

Project Narrative

SECTION I: INTRODUCTION

The Maine Educational Center for the Deaf and Hard of Hearing/Governor Baxter School for the Deaf requests funding to increase Maine's data in the area of timely diagnosis to support the continued success of referrals to early intervention, and to increase the number of children enrolled in early intervention by 6 months of age utilizing continuous quality improvement techniques to achieve measurable improvements in the number of infants who receive appropriate and timely follow up. In order to fulfill the purpose of the grant the Maine Educational Center for the Deaf and Hard of Hearing/Governor Baxter School for the Deaf (MECDHH/GBSD) must ensure that infants are not only screened but also diagnosed and have access to appropriate early intervention services. MECDHH/GBSD must also ensure that families receive support from a variety of support services using a coordinated system that ensures parent-to-parent support and family support from deaf and hard of hearing adults.

Since 1957 the Maine Educational Center for the Deaf and Hard of Hearing/Governor Baxter School for the Deaf has been providing state of the art services and support to children who are deaf or hard of hearing and their families throughout the state of Maine. The mission statement of MECDHH/GBSD states, "The Maine Educational Center for the Deaf and Hard of Hearing/Governor Baxter School for the Deaf will provide high quality, state of the art services to children who are deaf and hard of hearing, their families, and learning communities statewide." The vision of MECDHH/GBSD is to expand and continually improve educational opportunities, programs, and services for all children who are deaf and hard of hearing statewide. This will be done via partnerships, collaborations, and the sharing of human, fiscal and physical plant resources. MECDHH/GBSD will be recognized as both a state and national leader in deaf education by providing exceptional programs and services. MECDHH/GBSD has become a nationally recognized organization. The early intervention and preschool programs at MECDHH/GBSD are considered to be a national model that many states are replicating due to their unique aspects of family support and integrated systems. In an effort to improve outcomes for Maine's deaf and hard of hearing children, MECDHH/GBSD has formed collaborative partnerships with several statewide agencies in Maine that serve children who are deaf or hard of hearing and their families. Since 2004 the Maine EHDI program (MNHP) has become a model of success. Our 2014 state data collected from Maine's EHDI program documents that over 98% of infants are being screened. This data also informs us that 71% of infants received a diagnosis by three months. One concern in Maine is the lack of information regarding the critical importance of follow up after NHS. Education is needed in Maine for primary care physicians, audiologists and other service providers. Another recent concern in Maine is the lack of diagnostic audiology facilities to provide the testing that is needed to ensure a timely and accurate diagnosis. Of the children with a documented hearing loss, 100% were referred to EI and 52% were enrolled in early intervention by 6 months. MECDHH/GBSD and Maine EHDI know that much of the concern with Maine's data is due to lack of documentation of services. With EI services coordinated by a different state agency than the Maine EHDI program much

coordination is needed to ensure documentation of services is complete. Collaborative work is needed through learning communities to address the gaps from referral to enrollment into early intervention. MECDHH/GBSD has established MOUs with Part C in Maine and a contract with Maine's Family Support Program – GBYS.

MECDHH/GBSD recognizes the importance of connecting families and their deaf or hard of hearing child with deaf or hard of hearing individuals. In order to continue to increase the amount of family support in this area and embed these services into Maine's EI program, growth is needed in our Hands & Voices GBYS program, and a Deaf Guide program is warranted. MECDHH/GBSD recognizes the importance of embedding family perspective in all aspects of the EHDI program.

Maine's project will work toward achieving the Healthy People 2020 Objective for newborn hearing screening by "increasing the proportion of newborns who are screened for hearing loss by no later than age 1 month, have audiology evaluation by age 3 months, and are enrolled in appropriate intervention services no later than age 6 months".¹

This project will follow the Joint Committee on Infant Hearing (JCIH) guidelines in all areas of its program and service delivery.

This project will use continuous quality improvement; Plan, Do, Study, Act (PDSA) cycle as the primary tool to problem solving. MECDHH/GBSD will review the work of the Maine EHDI program's Quality Improvement Team and work collaboratively with the program to continue the work of the current QI team to continue the goal of quality improvement in all areas of the program.

SECTION II: NEEDS ASSESSMENT

This section provides information from the 2012 Maine CDC State Health Assessment and Maine's Newborn Hearing 2017 EHDI Data Summary giving the reviewer a broad understanding of Maine strengths and challenges to increasing timely and appropriate diagnosis, early intervention and family support.

Demographics

Maine's population is growing at a slower rate than most of the U.S. but aging at a faster rate. The majority of residents reside in rural towns and small cities. There are 1.34 million people residing in Maine.² According to the 2018 Census data from the US Census Bureau, Maine's population is 94.6% white, 1.6% American Indian or Alaska Native, 1.6% black or African American, 1.2% Asian, and 1.8% two or more races.

The Hispanic population is about 1.7%.³ Of Maine's children under the age of 18, 93.6% are non-Hispanic white and 1.6% Hispanic. There are five federally-recognized Indian

¹ <http://www.healthypeople.gov/2020/topicsobjectives2020/objectiveslist.aspx?topicId=20>

² <http://quickfacts.census.gov/qfd/states/23000.html>

³ <http://quickfacts.census.gov/qfd/states/23000.html>

tribes in Maine: Aroostook Band of Micmacs; Houlton Band of Maliseet Indians; Passamaquoddy Tribe of Indian Township; Passamaquoddy Tribe at Pleasant Point; and, the Penobscot Indian Nation.

Although Maine's population is predominately white, the state is gradually becoming more racially diverse. Emerging populations include people of Somali, Sudanese, and Iraqi ancestry arriving in Maine as primary refugees or secondary migrants.

Geography

Maine is the northernmost and largest state in New England and the easternmost state in the United States. New Hampshire, Vermont, Massachusetts, Rhode Island and Connecticut fit into the 35,385 square miles occupied by the state of Maine. Statewide, 40.6% of the population lives in rural areas. More than one-third of the population lives in the two southernmost counties (Cumberland and York), which accounts for only 6% of the state's land area. Maine has three major cities: Portland (pop. 66,417); Lewiston (pop. 35,994); and Bangor (pop. 31,997). Augusta, the state capitol has a population of 18,681.⁴

Income and Poverty

Based on ACS data, the median household income in Maine (2018) is approximately \$4,628 less than in the U.S. (\$53,024 vs. \$57,652) <https://www.census.gov/quickfacts/fact/table/ME,US/HEA775218> with considerable variation in income across Maine counties. The median household income ranged from \$38,797 in Piscataquis County to \$65,702 in Cumberland County.⁵ Across Maine, 13.4% of residents and 18.7% of children under the age of 18 years lived below the FPL 2015.⁶

Health Insurance and Access to Medical Care

According to 2018 estimates, 5.5% (15,000) of Maine children, age 0 -18 do not have health insurance compared to 5.2% of children nationally.⁷ MaineCare (Medicaid) provides health coverage to approximately one third of all children living in Maine (about 110,000 children) and nearly half (47%) of all births in Maine are financed by MaineCare. Currently, 45.1% of Maine children under the age of 18 participate in MaineCare.

Based on 2018 Maine health professionals license data from the Maine Board of Licensure in Medicine, which counts the number of providers in active practice, there were 6,187 allopathic (MD) and osteopathic (DO) physicians practicing in Maine. The data showed that 814 active physicians (MD/DO) listed family practice as their primary

⁴ <http://quickfacts.census.gov/qfd/states/23/2302100.html>

⁵ <http://quickfacts.census.gov/qfd/states/23/23005.html>

⁶ <http://www.census.gov/programs-surveys/acs/data/summary-file.2015.html>

⁷ <http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk>

specialty, 209 active physicians listed pediatrics as their primary specialty. Nearly 37% of all physicians, 29.3% of primary care providers, and 40.7% of pediatricians are located in Cumberland County.

These factors along with the current economy, high unemployment, as well as high heat, gas, and food prices are major issues facing Maine's most vulnerable. These factors create complex challenges for Maine Department of Health and Human Services, as well as Maine's Newborn Hearing Program as we strive to improve health outcomes for children with hearing loss.

Maine CDC Newborn Hearing Data

The Maine CDC Newborn Hearing Screening data for 2017 (Attachment 6) indicates that the maternal age at the time of birth in Maine ranged from <15 years to >50 years of age. Ninety-two percent 92.9% of Maine births were to mothers with at least a high school education; 90.3% of births were to non-Hispanic whites; and, 1.9% of births were among Hispanic women.

The 2017 EHDI data indicates that Maine continues to maintain a 98% screening rate. Of the 286 infants with a missed screen, 202 are considered LTFU/D; home births represent 197 of those infants. During 2017, there were a total of 231(2%) infants who did not pass screening; 180 (78%) completed an audiologic evaluation and 48 (20.8%) are considered LTFU/D. MNHP received 21 confirmed reports of a hearing loss from audiologists; 100% of those children were referred to Part C - early intervention services. MNHP received information confirming that 14 (67%) are enrolled in Part C and/or other non-Part C programs. The remaining 7 children are not confirmed as receiving early intervention services; 7 (33%) of whom are considered LTFU/D.

