2 – Partner with the ND EHDI-IS project funded by CDC to integrate VR data into OZ eSP. Vital Records information has addressed complete documentation of births occurring in ND, however the information received from VR cannot be used to pursue follow-up because of constraints within the Data Use Agreement. Thus, while ND EHDI is now able to identify the growing missed home birth population, the information received cannot be used to support follow-up efforts. NDEDHI in collaboration with the ND EHDI-IS grant will work with the Vital Records division at the North Dakota Department of Health to address data use for follow-up purposes via update(s) to the Data Use Agreement.

Objective 1.2 – 50% of home births will have a documented birth hearing screen within two weeks of birth.

Activity 1.2.1 – Establish a Community of Practice (CoP) team revolving around the midwifery community to ensure home births have a documented birth hearing screen by two weeks of age. ND EHDI staff will incorporate Quality Improvement using the Plan Do Study Act (PDSA) approach with a Community of Practice (CoP) team revolving around a voluntary midwife and additional team members will identify barriers and solutions within the home birth population. The CoP will identify strategies, prioritize, and implement as a PDSA cycle or series of cycles allowing for the cycle to be adopted, adapted or abandoned. The adopted strategies will be evaluated and a determination will be made if further amendments need to occur or if the outcome was positive and the replication or "spreading" of the PDSA will be shared with additional midwives leading to statewide improvement in the documented number of complete birth hearing screens at a statewide level. Several concepts have been identified by ND EHDI staff as potential strategies and/or needs. These concepts will be shared with the CoP team for possible inclusion within the quality improvement process as a focus for development and inclusion within a midwifery toolkit.

Activity 1.2.2 – Develop a "Midwifery Tool Kit". The tools/strategies may include: a developed *parental consent* for release of a home birth information and hearing care outcome to ND EHDI, an *instructional guide* for midwifery education related to ND EHDI practices in the 1-3-6 month concept for hearing care which includes screening/evaluation timelines to be shared with parents, early intervention support options and available result reporting methods. The toolkit may also include contact information for supportive services offered by North Dakota's early intervention programs, Hands and Voices, Family Voices, and

ND audiology providers. ND EHDI brochures referencing hearing care will be included as educational materials to be given to parents by their midwife.

Objective 1.3 – 100% of well-baby hospital births have a documented birth screen within two weeks of birth that are within acceptable missed and referred rates.

Activity 1.3.1 – Establish a Community of Practice (CoP) team(s) around Mercy Medical Center (oil country) and Quentin Burdick Memorial hospital (Turtle Mountain Indian Reservation) to identify barriers/solutions to high missed and referred birth screen refer rates. Both of these locations consistently demonstrate a high number of missed and referred birth screen outcomes with delayed documentation. Communities of Practice will be implemented utilizing National Initiative for Children's Healthcare Quality (NICHQ) strategies to identify barriers and solutions to these issues. Yet to be determined teams will be comprised of ND EHDI staff, hospital personnel, regional early interventionists from the Right Track Program or Tribal Tracking Program, a primary care physician representative, a parent of a child with a hearing loss, an audiologist and a data analyst. Identified strategies will be prioritized and implemented as a PDSA cycle or series of cycles allowing for the cycle to be adopted, adapted or abandoned. The adopted strategies will be evaluated by the team and a determination will be made if further amendments need to occur or if the outcome was positive and the replication or "spreading" of the PDSA should be shared at the second facility to improve LTF/D and high referral rates. It is understood that each facility will need to make modifications based on their unique needs.

Activity 1.3.2 – Implement auto imports of demographics into the OZ eSP data system at three birthing hospitals. The ND EHDI program has several hospitals utilizing auto importation of demographics from their hospital system into OZ eSP. The benefit of these imports include decreased manual data entry, elimination of user error and increased timeliness of completed birth screen documentation. ND EHDI staff will promote the use of imports to additional hospitals in an effort to increase timeliness from hospitals with delayed data entry issues.

Objective 1.4 – 100% of NICU babies have a documented birth hearing screen upon discharge.

Activity 1.4.1 – Train hospital staff to provide ND EHDI with results for infants transferred to out of state facilities for a higher level of care. To date, birthing hospitals have been responsible to provide ND EHDI with birth hearing screening documentation for all births; however, birth hearing screening results for infants transferred to an out of state facility for a higher level of care have been tracked and entered by ND EHDI staff. In an effort to promote self-reliance and sustainability, ND EHDI staff will train hospital staff to monitor, pursue and enter out of state transferred infants' results in OZ eSP.

