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## INTRODUCTION

Minnesota is well positioned to successfully address the HRSA Early Hearing Detection and Intervention grant program to support a state comprehensive and coordinated EHDI system of care so families with newborns, infants, and young children up to 3 years of age who are deaf or hard-of-hearing (D/HH) receive appropriate and timely services that include hearing screening, diagnosis, and early intervention (EI).

In May 2007, legislation was enacted to add hearing level to the panel of more than 60 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
- Establish and maintain a multidisciplinary EHDI Advisory Committee to advise and assist the Departments of Health and Education.

In the years since newborn hearing screening was mandated, MDH has made significant progress in working with stakeholders and developing an EHDI system to ensure that children who are deaf or hard of hearing are identified through newborn hearing screening and receive evaluation, diagnosis, and appropriate intervention that optimize their language, literacy, and social-emotional development. However, significant gaps in the system remain specifically in achieving timely diagnostic audiological evaluation and enrollment in D/HH specific services and supports.

This grant opportunity, partnered with legislation and a robust EHDI structure, will allow Minnesota to continue to work toward improving the EHDI system using these methods:

- Engage all EHDI system stakeholders to improve outcomes of children who are D/HH;
- Provide a coordinated infrastructure to:

- Ensure that newborns are screened by 1 month of age, diagnosed by 3 months of age, and enrolled in EI by 6 months of age (1-3-6 recommendations); and
- Reduce loss to follow-up/loss to documentation.
- Identify ways to expand Minnesota’s capacity to support hearing screening in young children up to 3 years of age;
- Strengthen capacity to provide family support and engage families with children who are D/HH and adults who are D/HH throughout the EHDI system;
- Engage, educate, and train health professionals and service providers in the EHDI system about the 1-3-6 recommendations; the need for hearing screening up to age 3, the benefits of a family-centered medical home and the importance of communicating accurate, comprehensive, up-to-date, evidence-based information to families to facilitate the decision-making process; and
- Facilitate improved coordination of care and services for children who are D/HH and their families through the development of mechanisms for formal communication, training, referrals, and/or data sharing between the EHDI Program and the Individuals with Disabilities Education Act (IDEA) Program for Infants and Toddlers with Disabilities (Part C) Program.

## NEEDS ASSESSMENT

U.S. Census Bureau (2010) figures show that Minnesota has almost 5.4 million residents. Of these, 53.7% live in the seven-county Minneapolis/St. Paul metropolitan area. The other 46.3% live in the remaining 80 counties, many of which are rural.

Minnesota has seen large increases in immigrant populations, especially among Hispanic, Hmong, and Somali individuals. In 2010, the Census Bureau counted 250,258 persons of Hispanic descent (accounting for 4.7% of the population, an increase of 3% from 2000); 66,181 Hmong individuals (an increase of 46% from 2000); and over 32,000 Somali individuals (an increase of almost 200% from 2000) in Minnesota. For many of these families, English is not the primary language used in the home.

Nearly 70,000 infants are born in Minnesota yearly. Without early identification of hearing difference and timely intervention, children who are D/HH will experience delayed language and learning.

Reporting of newborn hearing screening and diagnostic results to the Minnesota Department of Health became mandatory as of September 1, 2007. Data received through mandated reporting to MDH are analyzed regularly to determine timeliness of and loss to follow-up/documentation at each stage of the EHDI continuum (screening, diagnosis and entry to early intervention). Analysis of these data allows MDH to monitor progress, identify gaps, and recognize areas for improvement within the EHDI system. In 2018, 245 children were identified with permanent hearing loss and reported to MDH. One third of these children had late-onset hearing loss (21%), were born outside of MN (7%), or were not screened / lost to follow-up after newborn hearing screening (6%).

According to the 2017 CDC EHDI Hearing Screening & Follow-up Survey:

- Minnesota screened 66,792 infants (98.6%) for hearing loss.
- 981 (1.4%) infants had no documented screening or undetermined results for their most recent/final screen.
  - Of those 981 infants (minus infants who died or parent declined), the majority had a homebirth (36.9%).
- 64,939 (97.2%) of infants were screened before 1 month of age.

- 813 (1.2%) infants did not pass their most recent/final hearing screening
  - 308 (37.9%) of those infants that did not pass their final hearing screening received diagnosis before 3 months of age.
  - 327 children (40.2%) of those infants that did not pass their final hearing screening had no documented diagnosis
    - Of those 327 children, 179 (54.7%) children’s parents or family members were contacted, but unresponsive.
  - 162 children (20.0%) of those infants that did not pass their final hearing screening were diagnosed with permanent hearing loss.
    - Of those 162 children, 104 (64.2%) were diagnosed before 3 months of age.
    - Of those 162 children, 62 (38.3%) were known to be enrolled into Minnesota’s Part C Infant and Toddler Intervention Program. It is unknown how many children enrolled before 6 months of age. Based on data from previous years, it is presumed that more children enrolled, but have not yet been reported as such to MDH.

While MDH has made significant progress in the 1-3-6 goals of Minnesota’s EHDl program (screening by one month of age, diagnosis by three months of age, and intervention by six months of age) since legislation was enacted, gaps remain.

### Infants who receive a refer result but do not receive diagnostic testing

As recommended by Minnesota’s multidisciplinary EHDl Advisory Committee, MDH has provided a breakdown of the data allowing for a better understanding of the reasons why children may not meet the 1-3-6 goals. This breakdown includes those who have a refer result do not receive diagnostic testing. The most common reasons for this lost to follow-up is that families are contacted, but unresponsive or that families refused follow-up. Barriers related to social determinants of health and lack of knowledge/understanding by families or providers, are key factors related to completion of the diagnostic process.

### Barriers related to disparities

The Minnesota Department of Health released a report to the legislature titled “Advancing Health Equity in Minnesota” in February 2014. The report revealed that:

- Inequities in social and economic factors are the key contributors to health disparities.
- Structural racism is rarely talked about. Revealing where structural racism is operating and where its effects are being felt is essential for figuring out where policies and programs can make the greatest improvements.
- Improving the health of those experiencing the greatest inequities will result in improved health for all.

These findings motivate the MDH EHDl Program to include health equity as a foundational lens through which we examine and improve our program. The disparities by race and economic factors seen throughout the state are also observed in the data collected by the EHDl program. Analysis of Minnesota’s 2017-2018 loss to follow-up data shows significant racial disparities in rates of loss to follow-up (Figure 2).

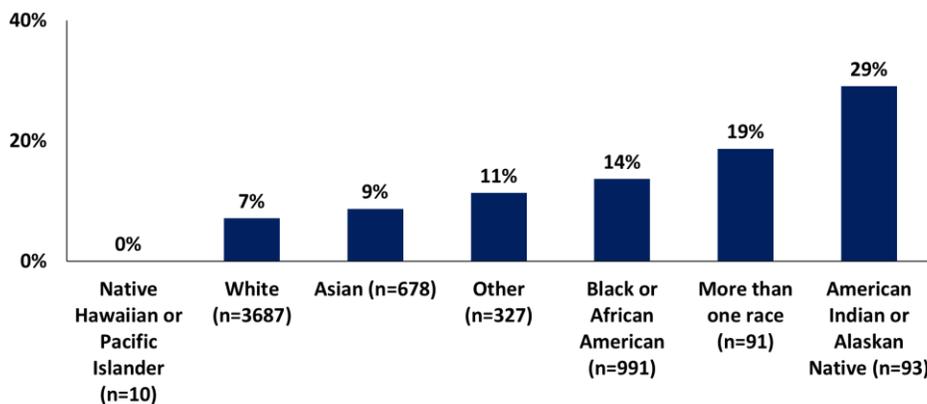


Figure 2: Lost to Follow-up by Mother's Race, 2017-2018 Births.