Screening

Currently, there are 26 hospitals in Maine with obstetrical service, two of these facilities Maine Medical Center in Portland and Eastern Maine Medical Center in Bangor are designated as Level III neonatal intensive care units, which have the staffing and technical capability to manage high-risk obstetric and complex neonatal patients. All birthing facilities have the ability to monitor and review newborn screen submissions to ensure that all babies born at the facility receive a screen for hearing loss prior to discharge. There are two free standing birth centers in Maine; the Birth House in Bridgton and Northern Sun in Topsham. MNHP has provided Northern Sun equipment to provide newborn hearing screenings. It is estimated that this birth center can provide hearing screening to at least a third of the home births.

Finally, for families who choose a home birth, accessing outpatient screening can be difficult. A physician or other licensed health professional must order the screen/lab

work. In most cases a physician will require that the infant become a patient of record which the family may or may not want to do.

Screening and LTFU/D 2017 Data

In 2017 there were a total of 21 infants diagnosed with hearing loss with 11 of the infants diagnosed within three months. Maine refers all infants diagnosed with hearing loss to Child Development Services (CDS). Of those 21 infants, MNHP received confirmation that 14 (67%) were enrolled in EI, with 9 reaching the goal of enrollment by 6 months.

Strengths

- ◇ All 26 birthing facilities in Maine screen infants prior to discharge using Auditory Brainstem Response (ABR) screening equipment.
- ◇ All birthing facilities licensed in Maine are required to report hearing screening results to MNHP, at least monthly.
- ◇ All birthing facilities upload hearing screening data electronically to the Maine CDC, Children with Special Health Needs (CSHN) Data and Surveillance System.
- ◇ All hearing screening results are linked electronically with birth and death certificates, metabolic (bloodspot), and birth defects.
- ◇ All birthing facilities are required by P.L. 2295 to schedule an audiological evaluation prior to hospital discharge and notify MNHP and the child's PCP of the appointment. MNHP and the PCP are notified by fax.
- ◇ All birthing facilities are able to review their own submissions through ChildLINK.
- ◇ One Midwifery practice uses an ABR screener.
- ◇ MNHP provides technical assistance to birthing facilities on screening, equipment, follow-up and uploading data to the Maine CDC, CSHN Data and Surveillance System.
- ◇ A representative of the Maine Hospital Association sits on the Maine Newborn Hearing Advisory Board.
- ◇ Maine CDC, CSHN has a contract with Maine Medical Center for Perinatal Outreach Education which provides MNHP access to Perinatal Nurse Managers throughout the state.
- ◇ Maine CDC Strengthening the Continuum of Care Committee with its mission to improve birth outcomes has provided an opportunity to build a solid relationship with the Maine Association of Certified Professional Midwives to improve birth outcomes for all mothers and infants.

Opportunities for Improvement

- ◇ Partner with the Maine Association of Certified Professional Midwives (MACPM) to improve the system for screening infants when they are born outside of the hospital system.
- ◇ Work with Birth Wise Midwifery School to present information to students on the importance of newborn hearing screening.

Audiological Assessment

Currently, there are seven Category A Facilities with 21 pediatric prepared audiologists. A Category A facility is a facility that provides full **audiological diagnostic evaluations** (this includes ABR with frequency specific results). There are a total of twenty-one Category B Facilities with a total of 32 audiologists. A Category B facility is a facility that provides **pediatric audiological testing procedures** for children over 6 months of age with services including but not limited to, soundfield testing, screening prior to electrophysiologic, otoacoustic emission testing, and support service for hearing aid fitting. Audiologists are represented on the MNHP Advisory Board and have been integral partners in the design and implementation of the on-line reporting form.

A collaboration with the University of New England and University of Maine LEND (Leadership Education in Neurodevelopmental and Related Disabilities) Program and the MCHB LEND pediatric audiology training programs will be explored to offer Maine audiologists continued training and support.

Diagnostic Evaluation and LTFU/D Data

- ◇ Of 231 infants that did not pass screening, 132 (57%) were evaluated by 3 months of age.
- ◇ A total of 51 infants did not receive an audiologic evaluation and of those 1 audiological diagnosis was in process, 13 families declined further services, 1 family moved out of state, 1 was unable to receive diagnostic testing due to medical reasons, and 26 families were unresponsive, leaving a total of 9 (4%) LFU/D.
- ◇ Twenty one infants were diagnosed with hearing loss.

Strengths

- ◇ There are 26 facilities serving infants and young children.
- ◇ The Pediatric Audiology listing is updated annually and mailed to all birthing facilities and primary care providers.
- ◇ P.L. 1142 mandates that all providers of hearing diagnostic procedures report the results of the evaluation and diagnosis of children up until the age of 3-years to MNHP.
- ◇ All audiologists have access to on-line reporting through Maine CDC, CSHN data and Surveillance System.
- ◇ Maine pediatric audiologists have recently established a learning community.
- ◇ Families are able to access early intervention services in a more timely manner given the new MOU with CDS and MECDDHH; because of this, audiologists have more direct contact with the child's IFSP and IEP team than in the past, given their ability to contact the child's early interventionist from MECDDHH.
- ◇ Maine's part C utilizes a database called CINC. This allows access to children's IFSP/IEP, related evaluations and makes child data more readily available to audiologists. This supports a multidisciplinary team approach.

- ◇ Given the population density of the state and the geographic spread, families have several options within a reasonable driving distance for diagnostic services. MNHP has done a great job collaborating with midwifery groups to ensure screenings are occurring for home births.

Opportunities for Improvement

- ◇ Develop a process for providing hearing screening up to age 3.
- ◇ Work with audiologists to encourage the use of the on-line reporting form.
- ◇ Monitor audiological referrals/faxes from birthing facilities via the Maine CDC, CSHN Data and Surveillance System.
- ◇ Educate and encourage all birthing centers to make audiological referrals for infants who do not pass their newborn hearing screening.
- ◇ Work with hospitals and ChildLINK to improve timeliness of reported equipment failures and data errors.
- ◇ Survey hospitals to determine if barriers exist that prohibit them from scheduling audiological appointments and notifying MNHP and the child's PCP.
- ◇ Maine CDC, CSHN Data and Surveillance System automatically notify EHDI Coordinator when audiology report is received.
- ◇ Review "at risk" children and recommended follow-up diagnostic evaluations.
- ◇ Collaborate with the other New England states to develop a quality improvement project that improves early access to border babies thereby decreasing LFU/D.
- ◇ Encourage audiologists to register with the EHDI-PALS website (Pediatric Audiology Links to Services). This is a web-based link to a national directory of facilities offering pediatric audiology services to children under the age of five.
- ◇ Work with the Audiology Workgroup to implement collaboration with The University of Maine Center for Community of Inclusion – Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program.
- ◇ Work with the Audiology Workgroup to increase the number of providers offering hearing aid and other rehabilitation services. This will also include investigating the barriers seen by audiologists.
- ◇ Work with the Audiology Workgroup to determine training needs within the audiology community.
- ◇ Educate Part C and pediatric audiologists on the importance of involving audiologists in the IFSP/IEP Process, including the development of goals and inclusion in the meetings.
- ◇ Work with hospitals in Maine with the goal of increasing ABR facilities, especially sedated ABRs. This is especially needed in the northern, more rural areas of our state.
- ◇ Work with birthing hospitals statewide with the goal of making sure their screening programs are overseen by a licensed audiologist that can support as needed.

Early Intervention

Effective March 1, 2014, the State Intermediate Educational Unit, Child Development Services (CDS) and the Maine Educational Center for the Deaf and Hard of Hearing/Governor Baxter School for the Deaf (MECDHH/GBSD) signed a Memorandum of Understanding to improve early intervention services for children who are deaf and hard of hearing. On August 1, 2016 a renewal of the MOU was signed (Attachment 10). Early Childhood and Family Services (ECFS) early interventionists for MECDHH/GBSD are now integrated members of the CDS Early Intervention teams. The purpose of the MOU is to develop a collaborative approach between CDS and ECFS to enhance and expedite the provision of early intervention services as it relates to children who are deaf or hard of hearing. MECDHH/GBSD and MNHP should see an increase in the documentation for children enrolled in EI by 6 months. This MOU is currently being revised and expected to renew by January 1, 2020.

Early Intervention and LTFU/D Data

In 2017 there were a total of 21 infants diagnosed with hearing loss with 11 of the infants diagnosed within three months. MNHP refers all infants diagnosed with hearing loss to Child Development Services (CDS). Of those 21 infants, MNHP received confirmation that 14 (67%) were enrolled in EI, with 9 (64%) reaching the goal of enrollment by 6 months. One (7%) family declined services, two families were contacted but were unresponsive and four were unknown.

