Michigan Early Hearing Detection and Intervention Program HRSA-20-047

HRSA-20-047 (CFDA) No. 93.251, New competing continuation application

Organization: Michigan Department of Health and Human Services Early Hearing Detection &

Intervention (EHDI) Program.

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Michigan Abstract

The overall aim of the Michigan Department of Health and Human Services Michigan Early Hearing Detection and Intervention (MDHHS- MI EHDI) program is to support a coordinated, community-based, comprehensive system of early hearing detection and intervention for newborns, infants and children up to three years of age who deaf or hard of hearing (DHH). This statewide system of care encompasses a family-centered, culturally competent approach with seamless transitions to facilitate care of newborns from initial hearing screening to early intervention (EI) services.

Goals: The overarching aim of this application will focus on Michigan EHDI systems of care to 1) lead efforts to engage all EHDI system stakeholders at the state/territory level to improve developmental outcomes of children who are DHH, 2) provide a coordinated infrastructure to ensure that newborns are screened by 1 month of age, diagnosed by 3 months of age, and enrolled in early intervention by 6 months of age, and reduce loss to follow-up/loss to documentation, 3) identify ways to expand state/territory capacity to support hearing screening in young children up to 3 years of age, 4) strengthen capacity to provide family support and engage families with children who are DHH and adults who are DHH throughout the EHDI system, 5) engage, educate, and train health professionals and service providers in the EHDI system about the 1-3-6 recommendations and medical home, 6) facilitate improved coordination of care and services for children who are DHH and their families through the development of mechanisms for formal communication, training, referrals, and/or data sharing between the state/territory EHDI Program and the Individuals with Disabilities Education Act (IDEA) Program for Infants and Toddlers with Disabilities (Part C) Program.

To accomplish this purpose, MI EHDI will: 1) continue to foster family engagement and provider education for adaptation and implementation of innovative family-centered medical home care, 2) sustain collaborative partnerships and formal agreements with early intervention programs for referrals and care coordination to support language acquisition, 3) engage health professionals in educational partnerships to support the a) 1-3-6 recommendations, b) facilitate evidenced -based information for families, c) increase capacity for hearing screenings for young children up to three years of age, d) coordinate care within the EHDI and early intervention systems.

Early Hearing Detection and Intervention Program HRSA-20-047 Narrative

Introduction and Needs Assessment

Introduction

The overall purpose of the Michigan Department of Health and Human Services (MDHHS) Michigan Early Hearing Detection and Intervention (MI EHDI) program is to support a coordinated, community-based, comprehensive system of early hearing detection and intervention for newborns, infants and children up to three years of age, who are deaf or hard of hearing (DHH). This statewide system of care encompasses a family-centered, culturally competent approach with seamless transitions to facilitate care of newborns from initial hearing screening to early intervention (EI) services.

Through this funding opportunity, MI EHDI seeks to continue a systems of care that will 1) engage all EHDI system stakeholders at the state/territory level to improve developmental outcomes of children, who are DHH, 2) provide a coordinated infrastructure to ensure that newborns are screened by 1 month of age, diagnosed by 3 months of age, and enrolled in early intervention by 6 months of age, and reduce loss to follow-up/loss to documentation, 3) identify ways to expand state/territory capacity to support hearing screening in young children up to 3 years of age, 4) strengthen capacity to provide family support and engage families with children who are DHH and adults who are DHH throughout the EHDI system, 5) engage, educate, and train health professionals and service providers in the EHDI system about the 1-3-6 recommendations and medical home, 6) facilitate improved coordination of care and services for children who are DHH and their families through the development of mechanisms for formal communication, training, referrals, and/or data sharing between the state/territory EHDI Program and the Individuals with Disabilities Education Act (IDEA) Program for Infants and Toddlers with Disabilities (Part C) Program.

Methods: To accomplish this overall purpose, MI EHDI will rely on nineteen years of programming experience and successes. EHDI will be strengthening the system of care that is currently in place and addressing any identified gaps. MI EHDI will 1) continue to foster family support and engagement, and provider education for adaptation and implementation of innovative family-centered medical home care; 2) sustain collaborative partnerships and formal agreements with early intervention programs for referrals and care coordination to support language acquisition; and 3) engage health professionals in educational partnerships to a) support the 1-3-6 recommendations, b) facilitate evidenced-based information for families, c) increase capacity for hearing screenings for young children up to three years of age, d) coordinate care within the EHDI and early intervention systems.