Children with mothers who identify as American Indian or Alaskan Native (29%), more than one race (19%), or black or African American (14%) are more likely to be lost to follow-up and not have a documented diagnosis compared to children with mothers who identify as white (7%) or Asian (9%). Initial hearing screen rates in Minnesota are around 95% for all children, regardless of a mother's race, suggesting that barriers to diagnosis arise after the family leaves the hospital. Barriers may include transportation, hearing loss knowledge, health care access, and speaking a language other than English.

Further, strong disparities in maternal education are found for children who do not receive timely diagnosis of hearing loss (diagnosed by 3 months of age). Data from 2017-2018 show that only 36% of infants of mothers who have not graduated high school receive a diagnosis by 3 months of age, compared to 53% and 67% of infants of mothers with a high school degree/some college and those with a Bachelor degree or higher, respectively.

Minnesota also encounters geographic disparities in timeliness of diagnostic testing with the percentage diagnosed within 3 months of birth ranging from 40-60% across regions (of those who received a diagnosis). Healthcare facilities with pediatric audiologists on site are limited in northern Minnesota, and families often find themselves driving many hours and incurring significant expense to have their infants diagnosed and referred for care. In addition, babies often sleep during extended travel times, making it less likely that a baby will be asleep for a diagnostic exam. With grant funding in 2016 and technical assistance from the Minnesota Department of Health, one clinic in Northeastern MN began offering teleaudiology for diagnostic testing in two sites. In 2019, 11 children were tested, with projections of 20 infants per year. It is estimated that families saved between 90 to 200 miles, and 1 to 4 hours traveling. Further work using quality improvement methodology is needed to identify strategies unique to other regions in MN to improve timely diagnosis.

### Barriers related to EHDI knowledge gap for professionals and parents

In 2012, Minnesota participated in a national survey of physicians conducted to understand knowledge, attitudes, and practices related to the EHDI system. A significant gap in understanding was evident, for example 45% of physicians were “unsure” if their training prepared them to adequately meet the needs of infants with permanent hearing loss

Lack of knowledge and understanding about best practices for timely identification of hearing loss is not limited to physicians. Through a quality improvement project implemented with local public health (LPH) nurses in 2014, a significant lack of knowledge from parents on the importance of follow-up after their child didn't pass hearing screening was identified. These nurses who are responsible to follow-up on children who

do not pass their newborn hearing screening and are lost to MDH’s surveillance system, found lack of parental understanding/education to be a barrier 32% of the time.

Additionally, in 2019, MDH’s Audiology Learning Community has been working on improving timeliness of definitive diagnosis of hearing status after referring on a newborn hearing screen. Six audiologists are working on different improvement projects at their clinic or hospital system. One common finding from this project included patient no-show as a leading cause of late diagnosis. While further testing is still needed, change ideas related to patient education using the teach-back method and addressing the lack of knowledge related to the importance of screening seem to improve attendance at appointments.

### Infants who are identified as D/HH - Enrollment in Early Intervention Services

For children who are D/HH to reach their full potential, it is critical that they and their families are connected to comprehensive family support and quality early intervention programs as soon as possible. This is not only important for children identified as infants through newborn screening, but also children with late onset or progressive hearing loss not previously detected. Audiologists are required to report MN children through the age of 10 who are newly identified as D/HH.

Since 2010, Local Public Health (LPH) agencies have been an important part of Minnesota’s EHD system to assure families are connected to resources including quality early intervention. Through formal contract agreements, LPH agencies utilize public health nurses to contact families of children newly identified as deaf or hard of hearing (D/HH) to provide education, family supports, and a connection to local resources including Part C Early Intervention. The results of this nursing assessment and the interventions provided are documented using a research-based standard taxonomy. Analysis of this documentation for 292 families of children who are D/HH from April 2017 – September 2018 show that nearly one third of children had documented signs/symptoms related to growth and development and over one quarter had documented signs/symptoms related to income. Lack of familiarity with available services was also a common finding for nearly 10% of families. As a result, assistance with accessing resources and services such as Early Intervention and health insurance were the most common interventions provided by LPH nurses during these assessments. Guidance on topics such as routine preventative care were also common. (Figure 4).

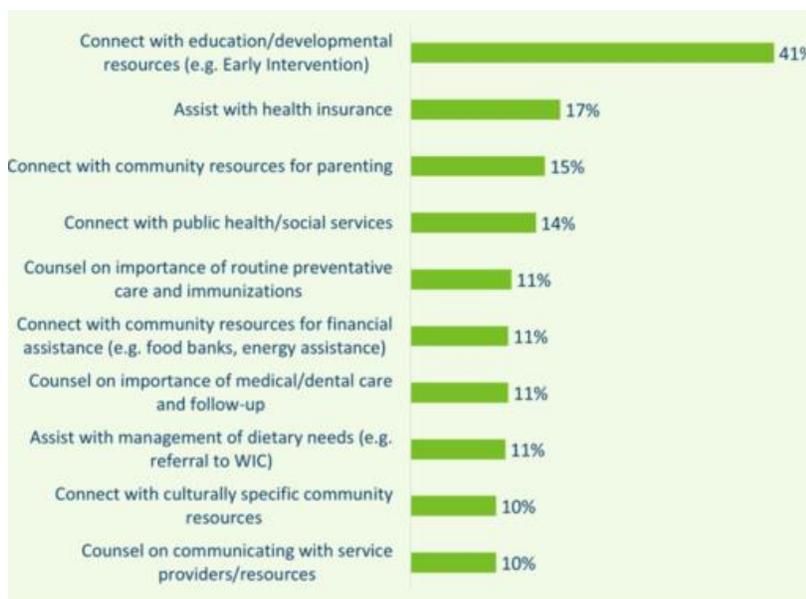


Figure 4 – The most common nursing interventions provided to 292 families of children newly identified as D/HH (April 2017 – Sept. 2018).

MDH’s EHDI Program is working with our partners at the Minnesota Department of Education (MDE) to improve our ability to ensure that children who are D/HH are enrolled in Part C Early Intervention services designed to meet their unique language and communication needs. Since late 2013, MDH has had a data sharing agreement with MDE that allows the EHDI program to annually match data with MDE to obtain Part C enrollment information. As of June 2017, the data sharing agreement lapsed and we are awaiting a signature for the renewal of the data sharing agreement.

Data from 2016 show that of the 128 children identified through newborn hearing screening, over three-fourths (76%) were eventually enrolled into Minnesota’s Part C Infant and Toddler Intervention Program as D/HH. Of those enrolled, 72% were enrolled by 6 months of age.

From 2012-2016, close to 80% of children identified as D/HH before age 3 eventually enrolled in Part C Early Intervention services. About 40% were enrolled within 2 months of diagnosis and about 60% were enrolled within 3 months of diagnosis. Resuming measurement of Part C Early Intervention enrollment will allow us to determine barriers and identify populations at highest risk for delayed or no enrollment.

Another significant partnership improving our ability to assess the status of coordination across programs is through Minnesota’s Early Childhood Longitudinal Data System (ECLDS). Data from ECLDS show increasing enrollment in Part B/ Special Education for children identified as D/HH through the MDH EHDI program (Figure 5) and that reading proficiency for 3rd grade children who are D/HH and identified through MDH’s EHDI program lags behind the general 3<sup>rd</sup> grade population.