Strengths

- ◇ MECDHH/GBSD has a Memorandum of Understanding with Maine's Part C agency (CDS) that embeds the early intervention specialists from MECDHH/GBSD into each regional CDS site to ensure an EI deaf specialist supports every child with a suspected or diagnosed hearing loss.
- ◇ Maine has a single point of entry into early intervention services.
- ◇ MNHP is required to refer all children with a confirmed hearing loss to CDS.
- ◇ MNHP refers 100% of infants with a confirmed hearing loss to CDS.
- ◇ MNHP/MECDHH/GBSD and Maine's Part C have a strong, collaborative working relationship.

Opportunities for Improvement

- ◇ Develop a tracking system to document provider documentation of part C services and referral to the MNHP.
- ◇ Provide outreach and education to all CDS site Directors to increase knowledge and awareness of the importance of early intervention for children who are deaf or hard of hearing and documentation of enrollment sent to MNHP.
- ◇ Provide outreach and education to all CDS regional site providers on the updated Memorandum of Understanding and the early intervention process for children who are deaf or hard of hearing in Maine.
- ◇ Ensure that the early intervention specialists at MECDHH/GBSD add MNHP to the release form of every child enrolled in early intervention so documentation of EI occurs.

- ◇ Quarterly meetings of the Early Intervention Community of Practice to ensure all providers follow the early intervention process in Maine for the single point of entry into appropriate early intervention and have an avenue for receiving support from their peers.
- ◇ A process of fidelity assurance is needed for Maine's early intervention exploration of communication opportunities process.
- ◇ Visuals (graphics/videos) displaying all communication opportunities in an unbiased manner for family exploration.
- ◇ Develop a statewide data system for monitoring referrals into services and language outcomes of children.

Family Engagement and Support

MECDHH/GBSD and MNHP have a strong history of family engagement in all aspects of the EHDI program and the programs of MECDHH/GBSD. Maine has followed the 2013 supplement to the 2007 JCIH Position Statement in order to engage families in every aspect of our EHDI programs, and our QI team is reviewing the newly released JCIH recommendations. Families are empowered to be active participants in the development of systems, on advisory boards, as parent leaders in Maine's GBYS program and providing presentations at conferences and trainings to a wide variety of stakeholders.

MECDHH/GBSD intends to continue supporting the evidenced-based parent-to-parent support program, Hands & Voices, Guide By Your Side (GBYS). Guide By Your Side is a program of Hands & Voices that provides emotional support, technical assistance, networking, and unbiased information from trained Parent Guides to other families and to the systems that support them. At the foundation of GBYS is the value of peer (parent-to-parent) support and a parent-driven agenda. There is a comfort level that happens naturally between parents who can relate to the experience of raising a child who is deaf or hard of hearing. Facing the challenges of navigating an unfamiliar service system upon diagnosis of a child's hearing loss can be confusing and overwhelming for parents. Therefore, the benefit of having a parent-to-parent support system is inestimable. Assuring that the quality of the interactions between parents upholds the mission of Hands & Voices and MECDHH/GBSD for unbiased support is the point of the in depth training parent guides will receive.

Maine's chapter of Hands & Voices established their GBYS program in 2014. Maine Hands & Voices GBYS program has an annual statewide conference that was widely attended this past year with over 150 participants from various stakeholder groups, including parents. The GBYS program in Maine continues to grow as it provides collaborative trainings and presentations throughout Maine explaining the value of parent-to-parent support.

Maine added a D/HH Guide component under the existing GBYS program in 2017. Deaf/Hard of Hearing (D/HH) Guides are specially trained to provide support to families. The D/HH Guide's purpose is to: provide a variety of personal perspectives and insight of the D/HH journey; influence and improve the systems designed to serve families and their children who are deaf or hard of hearing; provide trained D/HH Guides to families with newly identified babies, young children, or to seasoned parents with teenagers who are deaf or hard of hearing; and, to create a safe place in which parents, children, and professionals can ask questions about hearing loss or deafness. This is especially true when D/HH Guides attend activities and workshops with families, which allows for a natural environment to foster conversations.

MECDHH/GBSD recognizes the value of connecting families with deaf or hard of hearing individuals. Such individuals are typically adults who interact with the family and provide various types of assistance through one-on-one interaction. A variety of terms are used to describe such individuals: deaf mentors, deaf guides, role models and partners. The National Center for Hearing Assessment and Management (NCHAM) facilitated a Deaf/Hard of Hearing Adult Involvement Learning Community. The MECDHH/GBSD Director of Early Childhood and Family Services was one deaf adult involved in this learning community.

The benefits to implementing a Deaf/Hard of Hearing Guide program under Maine's existing GBYS program in Maine are based upon the collaborative activities of the National Hands & Voices trainers and state agencies, which will include training parent leaders, incorporating parental and deaf and hard of hearing perspectives, and embedding parent/professional collaboration into Maine's Early Hearing Detection and Intervention (EHDI), educational, and family support system. This comprehensive approach will strengthen the infrastructure and increase the effectiveness of state systems and their capacity to serve families.

Maine also implemented an ASTra (Advocacy Support Training) Program in April of 2019, which is a program of Hands & Voices. The ASTra Program matches a family with a trained advocate who helps the family prepare for their IFSP/IEP meetings, attends meetings with the family if requested and continues to support the family until the IFSP/IEP process is complete, depending on the requests of the family.

An oversight committee has been established with the Maine Hands & Voices chapter to oversee the Parent Guide, Deaf and Hard of Hearing Guide and ASTra Programs.

Strengths

- ◇ Maine has a strong Hands & Voices chapter.
- ◇ Maine has an existing GBYS parent-to-parent and Deaf/Hard of Hearing (Deaf Guide) support program that contracts with MECDHH to provide their financial infrastructure and support.
- ◇ MECDHH/GBSD and MNHP value family engagement in all areas of programming.
- ◇ MECDHH/GBSD has a Deaf Mentor Program that provides support to families.

- ◇ MECDHH/GBSD Director of Statewide Education and Family Services was involved with the NCHAM Deaf Mentor Learning Community and is currently involved in the FL3 Deaf Hard of Hearing Advisory Committee.
- ◇ MECDHH/GBSD has a Memorandum of Understanding with Maine's Part C agency that includes the integration of parent-to-parent support and the support of deaf guides and mentors early in the families EI process.
- ◇ Maine has a single point of entry into early intervention services so access to support from families and deaf adults is accessible.
- ◇ An early intervention community of practice is established for early intervention providers.
- ◇ Maine Hands & Voices, supported by MECDHH/GBSD and MNHP, has had four successful family support conferences.

Opportunities for Improvement:

- ◇ Training is needed on the importance of family engagement in healthcare agencies in our state.
- ◇ Training is needed on the importance of parent-to-parent support in our state.
- ◇ Training is needed on the importance of deaf and hard of hearing guide supports in our state.
- ◇ A needs assessment is needed to survey families on programming needs for family support in early intervention.
- ◇ A process of fidelity assurance is needed for Maine's early intervention exploration of communication opportunities process.

Medical Home

In the past, Maine participated in the National Center for Hearing Assessment and Management Survey: Knowledge, Attitudes, and Practices of Physicians Regarding Newborn Hearing Screening. Unfortunately, only 59 providers responded. The majority of respondents (52.5%) were family physicians; 30.9% were between the ages of 50 – 60 years; 36.9% had been in practice between 20-30 years; and, 74.6% were either in private practice or a community setting. Although, the number of respondents was small MNHP did note that 74% reported that they never connected with the state EHDI Program; 50% felt very confident explaining the newborn hearing screening process but they were less confident (60.3%) explaining the causes of hearing loss; and; 78.9% report that they never do hearing screening in their offices.

The Quality Improvement Specialist has established a strong collaborative relationship with one of Maine's largest hospitals. Maine's Chapter Champion is employed at this hospital and has been instrumental in setting up meetings with hospital administrators. Areas of focus have been their newborn hearing screening processes and follow up with the medical home.

MECDHH/GBSD and MNHP will conduct a needs assessment to establish training needs throughout the state with physicians and pediatricians statewide.

Strengths

- ◇ Maine Chapter of American Academy of Pediatrics appointed Dr. Duska Thurston as the Chapter Champion to increase the involvement of primary care providers in improving health outcomes for deaf and hard of hearing children.
- ◇ The Maine Chapter Champion sits on the Maine Newborn Hearing Advisory Board.
- ◇ A parent with a child who is hard of hearing is a physician and is actively involved in family engagement in Maine as well as providing presentations to physicians.

Opportunities for Improvement

- ◇ Provide outreach and education to physicians to increase knowledge in the areas of diagnostic evaluations, early intervention services and at risk conditions.
- ◇ Education is needed for physicians to understand the critical importance of referrals for timely diagnostics by 3 months and referrals to early intervention by 6 months.
- ◇ Continue to develop and maintain an updated physician database.
- ◇ Conduct a needs assessment to identify training needs statewide.

