Early Hearing Detection and Intervention Program
Wisconsin Project Narrative

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I. INTRODUCTION

This application is submitted by the Wisconsin (WI) Department of Health Services (DHS), Division of Public Health (DPH) in response to the CFDA # 93.251 – *Early Hearing Detection and Intervention Program.* This application is aimed at improving the system of care to ensure that children who are deaf or hard of hearing (D/HH) 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.

The early identification of infants with hearing loss is an important public health objective. The Joint Committee on Infant Hearing (JCIH), 2000 and 2007 Position Statements recommend that: 1) All infants should have access to hearing screening using a physiologic measure before 1 month of age; 2) All infants who do not pass the initial hearing screen and the subsequent rescreening should have appropriate audiologic and medical evaluations to confirm the presence of hearing loss before 3 months of age; and 3) all infants with confirmed permanent hearing loss should receive intervention services before 6 months of age. As noted in the Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing (D/HH), screening and confirmation that a child is D/HH are largely meaningless without appropriate, individualized, targeted and high-quality intervention, immediate and on-going family support, and access to support, mentorship, and guidance from individuals who are D/HH.

WI passed initial hearing screening legislation in 1999. In response to the legislation and to the Maternal Child Health Bureau (MCHB) National Hearing Screening Performance Measure, the Children and Youth with Special Health Care Needs (CYSHCN) Program in the Division of Public Health (DPH) established the Wisconsin Sound Beginnings (WSB) Program in 2000. Since then, WSB has made significant progress towards implementation of a statewide Early Hearing Detection and Intervention (EHDI) Program.

Permanent congenital hearing loss is one of the most frequently occurring birth defects. Approximately two infants per thousand are born with some level of hearing loss annually in WI. In May of 2010, the legislature updated the hearing screening legislation to include mandated hearing screening in Wisconsin and establishing that: "…the physician, nurse-midwife, or certified professional midwife who attended the birth shall ensure that the infant is screened for hearing loss before being discharged from a hospital, or within 30 days of birth if the infant was not born in a hospital." Currently, 100% of hospital birth units have implemented universal newborn hearing screening (UNHS) programs along with the vast majority of nurse-midwife, or certified professional midwife practices in WI. WI's progress may be attributed to the public-private partnerships established by the WSB Program and the Newborn Screening Advisory Hearing Subcommittee and its members *(Attachment 7a)*. Additionally, a signed memorandum of Understanding *(Attachment 4 MOU)* with the Department of Children and Families Maternal, Infant and Early Childhood Home Visiting (MIECHV) Program assures a home visitation representative will serve on the Newborn Screening Advisory committee, which make WI well positioned to address the new early and continuous screening planning requirement of this application.

Although much progress has been made toward the goal to screen all newborns, national data from the 2016 Centers for Disease Control and Prevention (CDC) EHDI Hearing Screening and Follow-up Survey (HSFS) indicate that 25% of all newborns who refer on the hearing screen do not return for follow-up services. Research indicates that infants enrolled in an intervention program by six months of age perform better on school-related measures than children who did not receive intervention. Yet nationally, only 67% of the infants identified as D/HH were known to have received some sort of early intervention, and according to the JCIH, most states/territories are not yet able to provide documentation of outcomes resulting from enrollment in EI services. It is critical that systems are put into place to ensure that infants receive timely diagnostic and high quality, culturally attuned, deafness specific intervention services. The primary focus of this grant application is for the WSB Program to strengthen identification and early intervention services through meaningful implementation and integration of family leadership development, engagement and culturally sensitive support within all stages of the EHDI continuum, in order to document family and child outcomes.

Improvements in early intervention and family support are meaningless if a program cannot identify which babies are D/HH because they are not screened or are lost to follow-up. Therefore, statewide data collection and surveillance is a critical component in implementing a sustainable system of early hearing detection and intervention. In WI, infants are tracked through a partnership with the metabolic blood screening program at the Wisconsin State Laboratory of Hygiene (WSLH). In April of 2002, hearing screening values were added to the metabolic blood screening card. Initial hearing screening results are recorded on the blood card and sent to the WSLH where hearing screening data is transmitted nightly via secure messaging from the WSLH database to the web-based WI EHDI Tracking Referral and Coordination (WE-TRAC) system's data repository. WE-TRAC is a part of the Wisconsin Public Health Information Network (PHIN), developed by the DPH. WE-TRAC business logic determines the appropriate action for each record, sending only babies that need further screening to individual hospital queues where users can view lists of babies associated with their organization. This system alerts well-baby birthing units, special care nurseries and audiologists that babies need follow-up and allows these providers to make electronic referrals and enter re-screening, medical home information and diagnostic results in real time.

WE-TRAC is currently utilized by 100% of birthing units and Neonatal Intensive Care Units (NICUs) representing 99% of Wisconsin births, as well as the majority of Homebirth Midwifery practices. All audiology organizations (109) that see babies born in WI enter screening and hearing evaluation information into WE-TRAC, make online referrals for additional testing and track individual babies through their confirmation of hearing loss, treatment and management and electronic referrals to the Birth to 3 Program. WE-TRAC provides the WSB Program the capacity to measure statewide loss-to-follow-up rates, monitor loss-to-follow-up by organization, track individual babies at-risk for loss-to-follow-up, evaluate the effectiveness of loss-to-follow-up reduction strategies, and record parent to parent support.

The WSB program is recognized by the Family Health Section (FHS) of DHS to be a core part of the larger Newborn Screening Program, which currently encompasses blood Screening, congenital heart screening and hearing screening. In a strategic effort to contribute to the sustainability of the program, many core screening functions of the WSB program are now being funded through the Federal Maternal Child Health Title V Block Grant. Additional funding to support hearing screening is being considered through a fee increase to the blood screening card. By diversifying funding, WI is able to focus these grant dollars on innovative strategies to address early diagnosis, intervention and family support.

II. NEEDS ASSESSMENT

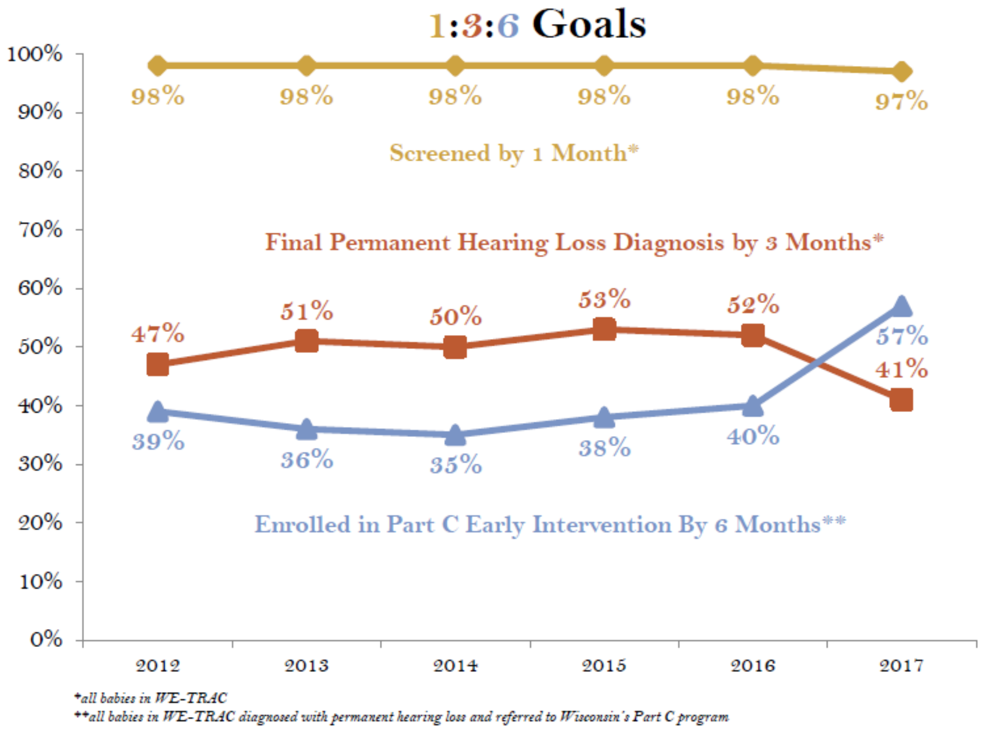
In Wisconsin in 2017, there were 64,556 occurrent live births with 62,818 babies born in one of 100 birthing hospitals or free-standing birth centers and the remaining 1,7741 (2.7%) documented as out-of-hospital (OOH) births. Wisconsin births by mother's race/ethnicity as reported via the birth record in 2017 are described in the table below:

