

# PROJECT NARRATIVE

## INTRODUCTION

Minnesota is well positioned to successfully address the purpose of this grant program to further focus Early Hearing Detection and Intervention (EHDI) Program efforts and improve loss to documentation/loss to follow-up after failure to pass newborn hearing screening.

In May 2007, legislation was enacted that mandated reporting of newborn hearing screening results and added hearing loss to the panel of more than 50 rare conditions for which every newborn in Minnesota is screened. This legislation requires:

- All hospitals to screen every newborn for hearing loss (unless a parent declines) and report the results to the Minnesota Department of Health (MDH)
- Professionals who conduct diagnostic procedures to confirm hearing loss to report the results to parents, primary care providers and MDH
- MDH to design, implement, and evaluate a system of follow-up and tracking
- MDH to evaluate program outcomes to increase effectiveness and efficiency and ensure culturally appropriate services for children with a confirmed hearing loss and their families

While MDH has made significant progress in the 1-3-6 goals of Minnesota’s EHDI program since legislation was enacted (screening by one month of age, diagnosis by three months of age, and intervention by six months of age), gaps remain. According to 2011 CDC data, Minnesota screened 66,363 newborns (97.9%) for hearing loss (Figure 1). The majority of children who did not pass their hearing screening received the follow-up needed and either a hearing loss was identified or was ruled out. However, 694 children (1%) did not pass their final (inpatient or outpatient) hearing screen. Of those, 341 children (49.1 %) were considered lost to follow-up/documentation. Of the 142 children identified with hearing loss, only 84 (59%) were documented as enrolled into a program of Early Intervention.

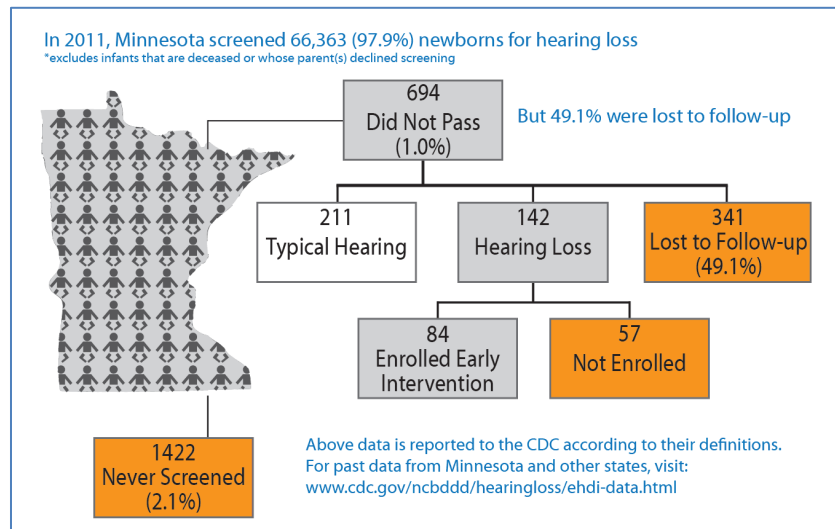


Figure 1: Number of children who did not pass their hearing screen and subsequent results for 2011.

## PROJECT NARRATIVE

### Quality Improvement and the Model for Improvement to Reduce Loss to Follow-up

Reducing loss to documentation/loss to follow-up continues to be a priority of the Department of Health's EHDI Program. Through this grant opportunity, for the purpose of reducing loss to follow-up, MDH will apply the framework learned through participation in a National Initiative for Children's Healthcare Quality (NICHQ) Learning Collaborative called Improving the System of Care For Children and Youth with Special Healthcare Needs that used a change model called the Model for Improvement. The Model for Improvement is a quality improvement methodology to identify small programmatic changes which result in documented improvements. It has been used successfully by hundreds of healthcare organizations to improve many different healthcare processes and outcomes.

Minnesota will engage four existing and successful teams of stakeholders (including two subcommittees within the statutorily required Newborn Hearing Screening/Early Hearing Detection and Intervention [NBHS/EHDI] Advisory Committee, one local public health team, and the MN Outcomes Collaborative Steering Committee) to assist in the quality improvement work. Teams will be led by an EHDI coordinator and include key members such as a pediatric audiologist, a parent of a child with a hearing loss, a representative from the early intervention program, and a data person.

The team will:

- Develop a specific, time-limited and measurable aim statement (what are we trying to accomplish?)
- Identify process and outcome measures to collect over time to track improvement and evaluate progress (how will we know if a change is an improvement?) and
- Identify areas for changes to try out (what changes can we make that will result in improvement?).

The teams will implement Plan-Do-Study-Act cycles to decide what changes lead to improvement, and spread successful changes throughout the system. Data will be collected in a timely manner, reviewed, and analyzed on an ongoing basis to determine if the changes have led to system-wide improvements. The results and data will be reported to appropriate stakeholders including the NBHS/EHDI Advisory Committee on a regular basis.

Using the Model for Improvement, MDH will focus its efforts to reduce loss to follow-up on specific areas of need as described in the needs assessment section. These may include ascertaining the name of the infant's primary care provider, making rescreening and or audiology appointments for the infant at hospital discharge, working with physicians and audiologists to not delay diagnoses for issues like middle ear fluid, streamlining the Early Intervention (EI) referral process, and obtaining a consent for release of information from the Part C Early Intervention system to the EHDI system in order to make further progress in loss to follow-up/documentation.

### Utilization of Local Public Health for Follow-up Coordination to Reduce Loss to Follow-up

For families who are lost to follow-up, this project will designate a dedicated local public health follow-up coordinator to offer follow-up support within the existing local public health system

## PROJECT NARRATIVE

and provide coordination with the Part C system and the child's health care home. In the spring of 2010, MDH was successful in spreading a change strategy realized as part of the (NICHQ) Learning Collaborative. This strategy included the utilization of strong and established local public health (LPH) systems to ensure children requiring hearing screening and/or interventions are not lost. The MDH contracted with local public health nurses to facilitate and document rescreening, diagnosis, and connection with early intervention programs for families whose infants are lost to follow-up or had an identified hearing loss. Overall, this model of care coordination/follow-up has been effective at reducing the numbers of children lost.

As LPH nurses become more proficient in follow-up activities, MDH recognizes that some agencies have been much more successful than others. MDH will establish a team of LPH nurses to use the Model for Improvement and identify small programmatic changes which result in documented improvements in the reduction of loss to follow-up/documentation and the improvement of appropriate, timely follow-up for children who have not passed their hearing screening or have been identified as deaf or hard of hearing. These tested and successful programmatic changes will be shared with all nurses providing EHDI follow-up during one annual meeting.

### Evaluation of Access to Timely and Comprehensive Services

An additional objective to successfully address the purpose of this grant includes the evaluation of access to timely and comprehensive services for children with hearing loss. For children identified with hearing loss, reducing loss to follow-up and improving access to timely and comprehensive services is critical. Research indicates that families who receive services from professionals knowledgeable about early development, communication, and language are more likely to witness greater progress in many areas of development than those without similar opportunities. Minnesota must evaluate its own EHDI system and determine how timely access to various medical, audiologic and early intervention services help children develop. The evaluation of developmental outcomes (including language and social/emotional development) for children who are deaf or hard of hearing is critical to understand how Minnesota's EHDI system is functioning. MDH's EHDI program will lead state efforts to track individual children not only from screening through diagnosis but also from audiologic confirmation to developmental outcomes as recommended in the *Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing*. MDH will accomplish this aim through the use of Quality Improvement teams and collaboration with multiple partners including Minnesota's Maternal, Infant, and Early Childhood Home Visiting Program.

### NEEDS ASSESSMENT

Reporting of newborn hearing screening and diagnostic results to the Minnesota Department of Health became mandatory as of September 1, 2007. Quantitative data based on the mandated reporting to MDH are analyzed regularly to determine loss to follow-up/documentation at each stage of the EHDI continuum (screening, diagnosis and entry to early intervention). The analysis

## PROJECT NARRATIVE

of these data allows MDH to monitor progress and identify areas for improvement within the EHDI system.

The number of children lost to follow-up at each stage of the EHDI system from January 1, 2012 through December 31, 2012 is as follows:

- 0.9 % of infants were reported to never have received a newborn hearing screening
  - Although screened, 2.7 % of infants were reported to have received a newborn hearing screening after 30 days of age.
- 8.1 % of infants that did not pass hearing screening were lost to follow-up/documentation from screening to diagnosis
  - 5.7 % of infants that did not pass hearing screening were lost to follow-up from screening to diagnosis
  - 2.4 % of infants that did not pass hearing screening were lost to documentation from screening to diagnosis
- 16 % of children with confirmed hearing loss were lost to the EHDI surveillance system after confirmed diagnosis of hearing loss and entry into a program of early intervention.
  - Of children reported as enrolled into a program of early intervention, 62 % of children with congenital permanent confirmed hearing loss were enrolled before 6 months of age.
  - Of children reported as enrolled into a program of early intervention, 53 % were enrolled within two months of diagnosis.

### Birth Hospital Stage

- 0.9 % of infants were not reported to have received a newborn hearing screening.

For a period after the EHDI legislation was passed in 2007, MDH struggled to obtain hearing results from Minnesota birth facilities which were not familiar with reporting results. However over the last five years, MDH has made significant progress in this area. MDH Newborn Screening program utilizes three to four Health Program Representative Staff dedicated to hearing follow-up which includes obtaining the initial screening results from hospitals. MDH continues to refine the process for follow-up and recently assigned each hospital an individual MDH contact for follow-up & reporting of missing results. This allows staff to identify trends in reporting and work more closely and continuously with facilities. MDH provides hearing Quality Assurance (QA) data to birth hospitals on a bi-annual basis. The Birth Center QA report is sent from MDH's Public Health Laboratory. This report provides site-specific data to hospitals including the number of infants screened and missed. The report allows each hospital to compare their performance to hospital performance statewide.

Based on a breakdown analysis of data for "missed" screenings that showed a high number of home-births, MDH initiated an Out of Hospital Birth Initiative in 2012. MDH worked with midwives to obtain screening equipment & training in order to screen & report hearing screening results for babies birthed at home. The initiative lead to significant improvements in reported hearing screenings for children birthed at home (43 % to 78 %).

## PROJECT NARRATIVE

MDH continues to use a breakdown analysis of data for “missed” screenings to make improvements. Recently, MDH identified a need to improve a neonatal intensive care unit (NICU) follow-up screening protocols to assure infants transferred to the NICU are screened and reported .

### Children Lost Between Screening and Diagnosis

As recommended by the NBHS/EHDI Advisory Committee, MDH has analyzed and separated the number of children lost to follow-up from those lost to documentation between screening and diagnosis. This breakdown provides MDH the opportunity to target interventions and better understand where children are becoming lost to Minnesota’s EHDI Surveillance system. This approach has allowed for great strides in reducing the number of children lost to follow-up after failure to pass an initial hearing screening (Figure 2). In total, 8.1 % of infants that did not pass hearing screening were lost to follow-up/documentation from screening to diagnosis in 2012.

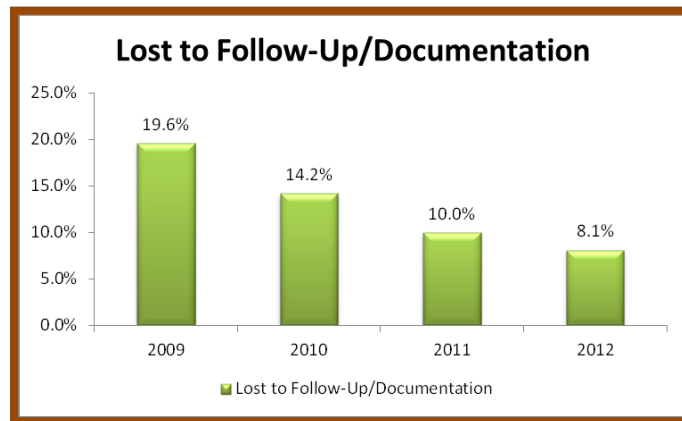


Figure 2: Percentage of Children Lost to Follow-up/Documentation after Failure to Pass an Initial Hearing Screening.

Further breakdown of the data allows MDH to better understand the reasons that nearly eight percent of children are lost to follow-up/documentation

- 5.7 % of infants that did not pass hearing screening were lost to follow-up from screening to diagnosis. Those children lost to follow-up include cases that are closed because:
  - The primary care provider (PCP) has recommended follow-up with audiology but an appointment was never made
  - The family has not shown or has canceled multiple appointments with audiology for follow-up.
  - The PCP has decided to monitor hearing and not refer for rescreen and/or diagnostic audiology
- 2.4 % of infants that did not pass hearing screening were lost to documentation from screening to diagnosis
  - The PCP is unknown to MDH
  - The PCP is known to MDH, however MDH has been unable to contact the PCP for follow-up

## PROJECT NARRATIVE

- The child has been seen by audiology but diagnostic testing has not been completed and/or reported to MDH
- The child has had more than appointments and/or the process has taken more than 6 months.

MDH has an extensive protocol that staff utilizes to follow-up on hearing screening/diagnostic results. In the last year, MDH has made nearly 15,000 contacts with hospitals and primary care providers as part of the protocol to follow-up on infants who needed further screening or diagnostic testing. While every effort is made, MDH is unable to resolve approximately 350 instances per year where infants/children who have not passed hearing screening are lost to follow-up/documentation. In over half of these instances, an appointment is never made for the child to receive an audiologic assessment.

Another common reason infants are lost to follow-up includes numerous “missed” or canceled audiology appointments. Research shows that families with multiple missed appointments tend to have: families with lower socioeconomic status, history of failed appointments, government-provided health benefits, and psychosocial problems. Logistical issues for keeping appointments often include trouble getting off work, child care, transportation, and cost.

Analysis of Minnesota’s 2012 loss to follow-up data shows significant age and racial disparities in rates of loss to follow-up.