**More children identified by MDH EHDI are served by Special Education**

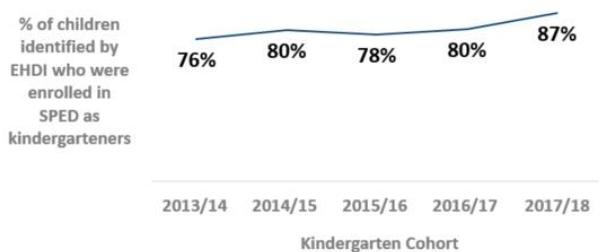


Figure 5 – Percent of children identified by MDH’s EHDI program who are also enrolled in Special Education (Part B) as Kindergarteners.

Past partnerships and engagement efforts have allowed Minnesota’s EHDI system to better connect families to services and ensure children who are D/HH are provided the opportunity of early identification and intervention that can optimize language, literacy, and social-emotional development. One such successful effort to engage partners and stakeholders to improve outcomes for children who are D/HH is the MN D/HH Collaborative. This effort led by the Minnesota Commission of the Deaf, DeafBlind, and Hard of Hearing (MNCDHH) since 2011, includes two MDH EHDI staff members, along with over 40 other D/HH and DeafBlind stakeholders. In fall of 2018, members convened for a 2-day retreat to review background research and a SWOT (strengths, weaknesses, opportunities and threats) analysis facing Minnesota’s D/HH service system. Summit attendees then identified issues and action steps for the Collaborative to address in a strategic plan.

The Collaborative Plan for Minnesota’s System Serving Children who are Deaf, DeafBlind, and Hard of Hearing: 2019-2024 provides a unique opportunity for MDH’s EHDl program to collaborate with non-traditional partners and promote our services and resources, and create positive, systemic changes that achieve better outcomes for children who are deaf, deafblind and hard of hearing.

## METHODOLOGY

This section describes the methods that will be used to address Minnesota’s needs, gaps and barriers as identified above, and perform work to meet described goal, objectives, activities, requirements and expectations. These methods include:

- Leading efforts to engage all stakeholders in the state/ territory EHDl system to improve developmental outcomes for children who are DHH.
- Engaging, educating, and training health professionals and service providers in the EHDl system
- Strengthening family support and engage families with children who are DHH as well adults who are DHH throughout the EHDl system.
- Improving coordination across early childhood programs and develop a plan to improve coordination of care and services for families and DHH children.

**GOAL:** Support the development of Minnesota programs and systems of care to ensure that children who are DHH are identified through newborn, infant, and early childhood hearing screening and receive diagnosis and appropriate early intervention to optimize language, literacy, cognitive, social, and emotional development.

### Objectives:

By March 31, 2024,

- 1) Maintain our baseline of at least 95.8% of newborns screened no later than 1 month of age.
- 2) Increase by 10 percent from our baseline of 37.9%, or achieve a minimum rate of 85 percent, the number of infants that completed a diagnostic audiological evaluation no later than 3 months of age.
- 3) Increase by 15 percent from our baseline of 0%, or achieve a minimum rate of 80 percent, the number of infants identified to be DHH that are enrolled in EI services no later than 6 months of age.
- 4) Increase by 20 percent from year 1 baseline the number of families enrolled in family-to-family support services by no later than 6 months of age.
- 5) Increase by 10 percent from year 1 baseline the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age.
- 6) Increase by 10 percent from year 1 baseline the number of health professionals and service providers trained on key aspects of the EHDl Program.

### Activities:

Lead efforts to engage and coordinate all stakeholders in the state EHDl system in order to meet the 1-3-6 EHDl goals.

Activity 1: Support screening for out of hospital births (OHB) and assure midwife access to screening equipment. (Objectives 1, 6)

A majority (36.9%) of children reported as not screened at birth had a homebirth and often were attended by a midwife practice. Outdated or lack of screening equipment has been identified as a barrier to improve screening rates by midwives. Supporting more midwife practices to purchase equipment will decrease the

number of infants not screened at birth, decrease loss to follow-up, and increase the number of professionals familiar with the goals of the EHDI program. In this activity, MDH will identify all certified midwife associations within MN (e.g. Minnesota Council of Certified professional Midwives). MDH will utilize EHDI data to identify particular areas of need related to out of hospital births, and contract with non-profit midwife organization for purchase and distribution of OAE equipment annually as needed. A plan for sustainability will be included within the midwife contract.

Activity 2: Develop a state plan to expand infrastructure, including data collection and reporting, for hearing screening of children up to age 3 (Objective 6)

MDH's EHDI program already has a working relationship with many early childhood hearing screening stakeholders—partnering in the past to develop guidelines for hearing screening after the newborn period up to kindergarten age. For the purposes of developing a plan to expand existing infrastructure, MDH will identify potential key stakeholders related to early childhood hearing screening that are not already involved. In year one, MDH will convene this expanded group of stakeholders, likely through a formal workgroup of the EHDI Advisory Committee, and begin to develop a plan to improve infrastructure for screening up to age 3. The plan will use a public health approach that aligns with other public health and/or service programs within the state as well as the role of the EHDI Program. Partners will include Maternal and Child Health, Children and Youth with Special Health Care Needs (CYSHCN) Program, newborn bloodspot screening program, Family Home Visiting Program, WIC, Early Head Start and Family-to-Family Health Information Centers. By the end of year two, this workgroup will finalize the plan and outline the resources, key stakeholders, partnerships, and services necessary to implement the plan. In subsequent years, MDH EHDI and stakeholders will take implantation steps as appropriate and evaluate the effectiveness of the plan's implementation. The outcome of this plan will improve timeliness of connection to resources and services for children with late-onset hearing loss, and expand the number of professionals integrated with and knowledgeable of EHDI in MN.

Activity 3: Establish and maintain partnerships for referral, training, and information sharing with various state stakeholder organizations and programs that include, but are not limited to, health professionals, service providers, birthing centers, and state organizations and programs. (Objectives 1, 2, 3, 4, 5, 6)

MDH is committed to maintaining and improving existing partnerships. Notable among these are members and organizations on the EHDI Advisory Committee and the MNCDHH Collaborative Plan. These partnerships span a wide range of local, regional, and state government agencies, birthing centers, health professionals, teachers, service providers, and families. Additionally, MDH is committed to identifying stakeholder groups that are not already involved in the EHDI system.

Work will include an inventory and assessment of current and potential partnerships. MDH will participate in state and regional level stakeholder collaborative workgroups/meetings to build partnerships and help address gaps in the EHDI system. MDH will identify additional key partners who could help address gaps in the EHDI system and strategies to improve existing partnerships. The results of this inventory, assessment, and plan to address gaps will be shared with the EHDI Advisory Committee and the MNCDHH Collaborative Plan. Expected outcomes of this activity will be improved coordination of partners to address gaps in the EHDI system, and improved data linkages to inform future program and policy decisions.

Activity 4: Employ Local Public Health (LPH)/MCH agencies to identify and report the needs of families, and provide timely connections to community supports/services including early intervention. (Required Family Engagement and Family Support Activity -25% of funding) (Objectives 3, 4, 5)

Public health nurses are uniquely suited to the role of identifying needs for families of children newly identified as D/HH, providing family support, and ensuring timely connections to community supports and services. 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 (including MIECHV) 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 and family support will end 12/31/2021. (Attachment 4: Description of existing contracts/grants with Community Health Boards for EHDI Follow-up and Family Support). These are dual contracts include both EHDI Follow-up as well as follow-up for identified birth defects through Minnesota's Birth Defects Information System. Forty-nine local Community Health Boards (including all 87 counties of MN) participate to identify family needs and ensure connection to services after identification of hearing loss.