Activity 1.4.2 – Implement and train birth hospitals to utilize a transfer protocol function in OZ eSP for in state and out of state transfers. Recently, an update or enhancement functionality was added to the OZ eSP data system called "transfer logic". This enhancement allows hospitals to track an infant's OZ eSP file when a transfer between facilities occurs. The functionality also indicates if the file was received, the outcome of hearing screening performed at the receiving hospital and eliminates the creation of duplicate files being created which now occurs due to the current transfer method. ND

EHDI staff will provide ND's birthing facilities with training to utilize the transfer logic function and monitor transfer outcome to determine further training needs.

Objective 1.5 – 85% of infants with a missed or referred birth screen result have documented outpatient screening results before one month of age.

Activity 1.5.1 – Establish a Community of Practice (CoP) team around the birth hospitals to identify LTF/D barriers and solutions needed to improve outpatient screening results by one month of age. With the greatest overall population of LTF/D at the outpatient level being infants referred during birth hearing screen who do not return, ND EHDI will establish a hospital based Community of Practice team including ND EHDI staff, hospital personnel, regional early interventionists, an audiologist, a primary care physician representative, a parent of a child with a hearing loss and a data analyst to identify barriers and solutions to the LTF/D population between the birth and outpatient hearing screens. Identified strategies will be prioritized and implemented as a PDSA cycle or series of cycles allowing for the cycle to be adopted, adapted or abandoned. The adopted strategies will be evaluated and a determination will be made if further amendments need to occur or if the outcome was positive and the replication or "spreading" of the PDSA should be shared at additional hospitals leading to statewide improvement in the LTF/D rate at the outpatient screen level. Several concepts have been identified by ND EHDI staff as potential PDSA activities and will be shared with the CoP team for possible inclusion within the quality improvement process as a focus for development. For example, ND EHDI has identified that hospitals who schedule an outpatient rescreen appointment for families prior to discharge indicate a lower LTF/D rate (Attachment 6.5: ND EHDI Outpatient Appointments in OZ). Additionally, ND EHDI currently has two public health units reporting outpatient screening results by way of the ND EHDI online reporting form and faxback form. The inclusion of additional public health units and/or early head start programs may be additional strategies. Other suggestions would include reminder calls a day prior to a scheduled appointment, parental reminder letters, and the inclusion of two points of contacts being entered at the hospital level.

Activity 1.5.2 – Outpatient providers who do not have access to OZ eSP will be knowledgeable in accessing and using ND EHDI online and fax-back reporting forms. ND EHDI staff will ensure outpatient providers including midwives, audiologists and clinic staff who do not have OZ eSP access are knowledgeable in the use of the ND EHDI Online Reporting Form and Fax back form for result submission to ND EDHI.

Activity 1.5.3 – Establish relationship with bordering states to obtain outpatient screening results. ND EHDI will convene a discussion group that will increase collaborative efforts with bordering states. This group will discuss and identify solutions to sharing outpatient follow-up screen results provided in the infant's home state.

Objective 1.6 – 100% of infants discharged with a missed screen or referral for a hearing screen will be referred to Right Track for follow-up.

Activity 1.6.1 – Hospital staff will be trained to enter Right Track referrals in OZ eSP at discharge. ND EHDI staff will promote and train hospital staff to enter Right Track referrals into OZ eSP.

Activity 1.6.2 – Train Right Track providers to perform in-home hearing screenings and follow-up protocols. To decrease LTF/D for families who do not return for outpatient

screenings, ND EHDI will work with the Developmental Disabilities Division at the North Dakota Department of Human Services Coordinator to establish additional trainings and follow-up protocols.

Aim Statement 2: ***By April 2017, ND EHDI will decrease the number of infants LTF/D by 5% annually at the audiological diagnostic level before three months of age.***
ND has an overall shortage of audiologists across the state. (Attachment 6.4: North Dakota Facilities and Diagnostic Audiology Service Locations). This shortage has forced many audiologists to travel to distant satellite clinics to provide needed outpatient services. While they are providing a much needed service, the increased travel time has decreased the number of infants they can see and decreased time left for documentation to ND EHDI and/or collaboration with other audiologists throughout the state. Furthermore, only one of the audiologists who travels has diagnostic equipment at their satellite location. On a statewide basis, ND EHDI has identified many infants are returning to an audiologist for evaluation however, the assessment results are not indicated in OZ eSP. Finally, ND EHDI data indicate a LTF/D of audiological services for the non-resident population birthed in North Dakota.