- Infants born to younger mothers (less than 25 years) are three times more likely to be LTFU than infants born to mothers older than 30 years of age.
- Babies born to Hmong and American Indian mothers are five times more likely to be LTFU than Caucasian babies

Additionally, infants of mothers with a high school degree or less are twice as likely to be LTFU than infants born to mothers with at least four years of college education.

No-show rates often increase with a larger time interval between scheduling and the actual appointment. For example, in Minnesota, if diagnostic testing is not scheduled before four months of age, the use of sedation is frequently recommended which adds an additional barrier for families and providers.

In Minnesota, local public health agencies (governed by Community Health Boards) are well positioned to help address many of the barriers to follow-up for newborn hearing screening and intervention. They are well-suited to meet the needs of infants and children with hearing loss and their families because of their direct work with: Part C/Early Intervention, primary care providers/health care homes, Home Visiting programs, and Local Head Start Agencies.

### *Implementation of Local Public Health EHDI Follow-up/Coordination*

The state’s local public health system is governed by fifty Community Health Boards. These boards are single county or multi county boards and are responsible for health services and the improvement of current systems in the state.

## PROJECT NARRATIVE

Local public health agencies in Minnesota continue to be successful in the coordination and management of services for infants and children. They have a responsibility to build state and local capacity for Minnesota's children and youth with special health needs including children who are deaf and hard of hearing. They are well-suited to meet the needs of infants and children with hearing loss and their families as they are actively involved in Part C/Early Intervention, their work with primary care providers/health care homes, implementation of Home Visiting programs, and work with Local Head Start Agencies.

In Minnesota, eleven tribal governments are sovereign nations with their own laws and governing bodies elected by members of each tribe or band. Each tribal government in Minnesota has a health system in place and is not obligated to participate in the implementation of the essential local activities in this framework. However, as dual citizens of the tribe and state, all members are entitled to have access to the essential activities in this project.

Since the spring of 2010, MDH has utilized this strong and already established state system of local public health to significantly enhance its efforts in reducing loss to follow-up/documentation. Contracts with all 87 counties and one tribe require local public health nurses to facilitate and document rescreening, diagnosis, and connection with early intervention programs for families whose infants are lost to follow-up or have an identified hearing loss. Contracted local public health agencies designated a staff member as the EHDI Key Contact to receive MDH notifications of children requiring EHDI follow-up. The identified contact is expected to provide guidance as the content expert for the agency. County EHDI Key Contacts receive notifications of infants/children who require follow-up after multiple attempts are made to close (resolve) the case by MDH EHDI staff. The majority of cases, often the most difficult, that cannot be closed by MDH are referred to LPH for follow-up. Often these cases involve families that have no identified primary care provider, frequently move, or where English is not the first language.

LPH plays a key role in reaching these families and connecting them to resources. Data from July 2011-December 2012 indicate that local public health nurses were able to facilitate screening/diagnosis and resolve the most difficult cases for nearly 40% of the infants referred by MDH for EHDI follow-up. Through their follow-up efforts, LPH helped to identify thirteen children with hearing loss who would otherwise have been lost.

While agencies continue to make improvements, the number of families that LPH are unable to contact continues to be significant and there are noteworthy differences between various agencies in the success of reaching families. LPH agencies are unable to reach up to 27 % of families to provide follow-up services (range 13 % to 38 %). Additional improvements and spread of successful strategies must be made in order to enhance follow-up coordination from LPH and continue to reduce loss to follow-up.

These LPH successful strategies in addition to identified promising strategies tested through the EHDI NICHQ Learning Collaborative will be very useful in reducing Minnesota's main reasons for loss to follow-up/documentation from screening to diagnosis. These may include:

- 1) Making rescreening and or audiology appointments for the infant at hospital discharge
- 2) Scheduling two audiology appointments two weeks apart at hospital discharge

## PROJECT NARRATIVE

- 3) Telephone reminders for appointments
- 4) Ascertaining the name of the infant's primary care provider

### Children Lost between Audiologic Diagnosis and Entry into a Program of Early Intervention

The number of children identified with hearing loss in Minnesota has continued to increase with 2.2 per 1000 infants identified with congenital hearing loss in 2012 (Figure 3). Although the number of children lost between audiologic diagnosis and entry into a program of Early Intervention is improving,

- 16 % of children with confirmed hearing loss were lost to the EHDI surveillance system after confirmed diagnosis of hearing loss and entry into a program of early intervention

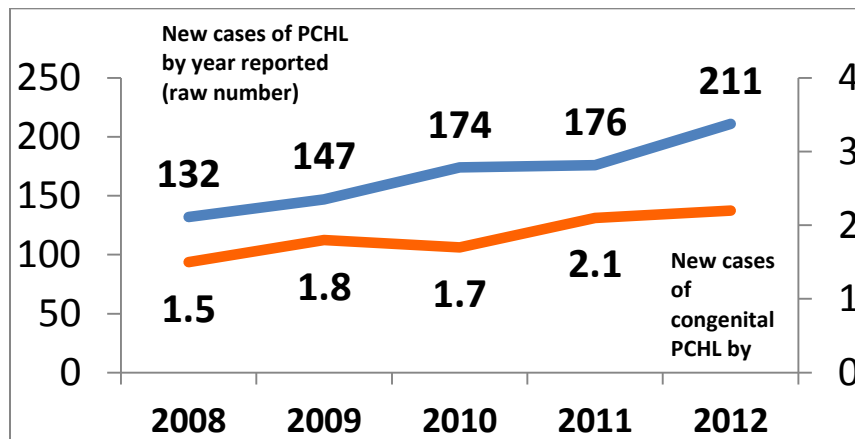


Figure 3: Cases of Permanent Confirmed Hearing Loss (PCHL) in MN by Year

In 2012, there were 211 children reported to MDH's EHDI Program with a permanent confirmed hearing loss (excluding children now deceased, those that had moved out of state, or hearing loss resolved). Of the 211 children, 167 were younger than three years of age at the time of diagnosis and were eligible for referral to and subsequent evaluation for Part C services.

Only 121 children (73 %) were found to have a documented Individual Family Service Plan (IFSP) date on file with MDH's EHDI Program.

- Three children (2 %) were evaluated and considered not eligible for Part C services.
- Seventeen children (10 %) had been offered and declined Part C/Early Intervention.
- Twenty-six children had no IFSP date on file with the Minnesota EHDI surveillance system, resulting in a loss to follow-up/documentation rate of 16 %.

Difficulties with making further progress in reducing loss to follow-up between diagnosis and Part C Early Intervention can be attributed to challenges in sharing data between MDH and the Minnesota Department of Education (Minnesota's lead Part C agency). Provisions in Part C



## PROJECT NARRATIVE

regulations and FERPA (Family Educational Rights and Privacy Act) require signed parental consent for a Part C program to share personal information including enrollment status. Provisions in Part C regulations and FERPA (Family Educational Rights and Privacy Act) require signed parental consent for a Part C program to share personal information including enrollment status. However, MDH and the Minnesota Department of Education (MDE) are nearing completion of a data sharing agreement allowing Part C to provide enrollment status and IFSP dates to MDH. While the information will be very useful, it will not be provided timely. Due to the way MDE collects the data from local school districts, the data can only be provided to MDH in January of each year for the period of July 1 through June 30 of the previous year. For example, data from July 1, 2012 – June 30, 2013 will be provided to MDH in January 2014, an entire 18 month later for children who enter Early Intervention in July.

### *Implementation of Local Public Health EHDI Follow-up/Coordination*

Since 2010, MDH has successfully utilized LPH agencies to make referrals to Part C and work within the Part C system to obtain and report timely IFSP dates to MDH. EHDI Key Contacts are notified of children newly diagnosed with hearing loss to assure families are connected to supports and services including Part C/Early Intervention and financial/health insurance resources.

This LPH follow-up strategy to reduce loss to follow-up between identification and early intervention has contributed to a sixty percent reduction in loss to follow-up and has more than tripled the documentation of Part C EI enrollment status to MDH (from 22 % in 2009 to 75 % in 2012).

However, MDH must continue to increase efforts to improve the timeliness of these connections to Early Intervention.

- 64 (53%) of the 121 children enrolled into the Part C/ Early Intervention program were enrolled within two months of diagnosis.
- 62 % of children with congenital hearing loss were enrolled into Early Intervention within 6 months of age.

Local public health departments are in an ideal position to assist families in facilitating follow-up audiologic testing as well as help families to connect to services and supports when hearing loss is confirmed. LPH agencies collaborate with many community partners and are actively involved in the following programs/activities:

### *Early Intervention:*

Agencies have a partnership role in Part C through participation in Early Intervention Committees and coordinating services through the interagency system for children with disabilities. The role extends from Part C, to referral services, acting as navigator/case coordinator and as health advocate in order to assist families with children birth to three, including those with disabilities.

## PROJECT NARRATIVE

### *Health Care Home:*

Local public health has a key role in the Health Care Home model (also known as medical home) where primary providers, families, patients, and local public health nurses work in partnership to improve quality and value in the health care system and improve health outcomes for individuals with chronic health conditions. Public health nurses, by definition, have extensive knowledge of community resources and established networks with Part C and the Health Care Home. Their multi-systems approach to care coordination is pivotal to the reduction of loss to follow-up.

### *Home visiting: Family Home Visiting*

Since 1992, The State of Minnesota has funded home visiting for families with children that utilize public health nurses (PHNs) for the initial assessment with ongoing visits carried out by PHNs or other trained home visitors. The 2007 legislature amended the Family Home Visiting statute originally passed in 2001 (Minnesota Statutes, section 145A.17) and increased Temporary Assistance for Needy Families (TANF) funding to Community Health Boards (CHBs) and Tribal Governments to support the services provided under the statute.

Minnesota's Family Home Visiting (MHV) has been effective in improving the health status of families, assisting families in becoming self-sufficient, improving positive parenting, reducing child maltreatment, and linking families to community resources. There is no uniform implementation model for Family Home Visiting. At the local level, family home visiting can look very different in terms of who is served and how. Each local public health department in Minnesota chooses how to implement its family home visiting program.

Minnesota Department of Health provides administrative oversight, training and technical assistance, and the collection of statewide outcomes and measures of FHV services delivered at the community level. In 2012, 16,134 children ages 0-6 years were served by public health home visiting in Minnesota.

### *Home Visiting: Maternal, Infant and Early Childhood Home Visiting*

The Affordable Care Act of 2010 created the Maternal, Infant, and Early Childhood Home Visiting Program (MIECHV) to respond to the diverse needs of children and families in communities at risk and through collaboration and partnership at the Federal, State, and community levels to improve the health and development outcomes for at-risk children through evidence-based home visiting programs (EBHV). MDH is the designated lead state agency for this program and grants funding to approved Community Health Boards (CHB). These locally-governed CHBs oversee local health departments that work in tandem with MDH to fulfill public health responsibilities and are the same entities that MDH EHDI contracts with for EHDI Follow-up. Their roles include assessing community health needs and assets, establishing public health priorities, and seeking public input on addressing local priorities and statewide outcomes.

In June 2011 the Health Resources and Services Administration (HRSA), in collaboration with the Administration for Children and Families, issued a competitive Funding Opportunity Announcement to expand the MIECHV Program. The program provides additional funding to states that have demonstrated capacity to expand and/or enhance their programs. The MDH

## PROJECT NARRATIVE

submitted a proposal in July 2011 and was one of ten states awarded the funding in April 2012. This expansion significantly expands MIECHV home visiting in Minnesota.

Minnesota's MIECHV Expansion Program aims to provide enhanced support statewide to:

- 1) Improve maternal, child and family health in Minnesota's communities at risk; and
- 2) Expand the reach of Healthy Families America (HFA) and Nurse-Family Partnership (NFP) programs with fidelity to the models.

Beginning in January 2013, MDH will require all LPH home visiting programs within counties funded by MIECHV to submit individualized benchmark data to MDH. These data will be added to the Minnesota Electronic Disease Surveillance System (the same system used for EHDI long-term follow-up) and includes collection of:

- Parent support for infant/child learning & development through the NCAST Teaching Assessment
- Developmental progress, as measured by ASQ-3 and ASQ:SE
- Referrals to community resources for further assessment &/or services

The collection of individualized home visiting data provides a unique opportunity to link home visiting program data and the EHDI program data at the state level to further identify gaps in services for families of children with hearing loss and inform opportunities for further collaboration between programs.

### *Head Start:*

At a local level, public health agencies collaborate frequently with MN Head Start agencies and provide health screening and consultation to their programs. In 2012, there were 17,514 children enrolled in one of Minnesota's 34 Early Head Start/Head Start Programs. Approximately 3200 of those children were under the age of three years. Estimates by the national Early Childhood Hearing Outreach (ECHO) Program indicate that 1 in 300 children in Head Start programs are identified with a late or progressive hearing loss. Thus, 58 children enrolled in MN Head Start programs may have a hearing loss. Many Head Start agencies in Minnesota have purchased and are utilizing Otoacoustic Emission hearing screening equipment to provide required hearing screening. MDH's Hearing and Vision consultant within the Community and Family Health Division provides ongoing education and training on childhood hearing (after the newborn period) and vision screening to all state public and private child health providers including Head Start and public health nurses.

Other assets the department already has in place include the following:

### An Established Newborn Hearing Screening Program

The state legislature created a voluntary universal newborn hearing screening program in 1997. Over the past ten years MDH has developed an integrated database for hearing and blood spot screening results, created material to inform parents and others about the program, instituted follow-up processes, established partnerships with a variety of stakeholders, supported referral of

## PROJECT NARRATIVE

newborns with a confirmed hearing loss to a health care home, and enhanced diagnostic and early intervention services.