Data Management

SMART Children Health Surveillance and Tracking System (CHSTS), Maine Newborn Screening Portal (MNHP tracking and surveillance system) tracks the approximate 12,500 infants born in Maine in a web-based system that seamlessly integrates data into a single user-friendly interface; all infants/children receive a unique identifier. SMART CHSTS links hearing screen data with multiple data sources including the electronic birth and death registry, metabolic (blood) screen data, audiology evaluation reports, birth defects and other CSHN programs such as the Cleft Lip and Palate and Partners in Care Coordination Programs. All records are linked using a cascading series of probabilistic linkage algorithms specifically designed for each input source, thus minimizing manual data matching and increasing the accuracy of individual level information across reporting sources. A key feature of SMART CHSTS is its ability to record all information on an individual child, including logging phone calls and correspondences. SMART CHSTS is able to organize individual contact information like mother's name, address, phone and infant's primary care provider, allowing MNHP to conduct follow-up on those infants who "refer." Identification of high-risk infants is made automatically through data included in the hearing screen. These infants are tracked closely to assess the degree to which high-risk infants develop hearing loss.

NebuLogic has developed and maintains SMART CHSTS, a web-based database system that integrates the information from the State Electronic Birth Registry System (EBRS) with data from the newborn hearing screen, the newborn bloodspot screen, and the birth defects registry and soon the CCHD screen. It allows programs within the Maine CSHN Program to access and share data about children, such as contact information or primary

care providers. SMART CHSTS enhances CSHN's capacity to provide seamless service to children and their families. Each module is described below.

Module People – Birth Certificate - Office of Data, Research and Vital Statistics (ODRVS) - ODRVS is the State's vital statistic agency. Birth and death certificates are uploaded on a weekly basis to CHSTS. ODRVS has implemented a new electronic birth certificate registration system for Maine. The system is web-based, bringing Maine in line with the National Center for Health Statistics (NCHS) 2003 standards, providing a number of benefits in terms of data timeliness, accuracy and flexibility.

Entered People – is a concept allowing the user to enter the name of a prospective infant/child who was not born in Maine and therefore has no birth certificate. CHSTS will assign the infant/child a unique identifier and then track the infant/child as they move through the system of care.

Module – Bloodspot - Newborn Bloodspot Program (NBSP) – is housed in the CSHN Program and data is uploaded and linked to hearing screen data in CHSTS. NBSP maintains a contract with the University of Massachusetts New England Newborn Screening Program to screen all bloodspots; this information is forwarded to CHSTS for upload. Bloodspot Screening data will be submitted to CHSTS using a web-based module reducing delays in linking bloodspot data that provides family and health care provider information.

Module – Hearing Screening – MNHP is housed in the CSHN Program. This module contains all screening, audiology and early intervention referrals. MNHP data is currently linked directly with bloodspot, birth defects and birth certificate modules.

Module – Birth Defects - Birth Defects Program (MBDP) – Maine hospitals and health care providers are mandated by law to report selected birth defects to MBDP; this data is uploaded and linked to hearing screen and bloodspot data in CHSTS.

Module- Critical Congenital Heart Defects- Birth Defects Program (MBDP)-CCHD - Maine hospitals are mandated by law to provide CCHD screening for all newborns and to report those results to the Maine Birth Defects Program. Discussions are being held with several birth hospitals to establish the capacity to extract required data from the electronic health record and transmit that data electronically to CHSTS. CHSTS is preparing the module that will accept this data and link it to hearing screen, bloodspot and birth defects data.

- MNHP and CEHD have demonstrated the ability to link data from newborn hearing screening with educational data.
- MNHP and CEHD have also demonstrated the ability to link hearing screening data with MaineCare (Maine's Medicaid Program) data.
- MECDHH and Maine CDC will work with NebuLogic to develop a plan for integrating health information technology and data access.

Maine's Part C agency, CDS, has an established database system called "Child Information Network Connection" (CINC). This is a statewide database system where all children involved in early intervention services and special education (3-5 year olds) have information entered into this one system. Information is child specific and includes the child's IFSP or IEP, evaluations, service logs, etc. All providers who work with the child

have access to the child's information. This allows for a multi-disciplinary team approach and ensures data is documented at the state level. This system brings Maine's early intervention data to a new level. MECDDH/GBSD's Director of Early Childhood Education and Family Services has access to every child with a documented hearing loss in Maine's CINC data to support the assurance of service delivery and appropriate and timely referrals and enrollment into early intervention.

Strengths

- ◇ Birth and death certificates uploaded on a weekly basis
- ◇ Bloodspot, birth defects and newborn hearing are all linked at the individual level
- ◇ Evaluated the effectiveness of SMART Children Health Surveillance and Tracking System (CHSTS) using the CDC's Guidelines for Evaluating Public Health Surveillance Systems.
- ◇ CDS's database CINC allows for a multidisciplinary team approach to early intervention and statewide access to a child's confidential file for providers and state level administrators.

Opportunities for Improvement

- ◇ Provide direct access to newborn hearing and newborn bloodspot extraction files "real time" data.
- ◇ Establish Standard Operating Procedures to clarify the data reporting process and improve timeliness of data reporting.
- ◇ Decrease the number of records requiring manual linkage.
- ◇ Training is needed statewide for staff and audiologists on the new CHSTS database system.
- ◇ Linking Part C data to the new CHSTS database system.

Statutes and Regulations

1995, 2005, PL 1995, c.676, 5(new); 2005, c. 279, 5 (rpr), The Maine Educational Center for the Deaf and Hard of Hearing and the Governor Baxter School for the Deaf is established as a public school pursuant to this chapter for the purpose for educating deaf and hard-of-hearing students. The school is a body politic and corporate and is an instrumentality and agency of the State. The exercise by the school of the powers conferred by this chapter is the performance of an essential public function by and on behalf of the State.

1999, Public Law 647, 22 M.R.S.A. c. 1686, establishes the Maine Newborn Hearing Program (MNHP) within the Department of Health and Human Services. The intent of the legislation was "to enable children and their families and caregivers to obtain information regarding hearing screening and evaluation and to learn about treatment and intervention services at the earliest opportunity in order to prevent or mitigate developmental delays and academic failures associated with undetected hearing loss."

The primary goals of the Newborn Hearing Screening Program are to ensure that: a) Every newborn in Maine receives a hearing screening prior to hospital discharge or by 1-month of age; b) Infants not passing the hearing screening receive an appropriate audiological diagnostic evaluation by three months of age; and c) Infants diagnosed with a hearing loss as a result of the newborn hearing screening program are referred to appropriate early intervention resources by six months of age. Program rules were adopted January 2004 defining the responsibilities of birthing facilities, primary healthcare providers, audiologists, and MNHP.

2007, P.L. 1142, “An Act to Enhance the Newborn Hearing Program” mandates that all providers of hearing diagnostic procedures report the results of their evaluation and diagnosis to the MNHP.

2008, P.L. 2106 “An Act to Enhance the Newborn Hearing Program” allows the MNHP to participate in a regional database with the other New England states to share hearing screening, evaluation and intervention data for those children who did not receive those services in their birth state.

2008, P.L. 2295, “An Act to Implement the Recommendations of the Working Group to Study the Effectiveness and Timeliness of Early Identification and Intervention for Children with Hearing Loss in Maine” requires that when a newborn receives a newborn hearing screen result of “refer,” the facility that performed the screen is mandated to schedule the newborn for a follow-up appointment with an audiologist.

2009, P.L. 450, “An Act to Improve Efficiency and Effectiveness of Early Intervention and Early Childhood Special Education for Children Birth to Eight Years of Age Through Improved Oversight, Accountability and Interagency Coordination” which requires MNHP to refer all children identified with a confirmed hearing to Part C – Child Development Services.

2016, Sec. 1. 20-A MRS 7413 , “An Act to Promote Private Fund-raising for the Maine Educational Center for the Deaf and Hard of Hearing and the Governor Baxter School for the Deaf.”

2019 - LD 642, “An Act regarding Kindergarten Readiness for Children who are Deaf or Hard of Hearing.” This act establishes a task force to recommend language development milestones for children birth to age five as well as recommend a system for monitoring language outcomes of Deaf and Hard of Hearing children.