Objective 2.1 – 100 % of audiologists will document diagnostic results

Activity 2.1.1 – Establish a Community of Practice (CoP) team to determine LTF/D barriers/solutions to improve audiological diagnostic results by three months of age. ND EHDI staff will incorporate Quality Improvement using the Plan Do Study Act (PDSA) approach with a Community of Practice (CoP) team revolving around audiologists to identify barriers and solutions that can be used to identify LTF/D. Possible concepts and ideas may include but are not limited to: surveying parents regarding distance factors, use of distance diagnostic techniques *(TeleAudiology), having audiologists travel to reduce parent travel time.* Identified strategies will be prioritized and implemented as a PDSA cycle or series of cycles allowing for the cycle to be adopted, adapted or abandoned. The adopted strategies will be evaluated and a determination will be made if further amendments need to occur or if the outcome was positive and ready to be shared statewide.

Activity 2.1.2 – Develop a quality improvement "Audiology Tool Kit". ND EHDI will work with audiologists to create an "Audiology Tool Kit". Components of the QI Tool Kit should include: a description of best practices, a quick reference sheet on audiological result entry into the OZ eSP data base, information on how to report results using the ND EHDI fax back form and online reporting form.

Activity 2.1.3 – Establish relationship with bordering states to obtain audiological diagnostic outcomes for entry into OZ eSP. Collaborate with EHDI Coordinators from ND's 3 border states (MT, SD and MN) to implement cross-border agreements to ensure reporting, tracking and follow-up of ND babies born out of state, and follow-up for out-of-state babies born in ND.

Aim Statement 3: ***By 2017, 100% of ND infants identified with a diagnosed permanent hearing loss will have documented Early Intervention (Part C) status by six months of age.***
ND EHDI believes that all infants are referred to Part C but has struggled to document enrollment because of federal privacy regulations. There are several ways to achieve the

information which will be pursued. We can however document that all infants have been referred to PIP which is a non-Part C state-run program through the ND School for the Deaf.

Objective 3.1 – 100% of infants with a permanent hearing loss will be referred to Part C and/or Parent Infant Program (PIP).

Activity 3.1.1 – ND EHDI staff will train 10 audiologists to use the OZ system to make direct referrals to Early Intervention. ND EDHI staff will utilize a "toolkit" to train audiologists.

Activity 3.1.2 – ND EHDI staff will provide audiologist with quarterly reports detailing results of referrals. ND EHDI will continue to perform follow-up duties by providing a monthly report card indicating the number of infants referred and the number with documented results in OZ.

Activity 3.1.3 – ND EHDI staff will train Right Track/Tribal Tracking to use the OZ system to make direct referrals to Early Intervention. A team of Right Track/Tribal staff will be recruited and using the QI approach ND EDHI Staff will identify techniques to improve their use of the OZ system.

Activity 3.1.4 – Develop a resource packet to be given out by audiology professionals to families at the time of diagnosis to educate families about the early intervention services and family support that is available. A resource packet will include: Parent Road Map, information on local/ state resources, *Chimes* newsletter, Hands & Voices brochure, etc.

Activity 3.1.5 – Collaborate with Hands & Voices to design and distribute a resource packet for parents of infants with a diagnosed hearing loss. A resource packet for parents will be disseminated at health fairs, conference, pediatrician offices, and audiology offices.

Activity 3.1.6 –Using the original ND NICHQ Team as the lead, additional audiology practices will be approached to spread the success that was achieved. The two audiologists who participated in the NICHQ collaborative have agreed to assist in recruiting other audiologists to participate in monthly conference calls as a start of a process to share and spread success stories, identify barriers and identify solutions.

Objective 3.2 – 100% of infants with permanent hearing loss will be referred and identified as eligible for Part C and/or the Parent Infant Program by 6 months of age.