### Newborn Hearing Screening Advisory Committee

The 2007 legislation established a Newborn Hearing Screening/ Early Hearing Detection and Intervention (NBHS/EHDI) Advisory Committee to advise and assist the Department of Health in: (1) developing protocols and timelines for screening, rescreening, and diagnostic audiological assessment and early medical, audiological, and educational intervention service for children who are deaf or hard-of-hearing; (2) designing protocols for tracking children from birth through age three that may have passed newborn screening but are at risk for delayed or late onset of permanent hearing loss; (3) designing a technical assistance program to support facilities implementing the screening program and facilities conducting rescreening and diagnostic audiological assessment; (4) designing implementation and evaluation of a system of follow-up and tracking; and (5) evaluating program outcomes to increase effectiveness and efficiency and ensure culturally appropriate services for children with a confirmed hearing loss and their families. This twenty six member committee includes representatives from across the spectrum of invested parties including parents, advocacy stakeholders, providers, and early intervention professionals.

### An Expanded Part C program

Minnesota's Part C Infant and Toddler Early Intervention system, named Help Me Grow, is a partnership between the Minnesota Departments of Education, Health and Human Services and families with young children, ages birth to three. Families who have an infant or toddler with developmental delays or disabilities work together with local service providers to access services and resources to help their child grow and develop. Early diagnosis and intervention can reduce the negative effects associated with hearing loss. Children whose hearing loss is identified at or before six months of age and who receive appropriate early intervention services have significantly larger vocabularies and better receptive and expressive language skills than those whose hearing loss is discovered after six months. Minnesota has significantly increased the number of children eligible for participation in its Part C program. Revised eligibility criteria allow for the vast majority of infants with a confirmed loss of hearing to be automatically eligible for Part C services. In this grant proposal, local public health nurses will work in collaboration with the Departments of Human Services and Education as a Part C partner to ensure that infants receive the proper screening, rescreening, diagnosis and connection to early intervention services as appropriate.

### Parent Support

In 2012, changes in MN Statutes 144.966 included the addition of parent support for families of children identified as deaf or hard of hearing. As a result, MDH has been fortunate to significantly increase grant funding to provide support and assistance to families with infants and children who are deaf or hard of hearing. In November 2013, nearly \$1.5 million dollars was awarded to Lifetrack Resources for the period of Nov. 1, 2013 to June 30, 2015. Lifetrack Resources is the parent organization to MN Hands and Voices and the MN Deaf Mentor Program.

## PROJECT NARRATIVE

This funding for family support provides:

- 1) direct hearing loss specific parent-to-parent assistance and unbiased information on communication, educational, and medical options through Minnesota Hands and Voices; and
- 2) access to individualized deaf or hard-of-hearing mentors who provide education, including instruction in American Sign Language as an available option.

In addition to providing parent support to all families of children newly identified with hearing loss, Minnesota Hands and Voices will recruit, hire and train cultural Parent Guides to provide direct support from a Guide who themselves is a parent of a child with hearing loss and shares the same language/culture. They will hire a Spanish Parent Guide working up to 1 FTE and a Somali and a Hmong Guide working up to 0.5 FTE each.

### Minnesota Outcomes Collaborative Plan for Deaf, Deafblind and Hard of Hearing Students

The purpose of the MN Collaboration Plan for Maximizing and Monitoring Learner Progress for Children who are Deaf, Deafblind, and Hard of Hearing and their Families is to improve educational outcomes so that each student upon graduation is prepared to enter the adult workforce or continue his/her education and be a productive member of each one's community. The idea was conceived by educators, parents and other representatives in the spring of 2011 and was a result of roundtable discussions that occurred during the 2009-2011 National Deaf Summit Teleconferences. The Collaborative Plan was formally endorsed by the boards or advisory committees of numerous D/HH related organizations including the EHDI Advisory Committee. A Steering Committee is responsible for to continue forward progress of the plan. The steering committee is made up of the following staff:

- Low-Incidence Supervisor, MN Department of Education
- EHDI Coordinator, MN Department of Health
- Coordinator, D/HH Special Education at University of Minnesota
- Director, MN Hands & Voices
- Executive Director, Commission of Deaf, DeafBlind and Hard of Hearing Minnesotans
- State Coordinator, Deaf Services at Department of Employment and Economic Development-Vocational Rehabilitation Services.
- Coordinator, State Services for the Blind

Improvement in the EHDI system is one of the three global goals and has been driven by MDH. The Collaborative plan outlines objectives or activities to improve Minnesota's EHDI system.

### Minnesota Electronic Disease Surveillance System (MEDSS)

An integral tool to ensure the success of this project is the use of a direct link to MDH through the Minnesota Electronic Disease Surveillance System (MEDSS). The Minnesota Disease Surveillance Modernization Initiative has assisted in developing an integrated state-local disease surveillance system to allow electronic data exchange with partners including hospital systems, local public health, public and private laboratory systems, and individual health care home

## PROJECT NARRATIVE

settings. This secure, web-based system will allow for rapid disease reporting, surveillance, and follow-up, thus allowing for case management for several reportable conditions in a person-centric statewide electronic system. Hearing loss was added to the core list of reportable conditions to use the MEDSS in late 2008. The modeling for variables and general organization of data to be collected through the use of ‘question packages’ began in late April 2009 and is currently being finalized. Statewide implementation commenced in early 2011. Local public health agencies receive referrals and provide updated information on clients assigned to their care through MEDSS. Coordinated case management for children with a hearing loss the state of Minnesota can thus occur in a secure and efficient environment, ideally reducing loss to documentation.

### Birth Defects Information System (BDIS)

State of Minnesota statutory language passed in 2004 (MS144.2215-2219) authorized MDH to collect information on birth defects in the state. The MN Birth Defects Information System, BDIS, follows National Birth Defects Prevention Network (NBDPN) Guidelines for Conducting Birth Defects Surveillance, and operates with consultation from the statewide Birth Defects Advisory Workgroup. BDIS is utilizing the Minnesota Electronic Disease Surveillance System (MEDSS) as described above. Unless the family chooses to “Opt-Out”, families are linked to local and state resources for support. Specific case information is sent to local public health agencies to provide follow-up and assure that families are connected with all appropriate available services. If this project is funded, MDH will provide a shared contract for local public health agencies to provide both EHDI and BDIS follow-up. The EHDI and BDIS programs will cross-train staff, provide joint training on care coordination to local public health follow-up staff and will work collaboratively with the EHDI program to decrease duplication and identify areas of improvement in LPH follow-up/care coordination activities based on outcomes and evaluation.

### Organizational Location

If funded, the grant activities will be housed in the Minnesota Children and Youth with Special Health Needs (CYSHN) section of the Community and Family Health Division. The Birth Defects Information System (BDIS) is also located within the CYSHN section providing the opportunity to work closely and collaborate on a framework of care coordination. Among other responsibilities, this division houses the Maternal Child Health and WIC Sections and is or has been responsible for the home visiting program, pediatric health care home activities, Part C outreach activities, newborn follow-up activities, Part B interagency coordination efforts, consultation and training for the EPSDT program, and childhood hearing and vision training. CYSHN works very closely and collaboratively with the MDH Newborn Screening Program housed in the MDH Public Health Laboratory Division. Newborn Screening and EHDI program staffs meet frequently as partners in joint projects and to solve complex systems issues. This grant will be a collaborative effort between MDH Newborn Screening Program and CYSHN. All of these assets impact the loss to follow-up proposal in an advantageous way.

## PROJECT NARRATIVE

### **METHODOLOGY**

**Goal 1: The Minnesota Department of Health, along with its partners will improve loss to follow-up/documentation for children that have not passed newborn hearing screening.**

**Objective 1: By March 2017, decrease the number of infants lost to follow-up from 5.7 percent to 2.7 percent and those lost to documentation from 2.4 percent to 1 percent between screening and diagnosis.**

Activities:

- 1.1) Establish and utilize Quality Improvement team(s) to implement PDSA cycles, determine which changes lead to improvement, and spread change throughout the system to improve loss to follow-up/documentation between screening and diagnosis (subcommittee overseen by the NBHS/EHDI Advisory Committee).

In 2007, Minnesota Statute section 144.966 mandated and established the Newborn Hearing Screening/EHDI Advisory Committee. The members are to advise and assist the Department of Health and the Department of Education in:

- (1) developing protocols and timelines for screening, rescreening, and diagnostic audiological assessment and early medical, audiological, and educational intervention services for children who are deaf or hard-of-hearing;
- (2) designing protocols for tracking children from birth through age three that may have passed newborn screening but are at risk for delayed or late onset of permanent hearing loss;
- (3) designing a technical assistance program to support facilities implementing the screening program and facilities conducting rescreening and diagnostic audiological assessment;
- (4) designing implementation and evaluation of a system of follow-up and tracking; and
- (5) evaluating program outcomes to increase effectiveness and efficiency and ensure culturally appropriate services for children with a confirmed hearing loss and their families.

Membership of the Committee is outlined in statute (Attachment 8: MN Statutes 2013- EHDI Program) and includes parents of children with a hearing loss, health care providers, hospital representatives, representatives from a consumer organization representing culturally deaf persons, consumers from organizations representing various communication options and other medical and education experts. Per the Committee by-laws, members meet quarterly and participate in various subcommittees.

Two to three simultaneous subcommittees are established to assist the NBHS/EHDI Advisory Committee in accomplishing its work. Committee members volunteer or are appointed based on their expertise and interest to serve on a subcommittee. Subcommittees are given a specified charge and period of time to fulfill that charge, and present their final report or recommendations to the Advisory Committee for approval at completion of its charge.

The chair may ask persons who are not Commissioner appointed Advisory Committee members, ex-officio members, or alternates to serve on subcommittees as necessary to fulfill a specialized

## PROJECT NARRATIVE

or technical charge. Each subcommittee may find it necessary to have co-chairs. These designated members report to the larger Advisory Committee on specific workgroup tasks and findings.

In an effort to address loss to follow-up /documentation between screening and diagnosis, the NBHS/EHDI Advisory Committee will appoint a subcommittee to focus on, and make improvements, during the period between screening and diagnosis (Quality Improvement Team #1 [QI1]). The QI1 will use the Model for Improvement to identify needs, implement small tests of change, use data to inform decisions, and through the NBHS/EHDI Advisory Committee will spread successful change strategies.

The Advisory Committee will identify and recruit additional ad hoc members as needed. At minimum, the QI1 will include a parent of a child who is deaf or hard of hearing, an audiologist, a local public health nurse providing EHDI Follow-up, a hospital representative, an MDH epidemiologist and an EHDI Coordinator who will lead the work of the subcommittee. QI1 meetings will be scheduled by the EHDI coordinator at least monthly.

Using a driver diagram to show desired outcomes and the key system components (drivers) needed to achieve them (Attachment 6: Driver Diagram), the QI1 will identify an area of need and a priority that it would like to address. QI1 members may suggest multiple areas that needing improvement, however the group will focus on one main improvement area.

The team will craft an aim statement, an explicit description of the team's desired outcomes expressed in a measurable and time-specific way. The aim statement will answer the question: **What are we trying to accomplish?** The team will also establish measures to answer the question: **How do we know that a change is an improvement?**

The QI1 will identify change strategies or ideas that the group feels that if implemented, would make an improvement. The change strategies may be based on brainstormed ideas or may come from promising strategies tested by other groups such as the NICHQ EHDI Learning Collaborative. Change ideas that impact the following characteristics may be weighted more heavily by the group.

- High volume, affecting a large number of patients
- High frequency
- High risk, placing patients at risk for poor outcomes
- Longstanding
- Multiple unsuccessful attempts to resolve in the past
- Strong and differing opinions on cause or resolution of the problem

Key change ideas are then implemented and tested using a cyclical Plan-Do-Study-Act fashion. The QI1 will thoroughly PLAN and test (DO) the change using the “Plan a Solution and Try It” worksheet (Attachment 9: PDSA Worksheet). The QI1 will track progress using quantitative measures and closely STUDY the results for insight on how to do better. Based on the results, the QI1 will then decide (ACT) to expand the test, refine the test and make changes to the procedure, or abandon the test. This process will continue serially over time and refinement is added with each cycle.



## PROJECT NARRATIVE

The QI1 will update the full NBHS/EHDI Advisory Committee of their progress in achieving their aim at each quarterly meeting. Once the work for the aim is complete, the QI1 will document and present their results and lessons learned to the NBHS/EHDI Advisory Committee. The Committee will then use the information to further spread changes within the Minnesota's EHDI system. Examples may include publication of Committee recommendations to stakeholders or revision of policies. The NBHS/EHDI Advisory Committee will then establish a new subcommittee to continue using the Model for Improvement and focusing on a new improvement area to improve loss to follow-up from screening to diagnosis.

For example, the QI1 may choose to address the large disparity in loss to follow-up rates for children of Hmong mothers. The team will identify:

- 1) Aim Statement – By Oct 2014, loss to follow-up/documentation for infants born to Hmong mothers will be reduced by 50%.
- 2) Change Strategy #1: Provide culturally responsive follow-up to infants born of Hmong mothers through a Hmong MN Hands & Voices Parent Guide working in partnership with a Local Public Health Nurse.
- 3) PDSA#1
  - PLAN/DO–The next infant born to a Hmong mother who has a REFER result on the hospital screening and does not return for rescreening within 1 month of age will be contacted by the Hmong MN Hands & Voices Parent guide.
  - STUDY – QI1 will hear from the Hmong guide regarding the success of the test. Questions to be answered may include: Was the parent guide able to reach the mom? Did the mom appreciate the call? Did the child receive follow-up testing? Were there barriers for mom to get follow-up screening?
  - ACT – QI1 will determine to expand the test (i.e. try it on the next 5 infants of Hmong mothers), refine the test (i.e. try it instead immediately after the baby REFERS on screening and not wait until 1 month of age) or abandon (try a different change idea).

**Goal 2: The Minnesota Department of Health, along with its partners will reduce loss to follow-up/documentation and improve appropriate, timely follow-up for children identified as deaf or hard of hearing.**

**Objective 1: By March 2017, decrease the number of infants lost to follow-up/documentation between initial diagnosis of hearing loss and entry into a program of early intervention from 16 percent to less than 5 percent.**

Activities:

- 2.1) Establish Quality Improvement team(s) to implement PDSA cycles, determine which changes lead to improvement, and spread change throughout the system to improve loss to follow-up/documentation between diagnosis and a program of early intervention (subcommittee overseen by the NBHS/EHDI Advisory Committee).