Specifically, with stakeholders, MI EHDI will use a public health approach to systems alignment to improve health and well-being for infants and children up to three years of age with hearing loss. MI EHDI will continue to foster strategic and collaborative relationships with the following programs and organizations to ensure comprehensive care is provided to infants who are deaf or hard of hearing: MDHHS-School Hearing Screening Program, Michigan Department of Education (MDE) Early On®, Michigan Hands & Voices (MHV) Guide by Your Side (GBYS)TM, Vital Records, Children and Youth with Special Health Care Needs (CYSHCN),

Family to Family Health Information Centers, Michigan Maternal, Infant, and Early Child Home Visiting Programs (MIECHV), Maternal Infant Health Program, Michigan Coalition for Deaf, Hard of Hearing, Deafblind People (MCDHHDBP), and Leadership Education in Neurodevelopment and Related Disabilities (LEND) programs, along with the EHDI Advisory and learning community members.

Outcomes: MI EHDI will support the development of statewide programs and systems of care to ensure that infants and children, who are deaf or hard of hearing, receive services that optimize their language, literacy and socio-emotional development. Michigan will continue to focus on improving data outcomes to reach the national EHDI goals of 1) a hearing screen completed no later than one month of age, 2) a diagnostic evaluation no later than three months of age for children not passing the hearing screening and 3) enrollment of all children with diagnosed hearing loss into early intervention services no later than six months of age.

Thus, MI EHDI is well-positioned to effectively implement the strategies outlined for this funding opportunity given its current work around educating and engaging professionals, stakeholders, and building collaborative relationships with families through Michigan Hands & Voices. MI EHDI will draw on the processes, strategic relationships and collaborations put in place over the past nineteen years to coordinate care for all infants and children who are DHH.

Needs Assessment

National Need

Within the United States, nearly 20% of children under eighteen years of age have a special health care need. In addition, one out of every five families has a child with a special health care need. Creating an effective system of care for children and youth with special health care needs to achieve optimal outcomes is one of the most challenging and pressing roles for public health leaders at the national, state and local level. Systems of care depend on ensuring families are partners in care with access to a variety of resources, including medical homes that provide coordinated equitable health care.¹

Among children and youth with special health care needs, congenital hearing loss affects approximately one to three of every 1,000 infants and can negatively impact children through delayed speech, language, social, and emotional development when undetected. Without necessary early intervention, infants and children may face lifelong impacts. More than 90% of children who are DHH are born to hearing parents.

The Centers for Disease Control and Prevention (CDC) reports that although substantial progress has been made in the provision and documentation of services, challenges remain. For example, unlike screening results, diagnostic test results and enrollment in early intervention are not consistently reported to the EHDI programs.

As of 2016, over 98% of newborns in the United States were screened for hearing loss. Of those babies not passing the hearing screening, over 75% were diagnosed as either having or not having a hearing loss before 3 months of age. In addition, between 2005 and 2016 over 58,000 deaf and hard of hearing infants were identified early. Of the infants diagnosed with hearing loss,

¹ Health Resources and Services Administration (2019). https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs

65% of the babies enrolled to Part C Early Intervention Services. ²

In addition, it is difficult for states and territories to know if infants received recommended follow-up services (diagnostic testing and/or EI services), often resulting in infants being classified as loss to follow-up/loss to documentation (LFU/D) and defined as parents being unable to contact, unresponsive or unknown for follow-up. Nationally, LTF/D is reported at approximately 25%.³

Michigan Need

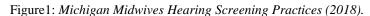
This section includes a snapshot of Michigan's screening, diagnostic, and loss to follow-up data. It also includes a summary of Michigan's Early Intervention programming, Michigan healthcare landscape, a target population overview which includes disparities, infant mortality special populations, health disparities, and how barriers will be addressed.

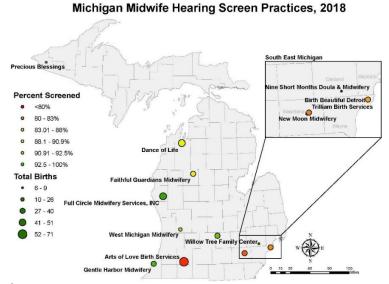
Michigan Overview of 1-3-6 Goals: Screening, Diagnostics, Early Intervention and Loss to Follow-up

Screening

In 2017, of the 107,359 infants screened, 104,130 (97%) were screened by one month of age. Universal newborn hearing screening started in Michigan in 1997 with 5% of infants screened by hospitals and has steadily increased to the rate of 97% of infants receiving screenings no later than one month of age in 2017.