WE-TRAC Data (DOB 1/1/2017 – 12/31/2017)				
Mother's Race / Ethnicity*	**# of Births**	**% of Births**	**% of closed cases by race/ethnicity**	**% (# closed/# births)**
Non-Hispanic White	45,897	71.1%	790	1.7%
Non-Hispanic Black	6,717	10.4%	85	1.3%
American Indian	814	1.3%	9	1.1%
Hispanic/Latino	5,097	7.9%	28	0.5%
Laotian/Hmong	1,301	2.0%	10	0.8%
Other Asian	1,567	2.4%	10	0.6%
Other (NHPI, unknown, other, multirace)	3,163	4.9%	61	1.9%
Total	**64,556**	**100%**	**993**	**1.5%**

Wisconsin was one of five states selected to participate in an MCHB supported Community of Learners facilitated by the National Center for Cultural Competence. This year long opportunity allowed the WSB team to emphasize our attention on the unique ways culture may impact family experience with the EHDI system. Team members engaged in individual reflection, as well as team exploration of Cultural Attunement, in pursuit of meeting each family where they are at. The exploration of implicit and systemic bias and equity in the EHDI system will be an on-going area of focus during this grant cycle.

Universal Newborn Hearing Screening (UNHS) is part of the standard of care in birth hospitals. In 2017, 97% of babies were screened prior to one month of age with a 0.8% refusal rate. In 2017, the statewide average rate of infants who do not pass the inpatient hearing screen was 3.1%, which falls within the American Academy of Pediatrics recommendation of less than 4%. The statewide average rate of infants who do not pass the final hearing screen was 1.1%. The WSB program periodically monitors both screen rate and referral rate by birth organization to aid in quality improvement (QI) efforts. WSB encourages Birth Units and OOH birth providers to monitor their own refer rates, as well as conduct annual screener competency training.

The data in WE-TRAC provides the framework for assessing programmatic need areas, tracking loss-to-follow-up (LTFU), and evaluating outcomes of the WSB program initiatives. WE-TRAC provides the WSB Program with the capacity to track individual babies as they progress through the EHDI continuum of care as well as the ability to track Wisconsin's progress toward meeting the JCIH identified targets. Wisconsin has made steady progress toward screening babies by one month of age (97%) and increasing access to a diagnostic evaluation by three months of age (70%). However, the average age at the time of confirmation of hearing loss has stayed steady at around 50% diagnosed by three months of age and declined to only 41% in 2017. Therefore, WSB will work closely with audiology partners, such as the Wisconsin Speech Pathology and Audiology Association and Children's Hospitals of Wisconsin, to conduct a needs assessment in year 1 to determine what the barriers are to early diagnosis, and understand what quality improvement strategies and training needs might result in improving this statistic.



*all babies in WE-TRAC
**all babies in WE-TRAC diagnosed with permanent hearing loss and referred to Wisconsin's Part C program

According to national incidence data, approximately 1 to 3 babies per 1000 live births should be identified with congenital hearing loss in the WI each year. Although there has been a steady decline in the number of WI live births (72,757 live births in 2007 to 64,556 in 2017) we have seen a steady growth in the number of babies identified as D/HH.

WSB identifies two main populations as "lost-to-follow-up" (LTFU):

1. babies who never had their hearing screened (*never screened*).
2. babies who were screened but did not pass and have not received follow-up (*did not pass*).

WSB addresses these two populations in separate ways, targeting interventions to meet each group's needs. However, to get a global picture of babies who need a service but did not receive it (either an initial screen or a follow-up screen/diagnostic evaluation), WSB combines these two populations to calculate our Total LTFU rate. WSB's efforts targeting the *never screened* population and the *did not pass* population have systematically reduced our LTFU rate. Wisconsin also tracks lost-to-follow-up/lost-to-documentation (LTFU/LTD) data as babies who have a confirmed hearing loss but are not known to be enrolled in Birth to 3. In 2017, there were 64,556 births recorded in WE-TRAC. Of those births: 114 were not screened (for a reason other than infant death or parent refusal); 1,318 did not pass the hearing screening; and 111 babies did not pass and did not receive follow-up due to LTFU/LTD or unresponsive family. Of the 503 babies who did not pass but did get reported audiologic follow-up, 108 had a permanent hearing loss. However, as mentioned previously, only 76 were enrolled in early intervention. WSB will analyze each of these LTD/LTFU categories quarterly throughout this grant cycle to continuously assess on-going need areas and drive improvement initiatives.

One of the most effective strategies for reducing LTFU is to ensure that every baby has an informed medical home with good communication among the medical home and specialty care providers. Since 2003, WI has been working to ensure that all children and youth with special health care needs (CYSHCN), including those with hearing loss, are connected to a medical home. In 2003, WI was one of 11 states selected to participate in a National Medical Home Learning Collaborative (MHLC) sponsored by the federal MCHB, National Institute for Children's Healthcare Quality (NICHQ), the Center for Medical Home Improvement (CMHI) and the National Center for Medical Home Initiatives for Children with Special Needs at the American Academy of Pediatrics. During the MHLC, all practices completed rapid-cycle quality. Based on the lessons learned, the www.wimedicalhometoolkit.aap.org was developed to facilitate implementation of care coordination at the practice level. WSB will continue to partner with the Children's Health Alliance of Wisconsin and Children's Hospital of Wisconsin

To address Wisconsin's LTFU/LTD rate for babies who are screened but did not pass, WSB employs an innovative 3-Step-Follow-Up (3SFU) intervention to prevent LTFU. Using the WE-TRAC system, WSB identifies babies as at-risk for LTFU as any baby who has not passed their inpatient screen and has not received follow-up by 30 days of age. When these at-risk babies 'time out' in WE-TRAC, WSB staff begins the 3SFU process, which includes Medical Home Outreach, Parent-to-Parent Support and In-home/In-community Hearing screening.

An area that needs continued attention is ensuring that a child who does not pass the newborn hearing screening is connected to an informed physician with whom they will follow-up after the baby is discharged from the hospital (a medical home). Having accurate data is essential as WSB staff reaches out to the infant's medical home if the baby does not pass the hearing screening and is identified to be at-risk for LTFU to provide information and partner with the medical home to get the family back into care and provides "Just in Time" packets of information to physicians of infants who are diagnosed with a permanent hearing loss ages 0 to 3 years of age.

WI was also one of eight states selected to participate in the 2007 NICHQ EHDI Medical Home Learning Collaborative sponsored by MCHB focusing on reducing loss to follow-up from newborn hearing screening programs through the medical home. Four practices were recruited from four distinct areas of WI to learn the "Model of Improvement" and how to apply it to early hearing detection and intervention. Based on these Learning Collaborative experiences, WSB has identified a "Model of Improvement" to other systems and organizations as an effective way of spreading effective strategies for the reduction of LTFU. Many of the current WSB staff were a part of the initial QI training and supported each of the WSB sponsored Learning Communities. Therefore, WSB is well positioned to use QI methodology to meet identified need areas in WI.

One area where the WSB Program has made significant progress is in bringing hearing screening to babies born out-of-hospital (OOH). Each year nearly 3% of Wisconsin births occur outside of hospital birth centers. In 2005, WSB enabled the Guild of Wisconsin Midwives to pilot a Homebirth outreach project whereby two groups of midwives shared two portable hearing screeners. The Wisconsin Guild of Midwives now owns 11 OAE (otoacoustic emissions) screeners that 24 Licensed Midwives share. Babies attended to by these OOH midwives typically receive initial hearing screening within two weeks of delivery. Babies who refer twice on OAE are referred to audiology for follow-up. Families with financial, cultural or transportation barriers to audiology care are referred to WSB staff for an in-home ABR (automated brainstem response) screen. To date, approximately ten OOH babies have been identified with hearing loss. In WI, there is a considerable population of Amish and Mennonite families who use Traditional Birth Attendants (TBA) from within their cultural communities rather than certified homebirth midwives. Prior to 2013, the size and whereabouts of this population was largely unknown. Due to the completion of a data linkage between the birth certificate and the blood card, WE-TRAC can now be used to identify infants with a birth certificate who have not had a blood or hearing screen. In 2017, only 156 live infants were never screened for hearing loss, 45 of whom actively refused screening when it was offered.