SECTION III: METHODOLOGY

The MECDDHH/GBSD Supporting 1-3-6 and Family Engagement in Maine's Newborn Hearing Program is committed to providing systematic monitoring and evaluation of all

aspects of the project. MECDHH/GBSD will use the following approach to continuous quality improvement:

We will utilize the services of a contracted QI specialist to assist MECDHH/GBSD in developing this integral process. With the guidance of our QI Specialist, MECDHH/GBSD will complete the following:

- Re-Assemble the team – designate the team leader and team members
 - The team leader will be a QI specialist.
 - The team will include the following stakeholders:
 - Karen Hopkins, MECDHH/GBSD Director of Statewide Education and Family Services and Grant Project Coordinator
 - Holly Richards, Newborn Screening and Follow Up Coordinator
 - Anne Banger, MNHP Coordinator (parent)
 - Darlene Freeman, Quality Improvement Specialist (parent)
 - Katie Duncan, MNHP Audiology Consultant
 - Roy Fowler, Child Development Services Director and Part C Technical Advisor
 - Dixie Herweh, Parent Consultant (parent)
 - The team will re-address the following questions:
 - Are all necessary stakeholders involved?
 - Does the team need any training?
 - Who will facilitate the team and the process?
 - Communication Plan:
The MECDHH Newborn Hearing and Family Support Program will utilize MECDHH's distance technologies to communicate progress to partners and families statewide on a regular basis. Storyboards will also be used to communicate the goals and progress.
 - The team will use the PDSA process to evaluate the project:
Implement the phases of the PDSA
 - **Plan** – explore the current situation in order to understand barriers and develop possible solutions.
 - Identify and prioritize quality improvement opportunities.
 - Develop an AIM statement – answer the following questions a) what are we trying to accomplish; b) who is our target population; c) What numeric measures do we want to achieve; and, d) refine AIM statement as needed.
 - Describe the current process through the use of flowcharts.
 - Collect data on the current process – use baseline data that describes the current state, make sure that the data collected aligns with the AIM statement.
 - Identify all possible causes of a problem to determine its root cause, use a fishbone if needed.
 - Identify potential improvements to the problem and agree on one to test.

- Discuss any potential problems that might arise if we engage in this particular improvement activity.
- Develop an improvement theory – what is it that we expect to happen if we initiate this particular improvement activity.
- Develop an action plan – specify what needs to be done, who is responsible and when it should be completed.
- **Do** – implement the action plan
 - Implement the improvement.
 - Collect and document data.
 - Document problems, lessons learned etc.
- **Study** – analyze the effect of implementing the improvement
 - Compare results with measurable objectives.
 - Document lessons learned.
- **Act** – was the improvement achieved?
 - **Adopt** – spread.
 - **Adapt** – revise intervention, if appropriate.
 - **Abandon** – solution did not work return the Plan Phase.

Maine's EHDI program established a Quality Improvement Team in 2013. This group did a considerable amount of work to improve the quality of the EHDI program in Maine. The MECDDHH/GBSD Supporting 1-3-6 and Family Engagement Program QI team reviewed the work of the MNHP QI team and continued to focus on the areas of focus in the original plan, updating relevant information and activities. The new QI team will review the work of the past team(s) and determine further areas of focus. The focus of this review will be on the seven standards of successful EHDI programs set forth by NCHAM and JCIH. They include:

1. All newborns will be screened for hearing loss by 1 month of age.
2. All infants referred from screening will have diagnostic evaluations before 3 months of age.
3. All infants identified with hearing loss will receive appropriate medical, audiologic, and educational intervention services before 6 months of age.
4. All infants with hearing loss will have a medical home.
5. Every state will have a complete EHDI tracking and surveillance system to minimize loss to follow-up.
6. All families will receive culturally competent family support.
7. Every state will do systematic monitoring and evaluation to improve the effectiveness of the EHDI program.

The newly released JCIH document adds 7 additional principles. The QI team will review these new principles and the new JCIH document as part of their needs assessment. Data related to Maine's screening, diagnostics, early intervention and family support will be reviewed in the QI PDSA process.

Maine Newborn Hearing Advisory Board

The Maine Newborn Hearing Advisory Board was created by the 119th Maine State Legislature through the enactment of Public Law 1999,c 647, 22 M.R.S.A. c. 1686.

Maine EHDI has had an advisory board since its inception. The Board consists of an odd number of members, appointed by the Governor, including but not limited to: an audiologist, a physician, a speech-language pathologist, a nurse, a certified teacher of the deaf, a person who provides early intervention services to children who are deaf or hard of hearing through the MECDDH/GBSD, a person who is culturally deaf, a person who is hard-of-hearing or deaf, a parent of a child who is culturally deaf, a parent of child who is hard-of hearing or deaf, a parent of a hearing child, and a representative of each of the following: hospitals, health carriers, early childhood special education program under Title 20-A, Chapter 303, and the Department. The MNHP Advisory Board meets at least three times per year. The Education, Membership, Quality Improvement and Rules committee meet sporadically throughout the year.

The purpose and duties of the Board, as set forth in statute, are to:

- Provide oversight and advice to the Maine CDC Newborn Hearing Program;
- Advise the Commissioner of the Department of Health and Human Services on issues relating to the Program;
- Make recommendations on the procedures for hearing screening, evaluation, treatment and intervention services; and,
- Submit an annual report on the percentages of children being screened and evaluated and those children being offered and receiving intervention and treatment services to the Joint Committee on Health and Human Services.

MNHP Advisory Board Members – October 2019

Advisory Board Seats	Name
Audiologist	Eileen Peterson, M.S., FAAA
Speech-Language Pathologist	Louise Packness, CCC-SLP
Certified teacher of the deaf	Donna Casavant, MED, CAS
Culturally deaf person	Catherine Lushman
Parent of a child who is culturally deaf	Jennifer Gaulen
Parent of a hearing child	vacant
Representative of health insurance carriers	vacant
Representative of DHHS	vacant
Physician	Duska Thurston, MD
Nurse	Nola Metcalf, RN-C
ECFS EI service provider	Karen Hopkins, M.Ed. CAGS
Hard of hearing or deaf person	Harriet Gray, Pd.D
Parent of a hard of hearing or deaf child	Laura Sweet
Representative of hospitals	vacant
Representative of CDS	Melinda Corey
Other	Katherine Duncan, audiologist
Other	vacant

Collaborations/Partnerships

Maine CDC and EHDI Program – Maine Newborn Hearing Program. The Maine EHDI program has been a model of success since 2004. This program has considerably improved Maine's screening, diagnostic and early intervention data. The MNHP has been a strong partner with MECDDHH in ensuring timely referrals to EI and supporting appropriate delivery of EI services. They have also been very supportive in the efforts of MECDDHH to provide parent-to-parent support and increase parent and family perspective throughout the EHDI program in Maine.

Child Development Services – The SIEU-CDS is an Intermediate Educational Unit that provides both Early Intervention (birth through two years) and FAPE (ages three through under school age 5) under the supervision of the Maine Department of Education. The SIEU-CDS system is responsible for ensuring fulfillment of the State's responsibilities under the IDEA of 2004 and its implementing regulations, 34 CFR Parts 300 and 303. SIEU-CDS consists of nine regional sites and a state office. The state SIEU-CDS office maintains a central data management system, system-wide policies and procedures, and provides centralized fiscal services for the regional SIEU-CDS sites.

MECDHH/GBSD has had a long-standing collaboration with CDS. MECDDHH/GBSD has a formal Memorandum of Understanding with CDS to coordinate early intervention services in Maine collaboratively. The MOU reduces duplication of services, builds collaboration and provides a single point of entry into quality programming for deaf and hard of hearing children age birth to under age 6 by formally embedding the early intervention specialists from MECDDHH/GBSD who have expertise in deafness.

Maine Chapter of Hands and Voices meets on a quarterly basis and has representation from MECDDHH, the D/HH community and families. This chapter of this parent-led organization fosters the national mission of “what works for your child is what makes the choice right.” MECDDHH/GBSD has established a strong collaborative relationship with Maine Hands & Voices and has chosen this organization to be our dedicated Family Based Organization for the most recent HRSA grant work.

Boston Children's Hospital – Deaf/Hard of Hearing Program provides comprehensive evaluation and consultative services to deaf and hard of hearing children. MECDDHH has a long-standing collaboration with this agency in collaboratively supporting children and families, developing conferences and educational materials together and working to establish on-going communication between providers. MECDDHH/GBSD and Boston Children's continuously seek ways to collaborate and ease the burden of services on families.

Hear ME Now! is a non-profit organization that specializes in Listening and Spoken Language. Their providers serve parents, educators, medical professionals, hearing professionals, children and adults with hearing loss. They are part of the MECDDHH/CDS

Early Intervention Community of Practice that meets quarterly to ensure all providers that work with deaf and hard of hearing children birth through age five are working in one collaborative system. Their offices are housed on the MECDHH/GBSD campus.

Cued Speech Association of Maine (CSAM) - The Cued Speech Association of Maine is a non-profit organization. They provide information, support, and cue classes for families, professionals and individuals with and without hearing loss. MECDHH/GBSD and CSAM have had a long-standing collaboration of supporting families. The president of CSAM is on the CDS/MECDHH Early Intervention Community of Practice for early interventionists in Maine.

Maine Families (Maine's home visiting program) is a statewide network of community teams serving the needs of pregnant women and parents with newborns. As an affiliate of Parents As Teachers, Maine Families is required to screen all participants for hearing loss. MNHP has worked with Maine Families over the last few years to establish a hearing screening program by educating home visitors on the importance of screening and how to use the equipment. MECDHH/GBSD plans to continue this collaboration.

New England Consortium for Deaf Blindness (NEC) - The New England Consortium on Deafblindness (NEC) is a federally funded grant serving Connecticut, Maine, Massachusetts, Vermont and New Hampshire, through the United States Department of Education, Special Education. Their purpose is to assist state and local education agencies in developing the capacity to serve children and youth who are deafblind. NEC provides training and technical assistance, disseminates information regarding evidenced-based practices, provides parent training and networking activities, and collaborates with local and state agencies serving children who are deafblind or at-risk. MECDHH/GBSD has formed a strong partnership with this agency.