Children will recieve necessary audiological intervention (which may include diagnostic testing, hearing aids or cochlear implants). Select audiologists will be provided access and support to OZeSP to ensure complete data entry of audiological evaluations and referrals to Early Intervention (i.e. Part C) as necessary. Entities providing audiological evaluations that do not have current OZeSP access will record information via paper form and fax the information back to ND EDHI staff who will a) enter early intervention service in OZeSP, b) track entry of early intervention service into OZeSP, and c) monitor to confirm the accuracy of the data.

Activity 3.2.1 – Develop an MOU with Part C professionals to allow the exchange of information related to referral and enrollment status. ND EDHI will obtain consent via a Memorandum of Agreement to share information with the infant development program.

Activity 3.2.2 – Train Part C Staff, PIP and DD Program Managers to document status in OZ eSP. ND EDHI Staff will develop a "toolkit" that Part C staff, PIP and DD Program Managers will use as a guide to documenting screen results in OZ, making referrals to

other professionals and documenting progression through the 1-3-6 stages. The kit will include consent forms, protocols, specific directions for accessing and using the OZ data system.

Activity 3.2.3 – ND EDHI staff will track entry of early intervention service into OZeSP and monitor to confirm the accuracy of the data and identify training needs. ND EHDI staff will use the OZ system to generate reports shared monthly with EI program indicating the number of infants referred to them and the documentation of enrollment.

Aim Statement 4: *Utilizing ND EHDI partnerships collaborate to identify a means of sustaining Early Hearing Detection and Intervention beyond federal funding.*

Objective 4.1 – By April 2017, all birth hospitals will pay 100% of OZ eSP user fees.
To address sustainability, ND EHDI 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 OZeSP access in Year 1. In Year 2, ND's eight largest hospitals will be requested to pay their access costs and in Year 3, all hospitals will be required to pay their access costs. Planning will also begin to look for alternative funding sources to cover the costs for other organizations such as Right Track, Part C and PIP user fees.

Activity 4.1.1 – Survey hospital administrators to obtain their opinions. Understanding that hospitals are a vital part of the documentation process, administrators will be contacted and surveyed to solicit their support for shifting OZ user fee costs to the hospitals.

Activity 4.1.2 – Establish a payment system to gradually shift costs over two years. Propose that the eight largest hospitals pay OZ fees by the end of the second year of the grant cycle and that the other four smaller hospitals are transitioned into paying their fees at the end of the third year of the project.

Objective 4.2 – By April 2017, ND EHDI staff will develop a "ND EHDI Protocol Tool Kit" for EHDI partners to use.

This tool kit will be the all-inclusive source of information for everyone associated with ND EHDI services. It will be used by hospitals, audiologists, EI personnel, midwives and state agency heads to describe their role in the EHDI processes. The tool kit will include a training module for participants and parents.

Activity 4.2.1 – Update ND EHDI Training Manual. To ensure that all partners in the ND EHDI process have protocols and procedures that delineate what their role and functions are and how to record information in the data system, ND EHDI staff will work with users to update the training manual. This activity will result in a document useable by all parties broken out by the level of service which is easy to understand, includes timelines of reporting and steps on how to report. ND EHDI staff will disseminate the document at community visits and conduct training as necessary with each group.

Activity 4.2.2 – Develop reference sheet for OZ eSP data entry. The OZ data system is the most critical element to documenting and tracking ND EHDI services. ND EHDI will develop a reference sheet that participants can use as a training tool and a guide for data entry for each provider.

Activity 4.2.3 – Update ND EHDI Road Map. The Road Map is the tool that can be used by parents, pediatricians and ND EHDI partners as a quick reference tool. The map identifies where a child is in the continuum of services and what the next step should be.

Objective 4.3 – Redefine the purpose and membership of the ND EHDI Advisory Board.

Activity 4.3.1 – Develop a work group of ND EHDI partners to establish guidelines. The Advisory Board needs to be the driving force to improvement of EHDI services to and for infants born in ND. Redefining their purpose and structure will be the first step in planning long term sustainability for ND EHDI. Through the cooperation of the ND Department of Health and the ND EHDI State Coordinator, a small work group will be established made up of the major participants in the process. Participants will include but not be limited to representation from: birth hospitals, audiologists, Infant Development (Part C early intervention), PIP (North Dakota School for the Deaf), AAP, Parents, Hands and Voices and ND EHDI PI. This group will outline the purpose of the Board and draft guidelines for its operation and membership. Draft guidelines will be distributed for comment throughout the ND EHDI provider network; revisions will be made as needed and formal acceptance of the structure and purpose accepted by the membership of the Board.