Within the first month of notification about an infant or child newly identified as D/HH, the PH nurse will, 1) contact the family, 2) identify concerns and needs with the family through a nursing assessment with a focus on income/finance, health care supervision, growth and development, caretaking/parenting, and connection to community resources 3) document current services being used, and identify and connect families to any additional services that may be beneficial and for which the family is eligible. These resources may include community resources, primary care, specialty care, early intervention, financial resources, transportation, parent-to-parent support, and other professionals/services as needed. All children with who are D/HH should be referred to Part C/Early Intervention Services.

LPH agencies will use a standardized process to guide their nursing assessments and documentation of family needs. Data from these assessments provides insight into the most common difficulties that families are facing after identification of hearing loss such as the financial burden of uninsured medical expenses.

Agencies will invoice MDH for providing and documenting the assessments and a **minimum of 25% of project funding will be used for this LPH Follow-up and Family Support**. Payment for local public health (excluding Hennepin and Ramsey Counties) in tiers one through three will be reimbursed per case as follows: CYSHN Level One: Payment of \$75.00 per case when the nurse provides minimal data to MDH (update of Address/Phone Number, Primary Language, Insurance status, Home visiting status, Referral to Idea Part C & Part B status) or attempts to contact the family but was unsuccessful in identifying needs with an initial needs assessment.

CYSHN Level Two: Contact with family in order to identify needs through an initial nurse assessment to identify current services being used, identify needs and/or additional services that may be beneficial and for which the family is eligible, and connect families to identified resources.

- Level 2A (non-face to face) = Payment of \$225 per case for successfully providing a non-face to face initial nurse assessment (e.g. phone visit)
- Level 2B (Face to Face) = Payment of \$375 per case for providing a home or clinic visit with the family and successfully conducting an initial nurse assessment

CYSHN Level Three: Confirm connection to referred service and second nurse assessment when indicated. Payment of \$125 per case when a nurse has identified needed services/resources during the initial nursing assessment and has determined that a second assessment to confirm connection to referred services, identify additional needs and/or services that may be beneficial and for which the family is eligible, or connect families to additional resources would be beneficial.

Payment for Hennepin and Ramsey Counties:

Due to the high volume of cases referred to Hennepin and Ramsey counties (the two largest in the Minneapolis/St.Paul metropolitan area), contracts are set up to provide a lump sum payment per calendar year rather than payment per case. In addition to the lump sum payment, Hennepin and Ramsey counties have incentives to meet 4 performance measures: 1) Resolution of at least 10% of cases referred when child is lost to follow-up after newborn hearing screening; 2) Completing initial nurse assessments on at least 60% of reimbursable notifications with two areas assessed; 3) Completing second assessments for at least 10% of cases after a need identified in first assessment; 4) Parent/guardian contact is timely (attempted within one month for 90% of notifications). Hennepin and Ramsey counties can receive additional payment per performance measure met by the end of the calendar year. Hennepin County contract is \$44,000 in each calendar year with up to \$11,000 additional incentive payment (\$2750 each of 4 accomplished performance measures) per year. Ramsey County contract is \$32,000 in each calendar year with up to \$8,000 additional incentive payment (\$2000 each of 4 accomplished performance measures) per year.

EHDI Key contacts will 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. Local Public Health then contacts the family and/or the child's health care provider to facilitate rescreening or diagnostic testing. This effort to resolve documentation related to loss to follow-up is funded through a Cooperative Agreement through the Centers for Disease Prevention and Control.

This activity is expected to improve engagement in the EHDI program, ensure families of children who are D/HH are supported with resources for their common needs, and improve the rate of enrollment in EI by 6 months of age.

Activity 5: Engage a multidisciplinary EHDI advisory committee to advise and assist the EHDI program (Objectives 1, 2, 3, 4, 5, 6)

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:

- 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;
- 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;
- designing a technical assistance program to support facilities implementing the screening program and facilities conducting rescreening and diagnostic audiological assessment;
- designing implementation and evaluation of a system of follow-up and tracking; and
- 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 and appointed by MDH Commissioner as openings arise. Membership includes consumers, D/HH adults, parents of children who are D/HH, health care specialists, early intervention professionals, audiologists, and other EHDI stakeholders. A significant portion of members

are parents of children who are deaf or hard of hearing and/or deaf or hard of hearing individuals. Per the Committee by-laws, members meet quarterly.

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 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. During the project period, workgroups will focus on and provide advice to MDH on potential mechanisms to achieve project objectives and strategies. The Committee will publish and distribute formal recommendations and best practices as they are developed or revised.

Activity 6: Develop a formal plan to address diversity and inclusion in the EHDI system (Objective 1, 2, 3, 4, 5, 6)

MDH has been a leader in identifying and working toward addressing social determinants of health to ensure improved health equity. MDH EHDI staff have been meeting at least quarterly with mentors from the MDH Center for Health Equity to analyze our data through an equity lens, and for practical ways to implement equity policies in EHDI work. EHDI staff have taken several trainings in racial equity and community engagement and attend Health Equity Community of Practice meetings.

MDH considers the preferred language of families when sending out materials and resources. The main brochure “A step-by-step road map to help parents of Children with a Hearing Loss” is available in English, Hmong, Somali and Spanish. When the preferred language of a family is known, efforts are made to send translated materials in their language whenever available.

In 2019, MDH contracted with Wilder Research to map the journey families take through the EHDI system in MN, with a focus on the experience of families who speak or use languages other than spoken English at home. Wilder’s report “Mapping the Journey of Families who have Children that are Deaf and Hard of Hearing through Social and Human Services, Medical, and Education Systems” shows ratings from families on their experiences with phases of identification, medical appointments, connections and resources, and language and communication access starting from birth to early school-age. Based on responses from families, Wilder proposed strategies for improvement. MDH will continue to work with partners to determine next steps to consider those strategies.

The MNCDHH Collaborative Plan is a network of agencies and organizations who work together to create positive, systematic changes in order to achieve better education and career outcomes for students who are deaf, deafblind, and hard of hearing. MDH EHDI staff are members of the Collaborative Plan workgroup. The Collaborative Plan birth- age 5 workgroup has worked in the past to review EHDI resources for families who are culturally or linguistically diverse.

In order to develop a formal plan to address diversity and inclusion, MDH plans to:

- Continue quarterly consultations with MDH center for health equity;
- Work with internal MDH staff to develop a draft plan to address diversity and inclusion for EHDI program processes;

- Continue participation in MNCDHH Collaborative Plan birth-5 work group to help develop a broader plan to address diversity and inclusion by the end of year 1;
- Finalize a plan across the EHDI system & share with EHDI Advisory Committee to address diversity and inclusion by the end of year 2.
- Implement plan in year 3.

Activity 7: Utilize quality improvement methodology to assess and improve program performance. Specifically,

- To improve diagnosis by 3 months of age
- To reduce gaps in EHDI goals of 1-3-6 for culturally and linguistically diverse populations (Objectives 1, 2, 3, 6)

The EHDI program has incorporated quality improvement methodology into nearly every aspect of its work and will continue to do so during this project period. While each activity will include pieces of quality improvement or quality assurance, specific focus on quality improvement methods to test effective strategies will be employed to improve diagnosis by 3 months of age and to reduce gaps in EHDI goals of 1-3-6 for culturally and linguistically diverse populations.

In 2018, MDH convened an Audiology Learning Community to work on the goal of improving timely diagnosis by 3 months of age. Audiologists from several MN clinics and schools continue their participation. Audiologists are expected to use quality improvement tools, including small tests of change with plan-do-study-act cycles to complete a project within their home clinics with the goal of timely diagnosis. Audiologists attend regular meetings with members from other clinics where they share strategies and lessons learned.