Head Start offers early childhood education for young children whose families meet federal poverty guidelines. Head Start is the federally funded, comprehensive preschool program designed to meet the emotional, social, health, nutritional, and psychological needs of children aged 3 to 5 and their families. It helps develop social competencies in children and promotes self-sufficiency through a family-focused approach. The Early Head Start program is the companion program created to address the same needs of children birth to age 3, expectant mothers and their families.

As part of the MECDHH/GBSD needs assessment in the first year of this grant, we will work collaboratively with Head Start to explore ways to provide training for their staff and look at possible collaborative activities that can be established for hearing screening practices up to age 3.

Sustainability

MECDHH/GBSD plans to build capacity for sustaining the work in this project by building funds into the current MECDHH/GBSD budget over the next three years. This will be done in the following ways:

1. Maine CDC has agreed to support necessary activities and positions that are not included in this grant and will collaborate with MECDHH/GBSD to develop a sustainability plan.
2. MECDHH/GBSD will use the evaluation and data from the QI team to document the need for increased budget within the MECDHH/GBSD budget to the MECDHH/GBSD school board.
3. MECDHH/GBSD will work collaboratively with Maine CDC to investigate options for continued sustainability through funds within the state's overall newborn screening program.
4. MECDHH/GBSD will work collaboratively with Maine Hands & Voices to investigate ways to increase the chapter's funding to be able to sustain the family support programs within the Maine chapter of Hands & Voices. Maine's Percival Baxter Foundation will support funding for parents to attend conferences and other family engagement activities.

SECTION IV: Work Plan

- **AIM 1 - By March 2024, MECDHH/GBSD's Supporting 1-3-6 and Family Engagement in Maine's Newborn Hearing Program will increase by 1 percent from baseline per year, or achieve at least a 95 percent screening rate, whichever is less, the number of infants that completed a newborn hearing screen no later than 1 month of age.**

MNHP has built strong relationships with its birthing centers, including the hospitals that are the first step after a referral in ensuring diagnosis by 3 months of age. The MNHP Coordinator has begun conducting regular trainings with birthing centers statewide. A training informational binder has been developed for consistency across sites. Trainings include hands on support on the completion of screenings using the facility's equipment, training on the delivery of screening results to families, and review of the state regulations guiding birth centers on the dissemination of screening results and scheduling of follow-up screenings post-discharge.

Primary Driver 1: Increase Birthing Facilities' knowledge of the importance for post-screen follow up on infants who receive a refer result on NHS.

- **Secondary Driver 1:** Provide re-education opportunities to all birthing facilities to refresh awareness of the need to make audiological referrals for infants that do not pass their newborn hearing screening.
- **Secondary Driver 2:** Conduct a needs assessment of birthing centers to determine current skills and areas of need in order to plan future trainings.
- **Secondary Driver 3:** Provide ongoing trainings to birthing centers to improve delivery of screening results to families.

Primary Driver 2: Increase midwives' knowledge of the importance of newborn hearing screening and follow up on infants that refer on NHS.

- **Secondary Driver 1:** Conduct a needs assessment of midwives to determine current skills and areas of need in order to plan future trainings.
- **Secondary Driver 2:** A presentation will be created to provide training and information to midwives about the NHS process and the importance of post-screen follow-up.

Primary Driver 3: Enhance knowledge of families on follow up after NHS.

- **Secondary Driver 1:** Distribute educational materials explaining about risk factors for hearing loss to families, childbirth classes, pediatricians, etc.
- **Secondary Driver 2:** Educate home visitors on the importance of follow up after NHS to accurately be able to share information.
- **Secondary Driver 3:** Educate families on the importance of CMV screening after a refer on newborn hearing screening.

Our evaluation strategy for this AIM involves the use of surveys of birthing facilities and the learning community to gather feedback on the effectiveness of the educational opportunities. The ultimate measure of the success of AIM 1 will be the increase in the number of newborns documented in the SMART Children Health Surveillance and Tracking System (CHSTS) who receive diagnosis by the end of three months of age.

Primary Driver 4: Investigate setting up a pilot with one hospital to provide targeted CMV screening to all babies who refer on NHS.

- **AIM 2 - By March 2024, MECDDH/GBSD's Supporting 1-3-6 and Family Engagement in Maine's Newborn Hearing Program will increase by 10% from baseline, or achieve a minimum rate of 85%, the number of infants that completed a diagnostic audiological evaluation no later than 3 months of age.**

MNHP has strived to implement a practice of 100% referral of all infants diagnosed with hearing loss to Early Intervention. As a partner with MNHP and the early intervention system, we are in a unique position to both support MNHP and providers so that there is truly “no wrong door” for referral to the early intervention system.

Primary Driver 1: Increase primary care physician knowledge of the most efficient process to refer to early intervention and the importance of physician encouragement to families to follow up with referrals to early intervention.

- **Secondary Driver 1:** Develop a packet of information, in collaboration with the Pediatric Audiology Workgroup, to be sent to primary care physicians after diagnosis, which outlines the impacts of

the child's hearing levels and provides information regarding the Early Intervention process in Maine.

Primary Driver 2: Increase parent familiarity with early intervention and the need for families to follow-up on EI referrals through a parent-to-parent perspective brochure created by Maine Guide By Your Side parent guides.

Primary Driver 3: Increase Audiologists' utilization of the online Maine Audiologic Assessment Report form, which is the most efficient means of expediting timely referrals to early intervention.

- **Secondary Driver 1:** Work with CDS and MNHP to identify ways to reduce reduplicative steps between CINC and the audiology assessment online reporting process.
 - **Secondary Driver 2:** Working with the new Data and Surveillance system, develop a streamlined approach to inputting information into the online Maine Audiologic Assessment Report form, including linking the online reporting form with the CDS referral form, and by allowing audiologists to easily update information on children whose information has previously been input.
 - Our evaluation of this AIM will rely on data from the CSHN Data and Surveillance system compared to the data regarding children with diagnosed with hearing loss to indicate whether audiologists are regularly completing the online reporting form for all children under age 3 diagnosed with hearing loss in the state.
- **AIM 3: By March 2024, MECDDH/GBSD's Supporting 1-3-6 and Family Engagement in Maine's Newborn Hearing Program will increase by 15% from baseline, or achieve a minimum rate of 80 percent, the number of children who are deaf or hard of hearing who are enrolled in Early Intervention services by 20% from 7 to 8.**

MNHP refers 100% of the children in Maine with a diagnosed hearing loss to CDS. Analysis of the underlying reason for low counts in the data indicate that the issue is not enrollment into CDS, but instead issues preventing the timely sharing of information between the two, somewhat separate and non-interacting systems. MECDDH/GBSD is now a partner with CDS and can bridge this gap.

Primary Driver 1: Increase documentation of early intervention referrals from CDS and MECDDH/GBSD to MNHP.

- **Secondary Driver 1:** Given staffing changes at both CDS and MECDDH, review MOU between CDS/ECFS with CDS sites and ECFS early interventionists to ensure that staff are aware of procedure and responsibilities for documenting enrollment in early intervention.

- **Secondary Driver 2:** Develop a tracking system for documentation of referrals being sent from CDS/ECFS to MNHP.
- **Secondary Driver 3:** Educate CDS site directors and program managers on the importance of documentation and the role of ECFS in this process to support state data collection.

Primary Driver 2: Educate primary care physicians on the importance of enrollment into early intervention by 6 months after diagnosis of hearing loss.

- **Secondary Driver 1:** Conduct a needs assessment of primary care physicians to determine current skills and knowledge, and areas of need in order to plan future trainings.
- **Secondary Driver 2:** Develop training plan and implement plan for educating primary care physicians, including training on the existing roadmap for families on the process of NHS.
- **Secondary Driver 3:** Develop training plan and implement plan for educating primary care physicians on Maine's early intervention process for children who are Deaf or Hard of Hearing.

Primary Driver 3: Investigate the role of parent-to-parent support in supporting timely enrollment into early intervention.

- **Secondary Driver 1:** Conduct a needs assessment on the needs of families for support in the early enrollment process of early intervention.
- **Secondary Driver 2:** Provide training to the newly hired parent consultant to call all families after diagnosis to support enrollment into early intervention.
- **Secondary Driver 3:** Include the parent consultant in the early intervention Community of Practice to share on-going family feedback on the enrollment process into early intervention.
- **Secondary Driver 4:** Develop training materials for the GBYS coordinator to use with parent guides on understanding the process from diagnosis of hearing loss into early intervention.
- The evaluation of AIM 3 will be based on data collected pre- and post-training of primary care providers to determine if their knowledge of the EI process has been increased as a result of trainings. Data regarding the success of the tracking system, as measured by the comparison of children identified in the tracking system to those in the MNHP system, will also support evaluation of this AIM.