In an effort to address loss to follow-up /documentation between diagnosis and early intervention, the NBHS/EHDI Advisory Committee will utilize the same methodology as

## PROJECT NARRATIVE

described for activity 1.1 listed under Goal 1, Objective 1 above. A second NBHS/EHDI Advisory subcommittee (Quality Improvement Team #2 [QI2]) will be appointed to focus on, and make improvements during the period between diagnosis and early intervention. The QI2 will use the Model for Improvement to identify needs, implement small tests of change, use data to inform decisions, and through the NBHS/EHDI Advisory Committee will spread successful change strategies.

The Advisory Committee will identify and recruit additional ad hoc members as needed. At minimum, the QI2 will include a parent of a child who is deaf or hard of hearing, an audiologist, a local public health nurse providing EHDI Follow-up, a representative from the Early Intervention Program, an MDH epidemiologist, and an EHDI Coordinator who will lead the work of the subcommittee. QI2 meetings will be scheduled by the EHDI coordinator at least monthly.

Similar to the QI1, the QI2 will determine what they would like to accomplish (set an aim statement), develop measures, implement PDSA cycles and identify changes leading to improvement. The QI1 will update the full NBHS/EHDI Advisory Committee of their progress in achieving their aim at each quarterly meeting. Once the work for the aim is complete, the QI2 will document and present their results and lessons learned to the NBHS/EHDI Advisory Committee. The Committee will then use the information to further spread changes within the Minnesota's EHDI system. Examples may include publication of Committee recommendations to stakeholders or revision of policies. The NBHS/EHDI Advisory Committee will then establish a new subcommittee to continue using the Model for Improvement to focus on a new improvement area to improve loss to follow-up from diagnosis to intervention.

### 2.2) Employ Local Public Health Agencies to provide follow-up and timely connections to community supports/services including Early Intervention for families of children identified with hearing loss.

Public health nurses are uniquely suited to the role of ensuring timely connections to community supports and services. As described in detail within the Needs Assessment section, local public health agencies work in concert with education, human services, health care, community organizations, families, and children on a routine basis in their local communities. They work closely with Early Head Start Programs and provide home visiting in Minnesota. Much of their funding comes from Title V. They also have established connections to federal, state, and local partners and participate actively in identifying best practices through research and data reporting.

Current contracts with local public health agencies providing EHDI follow-up will end 12/31/2013. Nearly all contracts to continue EHDI follow-up coordination from 1/1/2014 to 12/31/2016 sent to local public health agencies have been signed and are in place (Attachment 4: Contract with Community Health Boards for EHDI Follow-up). Funding for the first quarter of these contracts will be provided through current HRSA grant funding. These are dual contracts that include both EHDI Follow-up as well as follow-up for identified birth defects through the Birth Defects Information System. MDH staff anticipate that all 87 counties and one tribal government will participate in the next contract.

## PROJECT NARRATIVE

EHDI Key Contacts are notified of children newly diagnosed with hearing loss to assure families are connected to supports and services including Part C/Early Intervention. Of the 192 children LPH was notified of in 2012, EHDI Key Contacts were able to verify that 121 (63%) were enrolled in Part C/Early Intervention and documented the child's Individual Family Service Plan (IFSP) date.

Agencies will invoice MDH for cases completed. The data provided by EHDI Key Contacts in the previous contract round indicated that LPH was best able to ensure connection to supports and services including Part C/Early Intervention when they were in direct contact with the families. Some EHDI Key Contacts were able to ensure connection to services through contact with the Part C/Early Intervention service coordinator in place of direct contact with the family. However, review revealed that the data provided in these cases was not as complete.

It is proposed that payment for local public health in tiers one through three will be reimbursed per case as follows:

**EHDI Tier One:** Payment of \$75 per case for 1) attempting to contact the child's Part C/Early Intervention Service Coordinator and/or child's family but not being able to obtain information from either and; 2) documenting any information from available data sources regarding connection to services in MEDSS. Attempts at contact must include at least two attempts by phone and a letter sent to the family to assess current services use and offer assistance in connecting to other services as appropriate.

**EHDI Tier Two:** Payment of \$200 per case for checking available data sources and contacting the child's Part C/Early Intervention service coordinator to provide required documentation in MEDSS. Required information about services will be as defined by the State. If service coordinator is unable to share information with the nurse, the nurse should encourage the service coordinator to obtain a signed release from the family. Tier two payment will not be made if service coordinator is unable to share required information. If the nurse is unable to obtain required information from the service coordinator he/she is expected to contact the family to ensure connection to services.

**EHDI Tier Three:** Payment of \$400 per case for successful contact with the family by phone or in person and complete documentation of current known services in the LPH Wizard in MEDSS. The nurse will also ensure referral, application and/or connection to other services as needed.

Minnesota Department of Health will monitor incoming data and care coordination on incomplete or outstanding reports and data will be run monthly to monitor loss to follow-up/documentation rates. County-specific EHDI follow-up data will be provided to individual counties on a yearly basis.

EHDI Key contacts also receive notifications of infants/children who require follow-up between rescreening and diagnosis. The Public Health Laboratory (PHL) at MDH has an extensive follow-up protocol for infants after a REFER result is received from newborn hearing screening. Multiple attempts are made to close (resolve) the case. The majority of cases, often the most difficult, that cannot be closed utilizing the PHL protocol are referred to LPH for follow-up.

## PROJECT NARRATIVE

Local Public Health then contacts the family and/or the child's health care provider to facilitate rescreening or diagnostic testing. This effort is funded through a Cooperative Agreement through the Centers for Disease Prevention and Control.

### 2.3 Establish and utilize a LPH Quality Improvement team to implement PDSA cycles, determine which changes lead to improvement, and spread change throughout the system to improve follow-up and coordination of care provided by local public health agencies.

In an effort to improve EHDI follow-up efforts provided by LPH nurses, MDH will convene a LPH Quality Improvement (Quality Improvement Team #3 [QI3]) team to reduce loss to follow-up/documentation and improve appropriate, timely follow-up for children identified as deaf or hard of hearing.

MDH EHDI staff will identify LPH nurses recognized as leaders in providing EHDI follow-up coordination. MDH will utilize the same methodology as described for activity 1.1 under Goal 1, Objective 1 above. This third quality improvement team (QI3) will be appointed to focus on, and make improvements in connecting families to needed services between both rescreening and diagnosis, and the period between diagnosis and early intervention. The QI3 will use the Model for Improvement to identify needs, implement small tests of change, use data to inform decisions, and spread successful change strategies. .

At minimum, the local public health improvement team (QI3) will include 5-10 local public health nurses providing EHDI Follow-up, an MDH epidemiologist, and an EHDI Coordinator who will lead the work of the team. QI3 meetings will be scheduled by the EHDI coordinator at least monthly. At least three of the meetings will be held face-to-face.

Similar to the QI1 and QI2, the LPH Quality Improvement Team (QI3) will determine what they would like to accomplish (set an aim statement), develop measures, implement PDSA cycles and identify changes leading to improvement. The local public health representative for the NBHS/EHDI Advisory Committee will update the Committee of the QI3's progress in achieving their aim at each quarterly meeting. Once the work for the aim is complete, the QI3 will document and present their results and lessons learned at an annual training of local public health nurse in addition to the NBHS/EHDI Advisory Committee.

### 2.4 Plan and implement an annual state-wide training conference for EHDI Key Contacts to enhance the capacity of local public health nurses to provide follow-up for children who are deaf or hard of hearing.

Annual training conferences will be developed and implemented throughout the three years of this grant. MDH Staff including EHDI and Birth Defects Information System (BDIS) staff will identify and implement a workgroup to identify conference topics, agendas, and learning objectives. The conferences will enhance the knowledge and expertise of public health nurses who provide EHDI and BDIS follow up. It is anticipated that through joint EHDI and BDIS contracts local public health staff that provide EHDI follow-up will be the same staff providing BDIS follow-up. The planning workgroup will include project partners such as representatives from local public health, BDIS, medical facilities, and education.

## PROJECT NARRATIVE

Topics will be generated through discussions with public health nurses who can identify areas of additional training needed with regard to EHDI follow-up. In addition a literature review on best practices related to follow up coordination and on care coordination for children and youth with special health needs in a health care home and other care/care coordination training curriculums will help to inform training focuses. Expert local and national speakers will be engaged to conduct specific training topics.

Training conferences will include opportunities for public health nurses to share information and problem solve with each other and opportunities for refreshing their knowledge about reporting. MDH will partner with BDIS and Home Visiting staff to implement these trainings, as some of the local public health staff participating in EHDI follow-up will also be involved in the BDIS and Home Visiting programs at the Minnesota Department of Health. MDH staff will secure conference locations and speakers, invite and provide support to agency nurses so they can attend the training, and will identify additional partners to invite to the training. MDH staff and the planning workgroup will develop a conference evaluation that will demonstrate what has been learned, whether participants will utilize what they learned, what would be helpful for future learning topics, and suggestions for improvement. The planning workgroup will analyze training evaluations for use in improving and enhancing the next years training.

In years one and two these training opportunities will include periodic web-based and one annual in-person training. In year three, the training will be we web-based.

**Objective 2: By March 2017, collect developmental outcome information for at least 20% of children diagnosed before 3 years of age.**

- A. Obtain language/communication development data through Part C IFSP/assessment data for 25% of children in the EHDI-IS (EHDI – Information System) who were reported to be enrolled in Part C.**
- B. Obtain social-emotional development data for 100% of children in the EHDI-IS who were also reported to MDH’s Family Home Visiting program.**

Activities:

2.5 Enter into a data sharing agreement with MIECHV Family Home Visiting in order to access social/emotional development data for children in the EHDI-IS who are also in MDH’s Family Home Visiting database.

Minnesota was one of ten states awarded a competitive Federal Maternal, Infant, and Early Childhood Home Visiting (MIECHV) expansion grant in April 2012. As part of this grant, all Minnesota LPH agencies utilizing MIECHV funding for home visiting will administer a uniform set of assessments with their clients including the ASQ:SE assessment to screen for social-emotional development concerns. Assessment information for individual children will be reported to MDH Family Home Visiting Program (FHV) beginning in January 2014.

MDH’s EHDI program will work with the FHV program to begin sharing data for children with records in both the EHDI-IS and the FHV data system. MDH does not have information about how many children in the EHDI-IS are also enrolled in a MIECHV program. Once a data sharing arrangement is in place, MDH will be able to assess the utility of the FHV data as a

## PROJECT NARRATIVE

source of information about social-emotional development for children who are deaf or hard of hearing.

2.6 Utilize the LPH Quality Improvement team to develop a process for collecting social/emotional development data for all children in the EHDI-IS. Utilize the QI team to implement PDSA cycles, determine which changes lead to improvement in data collection, and spread change throughout the system.

Through various public health programs implemented locally (i.e. Family Home Visiting, Early Periodic Screening Diagnosis and Treatment, and a developmental and social-emotional screening program targeted at children ages birth to 36 months), LPH nurses frequently screen children for social/emotional risks. As part of the LPH Quality Improvement (QI3) team supported by MDH to improve appropriate, timely follow-up for children identified as deaf or hard of hearing, the QI3 team will set at least one of its aims to collect social/emotional development data for children identified as deaf or hard of hearing (see Activity 2.3 above).

MDH EHDI staff will identify LPH nurses recognized as leaders in providing EHDI follow-up coordination. MDH will utilize the same methodology as described for activity 1.1 under Goal 1, Objective 1 above. This third quality improvement team (QI3) will be appointed to focus on, and make improvements in connecting families to needed services between both rescreening and diagnosis, and the period between diagnosis and early intervention. The QI3 will use the Model for Improvement to identify needs, implement small tests of change, use data to inform decisions, and spread successful change strategies.

At minimum, the local public health improvement team (QI3) will include 5-10 local public health nurses providing EHDI Follow-up, an MDH epidemiologist, and an EHDI Coordinator who will lead the work of the team. QI3 meetings will be scheduled by the EHDI coordinator at least monthly. At least three of the meetings will be held face-to-face.

Similar to the QI1 and QI2, the QI3 will determine what they would like to accomplish (set an aim statement), develop measures, implement PDSA cycles and identify changes leading to improvement. The local public health representative for the NBHS/EHDI Advisory Committee will update the Committee of the QI3's progress in achieving their aim at each quarterly meeting. Once the work for the aim is complete, the QI3 will document and present their results and lessons learned at an annual training of local public health nurse in addition to the NBHS/EHDI Advisory Committee.

2.7 Establish a Quality Improvement team through the Minnesota Collaborative Plan to refine and expand the process for collecting language/communication development data for children in the EHDI-IS. Utilize the QI team to implement PDSA cycles, determine which changes lead to improvement in data collection, and spread change throughout the system.

The Minnesota Collaborative Plan is a diverse group of stakeholders committed to improving educational outcomes for children who are deaf, deafblind, or hard of hearing. The Collaborative includes stakeholders from a broad range of organizations and groups including

## PROJECT NARRATIVE

the MN Departments of Education, Health, and Human Services; MN Hands & Voices; audiologists; teachers and schools for the deaf and hard of hearing; and the University of Minnesota. MDH EHDI staff is part of the steering committee for the Collaborative. The Steering Committee has agreed to act as a quality improvement team for this grant, with the purpose of improving the process for collecting developmental assessment data for children in the EHDI-IS (Attachment 10: Letters of Commitment). As an improvement team, the Collaborative Steering Committee (Quality Improvement Team #4 [QI4]) would not change its already identified priorities and objectives. Instead, the QI4 will use the model for improvement to turn its broad goals into short-term aim statements, identify and implement change strategies, measure improvement, and spread successful changes throughout the system to meet project specific aims in addition to broad EHDI system goals.

The Steering Committee will utilize the same methodology as described for activity 1.1 listed under Goal 1, Objective 1 above. The Collaborative Steering Committee (Quality Improvement Team #4 [QI4]) will identify and recruit additional ad hoc members as needed and will include an MDH epidemiologist to assist with data collection. The EHDI Coordinator in collaboration with the Collaborative Coordinator will lead the work of the subcommittee. QI4 meetings will be scheduled at least monthly.