According to the Wisconsin Department of Regulation and Licensing, there are 375 audiologists who hold an active WI license to practice audiology. Of those licensed audiologists, 133 are active users of the WE-TRAC system, which indicates that they can provide some level of service to infants and their families. A list of audiologists who are currently able to provide the full range of diagnostic services for infants less than six months of age, is available on the www.improveehdi.org/wi website. Very few of the sites have access to sedation. Increasing the accessibility of pediatric audiology services will continue to be an important strategy to reduce loss to follow-up in Wisconsin.

Of the 172 infants identified between 2006 and 2008, 97 (56%) were enrolled in early intervention services. Although in 2017, 94.7% of infants with hearing loss were referred to the Birth to 3 Program through WE-TRAC, the enrollment rate has only improved modestly—only 76 of 108 infants (70%) were enrolled in the Part C Birth to 3 Program in 2017. Of the 76 infants enrolled, only 43 (57%) were enrolled before 6 months of age. This data demonstrates the need to focus on improving follow-up to ensure access and enrollment in intervention services.

Since the WSB Program's inception, parents of children who are D/HH have been involved. In January 2002, the WSB program convened an invitational Parent Network Summit, where families identified statewide family support needs such as the importance of continuing to have opportunities to come together to learn and socialize. In response, the first annual conference for parents was held and attended by 35 families. The conference attendance doubled the following year and has grown steadily since then, hosting as many as 109 families, 13 of whom were Spanish-speaking only.

Another important need that was identified was the importance of access to information about early hearing detection and intervention, as well as unbiased information at the time of diagnosis. WSB, with its family partners and the Birth to 3 Program, compiled unbiased information into the "Babies and Hearing Loss Notebook for Families" that is now available to families through all Wisconsin pediatric audiologists. Other print materials related to UNHS and diagnostic audiology were created in English and Spanish and have been widely disseminated. Approximately 60,000 copies of A Sound Beginnings for Your Baby are ordered each year. A ten-minute educational video featuring English, Spanish and Hmong participants was produced in all three languages as well as close captioned, in order to explain universal newborn hearing screening, audiologic referral, why accurate diagnosis is important, the noninvasive nature of audiologic testing procedures and the importance and impact of early detection and intervention to development of language and literacy with a focus on cultural sensitivity.

The most fervent recommendation to come out of the Parent Summit was the need for direct and immediate parent-to-parent support. From that recommendation the WI Chapter of Families for Hands & Voices was developed, and the now nationally recognized Hands & Voices Guide By Your Side (GBYS) Program was constructed. The WSB Program Director has held a position on the WI Hands & Voices Board of Directors since the chapter's inception. The GBYS Program was comprised of Parent Guides, who had experienced the joys and challenges of raising children who are D/HH.

The GBYS Program was historically supported in part by the federal MCHB grant dollars that have gone to the WSB Program and in part through grant dollars from the Department of Public Instruction's (DPI) IDEA preschool discretionary grant funds. However, in 2016, the WI GBYS Program was decommissioned by Hands & Voices Headquarters as the WI Chapter of Hands & Voices was no longer interested in running the program. Therefore, although the WI Families for Hands & Voices Chapter still exists and WSB staff remains on the WI H&V Board, there is no longer a GBYS Program in WI. Parent to parent support, however, is an essential component of EHDI and of many Maternal and Child Health initiatives funded by the Title V Block Grant. One family focused parent support initiative has been the creation of five Children and Youth with Special Health Care Needs (CYSHCN) Regional Centers, in 2000 (https://www.dhs.wisconsin.gov/cyshcn/index.htm). During the previous grant cycle, the WSB Program began offering systematic Parent to Parent support by WSB staff, two of whom had been originally trained as Parent Guides. These Parent to Parent support specialists were called WSB Parents Reaching Out (WSB PRO) and were hired and housed within the Regional Centers beginning April 2017. The development of outreach materials, protocols and consistent standard operating procedures, along with building a WSB PRO specific data collection, case management and tracking system in the WE-TRAC data system occurred throughout 2017. PRO support to English-speaking families began in March 2018. By October 2018, WSB PRO Outreach materials had been translated into Spanish and Spanish-speaking families were able to be supported as well. The WSB PROs offer several types of support; Phone / Zoom support, Email support, evening topic calls, Listserv support, and in community meet-ups and events.

The Regional Centers have been developed to support an integrated systems building approach to family support and parent engagement (www.dhs.wisconsin.gov/cyshcn/overview.htm) with one located in each of the five Division of Public Health (DPH) regions. The Regional Centers provide family support via information, referral, and follow-up services for families and providers along with outreach, education and training. The CYSHCN Program and the Birth to 3 Program (Part C) located in the Division of Long Term Care (DLTC) together fund Well Badger, a 24/7 toll free hotline (includes TTY and language line) and resource website for parents and providers. The RCs and FS provide a regional and statewide structure that supports the development of integrated service systems at the local community level. Each RC has distinct characteristics (2 are affiliated with children's hospitals, 1 is in an academic training center, and 2 are in local health departments) that collectively present a variety of viewpoints and areas of interest and influence. More recently the focus of the RCs has expanded to address elements of the CYSHCN National Performance Measures (NPMs). Beginning in 2010 the CYSHCN Program established "hubs of expertise" that work in close partnership with the CYSHCN Regional Centers to serve as leads for select NPMs. These hubs include: Family Voices of WI (FVW) (www.familyvoicesofwisconsin.com/) that supports family leadership, CYSHCN advocacy and public policy, family education and training; Parent-to-Parent of WI (P2P) (www.p2pwi.org) provides individual parent matching support; Wisconsin Medical Home Initiative (WisMHI) (www.wismhi.org/WiSMHI-home) promotes Medical Home implementation for providers and families, and practice-based screening quality improvement; ABC for Health, Inc. (www.safetyweb.org/) provides health benefits assistance in partnership with the RCs and supports health benefits advocacy for

CYSHCN; Youth Health Transition Initiative (www.healthtransitionwi.org/) provides outreach, education, and training through a website and Learning Community and grants to support youth health transition quality improvement at the practice/health system level; and the Genetics Systems Integration (www.geneticsinwisconsin.wisc.edu/index.htm) Hub supports genetics services. These partners form the CYSHCN Collaborators Network (www.dhs.wisconsin.gov/publications/p0/p00861.pdf) that works together to advance the CYSHCN NPMs. Due to the successful history of family support and engagement activities, along with the integrated systems approach, WSB will contract with three of the agencies that house the CYSHCN Regional Centers to address many of the family support and family engagement activities outlined in the methodologies section of the application so that initiative can be well coordinated and collaborative.

The WI Birth to 3 Program, WSB and the WESP-DHH Outreach team have been engaged in reimagining the system of care for children with low incidence sensory conditions such as kids who are deaf, hard of hearing or deafblind since 2008. In 2009, the Birth to Six Redesign Summit was held and was attended by over 50 participants from around the state. The Summit's goal was to enlist local experts and stakeholders in envisioning the critical components of a service delivery system that would meet the unique needs of these kids. Based on the key findings from the Summit, a Western Region Services Coordinator was hired using federal ARRA grant funding to perform a needs assessment, create a map of providers with specialized knowledge and skill sets related to deafness, and to create "creative collaborations" that would allow these partners to work with kids in counties that are without such providers. The *Final Summary Report* documented the effectiveness of the pilot and its activities. The materials developed during the pilot were organized into an *Implementation Guide* (see www.wesp-dhh.wi.gov/wesp/out-birth-six-redesign.cfm). After the pilot's completion and the end of the ARRA funding, the regional services coordinator position was dissolved, due to lack of funding.

The WSB Program worked in collaboration with the State Birth to 3 Program and with the Waisman Center University Center of Excellence on Developmental Disabilities (UCEDD) to design and implement a new model of Deafness-specific support for Birth to 3 Program providers and the families they serve. This new model called CARES (Coordination, Assistance, Resources, Evaluation and Services) was fully implemented in two regions. However, the CARES specialist resigned to move out of state and the position was not re-hired. Much of the focus of this grant application will focus on building on the strengths of that model in a more centralized, sustainable way, while addition additional language modality specific supports and social-emotional supports. According to a 2019 needs assessment, families of infants under age three needed more deafness specific early intervention supports, most especially around access to sign language supports and D/HH role models.