For this activity, MDH will continue to work with audiology clinics to identify goals and plan for QI Projects. MDH will continue to recruit more learning community members, establishing a meeting schedule for learning sessions between testing periods. MDH will provide technical assistance to help clinics craft AIM statements for within-clinic projects. MDH EHDI and the learning community will identify progress toward measures and decide what changes lead to improvement, and determine next steps to 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.

Additionally, MDH will continue work with the MNCDHH Collaborative Plan Birth- 5 workgroup on common goals to address disparities in 1-3-6 EHDI goals for populations that are culturally and linguistically diverse. MDH will do this by working with partners in the Collaborative workgroup to identify goals and QI project plans, recruit members that are not already in the Collaborative, as appropriate to meet the goal, establish a regular meeting schedule and an AIM statement for the proposed project. 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 from these quality improvement projects will be shared through newsletters for audiologists and reported to appropriate stakeholders including the EHDI Advisory Committee on a regular basis. The EHDI Advisory Committee will assist MDH in sharing the results with their stakeholders. EHDI staff will also share successes nationally through presentations at the National EHDI conference.

Activity 8: Maintain and promote an EHDI website or webpage (Objectives 1, 2, 3, 4, 5, 6)

During this project period, MDH will continue to maintain and promote three main EHDI related websites. These websites include: 1) the main MDH webpages for Newborn Screening and CYSHN; 2) ImproveEHDI.org/MN (Minnesota-specific information housed on a server at Utah State University along with

pages from several other states; 3) MN Early Childhood Longitudinal Data System (ECLDS) <http://eclids.mn.gov>. Websites are designed for parents and professionals to easily find user friendly, accessible, and culturally appropriate information for families and professionals. MDH staff will assure that information on these webpages is accurate, comprehensive, up-to-date, and evidence-based to allow families to make important decisions for their children in a timely manner, including decisions with respect to the full range of assistive hearing technologies and communication modalities, as appropriate.

### Engage, educate, and train health professionals and service providers in the EHD system

#### Activity 9: Support comprehensive education to early intervention providers on the importance of the EHD system. (Objectives 3, 6)

In each year of the grant, MDH will identify and partner with Early Intervention Stakeholders such as MN Department of Education’s Part C and the MN D/HH Collaborative facilitated by the MNCDHH to sponsor and help in the planning of an EHD focused pre-session or track for the Annual D/HH Symposium (D/HH conference for parents and teachers).

Early Interventionists are key stakeholders for EHD and will have focused opportunities to facilitate collaboration with the MDH EHD program, increase knowledge & skills, and improve practice. By utilizing a well-established educational venue the D/HH Collaborative reaches a large ‘target’ audience and ability to provide top experts.

Topics will be generated through discussions with Early Intervention stakeholders who identify areas of additional training needed with regard to intervention services for children who are D/HH. In addition a literature review on best practices related to care for children with hearing loss will help to inform training focuses. Expert local and national speakers will be engaged to conduct specific training topics.

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.

#### Activity 10: Provide comprehensive education to audiologists on the importance of the EHD system (Objectives 2, 3, 4, 5, 6)

In each year of the grant, MDH will identify learning needs of audiologists and develop, sponsor, or provide at least one learning opportunity for audiologists on the importance of the EHD system. Audiologists are key stakeholders for EHD and will have focused opportunities to facilitate collaboration with MDH, increase knowledge & skills, and improve practice. When possible, utilizing a well-established educational venue reaches a large ‘target’ audience and ability to provide top experts.

Topics will be generated through discussions with audiologists who identify areas of additional training needed with regard to diagnosis and management of hearing loss. In addition a literature review on best practices related to care for children with hearing loss will help to inform training focuses. Expert local and national speakers will be engaged to conduct specific training topics.

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.

Secondly, in each year of the grant, MDH EHDl staff will conduct at least 4-6 audiology clinic site visits in order to provide technical assistance and education. Together, MDH staff and audiologists will review their Audiology Clinic Data Quality Report to identify opportunities for improvement in care of children who are D/HH. MDH staff will provide recommendations, tools and support to advance the use of quality improvement strategies (e.g. improveaudiology.org) and measures for use in their practice. Successes will be shared and spread through the MDH MN Audiology Newsletter, Sound Matters, EHDl Annual Report, and nationally at the EHDl National Conference.

Activity 11: Conduct comprehensive education to home visitors/ LPH nurses on the importance of the EHDl system (Objectives 1 2, 3, 4, 5, 6)

Annual training conferences will be developed and implemented throughout the term of this project. MDH Staff including EHDl 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 EHDl and BDIS follow up. Resources will be leveraged through joint EHDl and BDIS contracts and local public health staff that provide EHDl 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.

Topics will be generated through discussions with public health nurses who can identify areas of additional training needed with regard to EHDl 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 EHDl follow-up will also be involved in the BDIS and Home Visiting programs at the MDH. 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.

Activity 12: Continue to provide outreach and education activities to health professionals including newsletters, presentations, grand rounds, etc. (Objective 6)

Throughout the grant period, MDH will review and assess current needs of health professionals and existing mechanisms for outreach and education. Based on the results, EHDl staff will utilize existing or identify new mechanisms to improve health professional understanding in the EHDl system. Current mechanisms include a quarterly audiology newsletter (Sound Matters), grand rounds, exhibiting at conferences, MN AAP Newsletter articles, etc.

Strengthen capacity to provide family support and engage families with children who are DHH as well adults who are DHH throughout the EHDl system

Activity 13: Collaborate with and maintain formal relationships with parent to parent support, D/HH Mentor and Guide organizations and enhance active family and D/HH Adult engagement and leadership efforts.

The 2012 Minnesota Legislature authorized over \$700,000 per year to provide parent support to families of children who are deaf and hard of hearing. The family support provides includes direct hearing loss specific parent-to-parent assistance and unbiased information on communication, educational, and medical options; and individualized deaf or hard-of-hearing mentors who provide education, including instruction in American Sign Language as an available option. The MDH EHDI Coordinator administers these family support grants and works closely with the grantee to collaboratively develop yearly budgets/work plans, and oversee grant activities. Grants were awarded through an RFP process and agreements are signed with a non-profit organization called Lifetrack to fund MN Hands and Voices (parent to parent support and D/HH guides) and the MN Deaf Mentor Family Program (Attachment 4: Description of Contracts). These programs work closely with MN's EHDI program collaboratively to serve families and children who are deaf or hard of hearing. The MDH EHDI program will continue to administer the grants and work collaboratively with these programs throughout the project.

To further family engagement and leadership efforts through MN H&V, MDH will meet with staff to identify and provide additional opportunities for parent leadership and engagement in MDH EHDI program including EHDI Advisory Committee and EHDI related stakeholder groups. EHDI staff will attend at least two MN H&V or D/HH Mentor events statewide annually to engage and improve relationships with MN's families and will fund at least one additional parent to attend the EHDI National meeting.

Activity 14: Participate in technical assistance, training, and other activities with the HRSA-20-051 (FL3 Center), HRSA-20-048 (EHDI NTRC), HRSA-16-190 (LEND), and HRSA-18-069 (NRC-PFCMH) program recipients and MCHB project officer for resources, technical assistance, training, education, QI and evaluation to strengthen the EHDI infrastructure and capacity for family engagement and family support in MN. (Objective 4)

Throughout the grant period and as needed, MDH staff will consult with the FL3 Center, EHDI NTRC, LEND, MCHB for resources, technical assistance, training, education, QI and evaluation expertise to strengthen the infrastructure and capacity for family engagement and family support in the state/territory.