Similar to the QI1, QI2, and QI3, the QI4 will determine what they would like to accomplish (set an aim statement), develop measures, implement PDSA cycles and identify changes leading to improvement. The QI4 will update the full NBHS/EHDI Advisory Committee of their progress in achieving their aim at each quarterly meeting. Once the work for the aim is complete, the QI4 will document and present their results and lessons learned. The Collaborative Steering Committee will then use the information to further spread changes within the Minnesota's EHDI system. Examples may include publication of Committee recommendations to stakeholders or revision of policies.

A priority of the Collaborative is to begin to measure developmental outcomes. In order to evaluate the effectiveness of early identification of hearing loss and determine which interventions improve outcomes, MDH and its partners need to begin collecting information about children's language development. Language assessments should be conducted routinely for children enrolled in Part C Early Intervention and it is known that at least 80% of children in the EHDI-IS are enrolled in Part C. One identified priority of the QI4 will be to design a process for obtaining parental consent for the EHDI-IS access to IFSPs and assessment data collected through Part C.

### **WORKPLAN**

The work plan/logic model is delineated in Attachment 1 and is titled "*Universal Newborn Hearing Screening and Intervention; Lost to Follow-up Logic Model*". The Model describes the inputs, activities, and processes targeted to achieve the reduction in loss to follow-up that MDH has established as the supplement's goal. The model also documents short and long-term outcomes for the activities.

## PROJECT NARRATIVE

The activities and progress of this grant will be monitored by MDH and the statutory Newborn Hearing Screening Advisory Committee. This committee meets quarterly (November, February, May, August) as described in legislation.

As indicated in the work plan and described further in the evaluation section, MDH program staff, which includes the EHDI epidemiologist, will analyze lost to follow-up data regularly. The analysis will measure the decrease in loss to follow-up, indicate areas (e.g. hospitals or local public health agencies) that may need additional technical assistance identify unexpected barriers to the project, and provide on-going data about the project's effectiveness.

### **RESOLUTION OF CHALLENGES**

There may be challenges to implementation of the activities described in the work plan. Much of this project focuses on the work of four Quality Improvement Teams (QI1, QI2, QI3, and QI4). With the exception of the Local Public Health Quality Improvement team, each of these groups is well established. EHDI/NBHS Advisory Subcommittee teams (QI1 & QI2) and the Local Public Health team (QI3) will be responsible to report to the full EHDI/NBHS Advisory Committee. Challenges that persist or cannot be easily resolved will be discussed, and guidance from the Newborn Hearing Screening Advisory Committee will be requested

In addition, this project focuses on building capacity and enhancing utilization of Minnesota Department of Health's local public health partners.

Local public health agencies have been partners in the local Interagency Early Intervention Committees and Part C Program for many years. This project requires the enhanced collaboration and integration with all partners to assure there is no duplication of existing services. At the same time, this project may increase public health's role within the existing early intervention system. Together, with the Collaborative Steering Committee, the Departments of Health and Education will provide guidance and decrease barriers for local partners to improve communication and work together within the current interagency systems to facilitate rescreening, diagnosis and connections to supports.

Local public health agencies also have multiple and competing demands and will need to balance training, case management and reporting requirements with capacity and competing priorities. Director and staff "buy-in" will be important to the success if this project.

### **EVALUATION AND TECHNICAL SUPPORT CAPACITY**

#### Datasets

The Minnesota EHDI Information System (EHDI-IS) for short-term and long-term follow-up is currently comprised of two separate systems: one system to address the short-term follow-up needs, and one system to address the long-term follow-up needs. Analyses are routinely conducted on data collected in the EHDI-IS. The EHDI-IS includes all reported screening data currently managed through the Laboratory Information Management System (LIMS) used by Minnesota's Newborn Screening Program as well as diagnostic and follow-up data for children with a confirmed hearing loss managed through the Minnesota Electronic Disease Surveillance System (MEDSS). LIMS and MEDSS are both secure, web-based systems that allows for rapid



## PROJECT NARRATIVE

reporting, surveillance, and follow-up, and assure timely case management. Local Public Health and Minnesota Hands & Voices staff who provide follow-up for the EHDI program have access to MEDSS and are able to enter follow-up information directly into the data system. This capacity for direct reporting enhances the timeliness and accuracy of data collection from reporting partners.

Records in both systems can be linked to birth certificate data for children born in Minnesota. Linkage with birth certificate data will allow stratified analyses based on demographic characteristics including mother's age, race, ethnicity and education. Other demographic characteristics are also available for children with a diagnosed hearing loss, including the family's preferred language and insurance status. These additional demographic characteristics are obtained either from the child's medical providers by MDH EHDI staff or by Local Public Health staff directly from the family. These data will allow us to investigate any potential difference in the effectiveness of service delivery and change strategies across demographic characteristics.

### Staffing and Technical Support

MDH will use existing Public Health Lab and EHDI Follow-up staff (including audiologists and public health nurses) to implement portions of the project. These staff have expertise in the technical and training aspects of newborn hearing screening, diagnosis, and intervention. There is also a research scientist who will be responsible for overseeing data collection and management and an epidemiologist who will be responsible for ongoing performance monitoring and evaluation. The EHDI program also has access to a full-time, Children & Youth with Special Health Needs Quality Improvement Specialist who will provide in-kind support for this project.

In addition to directly supporting the project, MDH staff will provide technical support to LPH key contacts and other reporting partners in order to assure quality and timely reporting. MDH staff will be available for technical, procedural and software questions with regard to the MEDSS information system and seamless data entry. MDH staff will also provide support to the quality improvement teams by training them in the use of the Model for Improvement, facilitating meetings, providing data to inform the development of change strategies and supporting the implementation of the chosen strategies.

Two positions will be directly supported by this grant: an epidemiologist (0.4 FTE) and a research scientist (0.5 FTE). The Epidemiologist Senior, Melinda Marsolek, is trained in data collection and analysis as well as program evaluation (Attachment 2: Job Descriptions for Key Personnel). Melinda has approximately five years of epidemiologic experience (Attachment 3: Biographical Sketches of Key Personnel). She is responsible for assisting with EHDI related evaluation activities including data analysis, evaluation of the project, and technical assistance to the grant activities. The epidemiologist stays current with methodology and developing standards as a member of the American Evaluation Association as well as through the CDC EHDI Data Committee and is a participant in several national data and epidemiology webinars, teleconferences, and grand rounds. She is on the MEDSS User's Group, working to improve the secure, web-based, integrated and shared statewide disease surveillance system. Hearing loss is

## PROJECT NARRATIVE

currently included in this system and it is the primary system used to analyze and collect EHDI data for children with a diagnosed hearing loss. The epidemiologist has experience with presenting data and producing data reports for EHDI stakeholders including those who will be key participants in the quality improvement (e.g audiologists, LPH staff, the EHDI Advisory Committee, and the MN D/HH Collaborative).

The 0.5 FTE Research Scientist 2, Nicole Brys, will be responsible for managing the MEDSS to ensure complete and accurate data entry through automated workflows and data quality checks (Attachment 2: Job Descriptions for Key Personnel). She will also be responsible for the management of numerous grant agreements with all community health boards to facilitate follow-up of infants who fail their newborn hearing screening and are lost at any of the stages in the Early Hearing Detection and Intervention process. The research scientist has over two years of experience in this role with the EHDI program (Attachment 3: Biographical Sketches of Key Personnel). She will be responsible for training on all required follow-up procedures including best practices, documentation and invoicing for payment. She will also provide training and technical assistance on the electronic EHDI surveillance system (MEDSS) for outside agency staff.

### Evaluation Plan

The goal of this project is to reduce loss to follow-up between screening and diagnosis as well as between diagnosis and early intervention. MDH also aims to begin collecting developmental outcome information for children with a confirmed hearing loss. A summary of the inputs, key processes, and expected outcomes of planned activities for each objective are provided in the logic model (Attachment 1: Work Plan).

A system-wide outcome measure has been identified for each objective. Quality improvement teams will be convened to generate change strategies for making progress on each of the three stated objectives. Quality improvement teams will utilize a simple and standard form for documenting their PDSA cycles (Attachment 9: PDSA Worksheet). The EHDI epidemiologist will be available to assist quality improvement teams with identifying appropriate measures for testing the effectiveness of change strategies. In addition to measuring the system-wide outcome for each objective, appropriate performance and process measures will be identified and tracked to help determine how well change strategies are being implemented. The EHDI epidemiologist will also analyze data from the EHDI-IS and provide summaries to the quality improvement teams so that they can react in a timely manner. Detailed descriptions of how MDH will evaluate each of our three stated objectives are below.

### **Objective 1.1: Reducing loss to follow-up/loss to documentation between screening and diagnosis**

Minnesota has a well-established protocol for tracking newborn hearing screenings. Hospitals are required to screen all newborns for hearing loss prior to discharge and report the results to MDH as well as the infant's primary care provider (PCP). For infants who do not pass their newborn screening, hospitals facilitate scheduling a re-screening or diagnostic appointment. Results of hearing screening are reported to the MDH PHL Newborn Screening program. When re-

## PROJECT NARRATIVE

screening and diagnostic evaluations are completed, PCPs and audiologists report results to the MDH via fax or mail. PHL staff enters data into the Newborn Laboratory Information Management System (LIMS).

Multiple attempts are made by PHL staff to ensure that screening, re-screening, and diagnostic appointments are completed as appropriate for all infants. Follow-up is accomplished through phone calls to hospitals and PCPs regarding screening or diagnostic results when no report or a partial report is received. If these internal quality assurance measures do not result in complete data and referrals, MDH notifies the appropriate LPH nurse key contact for further attempted follow-up and reporting of data.

The reasons for loss to follow-up and documentation (LTFU/LTD) are categorized and assigned to cases within the LIMS system as 'action codes'. Reasons for loss between screening and diagnosis include:

- The primary care provider (PCP) has recommended follow-up with audiology but an appointment was never made and/or results were not reported to MDH.
- The family has not shown up for and/or has canceled multiple appointments with audiology for follow-up.
- The PCP decided to monitor hearing and does not refer for rescreen and/or diagnostic audiology.
- The PCP is unknown to MDH.
- The PCP is known to MDH, however, the PCP or facility is unresponsive when contacted.

**Outcome measure:** System-wide progress on reducing loss to follow-up & documentation will be monitored by reviewing the percentage of cases that have been assigned any of the LTFU/LTD action codes. This measure is calculated annually in February for children reported in the previous calendar year.

**Performance measures:** More frequent analysis of performance measures will be done for populations within the scope of the change strategies. For example, if change strategies are directed at a particular reason for loss to follow-up, the percentage of cases in this category will be calculated before the strategy is implemented and throughout implementation to identify if improvement has been made. Or, if a change strategy is to be tested with a particular clinic, the percentage of cases that are LTFU/LTD from within that clinic will be determined before and periodically throughout implementation. The appropriate frequency of measurement will be determined by the collaborative team in consultation with the epidemiologist and the person(s) responsible for implementing the strategy. Data collected through the EHDI-IS can be accessed at any time and customized reports can be created within the system to automate the data generation as much as possible. Measurements will be frequent enough to inform decisions about adjustments to change strategies, but not so frequent that change cannot be detected or measurement is burdensome.

**Process measures:** In addition to measuring performance of change strategies, the quality improvement team will identify process measures as a means of evaluating how the strategies are

## PROJECT NARRATIVE

being implemented. For example, if a hospital agrees to attempt a strategy of scheduling audiology appointments for families whose infant has not passed newborn hearing screening, the team may ask the participating hospital to document:

- the number of families for whom appointments were made,
- the location and date of the appointments,
- the number of families for whom appointments were not made, and
- the reasons appointments were not made.

This information could be combined with information from the audiology clinics about whether or not families kept the appointments as well as information in LIMS about whether or not follow-up screening or diagnostic data were ultimately reported to MDH. Together, this information would give a fairly complete picture of:

- whether or not this strategy is feasible,
- whether or not hospitals scheduling appointments actually leads to decreased loss to follow-up, and
- where families are continuing to be lost between screening and diagnosis.

### **Objective 2.1: Reducing loss to follow-up/loss to documentation between permanent confirmed hearing loss and Early Intervention**

Infants and children who are diagnosed with a confirmed hearing loss are eligible for early intervention services in Minnesota's Newborn and Child Follow-up EHDI surveillance system. This system has primarily focused on the documentation of enrollment in Minnesota's Part C Early Intervention System; "Help Me Grow" (HMG). Provisions in Part C regulations and FERPA (Family Educational Rights and Privacy Act) require signed parental consent for a Part C program to share any personal information about children enrolled in the Part C program with providers outside the early intervention system. At this time, MDH's EHDI program is not considered a Part C participating provider and multiple barriers exist when working with local Part C Service Coordinators to obtain parental consent and the child's Individual Family Service Plan date. The most effective strategy to surmount these barriers utilizes LPH nurse key contacts to make referrals to Part C and report IFSP dates to MDH EHDI-IS. Local Public Health staff enters follow-up data for children with confirmed hearing loss directly into MEDSS. All data provided by Local Public Health are reviewed by MDH staff to ensure data entered are complete and accurate. In addition, monthly ad-hoc reports have been developed to ensure that all cases sent to Local Public Health for follow up have been received. This helps ensure that data on these cases is provided to MDH in a timely manner.

**Outcome measure:** System-wide progress on reducing loss to follow-up & documentation into Early Intervention will be monitored by reviewing the percentage of cases with a documented IFSP date recorded in MEDSS. This measure is calculated annually in August for children reported with a diagnosed hearing loss within the previous calendar year.

**Performance measures:** A county-specific data report with performance measures was provided to LPH key contacts in March 2013 (Attachment 11: Annual LPH Data Report).

## PROJECT NARRATIVE

Performance measures in the report include indicators of the timeliness and completeness of reporting. LPH staff were surveyed about the report and 85% indicated that they found it useful, so an updated report will be used by MDH and provided annually to LPH for continuous performance monitoring.