III. METHODOLOGY

The WSB program will continue to operate core functions of assuring universal newborn hearing screening and loss to follow-up prevention, such as 3-Step-Follow-Up and overall surveillance and monitoring of the EHDI system in WI as part of our Standard Operating Procedures. The WSB program is comprised of staff employed by the DHS, including the WSB Program Director, as well as several staff contracted through a variety of organizations. Monthly team meetings include both DHS and contracted staff. Oversite and guidance to the grant methods will be provided by the WI Newborn Screening Advisory Committee Hearing Subcommittee. The

WSB Program has been convening an advisory committee on newborn hearing screening and follow-up for nineteen years. The make-up of the advisory committee has shifted to meet emerging issues and needs of the EHDI System and provides guidance to the work of the WSB Program. The format of the advisory committee is divided up into three to four active workgroups that include a variety of additional ad hoc members. This advisory committee provides important direction and infrastructure for many of the activities included in the methodologies section. Intra- and interagency partnerships are a critical component of executing the activities in this grant application. Collaboration with partners such as the State Birth to 3 Program and the Office for the Deaf and Hard of Hearing, both co-located in the DHS, will be essential when planning for the deafness-specific early intervention initiatives. Collaboration with Children's Hospital of Wisconsin, the University of Wisconsin Communicative Disorders Program and LEND Supplement will be critical to initiatives targeted at reducing the age at diagnosis. WSB will focus heavily assuring that all workplan activities are inclusive of and address the needs of the populations we serve. Creative partnerships with agencies such as the Continuing Education Services Agency and Premiere Financial Services will allow WSB to offer enhanced early interventions, including grass roots family engagement activities and access to D/HH role models. By the end of year 2, WSB will develop a plan to address diversity and inclusion in the EHDI system in order to address disparity in populations, including geography, race, ethnicity, disability, gender, sexual orientation, family structure, and socio-economic status. By partnering with the Maternal Child Health Equity Consultant, WSB will also focus on aligning, partnering and integrating efforts with the larger Newborn Screening Program and Maternal and Child Health initiatives whenever possible in order to create a more equitable and sustainable system of care.

Goal 1: The WSB Program will ensure that infants receive appropriate, timely hearing screening and follow-up services. This includes increasing health professionals' training and knowledge of key aspects of the EHDI System by 10%. It also includes assuring that greater than 95% of Wisconsin births are screened no later than one month of age.

Objective 1.1: Increase providers' knowledge of key aspects of the EHDI System.
NCHAM conducted a multi-state survey of provider's knowledge and attitudes about newborn screening and follow-up on in 2005 and then repeated it in 2012. Wisconsin contributed data to that survey. Unfortunately, the survey determined that there was really no change in the lack of knowledge and understanding from the physicians. In order to try to improve the overall awareness of the physicians and other providers in WI, WSB will engage in strategic, culturally informed education and training activities. All activities will be created with the input and review of the FHS Health Equity Advisor to assure that we are meeting the goals of health equity and inclusion in our materials and content delivery.

Activity 1.1A: Expand and convene the Newborn Screening Hearing Advisory Committee to include families, EI Providers and D/HH consumers.

The Newborn Screening Hearing Advisory Committee has been convened for many years, and is chaired by the AAP EHDI Chapter Champion. It currently has a membership of 30 individual stakeholders and the focus has been narrowly on screening, diagnosing and reducing loss to follow-up *(Attachment 6a Roster)*. Currently 30% of the Hearing Advisory Committee is comprised of parents of children who are D/HH or adults who are D/HH. During this grant period the focus of Hearing Advisory Committee expansion will be on making sure that we have diverse perspectives included. The makeup of the Hearing Advisory Committee will include early intervention providers with a variety of backgrounds and D/HH role models with a variety of lived experiences. Consideration will be given to increasing the racial and ethnic diversity of the advisory committee as well. The focus of the Hearing Advisory Committee will be on increasing health professionals' engagement with and knowledge of the EHDI system. The Subcommittee will meet as a large group twice a year and the workgroups will convene as often as necessary determined by the tasks that they are addressing. Having access to the input of key stakeholders will be critical in assuring relevant content in a variety of professional domains.

Activity 1.1B: Create, disseminate and evaluate EHDI Online Learning Series that address key aspects of the EHDI system.

In the previous grant cycle the EHDI Learning Community developed a variety of presentations, covering key aspects of the EHDI system. Topics include Wisconsin Sound Beginnings and EHDI 101; JCIH 1-3-6 Timeline Recommendations; Parent Perspectives on WI EHDI; Barriers to Follow-up; Risk Monitoring for Delayed-Onset Hearing Loss in Young Children; Serving the Plain Clothes Community; Unique Considerations for Newborn Screening in the Plain Communities; and Importance of Data Collection and Tracking: WE-TRAC Overview. In year one, the Newborn Screening Hearing Advisory Committee will design additional modules. The WSB team will work with the University of Wisconsin - Department of Continuing Studies to convert the presentation content into an online interactive learning program, complete with tiered badge recognition based on the amount of content consumed and evaluation scores. This contract will also improve the WI improveehdi.org/wi website to be able to direct professionals to the learning series. Top-tier badge earners will receive EHDI Champion Certificates. Included will be a data collection component that will allow us to track who has completed the learning modules, from which professions, and locations, as well as evaluate increases in learning.

Activity 1.1C: WSB Staff and contracted partners will present on EHDI related content at two or more Wisconsin professional conferences each year.

WSB staff and contracted partners will present on key aspects of the EHDI system to provider groups in order to increase the knowledge so that infants receive appropriate, timely hearing screening and follow-up services. One example of a targeted conference is the Wisconsin Association for Perinatal Care and there are several others to choose from.

Activity 1.1D: The WSB AAP Chapter Champion will contribute EHDI related content to professional publications at least one time per year.

Both the WI AAP and the Wisconsin Association of Family Physicians publish a quarterly e-newsletter. In an effort to build awareness and knowledge of the EHDI system, the AAP Chapter Champion will author articles and submit them to the newsletters.

Activity 1.1E: The WSB Program will be represented as an exhibitor at one professional conference per year.

WSB staff and contracted partners will exhibit information and materials to increase the knowledge so that infants receive appropriate, timely hearing screening and follow-up services.

One example of a targeted conference is the Wisconsin Speech Pathology and Audiology Conference and there are several others to choose from.

Objective 1.2: Ensure that infants receive appropriate and timely screening and follow-up. Therefore, objective 1.2 focuses on ensuring that infants are screened and have timely and appropriate follow-up care. Although the majority of the focus on the grant is on access to family support, D/HH role models, and deafness-specific early intervention services, WSB cannot improve access to services unless we are able to accurately identify infants who are D/HH.

Activity 1.2A: WSB will conduct 3-step Follow-up to encourage timely and accurate data submission and follow-up.

Through contractual relationships with Children's Hospital of Wisconsin, Chippewa Health Department, and the City of Milwaukee Health Department, the WSB Program will continue to improve access to timely and effective hearing screening and follow-up services.

STEP 1: Medical Home Outreach—WSB identifies babies at risk for LTFU and reaches out to birth units, medical homes, primary care providers, and audiology clinics to determine if the child has received follow-up; informs primary care and medical home of hearing screening results and the need for follow-up. Cases are either completed at this step (the child received the follow-up they needed and this information has been accurately documented in WE-TRAC) or they move on to Step 2 or Step 3.

STEP 2: Parent-to-Parent Outreach—WSB provides parent-to-parent outreach to families with at-risk babies to encourage follow-up, address their concerns and answer questions. Cases are either completed at this step or they move on to Step 3.

STEP 3: Regional Outreach—WSB provides in-home or in-community rescreens for those families experiencing barriers (cultural, linguistic, logistical, etc.) to accessing the health care system, frequently collaborating with local Public Health departments, WIC clinics or community service agencies to help reach families. Cases that reach this step are usually the most resource intensive and families frequently have additional needs, stressors or issues occurring in their lives. Cases are either completed or eventually closed incomplete at this step.

Previously, data collection related to the 3-step Follow-up was collected in a separate stand-alone data system, called SharePoint. Data entry was inconsistent for a variety of reasons. However, during this grant cycle, new development within WE-TRAC will facilitate easier case assignment, tracking and evaluation of WSB LTFU prevention efforts. Data will be monitored throughout the grant cycle in order to identify areas of improvement.

Activity 1.2B: Continue to work with OOH Providers to conduct hearing screening.