Using data collected from year 1 as baseline data: Increase by 20 percent from baseline the number of families enrolled in family to family support services by no later than 6 months of age.

- **Primary Driver 1:** Using Guide By Your Side Parent Guides, train ECFS early interventionists on the process of referring families for GBYS services and the impact of referrals on outcomes using previously collected data.
- **Primary Driver 2:** Develop and distribute promotional materials to primary care providers regarding GBYS services, including information on the referral process.
- **Primary Driver 3:** Train CDS staff on the Communication Opportunities process and how Parent Guides are an integral part of this process.
- **Primary Driver 4:** Establish family events that encourage family to family support.

Increase by 10 percent the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age.

- **Primary Driver 1:** Using trained Deaf Guides, train ECFS early interventionists on the process of referring families for Deaf Guide services and the impact of referrals on outcomes using previously collected data.
- **Primary Driver 2:** Develop and distribute promotional materials to primary care providers regarding the Deaf/HH Guide program, including information on the referral process.
- **Primary Driver 3:** Train CDS staff on the Communication Opportunities process and how Deaf/HH Guides are an integral part of this process.
- **Primary Driver 4:** Establish family events that encourage families to meet Deaf and Hard of Hearing adults.

Increase by 10 percent the number of health professionals and service providers trained on key aspects of the EHDI program.

- **Primary Driver 1:** Using the Needs Assessment work plan in Attachment X, conduct a HRSA assessment of health professionals and service providers working with children who are deaf or hard of hearing to determine current skills and knowledge, and areas of need in order to plan future trainings.
- **Primary Driver 2:** Following completion of the needs assessment, provide trainings throughout the state to increase provider knowledge on identified key aspects of the EHDI program.

SECTION V: RESOLUTION OF CHALLENGES

MECDHH/GBSD continues to build collaborative partnerships including state agencies throughout Maine. Although these partnerships have been extremely positive, collaborative work takes time, cooperation and agreed upon goals and work plans. MECDHH/GBSD has agreed to request HRSA funding on behalf of the Maine CDC to work collaboratively to meet the goals of the CDC in implementing an effective EHDI program and embedding family engagement in all areas of programming and decision-making. Funding continues to be a challenge for both the CDC and MECDHH/GBSD. State funding is limited and the needs are vast. An additional challenge is staff shortages. It is difficult to find qualified professionals in our rural state. The audiology community

is small, we have few birthing facilities, and our early interventionists are spread thin traveling hours a day to meet the needs of children and their families.

- **AIM 1 - By March 2024, MECDHH/GBSD's Supporting 1-3-6 and Family Engagement in Maine's Newborn Hearing Program will increase by 1% from baseline per year, or achieve at least a 95% screening rate, whichever is less, the number of infants that completed a newborn hearing screen no later than 1 month of age.**

Low numbers of birthing facilities continues to be a challenge in our state. Families sometimes have to drive great distances to give birth to their babies. Turnover of staff at the hospitals continues to be a challenge in training staff to understand the importance of following protocols and stressing the importance of follow up with families. Another challenge is overall hospital screening processes, especially in their training protocols. Home births continue to be a challenge in encouraging the families to agree to screening or to follow through with re-screens. This is where we see the greatest lost to follow up. The MNHP has developed strong working relationships with hospitals and birthing centers in Maine. It is this relationship that will be instrumental in achieving this AIM.

- **AIM 2 - By March 2024, MECDHH/GBSD's Supporting 1-3-6 and Family Engagement in Maine's Newborn Hearing Program will increase by 10 percent from baseline, 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.**

It has been a challenge in Maine to educate physicians on the importance of follow up and referrals to audiologists to determine diagnosis. It has also been a challenge to support physicians in understanding the importance of evaluation by 3 months, not only referral for testing, but full diagnosis. Finding an avenue for educational opportunities has been challenging. Our Chapter Champion and QI Specialist will be instrumental in supporting our efforts to ensure physicians are recognizing the importance of follow up for children who have been diagnosed with a hearing loss. Another challenge is the rural nature of our state. Families often have to drive great distances for audiological evaluations and audiology facilities often have long wait lists for ABR evaluations. This often results in low follow up and diagnostic rates. Our strong connection with the current Hands & Voices/GBYS program will assist in ensuring successful outcomes as we will partner with them to create various materials for educating and supporting families on the importance of follow up after screening and ensuring parent-to-parent support is readily available.

- **AIM 3: By March 2024, MECDHH/GBSD's Supporting 1-3-6 and Family Engagement in Maine's Newborn Hearing Program will increase by 15% from**

baseline, or achieve a minimum rate of 80%, the number of infants identified to be Deaf or Hard of Hearing that are enrolled in early intervention services the number of children who are deaf or hard of hearing who are enrolled in Early Intervention services by 20% from 7 to 8.

MNHP refers 100% of children in Maine with a diagnosed hearing loss to Early Intervention. Analysis of the underlying reason for low counts in the data indicates the issue is not with enrollment into Early Intervention but instead continues to be in preventing the timely sharing of information between the two somewhat separate and non-interacting systems. With the Director of Statewide Education and Family Services supervising the early intervention specialists of MECDHH, the addition of a new database with tracking system for referrals and the revised MOU with CDS, we are equipped to focus on improvement with this AIM.

SECTION VI: Evaluation and Technical Capacity

The primary purpose of evaluation is to measure to what extent the program goals, strategies and activities were met. Through the four years of the project the MECDHH/GBSD QI Team will continually answer the following questions:

- Have the activities been effective in increasing the number of newborns who receive timely diagnosis per JCIH guidelines? Specifically, does MECDHH/GBSD on an annual basis see an increase in the number of newborns in Maine that receive a diagnosis by 3 months?
- Have the activities been effective in increasing the number of newborns/infants who receive timely referral to EI. Specifically, does MECDHH/GBSD continue to see 100% referral to EI by MNHP?
- Have the activities been effective in increasing the number of children with hearing loss enrolled in EI? Specifically, does MECDHH/GBSD see an increase in the ability of Maine CDC to be able to account for the number of children enrolled in EI?
- Have the activities developed partnerships supported by memorandum of understanding with identified statewide, family-based organizations or programs that provide family to support to families/parents/caregivers of newborns and infants who are deaf or hard of hearing? Specifically can MECDHH/GBSD document, on an annual basis, development and continued collaboration with family support agencies?

The QI Team will meet once a month in person or via MECDHH/GBSD distance technology to review current program activities, review and monitor data. The Data will be collected in CHSTS, Maine's surveillance and tracking system, and submitted annually to the MNHP Advisory Board, MECDHH/GBSD, CDC and the Maternal and Child Health Block Grant. The newborn hearing screening data is integrated with the birth and death certificate data, birth defects and newborn bloodspot data. Early Intervention data will also be housed in the Department of Education's CINC,

new database system. The MECDHH/GBSD Director of Statewide Education and Family Services will monitor this data weekly.

MECDHH/GBSD Director of Statewide Education and Family Services and MNHP Coordinator and other staff will monitor the following measures.

- Number of infants screened.
- Number of infants who “passed.”
- Number of infants who missed screens, excluding those who died and those whose parents declined screening.
- Number of infants LFU/D that includes number of home births, parents who are unresponsive and those infants transferred out of state and MNHP unable to get results.
- Number of infants who “referred,” excluding those who died, parent declined, moved out of state, and those with a diagnosis in progress.
- Number of infants with a completed diagnosis
- Number of infants LFU/D at diagnosis.
- Number of infants with a confirmed hearing loss.
- Number of infants referred to Part-C early intervention.
- Number of infants receiving Part-C and/or non- Part-C services (ECFS).
- Number of infants for whom MNHP can't confirm that they are receiving no early intervention, excluding those parents that have refused services.
- Number of infants LFU/D.

The grant application will be presented to the MECDHH/GBSD school board and the MNHP Advisory Board so they are aware of the grant activities. Thereafter, both Boards will be regularly updated on accomplishments through the presentations and data sharing.

- **AIM 1 - By March 2024, MECDHH/GBSD's Supporting 1-3-6 and Family Engagement in Maine's Newborn Hearing Program will increase by 1% from baseline per year, or achieve at least a 95% screening rate, whichever is less, the number of infants that completed a newborn hearing screen no later than 1 month of age.**
 - The success of this AIM will be monitored through CHSTS data analysis, and the needs assessment data in year one.
- **AIM 2 - By March 2024, MECDHH/GBSD's Supporting 1-3-6 and Family Engagement in Maine's Newborn Hearing Program will increase by 10% from baseline, or achieve a minimum rate of 85%, the number of infants that completed a diagnostic audiological evaluation no later than 3 months of age.**
 - The success of this AIM will be monitored through CHSTS data analysis.
- **AIM 3: By March 2024, MECDHH/GBSD's Supporting 1-3-6 and Family Engagement in Maine's Newborn Hearing Program will increase by 15% from**

baseline, or achieve a minimum rate of 80 percent, the number of infants identified to be Deaf or Hard of Hearing that are enrolled in early intervention services the number of children who are deaf or hard of hearing who are enrolled in Early Intervention services by 20% from 7 to 8.