More frequent analysis of performance measures will be done for populations within the scope of the change strategies. For example, if a change strategy is to be tested with a particular LPH agency, the percentage of cases with documented Early Intervention enrollment status will be determined before and periodically throughout implementation. The appropriate frequency of measurement will be determined by the collaborative team in consultation with the epidemiologist and the person(s) responsible for implementing the strategy. Data collected through the EHDI-IS can be accessed at any time and customized reports can be created within the system to automate the data generation as much as possible. Measurements will be frequent enough to inform decisions about adjustments to change strategies, but not so frequent that change cannot be detected or measurement is burdensome.

**Process measures:** MDH monitors process measures of LPH follow-up activities regularly. MDH staff review QA/QC workflows on a weekly basis to identify data quality concerns and run a quarterly report to identify cases where follow-up is not complete. Additionally, MDH staff review each case before categorizing it as complete and LPH staff are not reimbursed until cases are deemed complete by MDH. MDH also surveys LPH staff annually to evaluate the partnership. In the 2013 survey, LPH staff were asked to gauge their level of preparation for providing follow-up, their satisfaction with the reporting process, their satisfaction with training and technical assistance provided by MDH, and were also given the opportunity to provide additional feedback about the MDH-LPH partnership in an anonymous way.

For the activity related to using the quality improvement team to improve loss to follow-up between diagnosis and enrollment in Early Intervention, process measures will be used as a means of evaluating how the strategies are being implemented. For example, if a LPH key contact agrees to participate in a change strategy that involves identifying additional means of finding contact information for families, the key contact will be asked to document each attempted method and indicate which (if any) were successful (e.g. asking the Part C service coordinator, contacting the child's PCP, looking up the family in the WIC database, etc).

### **Objective 2.2: Increasing collection of developmental outcome information**

In Minnesota, developmental outcome information is collected by the child's early interventionist, but the availability of aggregate data on language/communication and social emotional development for children with hearing loss is limited. MDH will work collaboratively with state partners through the Minnesota Collaborative Plan to pilot a project to obtain parental consent to collect individual IFSP and assessment data for children identified with a permanent hearing loss through the EHDI system. The purpose of the pilot project is to determine the feasibility of collecting outcome information. In the first phase of the pilot MDH will attempt obtaining consent through Minnesota Hands & Voices parent guides. MDH staff will work with

## PROJECT NARRATIVE

a team from the MN Collaborative Plan to use PDSA cycles to evaluate the success of the pilot and identify small tests of change to improve the process.

MDH will also attempt to collect social-emotional assessment information by initiating data sharing with the MDH Family Home Visiting program. In January 2014, the FHV program will begin collecting individual assessment data for all children enrolled in MIECHV home visiting programs. Once an agreement is in place, assessment data for any children who have also been identified with a confirmed hearing loss through the EHDI-IS will be shared.

**Outcome measure:** System-wide progress on increasing collection of developmental outcome information will be monitored by reviewing the percentage of cases with an IFSP, Part C assessment data, or an ASQ-SE assessment score on file with the MDH EHDI program. This measure will be calculated annually in August for children reported with a diagnosed hearing loss within the previous calendar year.

**Performance measures:** More frequent analysis of performance measures will be done for populations within the scope of the change strategies. For example, one change strategy for attempting to increase the percentage of families who consent to share their IFSP with MDH might be to have one Hands & Voices Parent Guide explain the project and obtain consent from families in person instead of over the telephone. The percentage of families who meet with Parent Guide in person and agrees to consent will be measured periodically throughout implementation and will be compared to the percentage who are contacted by phone and agrees to consent. The appropriate frequency of measurement will be determined by the collaborative team in consultation with the epidemiologist and the person(s) who will be implementing the strategy. Measurements will be frequent enough to inform decisions about adjustments to change strategies, but not so frequent that change cannot be detected or measurement is burdensome.

**Process measures:** In addition to measuring the performance of change strategies, the quality improvement team will identify process measures as a means of evaluating how the strategies are being implemented. For example, Parent Guides may be asked to document which families they attempted to contact, whether or not the families were reached, whether or not they used the script developed for the project when speaking to the parents about sharing data, and parents' reasons for declining to give consent.

### **Potential Obstacles to Implementing the Evaluation Plan**

- In developing process and performance measures of identified strategies, quality improvement teams will benefit from the expertise of the CYSHN staff Quality Improvement Specialist, but this position is currently vacant. If the position is not filled in a timely manner, MDH staff will not have dedicated quality improvement support from this position. This gap can be addressed by drawing on several other staff on this project that have training in quality improvement including use of the Model for Improvement with the NICHQ Collaborative Teams as part of a previous EHDI grant.

## PROJECT NARRATIVE

- The identified outcome measures are already tracked by the EHDI-IS and regularly calculated and reported, but process measures that will be identified by quality improvement teams to evaluate change strategies are less likely to be captured by the EHDI-IS. The epidemiologist will work with quality improvement teams and the person(s) implementing the change strategies to ensure that appropriate measures are identified that are not overly burdensome to collect and analyze. The epidemiologist will assist with developing data collection tools as appropriate and will closely monitor data collection, especially during the beginning of implementation, to ensure that data are complete and accurate.

### **ORGANIZATIONAL INFORMATION**

If funded, this grant activity would be located in the Children and Youth with Special Health Needs (CYSHN) Section of the Community and Family Health (CFH) Division at the Minnesota Department of Health (Attachment 5: Project Organizational Chart). Two additional sections within CFH include the Women Infants and Children (WIC) and the Maternal Child Health Sections. All three sections are closely linked and are charged with developing and improving systems that impact families in Minnesota. Extensive interactions and opportunities to integrate with programs such as Family Home Visiting, the Child and Teen Check-up (EPSDT) program, and Birth Defects Information System (BDIS), ensure the best utilization of limited resources and best outcomes for families. The CYSHN program is also a key partner with the Public Health Lab and works closely to coordinate Newborn Screening point-in-time diagnosis with long-term health outcomes.

**Minnesota Department of Health**  
**Universal Newborn Hearing Screening and Intervention; Lost to Follow-up Logic Model**  
**December 20, 2013**

<b>Goal 1: The Minnesota Department of Health, along with its partners will improve loss to follow-up/documentation for children that have not passed newborn hearing screening.</b>						
Objective 1: By March 2017, decrease the number of infants lost to follow-up from <b>5.7% to 2.7%</b> and those lost to documentation from <b>2.4% to 1%</b> between screening and diagnosis.						
Inputs	Activities	Date		Process	Outputs	Outcomes
		Start	Due			
Lead MDH Staff: EHDI Coordinator (Kirsten Coverstone)  Existing EHDI Staff including epidemiologist  QI1 (Quality Improvement Team #1 - Advisory Subcommittee and ad hoc members)	Activity 1: Establish and utilize QI1 to improve loss to follow- up/documenta tion between screening and diagnosis	4/1/2014	Ongoing	1) QI1 will convene, identify needed ad hoc members, establish a meeting schedule & craft an AIM statement for the proposed project. 2) QI1 will identify change ideas to test and an entity to test the ideas 3) QI1 will implement PDSA cycles 4) QI1 will collect data to measure if change was an improvement 5) Successful ideas will be spread throughout the system 6) Results will be reported to stakeholders including the EHDI Advisory committee quarterly	<ul style="list-style-type: none"> <li>• Roster of QI1 members</li> <li>• Record of QI1 meetings (e.g. meeting dates &amp; notes)</li> <li>• PDSA documentation for QI1 (see Attachment 9).</li> </ul>	Decreased LTFU between Screening and Dx for the population within the scope of the PDSAs (short term).  Decreased LTFU between screening and Dx for entire population (long term).



**Goal 2: The Minnesota Department of Health, along with its partners will reduce loss to follow-up/documentation and improve appropriate, timely follow-up for children identified as deaf or hard of hearing.**

Objective 1: By March 2017, decrease the number of infants lost to follow-up/documentation between initial diagnosis of hearing loss and entry into a program of early intervention from **16 percent** to less than **5 percent**.

Input	Activities	Date		Process	Outputs	Outcomes
		Start	Due			
<p>Lead MDH Staff: EHDI Coordinator (Nicole Brown)</p> <p>Existing EHDI Staff including epidemiologist</p> <p>QI2 (Quality Improvement Team#2 - Advisory Subcommittee and ad hoc members)</p>	<p>Activity 1: Establish and utilize QI2 to improve loss to follow-up/documentation between diagnosis and connection to early intervention</p>	4/1/14	Ongoing	<ol style="list-style-type: none"> <li>1) QI2 will convene, identify needed ad hoc members, establish a meeting schedule &amp; craft an AIM statement for the proposed project.</li> <li>2) QI2 will identify change ideas to test and an entity to test the ideas</li> <li>3) QI2 will implement PDSA cycles</li> <li>4) QI2 will collect data to measure if change was an improvement</li> <li>5) Successful ideas will be spread throughout the system</li> <li>6) Results will be reported to stakeholders including the EHDI Advisory committee quarterly</li> </ol>	<ul style="list-style-type: none"> <li>• Roster of QI2 members</li> <li>• Record of QI2 meetings (e.g. meeting dates &amp; notes)</li> <li>• PDSA documentation for QI2 (see Attachment 9).</li> </ul>	<p>Decreased LTFU between Dx and Part C EI for the population within the scope of the PDSAs (short term).</p> <p>Decreased LTFU between Dx and Part C EI for entire population (long term).</p>
<p>Lead MDH Staff: Research Scientist 2 (Nicole Brys)</p> <p>Existing EHDI Staff</p>	<p>Activity 2: Employ Local Public Health Agencies to provide follow-up and timely connections to community supports/services including Early Intervention for families of children identified with hearing loss.</p>	4/1/14	Ongoing	<ol style="list-style-type: none"> <li>1) MDH notifies LPH agencies of infants/children who have been diagnosed with permanent hearing loss.</li> <li>2) EHDI F/U works with family to identify needs &amp; facilitates follow-up on connections to resources if needed</li> <li>3) EHDI F/U reports required data through MEDSS</li> <li>4) MDH staff review QA/QC workflows on a weekly basis to identify data quality concerns and runs a quarterly report to identify cases where follow-up is not complete.</li> <li>5) MDH staff review each case before processing the invoice</li> <li>6) MDH provides county specific data reports to LPH annually.</li> <li>7) MDH surveys LPH staff annually</li> </ol>	<p>Contracts with LPH agencies</p> <p>MEDSS records of LPH follow-up for individual children</p> <p>Annual reports to LPH with process and performance indicator data</p> <p>LPH annual survey results</p>	<p>Decreased LTFU between Dx and Part C EI for entire population (long term).</p>

<b>Goal 2: The Minnesota Department of Health, along with its partners will reduce loss to follow-up/documentation and improve appropriate, timely follow-up for children identified as deaf or hard of hearing.</b>						
Objective 1: By March 2017, decrease the number of infants lost to follow-up/documentation between initial diagnosis of hearing loss and entry into a program of early intervention from <b>16 percent</b> to less than <b>5 percent</b> .						
Lead MDH Staff: EHDI Coordinator and Research Scientist 2 (Nicole Brown & Nicole Brys)  Existing EHDI Staff including epidemiologist  QI3 (Quality Improvement Team #3 - LPH Key Contacts)	Activity 3: Establish and utilize QI3 to improve follow-up and coordination of care provided by local public health agencies.	4/1/14	Ongoing	<ol style="list-style-type: none"> <li>1) QI3 will convene, identify needed ad hoc members, and establish a meeting schedule.</li> <li>2) QI3 will craft an AIM statement for the proposed project.</li> <li>3) QI3 will identify change ideas to test and an entity to test the ideas</li> <li>4) QI3 will implement PDSA cycles</li> <li>5) QI3 will collect data to measure if change was an improvement</li> <li>6) Successful ideas will be spread throughout the system</li> <li>7) Results will be reported to stakeholders including the EHDI Advisory committee quarterly</li> </ol>	<ul style="list-style-type: none"> <li>• Roster of QI3 members</li> <li>• Record of QI3 meetings (e.g. meeting dates &amp; notes)</li> <li>• PDSA documentation for QI3 (see Attachment 9).</li> </ul>	<p>Decreased LTFU between Dx and Part C EI for the population within the scope of the PDSAs (short term).</p> <p>Decreased LTFU between Dx and Part C EI for entire population (long term).</p>
Lead MDH Staff: Research Scientist 2 (Nicole Brys)  Existing EHDI Staff	Activity 4: Plan and implement an annual state-wide training conference for EHDI Key Contacts to enhance the capacity of local public health nurses to provide follow-up for children who are deaf or hard of hearing.	4/1/14	Annual	<ol style="list-style-type: none"> <li>1) Identify and implement a training conference planning workgroup</li> <li>2) Secure conference location and speakers</li> <li>3) Invite and support local public health nurses to attend the training</li> <li>4) Identify additional partners to invite to the training</li> <li>5) Develop a conference evaluation</li> <li>6) Execute an annual state wide training conference for local public health and other partners.</li> <li>7) Analyze training evaluations for use in improving and planning for the next years training.</li> </ol>	<ul style="list-style-type: none"> <li>• Roster of attendees</li> <li>• Conference attendee evaluations</li> </ul>	<p>Majority of attendees will indicate in evaluations that they learned something at the conference that will improve their ability to provide follow-up (short term).</p> <p>Decreased LTFU between Dx and Part C EI for entire population (long term).</p>