Employ LPH/MCH agencies to identify and report the needs of families, and provide timely connections to community supports/services including early intervention. (see Activity 4 above, Required Family Engagement and Family Support Activity -25% of funding) (Objectives 3, 4, 5)

Facilitate improved coordination of care and services for families and children who are DHH through the development of mechanisms for formal communication, training, referrals and/or data sharing between the MN EHDI Program and early childhood programs including the IDEA Part C program

Activity 15: Assess the status of coordination across early childhood programs and develop a plan to improve coordination and care services through a variety of mechanisms based on the current level of integration across programs including early childhood programs (Objective 6)

Throughout this project, MDH will continue to partner with MNCDHH to support the work of the Collaborative Plan (<https://mn.gov/deaf-commission/advocacy-issues/education/collaborative-plan/>). Specifically, MDH will work with the D/HH Collaborative to focus on improving coordination of care and services for families of children who are D/HH. As needed, additional key stakeholders will be added. By the end of year 1, MDH will demonstrate evidence of planning and stakeholder engagement through development of a written plan in collaboration with the D/HH Collaborative. By the end of year 3, MDH will demonstrate evidence of formal communication, training, referrals and/or data sharing with early childhood programs including Part C.

Activity 16: Maintain a data sharing agreement with MDE Part C and the state’s Early Childhood Longitudinal Data System in order to match, analyze, and report on timely access to the Part C system and other outcome measures. (Objective 3, 6)

There are countless factors that influence children’s development, both positively and negatively. For children who are D/HH, access to services through Part C Early Intervention is one factor that can positively influence development. The EHDI Program at MDH has developed a data sharing agreement with the MN Department of Education’s (MDE) Part C program in order to confirm enrollment into Early Intervention services and identify factors that are associated with better developmental outcomes (i.e. social emotional skills and language development). This information will help MDH identify whether the programs, services, and guidelines that MDH supports are making a difference. It will also help to determine if there are groups of children who have significantly better or worse outcomes. The MDH EHDI research scientist will summarize Part C enrollment information and outcome data (as available) with stakeholders such as in the EHDI Annual Report, the CDC EHDI Hearing Screening & Follow-up Survey (HSFS), and at the EHDI Advisory Committee meeting.

The MDH EHDI program is also included on a data sharing agreement between the MDH and MDE that allows inclusion of EHDI data in Minnesota’s Early Childhood Longitudinal Data System (ECLDS). EHDI data have been included since October 2016 and are updated annually. The current analytics results in several graphs/charts showing children’s growth and achievement in relation their hearing loss (i.e. 3rd grade educational testing scores for children who are D/HH). Staff will continue to work with the ECLDS to enhance analytics to answer questions related to factors associated with outcomes. Graphs/charts and data will be available on the MN ECLDS website at <http://eclds.mn.gov>. MDH will promote use of this data by stakeholders by publishing it in newsletters and the EHDI annual report, linking to the EHDI website, sharing it with the EHDI Advisory Committee for them to send to their constituents, and through presentations to audiologists, LPH nurses and other stakeholders locally, statewide and nationally.

### Additional Plans

As discussed in activities above, at least 2 MDH EHDI staff and will attend the annual national EHDI meeting and will budget for at least one family leader to attend. MDH will also work with the EHDI National Technical Resource Center (NTRC) to implement the various initiatives that are outlined in the work plan.

### Project Sustainability

In addition to funding received by HRSA and the CDC, the MN EHDI program receives direct support from newborn screening fee dollars and through state funding for parent to parent support grants (MN H&V and the D/HH Mentor programs administered by the EHDI program.) MDH will utilize these funds to sustain many of the activities proposed in this project after the period of federal funding ends. During this project period, a detailed plan will be developed outlining additional strategies to sustain key elements of the projects which have been effective in improving infrastructure support mechanisms and those that have led to improved outcomes for children who are deaf and hard of hearing.

## WORK PLAN

The work plan is delineated in Attachment 1 and is titled “*Early Hearing Detection and Intervention: Work Plan.*” The Work Plan describes the inputs, activities, timelines, and processes targeted to achieve the projects goals and objectives. Attachment 1 also includes a logic model that describes the conceptual framework for the proposed project and explains the links among program elements.

## RESOLUTION OF CHALLENGES

There may be challenges to the implementation of the activities described in the work plan. Much of this project focuses on advancing partnerships, assuring parents and providers are engaged and have information they need to effectively contribute to the health care system as it relates to children who are D/HH and their families.

Many of the partnerships required in this project are already well established. Progress on the goals, objectives and activities of the project will be shared frequently with the full EHD Advisory Committee. Challenges that persist or cannot be easily resolved will be discussed, and guidance from the EHD Advisory Committee will be requested.

In addition, this project focuses on engaging, building capacity, providing parent support, 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 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 members of the EHD Advisory Committee and the D/HH 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 of this project. EHD staff will continue to engage LPH Directors in this work through group interactions (e.g. presentations at meetings/conferences) and through one on one contact (phone or in-person visits). EHD staff will continue to utilize LPH in planning conferences and providing feedback on implementation of change ideas.

MDH also recognizes that providers such as audiologists, primary care providers, care coordinators and parents also have multiple and competing demands. This will need to be balanced when recruiting for stakeholder groups and quality improvement activities.

## EVALUATION AND TECHNICAL SUPPORT CAPACITY

### Data systems

The Minnesota EHD Information System (EHD-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 EHD-IS. The EHD-IS includes all reported screening data currently managed through OZ System (MNScreen) 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). MNScreen and MEDSS are both secure, web-based systems that allows for rapid reporting, surveillance, and follow-up, and assure timely case management. Local Public Health and Minnesota Hands & Voices staff who provide follow-up for the EHD 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 (vital records) 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. Additional 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

The project will be overseen by the EHDI Coordinator, Nicole Brown (pediatric nurse practitioner and parent of two children who are deaf). MDH will use additional EHDI related Public Health Lab and CYSHN staff to implement portions of the project who are not funded through these program activities including audiologists and follow-up coordinators. These staff have expertise in the technical and training aspects of newborn hearing screening, diagnosis, and intervention.

Three positions will be directly supported by this grant: the EHDI coordinator/supervisor (0.1 FTE), a research scientist (0.3 FTE) and an informatics specialist (0.5 FTE). EHDI Coordinator/Supervisor, Nicole Brown, provides specialized child/pediatric nursing leadership, vision, consultation, and long-range planning for the development implementation and evaluation of statewide Early Hearing Detection and Intervention (EHDI) long-term follow-up for children once identified as D/HH. She is responsible for supervising and overseeing the implementation of project activities, coordination with other agencies, interpreting of required data, and overall program evaluation, and is responsible for ensuring necessary reports and documentation are submitted to HRSA. (Attachment 2: Job Descriptions for Key Personnel). (Attachment 3: Biographical Sketches of Key Personnel).

The 0.3 FTE Research Scientist 2, Lauren Schwerzler, is trained in data collection and analysis as well as program evaluation (Attachment 2: Job Descriptions for Key Personnel). Lauren has approximately two years of epidemiologic experience (Attachment 3: Biographical Sketches of Key Personnel). She is responsible for planning, designing, implementing, analyzing, interpreting and reporting on assessment and evaluation of long-term follow-up and data tracking for children who are D/HH. Lauren also provides expertise in scientific research, methodology and analysis and will provide consultation to other MDH and non-MDH partners involved in evaluating population-based EHDI program activities. She will work alongside EHDI Senior Epidemiologist, Melinda Marsolek who is funded outside of this grant.

The 0.5 FTE Health Informatics Specialist, Anna Lintelmann, will coordinate the ongoing involvement of local public health departments in providing follow-up of children lost after not passing hearing screening or identified with hearing loss using the Minnesota Electronic Disease Surveillance System (MEDSS). She will assure data collection, provide continuous quality assurance and management of data output resulting from the local public health follow-up project. In addition, the position will provide expertise and support for health information technology (HIT) and data integration with other related programs. (Attachment 2: Job Descriptions for Key Personnel). (Attachment 3: Biographical Sketches of Key Personnel).