Most of the 80 birthing hospitals are in more densely populated areas of the state, however some women in rural areas often travel great distances to access birthing facilities. These 80-birthing facilities account for 99% of the total births with about 1% of births occurring in birthing centers, homes, or physician offices. The Michigan Midwife Project, initiated in 2014, has facilitated





² Centers for Disease Control and Prevention. (2018). https://www.cdc.gov/ncbddd/hearingloss/2016-data/10-early-intervention-by-six-months.html

³ Centers for Disease Control and Prevention. (2018). https://www.cdc.gov/ncbddd/hearingloss/2016-data/01-data-summary.html

⁴ Figure 1: Michigan Midwives Hearing Screening Practices (2018). *Michigan Early Hearing Detection and Intervention*

twenty-six automated auditory brainstem response (A-ABR) hearing screenings (Figure 1)⁴ statewide at midwife hosting sites. This innovative program supports statewide screening to many Amish families and those living in rural areas. In 2017, 43%, of out of hospital birth babies were screened, which is an 18% increase from the 25% of out of hospital birth babies that completed a hearing screen in 2016. In addition, Michigan midwives are provided a list of resources for follow-up and diagnostic services as part of their initial equipment training. Since the initiation of the midwifery screening project, eight infants have been diagnosed with hearing loss.

Diagnostics

In 2017, of the 167 infants diagnosed as DHH, 96 (58%) were diagnosed by three months of age. EHDI has made steady progress in meeting the national goal of assuring diagnostic evaluation no later than three months of age. EHDI has 19 pediatric audiology diagnostic centers that provide comprehensive testing for infants and follow EHDI Best Practice Guidelines. Though it may appear that there are an adequate number of audiology diagnostic centers (19) in the state, some families may need to travel great distances in order to receive diagnostic testing. For example, there is not a pediatric diagnostic center in the Upper Peninsula at this time. In Southeast Michigan, a hospital system partnership in collaboration with Wayne State University (WSU) operates a free infant hearing screening/diagnostic clinic. This clinic is staffed by advanced audiology students under the guidance of professional audiology staff and is operated two and a half days per week during the academic year. This clinic provides a valuable resource in Wayne County, in the southeast region of Michigan.

To help improve education for audiologists, EHDI has provided yearly support for pediatric audiologists through professional development offerings/trainings via the Michigan Audiology Coalition. The number of providers who accept Medicaid has decreased significantly in recent years, a very important factor in Michigan, with 43% of women having Medicaid for the payment of infant delivery and subsequent follow up infant care in 2017 as opposed to 55% having private insurance. In addition, after diagnosis families struggle to find an audiologist that will provide infants with hearing aids if they have Children's Special Health Care services.

Currently, Michigan has twenty-one centers that provide hearing aids (Figure 2).5

Michigan Medicaid/CSHCS Providers for Pediatric Hearing Aids, 2019

Figure 2: Michigan Medicaid and Children Special Health Care Service Providers.

Loss to Follow-Up

Each year more than 40% of infants that fail a final screen do not receive additional testing in Michigan. Of the 111,507 total births in 2017, 107,359 infants passed the final hearing screen and 1,258 babies failed their final screen. Of these 1,258 babies, who failed their final screen, 47% were categorized as lost to follow-up. This equals 595 babies documented as Loss to Follow-up (LTF) and therefore it is unknown if follow-up testing and intervention services were received. EHDI analyzes the number of infants lost to follow up per hospital and per region each year. A variety of factors appear to be related to this LTF percentage. For example, social determinants, such as poverty, transportation and employment impact families daily and subsequently affect their ability to obtain follow up services for their infants. EHDI conducted a retrospective case control study in 2018, which was designed to evaluate differences between infant populations and their families that followed up with appropriate screening techniques after a failed hearing screen, compared to those who were lost to follow up.⁶ The following characteristics were associated with not returning for testing:

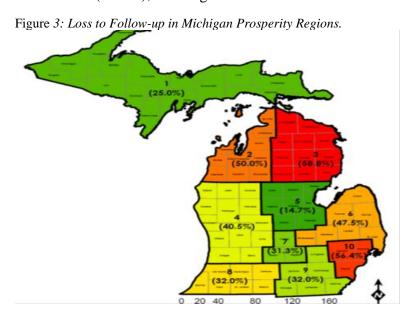
- > Having a younger mother
- ➤ Infant race of Non-Hispanic Black
- ➤ Women, Infant Children's (WIC) program enrollment
- ➤ Medicaid enrollment
- > Failing an initial hearing screen
- ➤ Lower maternal education
- ➤ Mother that smoked during pregnancy
- Late or no prenatal care
- ➤ Being tested by OAE (Otoacoustic Emission)
- ➤ Only one ear failed the hearing screen

⁵ Figure 2 Michigan Medicaid and Children Special Health Care Service providers. (2019). *Early Hearing Detection and Intervention*.