The majority of Wisconsin's never screened populations are babies born out-of-hospital (OOH). Babies born at home, especially those of the Amish or Mennonite faith groups, are a particularly challenging population. Each year about 2% of Wisconsin births occur outside of hospital birth centers. In 2005, WSB enabled the Guild of Wisconsin Midwives to pilot a Homebirth outreach project whereby two groups of midwives shared two portable hearing screeners. The Wisconsin Guild of Midwives now owns 13 OAE (otoacoustic emissions) screeners that 24 Licensed Midwives share. Babies attended to by these OOH midwives typically receive initial hearing screening within two weeks of delivery. Babies who refer twice on OAE are referred for either ABR screening or audiology follow-up. Families with financial, cultural or transportation barriers to audiology care have been referred to WSB staff for an in-home ABR (automated brainstem response) screen. To date, five OOH babies have been identified with hearing loss. In WI, there is a considerable population of Amish and Mennonite families who use Traditional Birth Attendants (TBA) from within their cultural communities rather than certified homebirth midwives. Prior to 2013, the size and whereabouts of this population was largely unknown. Due to the completion of a data linkage between the birth certificate and the blood card, WE-TRAC can now be used to identify infants with a birth certificate who have not had a blood or hearing screen. Based on preliminary 2015 data, there are 32 babies born in the Western Region that did not have access to hearing screening. The Western Region CYSHCN Center will work with the Plain Community to develop strategies to improve access to hearing screening, including providing in-home screening.

Goal 2: The Wisconsin Sound Beginnings Program will ensure that 80% or more of babies who did not pass their final screen will have completed a diagnostic audiological evaluation no later than 3 months of age as documented in WE-TRAC.
While the percentage of babies receiving diagnostic services regardless of outcome has stayed relatively steady at 72%, this is not the case for those babies being *diagnosed with a hearing loss* (and referred to Early Intervention). The percentage of babies with a confirmed hearing loss diagnosed by 3 months of age decreased from 53% in 2015 to 42% in 2017. Reasons for delays in diagnosis and referral to Part C EI included a combination of factors such as: complex medical needs; multiple screenings/diagnostic appointments; middle ear fluid with or without tube placement; Neonatal Intensive Care Unit stay and/or prematurity; appointments at more than one audiology clinic; and families cancelling or not showing up for appointments. Objectives and activities will target these causes of delay.

Objective 2.1: Understand the knowledge and training gaps of pediatric audiologists in WI and address the gaps through training and technical assistance.
WSB has been attempting to move the needle to reduce the age at identification for several years, without much success. In recent years, the percentage of babies diagnosed by three months of age has actually worsened. This concerning trend warrants a deeper investigation of the needs of audiology providers.

Activity 2.1A: Conduct the audiology needs assessment (See supplemental Application)

When conducting care reviews, late diagnosed infants often have four or more audiology appointments before finally receiving a confirmatory diagnosis. Case reviews also often show referrals from one diagnostic audiology clinic to another for a second opinion. These observations indicate that audiology providers may lack confidence or competence in their ability to conduct infant diagnostics. Therefore a needs assessment will be conducted to elicit a clearer picture of where the knowledge and training gaps might be.

Activity 2.1B: Provide targeted Quality Improvement (QI) technical assistance to Audiology clinics using NCHAM Audiology Action Kit.

The WSB Program Director will engage decision-makers at the Audiology Clinic to set up a training meeting related to quality improvement and introducing the NCHAM Audiology Action Kit and Pediatric Audiology Best Practice Guidelines. WSB will use organization-level data extracted from WE-TRAC to encourage participation QI initiatives to ensure that infants receive appropriate and timely diagnostic evaluation services. WSB will support audiology clinics to use the Model for Improvement to guide their organizations' efforts. Possible evaluation indicators might include: 1) percentage of babies identified as at-risk for LTFU/LTD and needing WSB intervention; 2) the average age in days at diagnosis of babies seen in the audiology clinic; 3) the average number of appointments reported prior to diagnosis; 4) the number of cases closed prior to diagnosis; and 5) the number of days on WE-TRAC queue. WSB will monitor data related to the reduction in the average number of audiology and ENT appointments prior to conclusive diagnosis and the care coordination between Primary Care, ENT and Audiology Care appointments. Audiologists will also be encouraged to reduce the appointments necessary to achieve a confirmatory diagnosis. Of those babies diagnosed with hearing loss when they were greater than 200 days old, 67% had four or more appointments prior to diagnosis.

Objective 2.2: Ensure that infants have access to appropriate and timely diagnostic evaluation services.

Activity 2.2A: Partner with LEND Audiology Supplement to investigate tele-audiology opportunities.

WSB conducted a survey of parents with diagnosed children and 56% of the respondents reported that access to comprehensive diagnostic audiology caused delays to identification and enrollment in early intervention services. Families repeatedly referenced issues including distance to appointments, time off from work due to the several hour drive one-way, time to next available appoint months out and the need for multiple audiology visits to confirm the hearing loss. WSB has piloted tele-audiology services in Marshfield Clinics with great success. However, over 90% of the patients that accessed the tele-audiology service had Medicaid insurance. The service was discontinued after about four years when it was determined to no longer be cost allowable to the organization because WI Medicaid did not cover tele-audiology,. However, in 2017, WI Medicaid Telehealth policy was updated to include Audiologists and pediatric audiology diagnostic codes. The WSB Program will partner with the WI LEND Pediatric Audiology Supplement, Meriter Hospital, and Children's Hospital of Wisconsin to explore ways in which tele-audiology might be integrated into Wisconsin's audiology services.

Activity 2.2B: Collaborate with the Medicaid Program to problem solve tele-audiology reimbursement issues.

As mentioned in Activity 2.2A, the lack of Medicaid reimbursement for tele-audiology services was approved in September 2017. However, no audiologist has requested or been granted reimbursement to date. Therefore, WSB will continue to promote tele-audiology and will work closely with Medicaid to assure timely and accurate reimbursement to providers.

Activity 2.2C: Collaborate with audiology partners to develop and disseminate criteria and protocols for conducting diagnostic ABR on NICU babies prior to discharge.

Currently, there is only one NICU in Wisconsin that conducts diagnostic audiology evaluations on infants in the NICU prior to hospital discharge. The others screen them and then send them home with directions to have their baby tested elsewhere. We know that a high percentage of babies discharged from an NICU have additional medical complications. Often the follow-up audiology appointment is the last to get made or never gets made. WSB will work with CHW to disseminate policies and procedures to other NICUs and associated audiology practices in an attempt to spread this promising practice to other areas of the state.

Activity 2.2D: Partner with CYSHCN Medical Home Initiative to educate the Primary Care Providers about the importance of timely diagnostic evaluation and enrollment in EI services.

WSB will partner with the CHW and the Medical Home Initiative to conduct EHDI specific outreach and education to primary care physicians in an effort to increase PCP advocacy and care coordination for babies who do not pass the hearing screening. Special attention will go to educating about the need for aggressive management of congenital effusion. Case review indicated that 67% of late identified infant records indicated that suspected or confirmed fluid was interfering with a conclusive diagnosis. Although the American Academy of Pediatrics Position Statement on Otitis Media with Effusion (OME) indicates that *"Early detection and treatment of OME identified by screening, however, have not been shown to improve intelligence, receptive-language or expressive language"* there is evidence in WE-TRAC to the contrary. If the OME is not aggressively managed and a comprehensive pediatric audiology assessment is not conducted, the OME can and often does, mask an underlying SNHL that is also present. In order to determine whether earlier and more consistent treatment of congenital OME reduces the age at identification of permanent hearing loss.

Goal 3: WSB will improve access to deafness specific Early Intervention and language acquisition services so that 80% of those infants diagnosed with PHL by 3 months of age will have a documented Individualized Family Services Plan (IFSP) by 6 months of age. This includes increasing by 10% from baseline, the number of families enrolled in Deaf and Hard of Hearing adult to family support services by no later than 9 months of age.

Evidence indicates that along with early identification, enrollment in high-quality Early Intervention programs leads to improved outcomes for children who are deaf or hard-of-hearing. To help facilitate this, audiologists are able to refer families automatically through WE-TRAC to local Birth to 3 Programs. In WI, any child with a diagnosed hearing loss may be found eligible for early intervention services. There is no restriction based on severity or type of hearing loss. WSB has been improving the enrollment percentage of infants who are D/HH in the past few years. The enrollment rate hovered around 40% between 2012 and 2016 but improved to 57% in 2017. However, the 2019 early intervention needs assessment indicates that families are dissatisfied with the quality of early intervention services, unless they are offered by the one agency who offers deafness specific early intervention support. Therefore, WSB will make strategic efforts to increase the number of children with congenital hearing loss who are found eligible, enrolled and continue participating in deafness-specific early intervention services through age three. In 2019, WSB and the State Birth to 3 Program updated a MOU *(Attachment 4)* initially developed in 2013 to create open communication, data sharing and collaboration between the two programs. The MOU establishes the WSB Program as a Birth to 3 participating provider. WSB will continue to partner with the State Birth to 3 Program, the WI Department of Public Instruction (DPI), the Wisconsin Educational Services Program Deaf and Hard of Hearing (WESP DHH) Outreach Program, the CYSHCN Regional Centers and the University of Wisconsin-Waisman Center to increase the capacity and competency of the Part C early intervention program, while developing additional deafness-specific language acquisition and early intervention opportunities.