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 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.

### Evaluation Plan

The goal of this project is to support the development of statewide programs and systems of care that ensure that children who are deaf or hard of hearing are identified through newborn and infant hearing screening and receive evaluation, diagnosis, and appropriate intervention that optimize their language, literacy, and social-emotional development. Specifically, the project aims to increase engagement, partnership and knowledge with families of children who are D/HH and health professionals. In addition, it intends to improve access to EI services and language acquisition. A summary of the inputs, key processes, and expected outcomes of planned activities for each objective are highlighted in the logic model and outlined work plan for this project (Attachment 1: Logic Model and Work Plan).

At least one system-wide performance measure has been identified for each objective. Quality improvement teams will be convened to generate change strategies for making progress for many of the objectives. Quality improvement teams will utilize a simple and standard form for documenting their PDSA cycles. The EHDI research scientist 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 measures will be identified and tracked to help determine how well change strategies are being implemented. The EHDI research scientist will also analyze data from the EHDI-IS and provide summaries to the quality improvement teams and to the EHDI Coordinator overseeing the project so that they can react in a timely manner. Detailed descriptions of how MDH will evaluate each of our six stated objectives are below.

**Objective 1: By March 31, 2024, maintain our baseline of at least 95.8% of newborns screened no later than 1 month of age.**

**Performance Measure:** The percentage of infants who have received a newborn screening no later than 1 month of age. [Denominator is total live births for the reporting year.]

We will monitor the percentage of newborns screened no later than 1 month of age at least annually. We know that across maternal race/ethnicity, education level, and age all infants have high screening rates. Multiple activities will ensure we continue to meet or exceed our baseline of 95.8% of newborns screened no later than 1 month of age, including supporting screening for out of hospital births, maintaining partnerships with stakeholders, including hospitals that screen infants. If at any point screening rates fall below 95% for any group, we will assess the root cause of the problem and identify solutions and actions through a quality improvement project.

**Objective 2: By March 31, 2024, increase by 10% from our baseline of 37.9% the number of infants that completed a diagnostic audiological evaluation no later than 3 months of age.**

**Performance Measures:**

- The percentage of infants with a completed diagnostic evaluation by 3 months of age. [Denominator is total not pass the most recent/final screen in a given birth year].
- The percentage of infants with a completed documented diagnosis who received their completed evaluation by 3 months of age. [Denominator is infants with a documented diagnosis]

(normal/transient or permanent hearing loss) after not passing the most recent/final newborn screen in a given birth year.]

Our performance measures will look at diagnostic timeliness for all children who did not pass the most recent screen as well as for the subset of children who did receive a completed diagnostic evaluation. This will allow us to determine how performance for this objective is influenced by loss to follow-up.

One of our activities is to develop and implement a strategy to monitor and assess program performance through quality improvement in diagnosis by 3 months of age and reducing gaps for culturally and linguistically diverse populations. A component of this activity will be more frequent analyses of the performance measure for populations within the scope of the change strategies identified. 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 in consultation with the research scientist and the person(s) responsible for implementing the strategy. Data collected through the EHDI-IS can be accessed and analyzed at any time. 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.

In addition to measuring performance of change strategies, EHDI staff will identify process measures as a means of evaluating how the strategies are 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 EHDI-IS 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 3:** By March 31, 2024, increase by 15 percent from our baseline of 0% the number of infants identified to be DHH that are enrolled in EI services no later than 6 months of age.

Performance Measures:

- The percentage of infants who are identified as DHH through newborn screening who are enrolled in EI services no later than 6 months of age. [Denominator is all infants identified as D/HH through newborn screening in a given birth year.]

- The percentage of children identified as D/HH before age 3 years who are enrolled in EI services. [Denominator is all children identified as D/HH (congenital, late, or unknown onset) before three years of age in a given calendar year.]
- The percentage of all children identified as D/HH before age 3 years who were enrolled in EI services within 2 months of diagnosis. [Denominator is all children identified as D/HH (congenital, late, or unknown onset) before three years of age in a given calendar year who had documented enrollment in EI services.]

Enrollment status and timeliness into Part C Early Intervention are obtained through a data sharing agreement with the Minnesota Department of Education. The data sharing agreement lapsed in June 2017, which is why our baseline data is 0% for 2017 births. We are awaiting a signature for the renewal of the data sharing agreement, at which point, we will be able to renew measurement of this performance measure. Data for children born from 2012-2016 show that about 80% of children identified as DHH before age 3 enroll in EI services. Of those who enroll, about 40% are enrolled within 2 months of diagnosis and about 60% are enrolled within 3 months of diagnosis. About half of infants identified as DHH through newborn screening were enrolled in EI services no later than 6 months of age.

Our performance measures will look at enrollment rate as well as timeliness of enrollment for all children identified as D/HH (within 2 months of identification) as well as specifically for those identified through newborn screening (within 6 months of birth). Having separate measures for enrollment rate and timeliness will allow us to determine if improvement efforts need to be directed at boosting enrollment or at prompting timelier enrollment (e.g. if enrollment is low, but most of those enrolled do so early, efforts would be directed at understanding and addressing barriers to enrollment rather than at shortening the timeline to enrollment). Additionally, we know that delays in diagnosis impact timeliness of enrollment into EI, so strategies that improve timeliness of diagnosis will also likely lead to improvements in timely EI.

**Objective 4: By March 31, 2024, increase by 20 percent from year 1 baseline the number of families enrolled in family-to-family support services by no later than 6 months of age.**

**Performance Measures:**

- The percentage of families with a child who is identified as D/HH through newborn screening who are enrolled in family-to-family support by 6 months of age. [Denominator is all infants identified as D/HH through newborn screening in a given birth year.]
- The percentage of families with a child who is D/HH who are connected with family-to-family support at any time. [Denominator is all children identified as D/HH through age 10 (congenital, late, or unknown onset) in a given calendar year.]
- The percentage of all families who were connected with family-to-family support that were connected within 1 month of their child's identification as D/HH. [Denominator is all children identified as D/HH through age 10 (congenital, late, or unknown onset) in a given calendar year who had documented contact with family-to-family support.]

The family-to-family support organization in Minnesota does not have a formal enrollment process, but they do attempt to contact all referred families for an initial conversation and to offer additional services such as an in-home visit, group events, and newsletter subscription. Enrollment for performance measurement will be defined as at least one direct contact with a parent guide. MDH has a grant with the family-to-family

support provider in Minnesota (Minnesota Hands & Voices). All families are referred around the time of diagnosis by MDH (and are often also referred earlier by their audiologist). Minnesota Hands & Voices reports whether or not a family contact has been made and the initial date of contact, allowing us to measure timeliness.

Our performance measures will look at contact rate as well as timeliness of contact for all children identified as D/HH (within 1 month of identification) as well as specifically for those identified through newborn screening (within 6 months of birth). Having separate measures for contact rate and timeliness will allow us to determine if improvement efforts need to be directed at reaching families or at reaching them sooner. For children born in 2017 and identified as D/HH through newborn screening, 86% were contacted by Minnesota Hands and Voices and 61% were connected to family-to-family support by 6 months of age. Importantly, families were much more likely to be connected by 6 months of age if the child was diagnosed by 3 months of age. Over 90% of families who had a child diagnosed before 3 months of age were connected to family-to-family support by 6 months of age, while less than 30% of those diagnosed after 3 months of age were. This suggests that improvements in timeliness of diagnosis will likely lead to improvements in the timeliness of family-to-family support.