⁶ Withrow, E. et al. Michigan Early Hearing Detection and Intervention. (2018). Loss to Follow-up brief.

EHDI has initiated a variety of activities to address the issues with varying success. To further refine the LTF work, and provide more prescribed initiatives to assist families, EHDI has assessed LTF with the overlay of the state prosperity regions as outlined in Figure 3⁷. This

assessment provides an opportunity to assess the number of infants referred for follow-up testing and LTF to target activities and partners for collaboration. Prosperity regions are denoted: Region 4 with 126 referrals and 51 infants LTF (40.5%); Region 6 with 122 referrals and 58 infants LTF (47.5%), and Region 10 with 628 referrals and 354 infants LTF (56.4%)



Reducing the LTF rate will continue to be a component of the state's plan to achieve the national EHDI goals. Monitoring and assessment of LTF will be implemented, as a quality improvement benchmark to facilitate EHDI progress.

Early Intervention

In 2017, of the 167 infants identified with hearing loss and referred, 61 of 93 infants received services by six months of age, for a total of 66%. Hearing loss can affect a child's ability to develop communication, language, and social skills. The earlier children with hearing loss start receiving early intervention services, the more likely they are to reach their full potential. Children birth to three who are identified as having, or being at risk for, hearing loss of any degree are eligible for services through (EI) programs under Part C of the Individuals with Disabilities Educational Act (IDEA). When a hearing loss report is sent to the EHDI program, a referral is immediately sent to Early On® (Part C) program as a backup to the initial referral, which should be sent from the diagnostic audiology site. The EHDI program has encountered challenges in ensuring that families were being offered early intervention services and resources, and confirming they made it to the referral. Early Intervention services are provided under the jurisdiction of the Michigan Department of Education (MDE) and the difficulty in receiving feedback information on early intervention services is due to the regulatory requirements under the Family Educational Rights and Privacy Act (FERPA). However, in 2015 a data sharing agreement was reached with MDE for the annual release of aggregate data. While less than

⁷ Figure 3 Loss to Follow-up in Michigan Prosperity Regions. (2019). Early Hearing Detection and Intervention.

optimal, this agreement has fostered some improvement in reporting. Michigan eligibility requirements related to hearing loss are defined as an established Condition Hearing Deficiency with bilateral or unilateral hearing loss of greater than or equal to 25 dB at a minimum of 2 frequencies between 500 and 4000 Hz. Although MDE- Early On® and EHDI have developed methods to define hearing loss, there is wide variability in the relative breadth of interpretation of state eligibility policies from coordinator to coordinator around the state. In addition to these issues, EHDI completed an analysis and identified gaps in early intervention enrollment as depicted in Figure 4.8 Enrollment into Early On ® is low statewide, with approximately 3.1% of infants and children age zero to two population being served.

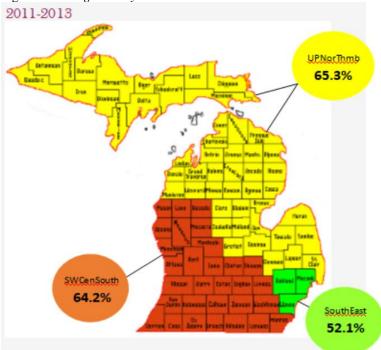


Figure 4: Michigan Early Intervention Enrollment.

Needs and Barriers

Michigan is the tenth most populous state in the United States with an estimated population of 9.96 million people in 2017, and estimated growth at 0.25% in 2019; the median age is 39.6.9 The state, made up of two peninsulas, has an area of 96,716 square miles, making it the 10th largest state in the country, and is surrounded by four of the Great Lakes. According to the United States Department of Agriculture (USDA), Economic Research Service (ERS), the average per-capita income average for Michigan residents in 2017 was \$49,576 with \$58,779 for urban residents, while rural per-capita income lagged at \$42,026. 688,863 residents are designated low income population, or 2.5 times below the national poverty level. In the

American Community Survey (ACS) data, the poverty rate in rural Michigan is 13.9%, compared with 14.2% in urban areas of the state, with 13.6% of households reporting food insecurity. Michigan's unemployment rate averages 4.4% and 5.5% in urban areas and rural areas, respectively.¹⁰

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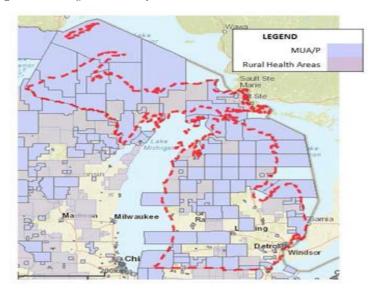
⁸ Figure 4 Michigan Early On® Enrollment (2013). Early Hearing Detection and Intervention.