- The success of this AIM will be monitored through CHSTS data analysis.
- MNHP refers 100% of children in Maine with a diagnosed hearing loss to Early Intervention. We will evaluate the follow up by families and Early Intervention by monitoring the data in both CHSTS and CINC. With the Director of Statewide Education and Family Services supervising the early intervention specialists of MECDHH, and the revised MOU with CDS, we are equipped to support this AIM.

SECTION VII: ORGANIZATIONAL INFORMATION

Applicant Experience and Structure

Since 1957 the Maine Educational Center for the Deaf and Hard of Hearing/Governor Baxter School for the Deaf has been providing state of the art services and support to children who are deaf or hard of hearing and their families throughout the state of Maine. Currently MECDHH/GBSD serves over 700 deaf and hard of hearing children and families throughout Maine. Since its inception, MECDHH/GBSD has been actively and dynamically engaged in supporting parents and families of children with hearing loss. This has included a wide array of offerings including, but not limited to, consultation, education, informal advocacy, networking, creating parent-to-parent relationships, developing connections with readily available resources pertinent to the individual needs of a family/parent and supporting infants, toddlers, children and adolescents with hearing loss. Our Early Childhood and Family Services program has been providing services, statewide, tailored to the needs of Deaf and hard of hearing children and their families. Over the years support has been provided for all children who are deaf or hard of hearing and their families regardless of their chosen mode of communication. Support has been unbiased, designed to meet the needs of the individual child and family and steeped in best practice and research. Our staff are specifically trained to work with infants, children and adolescents who are Deaf or hard of hearing and their families. This includes Teachers of the Deaf, Special Educators, an Educational Audiologist, Early Childhood Educators, Speech/Language Pathologists and a Licensed Clinical Social Worker. Several of our staff received training in Ski HI, a nationally recognized training model, with a proven record of success, for professionals working with the parents/families of Deaf and Hard of Hearing infants, toddlers and children. This experience and training is critical to the work we will need to do in our “Supporting 1-3-6 and Family Engagement in Maine's Newborn Hearing Program” program. We have a strong and mutually respectful relationship with Part C, as demonstrated by the MOU, co-authored by CDS and MECDHH/GBSD and our ongoing professional relationship with CDS Site Directors across the state. We continue to strengthen and expand the skills, knowledge and

understanding of our staff via professional development regarding all communication options (Listening and Spoken Language, ASL, Cued Speech, and Bi-lingual/Bi-modal). MECDHH/GBSD has entered into a Memorandum of Understanding with Child Development Services, Maine's Part C agency. The purpose of this MOU is to develop a collaborative approach between the SIEU-CDS and MECDHH/GBSD while clarifying roles and responsibilities and enhancing and expediting the provision of early intervention services and/or special education/related services for children, birth to under school age 6 in accordance with the IDEA laws and regulations and Maine statutes and regulations. It was agreed that collaboration and cooperation are necessary components to ensure effective implementation of the Individual Family Service Plan (IFSP) in the natural environment and Individual Education Plan (IEP) in the least restrictive environment. These efforts will reduce duplication of services, build collaboration, and continue to provide quality programming for deaf and hard of hearing children birth to under age 6. This agreement shows collaboration with a state agency.

The organizational chart of our organization (see attachment) shows our experience into age spans from birth through the age of 20 (or upon high school graduation). For the purposes of this grant, we will focus on experience and expertise in working with infants, toddlers and young children who are Deaf and Hard of Hearing and their parents/families.

In 2011 MECDHH/GBSD was awarded a three year Distance Learning Telemedicine Grant from USDA for \$476,336.00 to develop video conferencing capability to twelve towns populated by 38,581 residents. The grant enabled children who are deaf and hard of hearing and their families to overcome geographic, language and cultural barriers to access rich and diverse programming from designated Hub sites. This three year grant provided MECDHH/GBSD with an extraordinary experience to connect with families who live in remote areas of Maine who are often isolated from critical resources. Through video conferencing technology MECDHH/GBSD provided ongoing information and support by expanding parent programs into rural communities with our Hub sites that facilitated access to specialists. It provided wonderful collaborations with Boston Children's Hospital, hear ME now, Clarke School for Hearing and Speech, and the Rochester Institute of Technology as well as hands on technology experience for parents and families. MECDHH/GBSD will continue to utilize this robust distance technology in all aspects of the Newborn Hearing and Family Support Program.

With this technology we have produced several fully-accessible professional webinars on various topics related to early intervention, hearing assistive technology, communication opportunities, literacy and other pertinent topics in the field of deafness today. Our webinar series have been accessed in every county throughout the State of Maine, across the United States and Canada.

In 2016 MECDHH/GBSD Early Childhood Program was awarded a "mini grant" for \$3,300 from the Gorman Foundation to improve the outside educational environment of the early childhood classrooms at MECDHH. The early childhood team members were instrumental in writing this grant and monitoring outcomes as the project progressed.

In 2019 MECDHH/GBSD Statewide Educational Services Department was awarded a \$200,000 2 year grant from the state of New Hampshire to implement the new NASDE Guidelines for Deaf Education document.

Our collaborative partner, the Maine CDC Newborn Hearing Program is a program within the Maine Department of Health and Human Services (DHHS), whose mission is to “assist individuals in meeting their needs, while respecting the rights and preferences of the individual and family, within available resources.”⁸ The Maine Center for Disease Control and Prevention (MECDC), Division of Population Health (DPH) oversees the project through the Children with Special Health Needs Program (CSHN), which ensures “the health and well-being of the CSHN population by developing and sustaining community-based systems of care”.⁹

CSHN is a multi-faceted children’s public health program that includes Newborn Hearing; Newborn Bloodspot (metabolic); Birth Defects; Comprehensive Genetics; Perinatal Outreach and Education; Maternal Fetal and Infant Mortality Review Panel; Partners in Care Coordination; Cleft Lip/Palate; and, MaineCare (Medicaid) Member Services (EPSDT). DHHS, MECDC/DPH and CSHN organizational charts are located in Attachment 5. The ME CDC CSHN Program is guided by the following six strategies that maximize systems integration:

1. Build, enhance and maximize partnerships;
2. Engage families and youth as partners;
3. Use continuous quality improvement (CQI);
4. Use data to build capacity and measure impact;
5. Provide technical assistance, resources and supports; and,
6. Promote policy and legislative changes.

The CSHN Program is a highly specialized team of 12 individuals (nurses, social workers, benefits specialists, and administrative and fiscal support personnel). Several advisory boards provide access to a multitude of private and public health care professionals, including parents that help guide the program; these boards include the Birth Defects, Newborn Bloodspot, and Newborn Hearing Advisory Boards. In addition, the CSHN Program maintains several contracts with hospitals to ensure that infants and children have access to clinical services. These include Genetics, Cleft Lip and Palate, and Perinatal Outreach, and one cooperative agreement with the University of Maine College of Education and Human Development (CEDH). CSHN maintains a management team that includes the Director, Assistant Director for CSHN, and the Director of Genetic Services.

Personnel Resources

⁸ http://www.maine.gov/dhhs/mission_vision.html

⁹ <http://www.maine.gov/dhhs/mecdc/population-health/cshn/index.html>

The Maine Newborn Hearing Program (MNHP) has been in existence since 1999 and Anne Banger, the current coordinator has been with MNHP since 2012 and was recently named the program coordinator. Anne is supervised by Holly Richards, the program manager of the Newborn Hearing Screening Program.

MECDHH/GBSD and its project partner, MNHP will work toward increasing the number of infants that are screened no later than 1 month of age; have diagnosis of hearing loss by 3-months of age; and are enrolled in appropriate early intervention services by 6 months of age. MECDHH/GBSD and MNHP will conduct a needs assessment in year one then provide education to parents, health professionals, audiologists, EI providers, and others; provide training and technical assistance to birthing facilities on screening procedures; offer assistance with follow-up for diagnostic evaluation; referral to EI services (Part C – CDS); and, promote family choice through education on available options. Staff pertinent to the MECDHH/GBSD “Supporting 1-3-6 and Family Engagement in Maine’s Newborn Hearing Program” include the following: Karen Hopkins, Project Director, Holly Richards, Newborn Screening Program Manager, Anne Banger Newborn Hearing Screening Coordinator, Katie Duncan, Audiologist, Darlene Freeman, Quality Improvement Specialist, Virginia Herweh, Parent Consultant, Catherine Murphy, Financial Officer.

See Attachment 2: Staffing Plan and Job Descriptions and Attachment 3: Biographical Sketches for Key Personnel

MECDHH/GBSD and MNHP staff regularly collaborates with individuals from the Birth Defects Program, Cleft Lip and Palate Program, Newborn Bloodspot Program, Public Health Nursing, Date, Research and Vital Statistics, Department of Education – Part-C, WIC, Maine Families - Maine’s Home Visiting Program, programs that serve deaf and hard of hearing children such as hear ME now!, the Maine Cued Speech Association, and others.