Objective 3.1: Recruit and train WSB Early Intervention staff and consultants.
Due to the low incidence of congenital hearing loss and the expansive, mostly rural make-up of the State of Wisconsin, County Birth to 3 Programs rarely have a member of their staff that is an expert on hearing loss in infants. Therefore, WSB will recruit a deafness-specific early intervention team that can assist counties and families across the state. Due to the lack of educational programs that focus on both deafness and early infancy child development, it is assumed that recruits will have gaps in their knowledge base. Those gaps will be assessed and met by established, highly regarded academic programs.

Activity 3.1A: Recruit an Early Intervention Coordinator, American Sign Language (ASL) specialist, Listening and Spoken Language (LSL) Specialist, and Social Emotional Development (SED) Specialist.
Position descriptions will be created in year one. However a brief description of the positions follows. The WSB Early Intervention Coordinator will be responsible for leading the development of a deafness-specific early intervention action plan (objective 3.2) and overseeing planning and implementation of deafness-specific early intervention services. The ASL, LSL and social emotional development specialists will be independently contracted or contracted through Department of Public Instruction. The SED Specialist will provide direct support around the parent child early relationship development, initial learning and decision-making process. When the family is ready, the SED Specialist will refer the family to the most appropriate ASL or LSL specialist based on the communication approach that the family wants to focus on with their child. Diversity will be considered when recruiting and hiring for these positions.

Activity 3.1B: Provide access to professional development training to address knowledge gaps.
Most professionals have either:

- a wide knowledge base but no specific training about the unique needs of D/HH infants and their families(ie Speech Language Pathologists)
- A strong knowledge of deafness but not if infant development and parent child early relationships (ie teachers of the deaf and hard of hearing)
- Fluency in American Sign Language but no child development or early intervention training (Deaf Mentor)

Therefore, a training budget will go for education and training to fill in whatever gaps the applicants may have. For example, if they have knowledge of deafness but not of child development they could attend the Gallaudet infants Toddlers and Families Program. If they have knowledge of deafness and early intervention but not of the Parent Child early relationship, they could attend the Infant and Family Mental Health trainings. This will create a well-rounded deafness-specific early intervention team.

Objective 3.2: Create a deafness-specific early intervention action plan. This plan will include access to WSB early intervention support and access to deaf/hard of hearing role models.
The creation of the deafness-specific action plan will address improving coordination of care and services for families of children who are D/HH across programs including EHDI, Birth to 3 Program, Home Visiting, Early Head Start and other early childhood program services.

Activity 3.2A: Meet with early intervention stakeholders for planning purposes.

The early intervention specialist will convene a series of stakeholder meetings to gain insight, understanding and buy-in to deafness-specific early intervention supports. The 2019 Early Intervention Needs Assessment will guide the work of this group. This stakeholder group will assist in the creation of an early intervention Action Plan which will guide program development and implementation. This stakeholder group will be kept apprised of progress and will continue to advise the WSB Program throughout the project period.

Activity 3.2B: Develop and design policies, protocols, forms etc. for systematic, statewide, deafness-specific Early Intervention Support through in person and tele-support options.

Based on the deafness-specific early intervention action plan, the WSB Early intervention team will begin to develop the necessary policies and protocols to execute the system of support along with the forms required for documentation, data collection and evaluation.

Activity 3.2C: Provide EHDI Professional outreach and education to local Birth to 3 Programs about the need for deafness-specific supports and how to get access for families.

In order for the WSB EI Support services to be effective, the local County run Birth to 3 Programs will need to understand the need for unique population based services. The WI Birth to 3 Program is a non-categorical early intervention system that utilizes the research supported model called Primary Service Provider Approach to Teaming. (Shelden, M. L., Rush D. D. (2013) *The Early Intervention Teaming Handbook: The Primary Service Provider Approach*. Baltimore, MD: Paul H. Brookes Co.) Therefore, counties will need to learn how to incorporate the WSB early intervention supports into their team structure.

Objective 3.3: Implement the deafness-specific early intervention action plan.
Evidence indicates that along with early identification, enrollment in high-quality Early Intervention programs with providers that have a professional background in deafness, leads to improved outcomes for children who are deaf or hard-of-hearing. The Part C EI Program in Wisconsin (the Birth to 3 Program) is administered by 72 different counties and is a non-categorical system that has embraced the Primary Coach Approach to Teaming model. Because of the way that the Part C system is implemented in Wisconsin and because hearing loss is a low-incidence condition, providing infants and families systematic access to deafness specific early intervention has been challenging. The activities below will test the interest of families in different kinds of intervention services and attempt to measure the developmental impact of deafness specific early intervention, including parent to parent support.

Activity 3.3A: Provide on-going Early Intervention Support through age 3.

According to the JCIH 2007 Position Statement, "Recent research suggests that outcomes for young children and their families are better when providers have specialized training specific to working with infants and toddlers who are D/HH and their families, although more evidence is needed. Professional consensus statements acknowledge the need for service providers with specific training in serving children who are D/HH. Therefore, it will be critical to implement a system of support that is accessible regardless of where a family lives in Wisconsin or what kind of insurance they have or don't have. Therefore, we will utilize a hybrid support method of in-person visits, tele-coaching and zoom meetings to support all areas of the state with only a handful of trained and knowledgeable folks. Designing an accessible, relational and sustainable model will take planning, testing and revising strategies and methods. Quality Improvement methodology will be utilized by the EI team to test and document different approaches and strategies.

Activity 3.3B: Provide coaching and teaming support to county Birth to 3 Programs.

Because a single member of the team serves as the primary liaison between the family and other team members coaching from other members of the team with differing areas of expertise, becomes an essential component of the Birth to 3 Program model. Therefore the WSB EI specialist will participate in all team meetings concerning D/HH children on their caseload. Teaming will be conducted largely remotely using distance technology.

Activity 3.3C: Partner with local resources to support Parent Infant Playgroups designed to enhance the parent infant relationship and language acquisition skills.

Research indicates that some parents learn best through a group peer to peer support model. Therefore, the WSB Program will collaborate with Head Start, Early Head Start and other local community programs to increase the locations of deafness-specific Parent Infant Playgroups designed to enhance the parent infant relationship and language acquisition skills. A parent leader, WSB EI staff, and deaf role models will co-facilitate some of these sessions.

Activity 3.3D: Evaluate and monitor developmental and wellness outcomes of children and families served.

According to the Supplement of the 2007 JCIH position statement, "All children who are D/HH should have their progress monitored every 6 months from birth to 36 Months of Age, through a protocol that includes the use of standardized, norm-referenced developmental evaluations, for language (Spoken and/or Signed), the modality of communication (Auditory, Visual, and/or Augmentative) and Social-Emotional skills." WSB will develop an appropriate assessment protocol that will be administered in conjunction with the Birth to 3 Program. WSB will look at enhancing WE-TRAC to collect Part C Benchmark data and create an EI Case management system that will allow the WSB EI team to enter and track developmental assessment scores over time.

Activity 3.3E: Evaluate retention in Birth to 3 with WSB EI Support.

The goal is for families to remain in early intervention supports through transition to Part B services. WSB will track and monitor number of months that families participate in Birth to 3 services with WSB EI Support compared to without WSB support. If families are not remaining in services, WSB will develop a parent survey to help understand why and how to better meet family needs.

Objective 3.4: Increase exposure to deaf and hard of hearing role models.

The Supplement to the 2007 JCIH Position Statement states that "Providing families who are hearing with opportunities to learn more about being D/HH reduces family stress and promotes family support of the child."

Activity3.4A: Collect additional diverse video stories of successful deaf and hard of hearing young adults.