Activity 4.3.2 – Invite key partners to fully participate in Board activities. Any additional members will be invited to join the Board with an emphasis on representation of partners. This may include representation of midwifery, legislature, insurance companies, Medicaid providers, etc.

Activity 4.3.3 – Encourage all of the ND EHDI partners to spread successful PDSA activities. The Board will be updated regularly of the progress toward reducing LTF/D and results of the QI process. Members will be encouraged to discuss successes with their respective groups and encouraged to spread those successes to other areas of the state.

Activity 4.3.4 – The Board will help to identify funding streams that can be used to sustain EHDI activities. After the Board has been reorganized it will begin to look for alternative funding sources which may include service club partnerships, state funding, corporate funding, insurance and Medicaid reimbursement.

Objective 4.4 – Introduce legislation to mandate established ND EHDI protocols in the 2017 ND Legislative Session.

Activity 4.4.1 – Identify legislators who have an interest in EHDI. The Board will discuss the merits of an ND EHDI mandate and develop a rationale. Legislation from other states will be reviewed and there will be discussions with state EHDI Coordinators to identify the merits or shortfalls of their mandate. Upon development of a rationale key, legislators will be approached to solicit their support for submitting legislation.

Activity 4.4.2 – Solicit support of a mandate from the Advisory Board. The Board will take an affirmative stance by resolution or vote to support the proposed legislation. Each member will be asked to obtain support from their respective organizations/agencies.

Activity 4.4.3 – Identify organizational support. The board will look within the state for support from organizations like Easter Seals, Hands and Voices, Family Voices, etc.

Activity 4.4.4 – Develop a plan. When sufficient support has been garnered a complete plan will be developed including the development of informational/educational materials to inform the public of the benefits of ND EHDI and a process of obtaining the necessary legislative support.

RESOLUTION OF CHALLENGES

As implementation of the activities specified in this proposal begins, grant staff anticipate several challenges and offer corresponding solutions. The challenges listed below are a combined result of data analyses conducted in the Needs section of this proposal, findings from community visits conducted within birth facility cities across North Dakota and hearing healthcare providers/family support groups.

Challenge 1: ***Finding team members willing to participate in QI strategies.***
NICHQ identified time as a major barrier to participation. Professionals are tasked every day to do more in less time. Audiologists specifically are forced to be profit centers for their facilities and adding duties can take away from patient time. Right Track providers have large caseloads with in home hearing screening only a small portion of their duties. Parents who chose home birthing have a tendency to limit intrusions upon their families, therefore soliciting their involvement with hearing screening and follow-up may be difficult. Midwives often accept that home birth parents want to limit intrusion and may also be reluctant to participate in QI activities.
Resolution: The project staff will develop QI teams to address the issue of LTF/D. Teams will be structured around each birthing hospital, as well as partners of Right Track, PIP, Head Start, and audiology. The resolution is to provide training on QI techniques as a process of implementing small tests of change. ND EHDI will need to take the lead in developing teams and then slowly shift that role to a member of the team.

Developing teams that begin with one midwife and one or two parents who can utilize the QI activities may lead to an understanding of techniques, materials and approaches that can be useful with other parents and midwives.

Challenge 2: ***Parent Involvement***
Many ND parents with children with permanent hearing loss hold jobs that do not allow them to fully participate on QI activities on a Monday through Friday, 8-5 schedule that coincides with hours other professionals work. In addition adding travel and other expenses such as child care costs may discourage many from fully participating.
Resolution: Solicit participation from parents closest to where that team is located, this may mean that not all parents will be able to become part of a QI team. Work with parent groups to solicit input through surveys and focus groups held during their regular support group meetings. Use in home visiting staff to solicit feedback on techniques and approaches. Use conference calling after hours to bring the team together. Keep meeting times organized and short.

Challenge 3: ***Ability to meet with team (ND topography, distance, weather)***

Miles and weather are two factors that will alter the best laid plans in ND. Meetings will undoubtedly be postponed or cancelled due to weather. Timing of meeting will need to juggle the schedules of professionals and parents.
Resolution: Plan the majority of team meetings and work during the better weather months of the year and rely on web or conference call meetings during the other months. Put a strong emphasis on using phone, Skype, Interactive Video Network (IVN), or other internet solutions to conduct meetings. Use an electronic scheduling tool to establish the best meeting times. Mail, fax, scan and email information prior to meetings to keep time frames as short as possible. Solicit feedback on ideas prior to meeting times.