<b>Goal 2: The Minnesota Department of Health, along with its partners will reduce loss to follow-up/documentation and improve appropriate, timely follow-up for children identified as deaf or hard of hearing.</b>						
Objective 2: By March 2017, collect developmental outcome information for at least 20% of children diagnosed before 3 years of age.						
a) Obtain language/communication development data through Part C IFSP/assessment data for 25% of children in the EHDI-IS who were reported to be enrolled in Part C.						
b) Obtain social-emotional development data for 100% of children in the EHDI-IS who were enrolled in MIECHV Family Home Visiting programs.						
Inputs	Activities	Date		Process	Outputs	Outcomes
		Start	Due			
Lead MDH Staff: EHDI epidemiologist (Melinda Marsolek)  Existing EHDI Staff including epidemiologist	Activity 1: Enter into a data sharing agreement with MIECHV Family Home Visiting in order to access social/emotional development data for children in the EHDI-IS who are also in the MDH Family Home Visiting database.	4/1/14	8/1/14  12/1/14  4/1/15  7/1/15	1) Identify staff within the Department of Health to work with on a data sharing agreement. 2) Determine what data is needed from the MIECHV 3) Develop and implement an agreement that fits both program's needs. 4) Run data reports to evaluate how the agreement is working.	Completed data sharing agreement  Number of shared cases between MDH EHDI and MDH FHV  Percentage of shared cases for which social/emotional assessment information was available	Increased percentage of children with documented developmental outcome information
Lead MDH Staff: EHDI Coordinator & Data Coordinator (Nicole Brown & Nicole Brys)  Existing EHDI Staff  QI3 (Quality Improvement Team #3 -LPH key contacts)	Activity 2: Establish and utilize QI3 to develop a process for collecting social/emotional development data for all children in the EHDI-IS.	4/1/14	Ongoing	1) QI3 will convene, identify needed ad hoc members, and establish a meeting schedule. 2) QI3 will craft an AIM statement for the proposed project. 3) QI3 will identify change ideas to test and an entity to test the ideas 4) QI3 will implement PDSA cycles 5) QI3 will collect data to measure if change was an improvement 6) Successful ideas will be spread throughout the system 7) Results will be reported to stakeholders including the EHDI Advisory committee quarterly	<ul style="list-style-type: none"> <li>Roster of QI3 members</li> <li>Record of QI3 meetings (e.g. meeting dates &amp; notes)</li> <li>PDSA documentation for QI3 (see Attachment 9).</li> </ul>	Increased percentage of children with documented developmental outcome information

**Goal 2: The Minnesota Department of Health, along with its partners will reduce loss to follow-up/documentation and improve appropriate, timely follow-up for children identified as deaf or hard of hearing.**

Objective 2: By March 2017, collect developmental outcome information for at least 20% of children diagnosed before 3 years of age.  
 A. Obtain language/communication development data through Part C IFSP/assessment data for 25% of children in the EHDI-IS who were reported to be enrolled in Part C.  
 B. Obtain social-emotional development data for 100% of children in the EHDI-IS who were enrolled in MIECHV Family Home Visiting programs.

Inputs	Activities	Date		Process	Outputs	Outcomes
		Start	Due			
Lead MDH Staff: EHDI epidemiologist (Melinda Marsolek)  Existing EHDI Staff  QI4 (Quality Improvement Team #4 - MN Collaborative Plan Steering Committee)	Activity 3: Establish & utilize QI4 through the Minnesota Collaborative Plan to refine and expand the process for collecting language/communication development data for children in the EHDI-IS.	4/1/14	Ongoing	1) QI4 will convene, identify needed ad hoc members, and establish a meeting schedule. 2) QI4 will craft an AIM statement for the proposed project. 3) QI4 will identify change ideas to test and an entity to test the ideas 4) QI4 will implement PDSA cycles 5) QI4 will collect data to measure if change was an improvement 6) Successful ideas will be spread throughout the system 7) Results will be reported to stakeholders including the EHDI Advisory committee quarterly	<ul style="list-style-type: none"> <li>• Roster of QI4 members</li> <li>• Record of QI4 meetings (e.g. meeting dates &amp; notes)</li> <li>• PDSA documentation for QI4 (see Attachment 9).</li> </ul>	Increased percentage of children with documented developmental outcome information

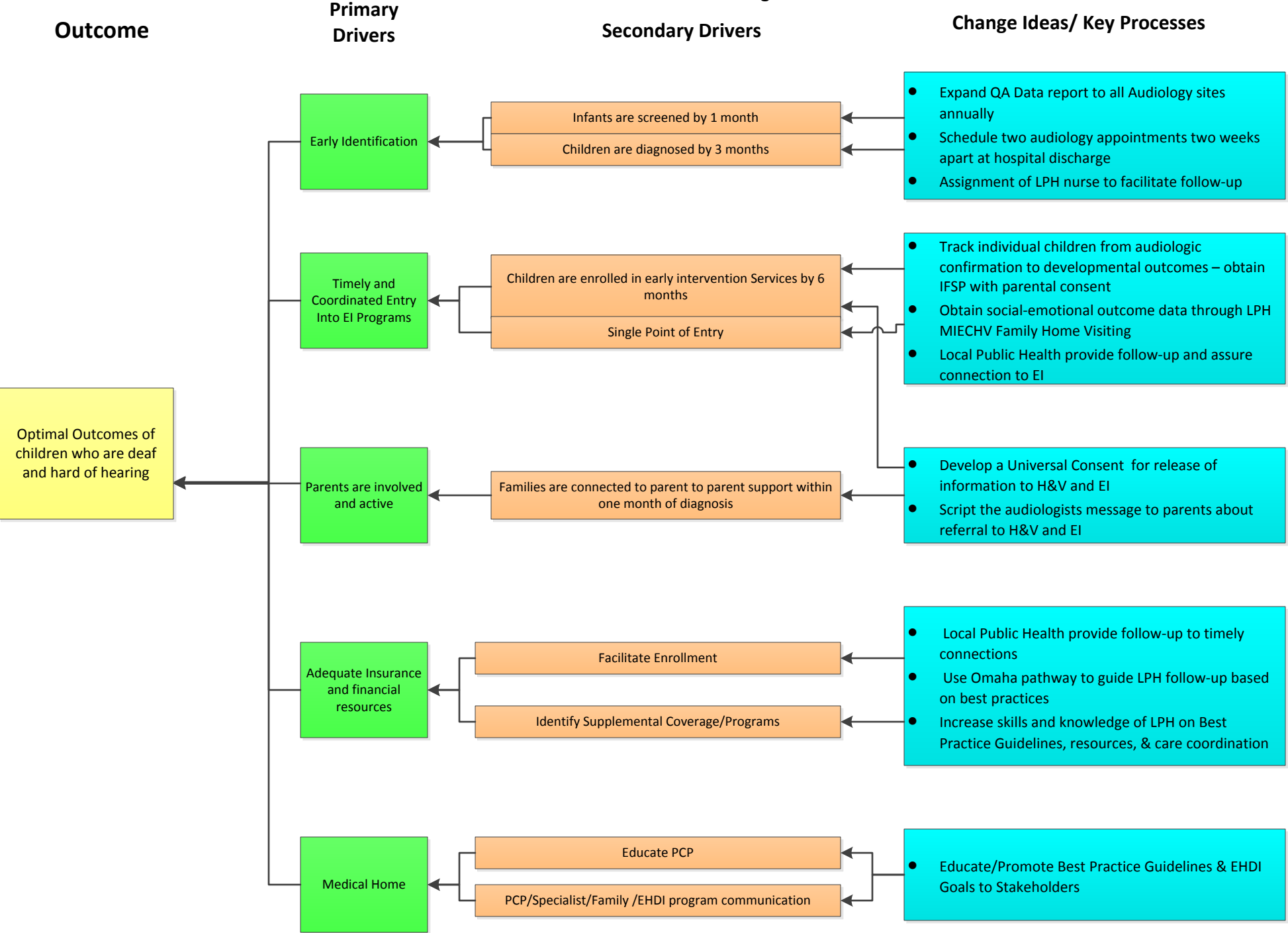
Quality Improvement Team #1 (QI1): EHDI Advisory Subcommittee related to LTFU/LTD from screening to diagnosis.

Quality Improvement Team #2 (QI2): EHDI Advisory Subcommittee related to long term follow-up

Quality Improvement Team #3 (QI3): LPH Follow-up Quality Improvement Team

Quality Improvement Team #4 (QI4): MN Collaborative Plan Steering Committee Quality Improvement Team – focus on collecting outcomes information

ATTACHMENT 6: Driver Diagram



**144.966 EARLY HEARING DETECTION AND INTERVENTION PROGRAM.**

Subdivision 1. **Definitions.** (a) "Child" means a person 18 years of age or younger.

(b) "False positive rate" means the proportion of infants identified as having a significant hearing loss by the screening process who are ultimately found to not have a significant hearing loss.

(c) "False negative rate" means the proportion of infants not identified as having a significant hearing loss by the screening process who are ultimately found to have a significant hearing loss.

(d) "Hearing screening test" means automated auditory brain stem response, otoacoustic emissions, or another appropriate screening test approved by the Department of Health.

(e) "Hospital" means a birthing health care facility or birthing center licensed in this state that provides obstetrical services.

(f) "Infant" means a child who is not a newborn and has not attained the age of one year.

(g) "Newborn" means an infant 28 days of age or younger.

(h) "Parent" means a natural parent, stepparent, adoptive parent, guardian, or custodian of a newborn or infant.

Subd. 2. **Newborn Hearing Screening Advisory Committee.** (a) The commissioner of health shall establish a Newborn Hearing Screening Advisory Committee to advise and assist the Department of Health and the Department of Education in:

(1) developing protocols and timelines for screening, rescreening, and diagnostic audiological assessment and early medical, audiological, and educational intervention services for children who are deaf or hard-of-hearing;

(2) designing protocols for tracking children from birth through age three that may have passed newborn screening but are at risk for delayed or late onset of permanent hearing loss;

(3) designing a technical assistance program to support facilities implementing the screening program and facilities conducting rescreening and diagnostic audiological assessment;

(4) designing implementation and evaluation of a system of follow-up and tracking; and

(5) evaluating program outcomes to increase effectiveness and efficiency and ensure culturally appropriate services for children with a confirmed hearing loss and their families.

(b) The commissioner of health shall appoint at least one member from each of the following groups with no less than two of the members being deaf or hard-of-hearing:

(1) a representative from a consumer organization representing culturally deaf persons;

(2) a parent with a child with hearing loss representing a parent organization;

(3) a consumer from an organization representing oral communication options;

(4) a consumer from an organization representing cued speech communication options;

(5) an audiologist who has experience in evaluation and intervention of infants and young children;

(6) a speech-language pathologist who has experience in evaluation and intervention of infants and young children;

- (7) two primary care providers who have experience in the care of infants and young children, one of which shall be a pediatrician;
- (8) a representative from the early hearing detection intervention teams;
- (9) a representative from the Department of Education resource center for the deaf and hard-of-hearing or the representative's designee;
- (10) a representative of the Commission of Deaf, DeafBlind and Hard-of-Hearing Minnesotans;
- (11) a representative from the Department of Human Services Deaf and Hard-of-Hearing Services Division;
- (12) one or more of the Part C coordinators from the Department of Education, the Department of Health, or the Department of Human Services or the department's designees;
- (13) the Department of Health early hearing detection and intervention coordinators;
- (14) two birth hospital representatives from one rural and one urban hospital;
- (15) a pediatric geneticist;
- (16) an otolaryngologist;
- (17) a representative from the Newborn Screening Advisory Committee under this subdivision; and
- (18) a representative of the Department of Education regional low-incidence facilitators.

The commissioner must complete the appointments required under this subdivision by September 1, 2007.

(c) The Department of Health member shall chair the first meeting of the committee. At the first meeting, the committee shall elect a chair from its membership. The committee shall meet at the call of the chair, at least four times a year. The committee shall adopt written bylaws to govern its activities. The Department of Health shall provide technical and administrative support services as required by the committee. These services shall include technical support from individuals qualified to administer infant hearing screening, rescreening, and diagnostic audiological assessments.

Members of the committee shall receive no compensation for their service, but shall be reimbursed as provided in section 15.059 for expenses incurred as a result of their duties as members of the committee.

(d) By February 15, 2015, and by February 15 of the odd-numbered years after that date, the commissioner shall report to the chairs and ranking minority members of the legislative committees with jurisdiction over health and data privacy on the activities of the committee that have occurred during the past two years.

(e) This subdivision expires June 30, 2019.

**Subd. 3. Early hearing detection and intervention programs.** All hospitals shall establish an early hearing detection and intervention (EHDI) program. Each EHDI program shall:

(1) in advance of any hearing screening testing, provide to the newborn's or infant's parents or parent information concerning the nature of the screening procedure, applicable costs of the

screening procedure, the potential risks and effects of hearing loss, and the benefits of early detection and intervention;

(2) comply with parental election as described under section 144.125, subdivision 4;

(3) develop policies and procedures for screening and rescreening based on Department of Health recommendations;

(4) provide appropriate training and monitoring of individuals responsible for performing hearing screening tests as recommended by the Department of Health;

(5) test the newborn's hearing prior to discharge, or, if the newborn is expected to remain in the hospital for a prolonged period, testing shall be performed prior to three months of age or when medically feasible;

(6) develop and implement procedures for documenting the results of all hearing screening tests;

(7) inform the newborn's or infant's parents or parent, primary care physician, and the Department of Health according to recommendations of the Department of Health of the results of the hearing screening test or rescreening if conducted, or if the newborn or infant was not successfully tested. The hospital that discharges the newborn or infant to home is responsible for the screening; and

(8) collect performance data specified by the Department of Health.

Subd. 3a. **Support services to families.** (a) The commissioner shall contract with a nonprofit organization to provide support and assistance to families with children who are deaf or have a hearing loss. The family support provided must include:

(1) direct hearing loss specific parent-to-parent assistance and unbiased information on communication, educational, and medical options; and

(2) individualized deaf or hard-of-hearing mentors who provide education, including instruction in American Sign Language as an available option.

The commissioner shall give preference to a nonprofit organization that has the ability to provide these services throughout the state.

(b) Family participation in the support and assistance services is voluntary.

Subd. 4. **Notification and information; data retention and destruction.** (a) Notification to the parents or parent, primary care provider, and the Department of Health shall occur prior to discharge or no later than ten days following the date of testing. Notification shall include information recommended by the Department of Health and information regarding the right of the parent or legal guardian to discontinue storage of the test results and require destruction under paragraph (d).