**Objective 5: By March 31, 2024, increase by 10 percent from year 1 baseline the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age.**

Performance Measures:

- The percentage of families with a child who is identified as D/HH through newborn screening who are enrolled in adult-to-family support by 9 months of age. [Denominator is all infants identified as D/HH through newborn screening in a given birth year.]
- The percentage of all families with a child who is D/HH who are enrolled in adult-to-family support at any time. [Denominator is all children identified as D/HH through age 10 (congenital, late, or unknown onset) in a given calendar year.]

We currently do not collect this data. We have a relationship with the deaf role model and mentor programs, who are the providers of adult-to-family support services. We currently collect information from MN Hands and Voices related to D/HH guides and also have a formal data sharing agreement with the Department of Human Services (DHS) who is currently managing the Deaf Mentor Program. During year 1, we will explore the best way to obtain individual-level data on dates of enrollment in these programs from DHS. Part of this process will be determining what ages these programs target and whether it's appropriate to have a timeliness goal. Families' changing needs and interests may affect when families choose to utilize these programs.

System-wide progress to improve the numbers of families who receive adult-to-family support will be monitored by reviewing the percentage of children enrolled. Activities to promote adult-to-family support include identifying who should make referrals to these programs, engaging with providers of adult-to-family support to understand family experience with their programs, and assessing the capacity of these programs to determine how many families they can serve.

**Objective 6: By March 31, 2024, increase by 10 percent from year 1 baseline the number of health professionals and service providers trained on key aspects of the EHDI Program.**

Performance Measures:

- Number of trainings on key aspects of the EHDI Program provided to individual health professionals or service providers in a given calendar year.
- Percentage increase in number of trainings provided to individual health professionals or service providers in a given calendar year. [Numerator is the number of trainings provided in the current calendar year minus the number of trainings provided in the previous calendar year. Denominator is the number of trainings provided in the previous calendar year. Individuals trained multiple times will be counted multiple times (e.g. an individual who receive two trainings in a given calendar year will be counted twice for that year).]

The number of these providers is fluid, so a 10% increase will be based on the number of providers trained in the first year. For example, if we train 500 providers in the first year, we will aim to train 550 providers in the second year, 605 in the third year, and so on. If a person attends multiple trainings, we will count them multiple times. If a precise head count cannot be obtained for a training, an estimate of the number of attendees will be used.

We have identified 10 categories of providers that would be targeted for training: hospital birth screeners, midwives, audiologists who see children, LPH staff who provide follow-up for children who are D/HH, PCPs who see children, MN Hands & Voices parent guides, deaf mentors and role models, MDH staff, EI service providers, and ENTs. We will regularly assess the types of providers who have been trained to ensure that all provider types are targeted as necessary. In addition, data from performance measures defined for other objectives will be used to prioritize training that may result in performance improvement.

In this upcoming grant cycle, we plan to offer multiple training opportunities to our targeted providers. Examples include, collaborating with the MNCDHH to support EHDI related content during Annual D/HH Symposium for parents and teachers, executing an annual statewide training conference for local public health and other partners, and offering at least one learning opportunity for audiologists on the importance of the EHDI system.

## ORGANIZATIONAL INFORMATION

### 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 (Attachment 5: Project Organizational Chart). The CYSHN Section at the Minnesota Department of Health serves families with children with, or at risk for, special health needs in multiple ways including work to prevent birth defects, monitor diagnoses of special health needs, coordinate follow-up for children with a special health need, promote care coordination, develop policies to support the community, and plan for the future of this work.

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 MIECHV 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 staff 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 objectives of the grant.

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 and mandated newborn hearing screening in 2007. Over the past twenty 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 newborns with a confirmed hearing loss to a health care home, enhanced diagnostic and early intervention services, advanced parent to parent support and D/HH mentor 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 eight member committee includes representatives from across the spectrum of invested parties including parents, advocacy stakeholders, primary and specialty health care 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. Minnesota has significantly increased the number of children eligible for participation in its Part C program. Revised eligibility criteria allow for all infants who are deaf or hard 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 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 over \$700,000 per year to provide support and assistance to families with infants and children who are deaf or hard of hearing. Lifetrack is the non-profit organization awarded this grant from MDH's EHDI

program and houses MN Hands and Voices (which includes parent to parent and D/HH adult guides) and the MN Deaf Mentor Programs.

This funding for family support provides:

- direct hearing loss specific parent-to-parent assistance and unbiased information on communication, educational, and medical options through Minnesota Hands and Voices; and
- 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 as deaf or hard of hearing, Minnesota Hands and Voices has recruited, hired and trained 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.

### [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 staff from the Minnesota Departments of Education, Health, and Employment and Economic Development, State Services for the Blind, MN Hands & Voices and the University of Minnesota. Improvement in the EHDI system is one of the three global goals of the Collaborative and has been driven by MDH. The Collaborative plan outlines objectives or activities to improve Minnesota's EHDI system. The Collaborative is led by the MNCDHH.

### [Minnesota Health Care Homes](#)

The MDH Health Care Homes Program (HCH) is one of the centerpieces of Minnesota's health reform initiative and is Minnesota's answer to the medical home model. Currently, the majority of Minnesota primary care clinics are certified as Health Care Homes. The program has increased its focus on the State Innovation Model by creating a stronger emphasis on community engagement, partnership, and integration of primary care clinics. The State Innovation Model improves health care through integrated, accountable care that is supported by innovative payment and care delivery that is responsive to the needs of each identified community. CYSHN staff (including the EHDI Staff) meet bimonthly with nurse consultants from MDH's Health Care Homes to share ideas and opportunities for collaboration to improve care coordination for CYSHN.

### [Minnesota EHDI Information System](#)

Minnesota's Newborn Screening Program contracted with OZ Systems to provide MNScreen, a secure, web-based system for reporting screening results to the Program. MNScreen also allows both Newborn Screening Program staff and birth facilities to monitor their own screening programs on an ongoing, real-time basis, which will help improve services for all Minnesota newborns. In the future, outpatient providers will also have access to MNScreen to report diagnostic test results and refer newborns for other early interventions as needed, helping to improve access and reduce disparities in care. The goal is to have all birth facilities, as

well as midwives, using the MNScreen/EHDI-IS by the end of 2016. In addition, we plan to pilot with an audiology clinic for implementation in 2016.

Minnesota Department of Health also uses a surveillance system called the Minnesota Electronic Disease Surveillance System (MEDSS) for long-term follow-up of children with confirmed hearing loss. The Minnesota Disease Surveillance Modernization is an integrated state-local disease surveillance system to allow electronic data exchange with partners including local public health agencies. This secure, web-based system allows for rapid disease reporting, surveillance, and follow-up, thus allowing for case management for several reportable conditions in a person-centric statewide electronic system. MDH has identified the need to achieve interoperability between MNScreen and MEDSS. The objectives will be to contract with OZ Systems to build a connection between MNScreen and MDH's Internal Exchange Hub, and to contract with MN. IT to build a connection between the Internal Exchange Hub and MEDSS.

### Local Public Health (LPH) EHDI Follow-up/Coordination

In Minnesota, local public health agencies (governed by Community Health Boards) are well positioned to connect families to services after diagnosis and help address many of the socioeconomic barriers to follow-up for newborn hearing screening and intervention. 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, work with primary care providers/health care homes in their community, provide Home Visiting programs, and work closely 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 utilized this strong and already established state system of local public health to significantly enhance its efforts in identifying needs of families with children newly identified as D/HH and connecting families to services. Contracts with all 87 counties require local public health nurses to facilitate and document rescreening, diagnosis, and connection with early intervention programs and resources for families whose infants are identified with hearing loss.