Challenge 4: ***ND EHDI staff are unable to use vital records data in the Home Birth follow-up process in reducing LTF/D.***
Resolution: Solicit assistance from policy analysts on how to resolve this challenge. Establish a modified MOU that would allow for this use.

Challenge 5: ***ND EHDI does not receive Part C enrollment dates, which would assist ND EHDI to fully comply with 1-3-6 month documentation.***
If ND EHDI could receive notification either within the OZ system or through fax, email or phone call of enrollment into Part C, it would be possible to accurately report on the CDC report. Currently ND EHDI staff believe that a very high percentage of infants are enrolled in Part C on a timely basis but the lack of confirmation does not allow us to report it.
Resolution: Use the ND EHDI Advisory Board as a tool to discuss policy issues with an emphasis on finding solutions. Bring national Part C representatives together with ND Part C personnel to discuss the useful exchange of information.

Challenge 6: ***Timely audiology diagnostic input of data***.
In ND the majority of audiologist do use OZ as a data reporting format, but timely reports do not occur without reminders from EDHI staff.
Resolution: Use the Advisory Board as a tool to solicit timely reporting. Provide data to each audiology practice documenting their level of participation.

Challenge 7: ***Sustaining EHDI activities and protocols with limited or no federal funding.***
There has not been a successful attempt at mandating EHDI in ND. This would be the first step toward sustainability. Without this hospitals and other partners may find themselves sliding away from efforts. ND is in a very opportune situation with the recent energy boom. There are resources available to be used if legislators can be convinced it is a worthy cause. Hospitals have accepted EHDI screening as their duty through MOUs as well as the development of protocols internal to their operation. Hospitals are, however, under increasing financial pressure to be profitable and dropping a non-mandated service could be easy to do.
Resolution: Restructure the Advisory Board with an emphasis on policy and protocol development. Use the Board to develop a short and long range plan for sustainability. Solicit involvement from legislators who have a stake in EHDI activities. Look for an outside partner to instigate a mandate, this could come from Easter Seals, Hands and Voices or other national organizations. The CCHD mandate was initiated by the American Heart Association. Look for funding to begin a public information campaign designed around bringing awareness to all NDs of the prevalence of congenital hearing loss and the benefits of early detection and intervention.

Challenge 8: ***Resistance by birth hospital staff to accept additional duties.***
If ND EHDI established protocols are to be maintained when federal funding ends, birth hospitals and other partners will have to accept the additional duties currently performed by ND EHDI Follow-up Coordinators.
Resolution: ND EHDI staff will use small tests of change to show hospital personnel that using the OZ tools can simplify effort, significantly improve results and reduce time spent tracking infants. One hospital, two staff, one small test that is expanded/adapted and then adopted can lead to one hospital tracking hearing results for every infant they birth. That hospital staff tells their story to another hospital staff person and the process is spread.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

ND EHDI will have two main evaluation systems in place for the duration of the grant. Measures will be collected on an ongoing basis regarding the loss of follow-up/loss to documentation (LTF/D) at each of the milestone periods of one month, three months and six months. As the QI system utilizing small tests of change are implemented, impacts will be seen in the LTF/D numbers. If the QI system is working correctly, there will be a 5% per year decrease in LTF/D numbers.

Measuring success toward meeting project aims

ND EHDI uses a web based data system developed by OZ Systems, Inc. OZ has remained dedicated to the needs of the national EHDI project by modifying and enhancing software capacity to report the specific data inherent in the CDC report. OZ also offers ND EHDI support services to make data collection unique to ND. The data reported in the attachments are directly pulled from OZ eSP software. Recently, ND EHDI worked with OZ to enhance the software to allow time sensitive reports (Aging Reports). This report function offers ND EHDI staff the ability to monitor progress toward the 1-3-6 month stages by each birthing hospital. The partnership with OZ has been instrumental in tracking infants and reporting progress.

ND EHDI provides birthing hospitals quarterly progress reports designed specifically to monitor their efforts to ensure hearing screening services for all children. These reports feed hospitals and audiologists data to monitor their own progress. ND EHDI staff will communicate with each facility to ensure they are receiving the data they require in a format that is most useful.