In 2018, a collaborative project between a high school senior who is deaf, an audiology student and the EHDI program resulted in 6 videos of young D/HH adults, called the Sound

Futures project. The purpose of the videos was to provide parents of newly identified children an idea of what life can be like for their child when they grow up, a glimpse into the "deaf experience". The videos have been reviewed by deaf and hearing stakeholders and everyone agrees that they are wonderful. However, the small number of videos does not represent the diversity of experiences. Therefore, a focus of this grant will be to continue to collect video stories that capture the rich variety of D/HH experiences including from individuals who are deafplus and deafblind.

Activity3.4B: Create a technological access point for families to be introduced to Deaf / hard of hearing Adult role models.

In addition to the limited number of video stories, WSB does not currently have the technological infrastructure to make house the videos and make them accessible to families. Therefore, WSB will work with the UW Madison-Department of Continuing Studies to enhance the improveehdi.org website to create a parent portal that can house a variety of family resources in addition to the Sound Futures videos.

Activity3.4C: Develop and implement process for connecting families to Sound Futures by the time the child is 9 months of age.

This grant will focus on connecting families with D/HH role models in a variety of ways. A stakeholder think tank meeting, comprised parents as well as deaf professionals and agency partners, was convened prior to writing this application. This stakeholder group felt that a "soft introduction for families of infants under 9 months was the best approach. Therefore, WSB will systematize parental access to the Sound Futures videos as a part of the information sharing and early decision making process. Access will be documented for evaluation via a brief sign-in process developed as a part of activity 3.4B.

Objective 3.5: Identify, train and develop deaf / hard of hearing role models.

Activity 3.5A Recruit one role model per region to provide relationship development and sign language support.

WSB will develop a scope of work and contract with one individual who is D/HH per DHS region.

Activity 3.5B: Provide access to professional development training to address knowledge gaps.

Most Deaf adults have careers that have nothing to do with parent support or early intervention and therefore, will have fluency in American Sign Language but no child development or early intervention training. Therefore, a training budget will go for education and training to fill in whatever gaps the applicants may have. For example, if they have knowledge of deafness but not of child development they could attend the Gallaudet infants Toddlers and Families Program. If they have knowledge of deafness and early intervention but not of the Parent Child early relationship, they could attend the Infant and Family Mental Health trainings. This will assure that they have similar baseline knowledge of how to work with families as the other WSB EI specialists and add to a well-rounded deafness-specific early intervention team.

Objective 3.6: Provide access to Deaf / hard of hearing Adult-to-family support services through age 3.

According to research cited in the Supplement to the JCIH 2007 Position Statement, “Families who have many contacts with adults who are D/HH exhibit a strong sense of competence with regard to raising their child who is D/HH. When there are no other D/HH members in the family, parents identify deaf individuals as one of the most important sources of support in addition to teachers, therapists, other parents, and spouses. Community members who are deaf are able to provide children who are D/HH with unique perspectives that parents who are hearing cannot.”

Activity 3.6A: *Provide on-going access to D/HH role models through age 3.*

WSB will organize family events that will be allow for informal relationship development with the D/HH role models. If the family builds a relationship with one of the role models and would like additional one-on-one interactions, they can request additional support through WSB. Part of the one on one can be conversational practice in order to build sign language skills in the family. Another part is to gain practical insights as to what it is like to live with hearing differences.

Activity 3.6B: *Provide the lived experience perspective and expertise to county Birth to 3 Programs.*

As the primary early intervention support to families, it may also be important for Birth to 3 Providers to have access to deaf and hard of hearing adults so that they can also learn from their lived experience. Birth to 3 programs can request D/HH role model consultation through WSB.

Activity 3.6C: *Support Parent Infant Playgroups with a deaf/hard of hearing role model to enhance identity development and social emotional behavioral skills.*

As mentioned in 3.3C some parents learn best from an interactive group peer to peer support model. Families also learn how to engage and interact with infants who are deaf by observing the natural ways that deaf people use touch to gain a babies’ attention, use facial expressions to indicate a question and navigate interactions with hearing people. Therefore, D/HH role models will attend and support the Parent Infant Playgroups.

GOAL 4: The WSB Program will increase by 20% from baseline, the number of families enrolled in family to family support services by no later than 6 months of age. The WSB program will strive to improve family leadership and engagement at all levels in the EHDI programs and systems.

Objective 4.1: Identify and develop parent leaders and increase family leadership within the WI EHDI programs and systems.

Activity 4.1A: Identify parent leaders who have children who are D/HH.

Partner with family organizations like Parent to Parent, Family Voices Hands & Voices, FACETS and others to identify parents of children who are D/HH that could be trained to provide parent support and encourage family engagement at a regional level.

Activity 4.1B: Increase family engagement and leadership within the WI EHDI programs and systems.

The WSB Program will collaborate with partners such as WESP-DHH and Hands & Voices and others to put on trainings and a variety of social events that support parent connections and learning. WSB will utilize a contract with CESA 1 to offer parent stipends to support grass roots family leadership at the community level.

Objective 4.2: Provide Professional Development to WSB Parent Leaders

Activity 4.2A: Provide training and reflective consultation to identified parent leaders.

Evidence suggests that the emotional relationship-based work of providing parent support to other parent that have gone through what can be similar traumatic experiences of infant diagnosis, can result in vicarious trauma or at the very least a high degree of turnover. In an effort to sustain and retain family support providers while promoting high quality support, we will build, increase, and sustain reflective capacities and infant mental health competencies in the WSB Program at the provider, supervisory and organizational levels by participating in monthly Reflective Supervision/Consultation (RSC) with a qualified professional.

Activity 4.2B: Support parent attendance at state and national professional development conferences targeting family leadership development.

WSB Family Support Specialists or other parents in the community that express interest in enhancing their engagement and leadership skills will be supported to attend state and national conferences, such as the Hands & Voices Leadership event or the national EHDI conference.

Objective 4.3: Enroll newly identified families in family-to-family support services.
Research indicates that families require emotional support to cope with his or her needs in order to be emotionally available for their child. Many articles indicate that the support of another parent with lived experience positively influences family well-being.

Activity 4.3A: Provide Parent-to-Parent Support within 1 month after identification.

WSB will partner with the Waisman center to provide parent-to- parent support at the time of identification for families of children under age three. Shortly after diagnosis, the family is sent a WSB card introducing the Parents Reaching Out Program. Within a week of getting the card, the WSB family support specialist/s, who are themselves parents of children who are D/HH, will call the family to connect. The majority of contact is via phone, text or email. However, should a family be interested in face to face contact, video conferencing or in-person events offer that. Consent for family support will be recorded in WE-TRAC and a report that allows tracking of this benchmark will be created in grant year 1.

Activity 4.3B: Provide on-going Parent-to-Parent Support through age 3.

Parent-to-parent support is critical for emotional well-being, perhaps most significantly in the first year after identification. However, the importance of having the safety of the trusting relationship of another parent may continue to be important as the types of questions or concerns change in nature. The parent need for support may focus more on communication concerns, advocacy issues, behavioral questions related to the hearing loss, etc. While professional support is also critical, families find that talking through these concerns first with another parent helps them feel more prepared to broach the topics with their professional support team as well. This support may take the form of phone, email, or text communication more often than face to face visits.

Activity 4.3C: Promote and share other state and national resources for families.
There are many other wonderful opportunities for families to engage in systems and activities in WI. As WSB staff are interacting and communicating with newly identified families, they will be listening for opportunities to share and promote other relevant deafness specific programs and supports in the state. For example, WI Families for Hands & Voices has family picnics and Mom's only events. WESP DHH has an annual family conference and additional seminars that may be of value for families to attend. WSB will also maintain a listserv for families that includes upcoming events, new resources and educational information.

IV. WORK PLAN

The WSB Project Work Plan *(Attachment 1)* describes the goals and objectives, proposed timelines and responsible lead staff for each activity. The activities that will be used to achieve each of the proposed goals are explained in greater detail in the Methodologies section.

V. RESOLUTION OF CHALLENGES

Although Wisconsin has made major accomplishments towards the universal screening and early access to diagnostic evaluation of infants, there continue to be challenges to progress.