(b) A physician, nurse, midwife, or other health professional attending a birth outside a hospital or institution shall provide information, orally and in writing, as established by the Department of Health, to parents regarding places where the parents may have their infant's hearing screened and the importance of the screening.

(c) The professional conducting the diagnostic procedure to confirm the hearing loss must report the results to the parents, primary care provider, and Department of Health according to the Department of Health recommendations.



(d) The Department of Health may store hearing screening and rescreening test results for a period of time not to exceed 18 years from the infant's date of birth.

(e) Notwithstanding paragraph (d), a parent or legal guardian may instruct the Department of Health to discontinue storing hearing screening and rescreening test results by providing a signed and dated form requesting destruction of the test results. The Department of Health shall make necessary forms available on the department's Web site. If a parent or legal guardian instructs the Department of Health to discontinue storing hearing screening and rescreening test results, the Department of Health shall destroy the test results within one month of receipt of the instruction or within 25 months after it received the last test result, whichever is later.

Subd. 5. **Oversight responsibility.** The Department of Health shall exercise oversight responsibility for EHDI programs, including establishing a performance data set and reviewing performance data collected by each hospital.

Subd. 6. **Civil and criminal immunity and penalties.** (a) No physician or hospital shall be civilly or criminally liable for failure to conduct hearing screening testing.

(b) No physician, midwife, nurse, other health professional, or hospital acting in compliance with this section shall be civilly or criminally liable for any acts conforming with this section, including furnishing information required according to this section.

Subd. 7. **Fees.** The commissioner shall charge a fee so that the total of fees collected will approximate the costs of implementing and maintaining a system to follow up on infants and provide technical assistance, a tracking system, data management, and evaluation. The fee shall be incorporated in the fee charged under section 144.125.

Subd. 8. **Construction.** Notwithstanding anything to the contrary, nothing in this section shall be construed as constituting newborn screening activities conducted under sections 144.125 to 144.128. Data collected by or submitted to the Department of Health pursuant to this section is not genetic information for purposes of section 13.386.

**History:** 2007 c 147 art 16 s 10; 2009 c 79 art 10 s 18; 2009 c 86 art 1 s 18; 2013 c 82 s 13-16; 2013 c 108 art 12 s 34,35



# Plan a Solution and Try It

PDSA Planning Worksheet

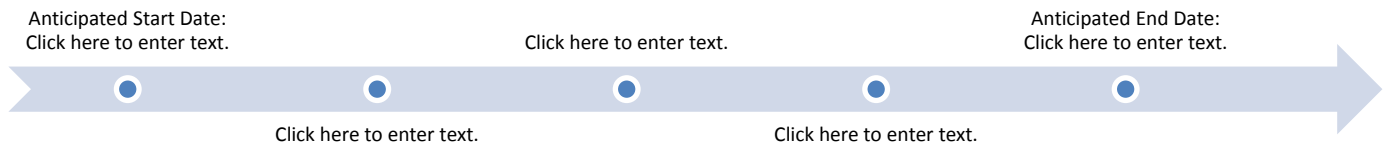
**TEAM:** [Click here to enter text.](#)

**Lead Person:** [Click here to enter text.](#)

**Cycle #:** [Click here to enter text.](#)

**Date Submitted:** [Click here to enter text.](#)

**Add any key dates or milestone to timeline that need to be achieved to carry out plan.**



- 1. What is the problem or opportunity to be addressed with this PDSA cycle (small test of change)?**  
[Click here to enter text.](#)
- 2. What do we hope to accomplish (AIM statement)?**  
[Click here to enter text.](#)

## PLAN

- 3. Describe the change you are testing:**  
[Click here to enter text.](#)
- 4. What is the question you want this test to answer?**  
[Click here to enter text.](#)
  - a. What will be done?**  
[Click here to enter text.](#)
  - b. Who will be doing it?**  
[Click here to enter text.](#)
  - c. Where (This could be a location or point in a process)?**  
[Click here to enter text.](#)
  - d. When?**  
[Click here to enter text.](#)
- 5. What do you predict will happen when the plan is carried out? How will you know the change is an improvement?**  
[Click here to enter text.](#)



# Plan a Solution and Try It

PDSA Planning Worksheet

**TEAM:** [Click here to enter text.](#)

**Lead Person:** [Click here to enter text.](#)

**Cycle #:** [Click here to enter text.](#)

**Date Submitted:** [Click here to enter text.](#)

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## 6. Collection of data:

a. What data will be collected?

[Click here to enter text.](#)

b. Who will collect the data?

[Click here to enter text.](#)

c. Where will the data be collected?

[Click here to enter text.](#)

d. When will the data be collected?

[Click here to enter text.](#)

**DO:** Carry out the plan and collect data.

- Describe what actually happened? [Click here to enter text.](#)
- Document problems and any unexpected or special circumstances. [Click here to enter text.](#)
- Did anything occur that was not part of the plan? [Click here to enter text.](#)

**STUDY:** Complete analysis of measured results.

- What were the answers to the questions in the plan compared to your predictions? [Click here to enter text.](#)
- What was learned? [Click here to enter text.](#)
- Any surprises? [Click here to enter text.](#)

**ACT:** What will you do next?

Adopt – this worked great 😊

[Click here to enter text.](#)

Adapt – what changes should be tried in the next cycle?

[Click here to enter text.](#)

Abandon – this didn't work at all 😞

[Click here to enter text.](#)

# Early Hearing Detection and Intervention (EHD)

## Partnership with Local Public Health:

Reducing loss to follow-up and improving outcomes for children with hearing loss



Newborn & Child Follow-up  
PO Box 64882

St. Paul, MN 55164-0882

Phone: 651-201-3650, TDD: 651-215-8980

The MDH-LPH partnership has contributed to:

- 60% reduction in loss to follow-up

- Tripling of Part C Early Intervention enrollment status reported to MDH (from 22% in 2009 to 67% in 2011)

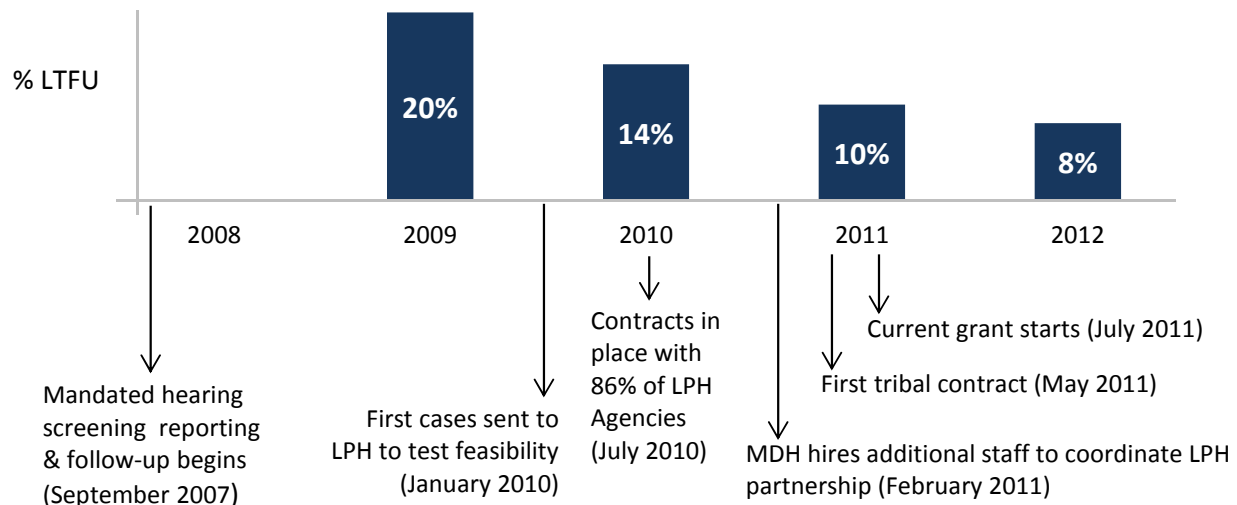
National 1-3-6 goals for EHD programs include:

- Screening before 1 month of age for all newborns
- Diagnosis before 3 months of age for those who screen positive
- Early Intervention before 6 months for those with permanent loss

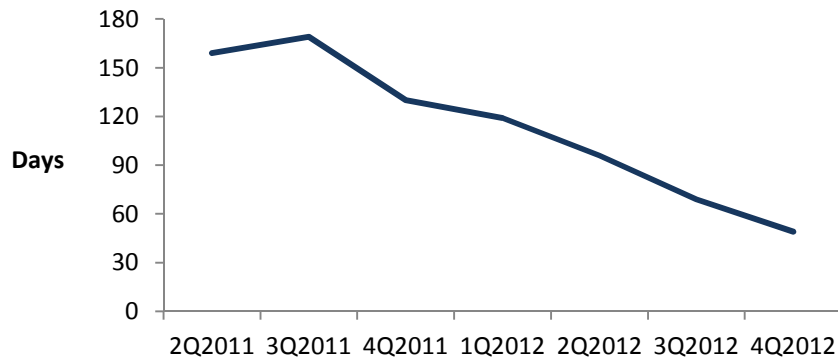
In Minnesota in 2011:

- 97% of newborns were screened before 1 month
- 23% of infants were diagnosed before 3 months
- 70% of infants with hearing loss who received Part C Early Intervention services were enrolled before 6 months

### Percentage of Children Lost to Follow-up After Screening has Decreased by 60%



### Average Follow-up Completion Time has Decreased by 3 Months



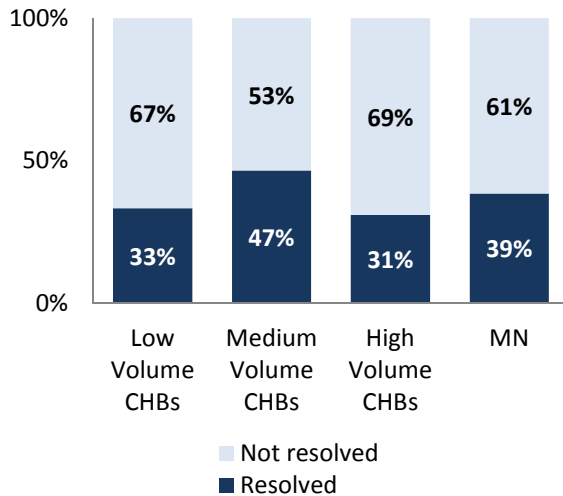
Between April 2011 and December 2012, LPH decreased the time taken to complete follow-up by 3 months to the current average of 69 days.

The longest completion time for a notification dropped by 8 months from 465 days to 210 days.

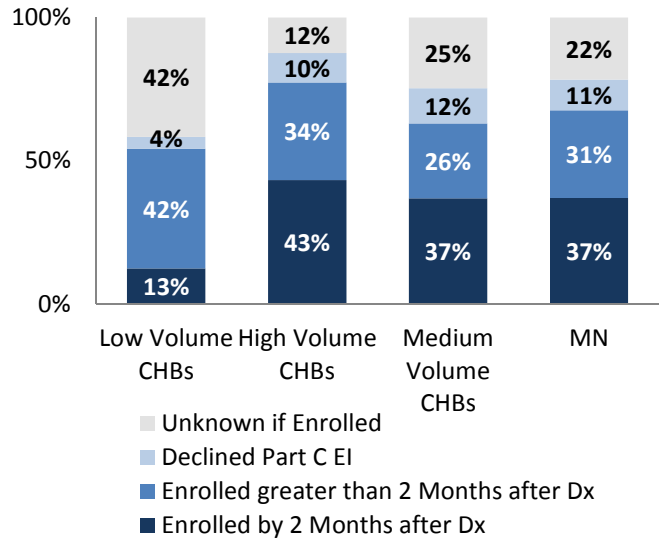
# Statewide Follow-up Outcomes for Notifications Sent July 2011-December 2012

MDH notified Community Health Boards of **585 children lost to follow-up** at rescreening and diagnosis & **298 children with confirmed hearing loss (CHL)** between July 2011 & December 2012.

**Resolution of Completed Rescreening/Dx Notifications**



**Part C Early Intervention Enrollment Status of Eligible Children for CHL Notifications**



Rescreening/Dx Follow-up Outcomes		Low. Vol. CHBs		Med Vol. CHBs		High Vol. CHBs		Minnesota	
Resolved	Passed screen: report provided	9	13%	70	26%	42	17%	121	20%
	Family declined rescreening/diagnosis	4	6%	29	11%	16	6%	49	8%
	Diagnosed with hearing loss	3	4%	3	1%	7	3%	13	2%
	Does not live in MN	0	0%	6	2%	1	0%	7	1%
Not Resolved	Unable to contact family	9	13%	58	22%	95	38%	162	27%
	LPH follow-up not complete	20	29%	36	13%	36	14%	92	19%
	Family not following up (e.g. has not kept appts.)	6	9%	21	8%	26	10%	53	8%
	Passed screen: report not provided	7	10%	22	8%	7	3%	36	6%
	Family not located	4	6%	12	4%	9	4%	25	4%
	Rescreening still needed	4	6%	9	3%	8	3%	21	4%
Another refer screening result	2	3%	2	1%	2	1%	6	1%	
<b>Total</b>		<b>68</b>	<b>100%</b>	<b>268</b>	<b>100%</b>	<b>249</b>	<b>100%</b>	<b>585</b>	<b>100%</b>
<b>CHL Follow-up Outcomes</b>									
Part C EI status known (enrolled/declined/ineligible)		24	71%	122	78%	96	89%	242	81%
LPH follow-up not complete		8	24%	18	12%	9	8%	35	12%
Family unresponsive or declined follow-up		1	3%	8	5%	3	3%	12	4%
Unable to locate family		1	3%	8	5%	0	0%	9	3%
<b>Total</b>		<b>34</b>	<b>100%</b>	<b>156</b>	<b>100%</b>	<b>108</b>	<b>100%</b>	<b>298</b>	<b>100%</b>

February 2013