The target populations are; 1) infants whose parents were contacted but unresponsive, 2) infants whose parents were unable to be contacted and, 3) infants falling into the category of unknown. This total divided by the total number of infants who did not pass a hearing screen results in the LTF/D reported in the CDC HSFS and will be the system used to monitor loss at all of the 1-3-6 month stages.

Progress performance reports

HRSA requires semiannual progress performance reports. Performance reports are used as a means of recording EHDI activities. Information included in these reports consists of project findings; outcomes; activities; training and management activities; methods; lessons learned; and, products of significance. Performance data will be analyzed; and we will work with the

HRSA project officer if a plan of action is needed for improvement. Targeted activities will be identified and reported on the semiannual performance report

Measuring the use of small tests of change

While OZeSP is a great tool to monitor each infant and evaluate progress monthly or quarterly, it is not a tool that will be beneficial to measure the outcomes of small tests of change in the short term. This will need to be done using tools developed for each test. ND EHDI staff are proficient in the use of spreadsheet software that can be designed to track these small tests of change, turning data into run charts to show progress. This is a function that can be filled by any member of the QI team. To ensure that the teams sustain their knowledge and understanding of the QI approach, the function may begin with the ND EHDI staff member assuming this role.

ND EHDI staff will use the tools made available through the NICHQ Collaborative as the basis for assisting teams to develop aim statements and for documenting results of small tests of change. The ND EHDI staff member will coach each team through the process and may at first function as the team lead with the goal of each of the teams to function independently after one year. Through ongoing support meetings, EHDI staff will monitor the fidelity, or accuracy, of use of the QI process by teams.

Measurement of success will be monitored at the implementation level by using the teams' use of the decision-making worksheets to determine the level of QI team accuracy in using the process. If QI teams have less than 90% fidelity in carrying out small tests of change and using data gathered to make decisions that lead to meeting aims, the team will be coached in the process until they are using the process with 90% or higher fidelity. Fidelity will be measured as the number of steps in the QI process for small tests of change completed correctly by the team divided by the total number of steps used and multiplied by 100 to determine the percent of accuracy in using the procedure.

Monthly progress reports

At the monthly EHDI meetings, staff will report their progress on the assigned activities. Barriers and solutions will be logged in meeting minutes so semiannual and annual reports can be constructed on project progress and issues.

Lessons Learned

An important feature of our local and national reporting will be our compilation of lessons learned. EHDI staff will talk frequently with QI teams and data records and ask for descriptions of effective strategies. The EHDI staff will include the following in their summary: description of the problem, the solution, the process to reach the solution, and the lessons learned. These lessons will be compiled and included in our presentations and reported in the HRSA Performance Reports as appropriate.

ORGANIZATIONAL INFORMATION

The North Dakota Center for Persons with Disabilities (NDCPD), is a University Center of Excellence in Developmental Disabilities (UCEDD) at Minot State University (MSU). NDCPD will serve as the lead agency for the ND EHDI Program. NDCPD 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 types of activities include education, research, community service, personnel training, and information dissemination to service agencies and state programs as well as individuals with developmental disabilities. The current mission of NDCPD is "to provide service, education, and research which empowers communities to welcome, value, and support the well-being and quality of life for people of all ages and abilities."

NDCPD is located on the campus of MSU which has 55 undergraduate and 11 graduate degree programs for students to enroll. NDCPD has full access to all university Information Technology services, library, online instructional resources, and media facilities including high speed internet connections and an interactive video conferencing studio for distance meeting collaborations. NDCPD has an experienced website development staff and support resources through its design lab. These resources are used to carry out a variety of project activities that help support the project.

Since NDCPD was established, NDCPD has successfully developed a wide range of programs serving the needs of people with disabilities. In 2012-2013, NDCPD provided direct services to over 1,500 persons with disabilities and their families and produced over 65 publications. Training and technical assistance was provided to 31,000 people working with and for persons with disabilities. NDCPD's operating budget, combined across 49 different grants and contracts, is over [redacted] 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 thirteen years, NDCPD has helped carry out collaborative activities to enhance EHDI in ND. NDCPD hosts statewide collaborative conferences for families and professionals. Many of NDCPD projects involves working directly with early intervention services and 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 through the state. Continued funding would carry the momentum of our progress and achieve a higher level of hearing health care in North Dakota.