A potential challenge is that WI EHDI legislation does not provide funding to support program sustainability. Therefore, the WSB Program is currently entirely supported by federal grants. However, several key positions historically funded by the MCHB EHDI Funding, have been absorbed into the Title V Block Grant, in order to fund core activities such as loss to follow-up prevention, and free up funds to address the new requirements of this funding opportunity. Yet, a particular challenge of this grant project will be to redirect our priority focus areas to early intervention without losing the gains made in screening and reducing loss to follow-up. The goal of expanding the scope of EHDI to include hearing screening in young children up to 3 years of age requires complex partnerships, data sharing agreements, and systems development similar to the scope of installing universal newborn hearing screening. Without significant staffing and financial resources to support it, it will be difficult for WSB to achieve. However, bringing on an early intervention specialist as a core member of the WSB team will help in organizing stakeholder conversations and facilitating collaboration and partnership in a way that shares the burden of responsibility. Additionally, previous partnership as demonstrated by the established MOUs with the Birth to 3 Program and Department of Children and Families Home Visitation Program will be extremely beneficial in achieving this goal.

Finally, while the WSB Program is well-positioned to design and implement deafness specific early intervention services, assuring that services are available in all areas of Wisconsin will be a challenge. Cost of travel across such a large state makes in-person support limited. This will be supplemented through tele-support whenever possible. However, in some of the areas that are most remote geographically, are also the least technically well connected. This challenge will be mitigated through fostering local partnerships and thinking creatively about where families might access early intervention support.

VI. EVALUATION AND TECHNICAL SUPPORT CAPACITY

The WSB Program has been funded through federal Maternal and Child Health dollars for the past nineteen years, and therefore has experience with individual and state level program evaluation. Process, Outcome, and Balancing Measures will be utilized throughout the project to inform decisions about high leverage, sustainable ways to improve the EHDI Program in WI. Statewide data related to loss to follow-up at each specific stage of the EHDI continuum will be tracked and monitored and compared to the 2017 baseline rates which are documented in the 2017 Annual Report. The changes diagnostic evaluation and age at identification data will be assessed quarterly to determine progress toward meeting the identified targets outlined in the Methodologies section. WSB will consult with the MCH Epidemiology Group to ensure accurate data and its use.

Individual hospital and audiology organizations will learn how to access and use their aggregate data. Their performance will be evaluated. WSB will evaluate changes in knowledge, attitudes and practices related to EHDI using the new learner registration and tracking system. These data will be shared with HRSA and others on a regular basis.

Internal grant process and outcome evaluation and monitoring will be completed to ensure that the project is being implemented as expected, and information and feedback is used to modify strategies as needed to achieve program objectives. However, it is valuable to have external partners evaluate particular objectives – particularly those related to new initiatives and external partnerships using nationally-relevant measures. WSB will organize an evaluation team led by the early intervention specialist and will also consult in evaluation planning for the early intervention and family engagement components of this application.

In addition to the evaluation activities of the WSB Program and the internal DHS program staff, this grant focuses on both local and State level quality improvement efforts will also be evaluated using data collected by the WSB Team during rapid-cycle quality improvement projects. Monthly data measures will be collected as they relate to the over-all improvement goals and the WSB's individualized Plan, Do, Study, Act (PDSA) models for improvement. Examples of improvement efforts that will be measured are outlined in the Project Work Plan. Trends will be charted by the WSB staff to look for "break-throughs."

Overall progress of the WSB Program in reducing loss to follow-up and implementing a high quality EHDI system will be measured by increasing the number of children who are meeting the JCIH targets and through demonstrated outcomes of the children identified as D/HH which will be coordinated by the WSB Program Director and assessed by the WSB early intervention team and local early intervention providers. The WE-TRAC data system development will be enhanced to be a repository of developmental assessment data, that will allow tracking of outcome data for children identified through EHDI initiatives.

Having a knowledgeable and indoctrinated staff is essential to executing key functions of the EHDI surveillance work and allowing space to develop and implement the innovative strategies outlined in the methodologies section. The WSB staff has been in incredibly stable workforce. Several of the contracted staff have been team members for more than ten years. All positions are currently filled with the exception of the Early Intervention Specialist. Staffing for this grant will include contracted staff funded by other grant dollars and includes staff from the DHS and from the WI State Laboratory of Hygiene, UW–Waisman Center, Chippewa County Health Department, and City of Milwaukee Health Department. Staffing Plan Staffing Plan and

Job Descriptions for DHS and contracted Key Personnel *(Attachment 2)* and Biographical Sketches for Key Personnel *(Attachment 3)* are included.

VII. ORGANIZATIONAL INFORMATION

Organization Structure and Capacity: The WSB Program is located in the Family Health Section (FHS) in the Bureau of Community Health Promotion (BCHP) in the Division of Public Health (DPH), Department of Health Services (DHS) *(Attachment 5)*. The DHS has as its mission to protect and promote the health and safety of its citizens. The FHS administers the Title V MCH/CYSHCN Block Grant for WI and awards statewide and regional projects to address important maternal and child health issues and system development such as regional centers for children and youth with special health care needs and genetic counseling services. The FHS has oversight responsibility for meeting the Title V Block Grant National Performance Measures including "early and continuous screening".

A 2004 reorganization of the DPH strategically placed the WSB Program in the FHS. A new team was created called "Early Screening". The team includes Genetics Services, the Metabolic Screening Program, the Screening Hearts in Newborns (SHINE) Program and the WSB Program that includes the EHDI data collection/ tracking system known as WE-TRAC. Programmatically team members work closely with the CYSHCN Medical Director and CYSHCN epidemiologist and are supervised directly by the CYSHCN Unit Supervisor. Other programs within this section include the Title V MCH and CYSHCN Programs, Statewide Systems Development Initiative (SSDI), and the Birth Defects Surveillance Program. This organization and management structure was created to positively impact data collection efforts as well as the coordination and integration of the screening/surveillance programs (hearing, metabolic, heart and birth defects) with support and services (genetic services, Title V funded Regional CYSHCN Centers, Medical Home initiatives including Learning Collaboratives).

In addition, as part of the Division of Public Health reorganization, the Bureau of Health Information (Vital Records) relocated to the DPH and a new bureau was created called Health Information and Policy that includes the Public Health Information Network (PHIN) and a Project Manager for PHIN Project Integration. This structure has enhanced the Division's ability to integrate data systems such as WE-TRAC, a Project Area Module (PAM) of the PHIN.

Key Partners: Other key programs located within the Department include: the Birth to 3 Program (Part C) in the Bureau of Long Term Care and Support, the Wisconsin Office for the Deaf and Hard of Hearing, and the Wisconsin Infant Supplemental Nutrition Program (WIC), Title XIX Program and Medicaid Services (Badger Care) in the Division of Health Care Access and Accountability. The CYSHCN, Early Screening and WSB Program staff who will be involved in this grant represents a broad array of experienced health care professionals (audiologist, epidemiologist, health educator, pediatrician, etc.) and includes individuals with expertise in deaf and hard of hearing services and experience in data collection, analysis, and data integration. Staff has participated in and acted as Faculty Advisors to the National Institute of Children's Healthcare Quality EHDI and Medical Home Learning Collaboratives and has successfully implemented a Wisconsin "replication" of the Learning Collaborative model. Staff have completed professional development in infant and family mental health and reflective consultation.

Legislation: In October 1999, the Wisconsin legislature passed Act 9 s.253.115 which requires the DHFS to report EHDI data annually to the legislature and, "if by August 5, 2003 less than 88% of deliveries in Wisconsin are performed in hospitals that have a newborn hearing

screening program, each birthing hospital will be required to implement UNHS by January 1, 2004." In May of 2010, the newborn hearing screening legislation was revised to be integrated within the newborn blood screening legislation. The major changes to the legislation includes making hearing screening mandatory with an opt-out provision, as well as the inclusion of certified midwives amongst the providers who must ensure that newborns are screened "253.115 **(4)** SCREENING REQUIRED. Except as provided in sub. (6), the physician, nurse−midwife licensed under s. 441.15, or certified professional midwife licensed under s. 440.982 who attended the birth shall ensure that the infant is screened for hearing loss before being discharged from a hospital, or within 30 days of birth if the infant was not born in a hospital.
(6) EXCEPTIONS. (a) Subsection (4) does not apply if the parents or legal guardian of the child object to a screen for hearing loss on the grounds that the test conflicts with their religious tenets and practices." The new legislation also states that, "**(5)** REFERRAL TO FOLLOW−UP SERVICES. The department shall provide referrals to intervention programs for hearing loss." Under public health authority, newborn hearing screening results are reported to the SLH on the metabolic blood screening card and all hearing results are messaged daily to the WE-TRAC data repository. As detailed earlier, those infants who have failed the screening test are then tracked. WE-TRAC participation is voluntary and families may withdraw from WE-TRAC at any time but nearly all families chose to participate.