

NDCPD Research Mini Grant Program

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EHDI Reverse Tracking

I. Introduction

The current ND EHDI system has a 40% loss to follow up rate, we believe it would be beneficial to perform a reverse tracking research project that would identify all children in ND that are two to five years old with identified hearing loss then using a survey and interview format we will determine how the EHDI system either succeeded or failed to identify the hearing loss on a timely basis based on the 1-3-6 CDC guidelines. In cooperation with our EHDI partners, NDDPI, NDDHS, and NDDOH we will identify all children who are currently receiving services for an identified hearing loss most of who should be served by the infant development programs and/or early childhood education system. After identification surveys will be sent to parents/guardians that will be designed to identify where the current EHDI system broke down. This information would be most helpful when attempting to determine why the loss to follow up rate is so high.

II. Work Statement

Statement of overall objectives and justification of the work:

The ND EHDI system has been operating for ten years, the goal is to screen every newborn while in the hospital. If the infant passes the screen there is no need for further follow up, if however the infant fails the first screen the parent is asked to bring the child back for a second screen. With a pass at this screen there is no need for additional follow up, if however the child fails the screen a second time the child should be referred for additional audiological evaluation. If during this evaluation a hearing loss is confirmed there is subsequent intervention planned. The current ND EHDI system is funded by grant money from CDC and HRSA with established guidelines of screening an infant by one month of age, having the audiological eval completed by three months and designing intervention by six months of age. This is better known as the 1-3-6 guideline that all programs are judged by.

The screening data is tracked using a commercial software program purchased from the OZ company located in Texas. The current system is called OZ eSP and is used by all birthing hospitals. Rights have been given to pediatric audiologists to afford them the opportunity to update the system after evaluations are complete. Tracking of this data is performed by NDCPD staff as part of the grant process.

Currently 17 birthing hospitals are responsible for approximately 10,000 births per year in ND. They perform hearing screens on 98% of all live births in ND. Utilizing national norms we should be identifying 4% of these with a hearing loss or 400 infants/year. Hospitals are doing an excellent job of providing the first screen, but we have 40 percent of the infants that are referred for a second screen or subsequent evaluations that are lost to follow up or in other words either get the screening and/or audiological evaluations but data is not entered into OZ or they are never brought back for testing by the parent.

To identify where the system is breaking down it would be beneficial to conduct a reverse tracking of the children with an identified hearing loss and find out where the system failed with them. Prior to the EHDI system children with hearing loss were typically identified by three years of age, using this statistic we are proposing to first identify all children three years of age and younger that are receiving services for an identified hearing loss. We will then cross check this list of names with those infants who are in the OZ system. For those infants who were successfully identified and the system captured the data we will do no follow up. For those children that were either not identified in the OZ system or those who were lost to follow up we will send their parent/guardian a survey that asks a series of questions to determine where the system broke down.

These parents/guardians will also be contacted by telephone and/or email to further determine at what point the system failed.

We will begin by contacting DPI to determine which children they are serving that have an identified hearing loss; we will also contact NDDHS to determine any children they are serving in infant development programs that have a hearing loss. This will be the basis for the study.

Relation of proposed work to present state of knowledge in field:

The ND loss to follow up data is comparable to other states who have an EHDI system in place the difference is that ND births such a small number of infants that tracking should be much easier. With the EHDI maturing and the real possibility of continued grant funding ending there have been efforts to bring EHDI constituents together to discuss how ND can continue to fund this effort.

These discussions have led to people not directly involved with EHDI to ask where the system is failing. The best answer to date is that we may in fact be identifying these children but the data is not being entered into OZ. The other answer is that professionals that have specific responsibility to contact parents to bring their child in for subsequent testing are not completing these duties successfully. The last response is that parents are taking a nonchalant approach to hearing testing and do not follow through to bring their child into a clinic.

Without doing a reverse tracking survey and interview process with parents/guardians of children identified with hearing loss it is impossible to determine where the current system is breaking down. If we do not determine this soon the final two years of the current grant may be a wasted effort.

Goals:

1. Identify all children in ND who are 2-5 years old with an identified hearing loss by February 1, 2009
 - a. Contact DPI for names of children they serve with identified hearing loss

- b. Contact DHS for names of children/infants they serve with an identified hearing loss
 - c. Develop release of information to allow survey instrument to be sent
- 2. Send survey instrument to child's parent/guardian by March 1, 2009
- 3. Compare that data with the OZ data to identify who was lost to follow up by May 1, 2009
- 4. Complete telephone follow up conversation to confirm survey data and expand qualitative information by June 1,2009
- 5. Compile survey results by August 30, 2009
- 6. Utilize survey data to enhance current EHDI system there by reducing the loss to follow up issue on going

Evaluation criterion:

Because this research will involve human subjects the proposal will be submitted to the MSU IRB Committee for approval should it be considered for funding.

Other evaluation criterion that will be used is target numbers of 400 children in each age group to be identified and a survey return rate of 60%.

How will this research lead to follow-on funding?

Current funding of the ND EHDI system is dependent on grant funding; efforts are under way to eliminate the loss to follow up issue prior to the current funding cycle ending. Addition efforts are taking place to convince our partners that newborn hearing screening should be a priority funding portion of their budgets. If we do not make every effort to reduce the loss to follow up problem there is little chance that agencies will want to fund a flawed system. This research will provide us with information that will allow our efforts to fix the system to be directed and efficient.

III. Budget

1. Operating Expenses

- a. Supplies: Paper 1 case
 - Printer cartridges 3
 - Telephone long distance
 - Postage
 - Note books 10

IV. Publications/Sponsored Research none

V. Previous Mini Grants none

VI. Vita see attached