Starting in 2011 and concluding in 2013, the ND EHDI project participated in the National Initiative for Children's Healthcare Quality (NICHQ). NICHQ mission is to "better children's health and healthcare through quality improvement." During the course of the initiative ND EHDI developed a team of professionals and parents to address loss to follow up issues at one birthing hospital. The team consisted of two pediatric audiologists, a parent of a child with a hearing loss, an early interventionist trained in education of the deaf, the Project Director of the CDC funded EDHI-IS project as the data person and the Project Director of the ND EHDI project.

The experience led to an understanding of the small tests of change concept, but also a realization that other professionals and parents see the EHDI process from a different perspective than the project staff see it. The collaborative showed us that without a mandate to report, ND EHDI staff can only guide and encourage our partners in seeking better ways to approach loss to follow-up.

The ND NICHQ Team worked diligently from August 2012 to September 2013 to understand the concept of quality improvement through small tests of change and then to begin designing and testing those changes. The initial focus was to ensure that the parents of infants whose child had referred on a birth screen returned for an outpatient screen at Trinity Hospital. The first test was to have our parent develop a letter that would be sent to other parents emphasizing the need for a final hearing outcomes for their child. This was then sent to five parents. The parents who returned were then asked if the letter was the determining factor in bringing their child back.

Efforts were made to adapt, increase the number of tests, adopt or abandon the effort as unsuccessful. Many small tests of change were tried covering a variety of areas and success was shown in many of these areas. Audiologists implemented a phone call to parents reminding them of a scheduled appointment. The results were favorable with 3 of 5 attending, this test was expanded and proven effective. It resulted in a protocol change that instilled the practice of reminder calls.

While this was a success, the birthing hospital had a significant problem with late entry of demographic data and birth screen results. Sometimes going past 30 days. Without this information, ND EHDI had no record of the birth, if a birth screen was done or the results. The Team Lead attempted to get the team to focus on these issues without success. This illustrates the importance of working with entities that are willing to improve the process.

NDCPD implemented a project funded by the Health Resources and Services Administration for the North Dakota Integrated Services (NDIS) project. The purpose of the NDIS project was to assist state agencies, local medical providers, and families of Children and Youth with Special Health Care Needs (CYSHCN) to develop the knowledge and infrastructure needed to ensure that all youth receive the coordinated care they deserve. Project goals included developing a learning collaborative network for medical home, healthy transitions and family involvement and cultural competence; establishment of pilot programs to implement the medical home model of care for CYSHCN; and a comprehensive state plan for integrating services for CYSHCN. The pilot programs each engaged in quality improvement strategies using the Plan-Do-Study-Act (PDSA) method. NDCPD staff member, Emily Rodacker, provided technical assistance to the pilot programs on PDSA development and implementation. NDCPD continues to have the expertise and knowledge of quality improvement and PDSA cycles to spread to current and future programs working with quality improvement initiatives.

ND EHDI has the benefit of having staff with long term experience. Neil Scharpe, Principal Investigator (PI) (30% FTE) has been employed with NDCPD for five years, first with the CDC EHDI Data Integration project and for the past year as PI on the HRSA funded ND EHDI grant. Mr. Scharpe also functions as the PI on the statewide Navigator project designed to provide public information and assist people in accessing health insurance through the Marketplace. Mr. Scharpe also was the PI on a two year HRSA project which developed protocol for using the internet as a resource for completing hearing diagnostics with 0-6 month old infants.

Sue Routledge (70% FTE), and Julie Wetzel (80%FTE) have both been follow-up Coordinators with ND EHDI for a combined 13 years. Ms. Routledge also performs data duties (20% FTE) on the ND EHDI-IS grant funded by CDC. Rhonda Weathers (50% FTE) is a recent addition and

comes with a background in education and community involvement. The three Coordinators are each assigned specific birthing hospitals to assist in development of CoP Teams. They also will continue to focus efforts on providing follow-up services as those responsibilities are transitioned to the birthing hospitals or other relevant organizations/agencies.

Emily Rodacker (10% FTE) will provide training in quality improvement techniques to ND EHDI staff who will in turn train the teams they work with. Ms. Rodacker will also provide website content management and ND EHDI social media and outreach. Vicki Brabandt will provide secretarial support at 10% FTE.

Figure 1: NDCPD Organizational Chart is included in Attachment 5