⁹ United States Department of Agriculture, Economic Research Service. (2019). *Michigan State Fact Sheet*.

¹⁰ American Community Survey. (2017). *Michigan Fact Table*, 2013-2017.

Michigan is divided into 83 counties by which census and demographic data are maintained in Michigan Vital Statistics. Most of the larger population centers are in the bottom half of the Lower Peninsula, including Detroit, Grand Rapids and Lansing. More than half the counties in Michigan are rural, and roughly 18% of the population resides within these rural areas. Of Michigan's rural counties, 50 are designated Medically Underserved Areas (MUA), or populations as having too few primary care providers, high infant mortality, high poverty or a high elderly population (Figure 5).¹¹

Figure 5: Michigan Medically Underserved.



Michigan birth demographics for 2017 include: 111,507 births with the racial and ancestry of mother consisting of: 72.6% White, 19.6% Black, 0.6% American Indian, 4.2 % Asian and Pacific Islander, 2.6% all other races, 4.7% Arab, and 6.8% Hispanic. In 2017, 11.3% of women giving birth had less than 12 years of education, 25% had a high school diploma, and 62.5% had some or had completed college.

Approximately 55% of women had private insurance for the payment of infant delivery, 42.7% had Medicaid, 1.5% and were self-paid, and about 0.5% had some other or unknown form of payment for delivery. Over 3.6 million Michigan residents (37%) rely on public health insurance, while 702,954 (7%) are uninsured (ACS, 2017). This is in comparison to national data of public insurance enrollment 55,473 (17.3%), and the uninsured of 28,019 (8.7%).

In Michigan, nearly 20% of infants and children have a special health care need, as compared to the national average of 17%, or about one in six children aged 3 through 17 years that have one or more developmental disabilities. However, nearly a third of non-Hispanic Black children (32.3%) were identified with a special health care need. Additionally, only 17.7% of parents of children with special health care needs report that their children receive care that includes all components of a well-functioning system. While 88.4% report the system is easy to access, only 16.6% report adequate transition support. Improving transition support is a critical goal for Michigan's CSHCS program (Title V, 2018). 12

¹¹ Figure 5 Michigan Medically Underserved areas. (2019). *Health Services Resources Administration (HRSA)* https://data.hrsa.gov/hdw/tools/MapTool.aspx

¹² Maternal and Child Health Services. (2018). Title V Block Grant Michigan.

Target Population Overview: Disparities, Inequities of the Population and Social Determinants of Health (SDOH)

Health equity is a complex and multifaceted issue impacted by multiple variables. Of these, social—cultural determinants of health include the overall factors of social, cultural, economic and environmental issues/conditions/systems that impact where one is born, grows, lives, works and ages. Social determinants have a tremendous impact on overall health and health outcomes. As health professionals, we need to be aware of the impacts of disparities/inequities and subsequent impacts on families with infants and children, who are deaf or hard of hearing. Michigan is home to 341,240 infants and toddlers, representing 3.4 percent of the state's population. Many of the state's infant and children struggle daily with two significant health indicators—poverty and infant mortality.

Poverty

As many as 48 percent of Michigan's infants and toddlers live in households with incomes less than twice the federal poverty line (in 2017, about \$50,000 a year for a family of four), placing them at economic disadvantage. Poverty is a powerful indicator of infant/child status, ultimately impacting developmental milestones. Michigan's poverty rate averaged 27%, compared to the national average of 23% in 2017. Approximately 167,000 of Michigan's children, from infants through age three live at or below 200 percent of the federal poverty level (Figure 6). ¹⁴

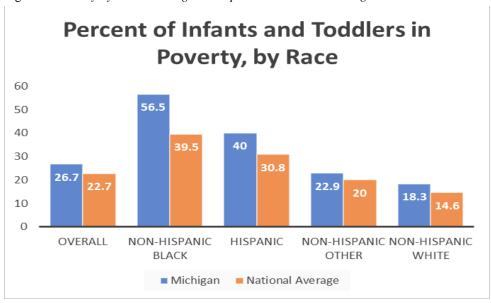


Figure 6: Poverty by Race-Michigan Compared to National Average.

Infant Mortality

Infant mortality in Michigan remains higher than the national average. Issues of health disparities, access to care, and poverty continue to impede the state's efforts for improvement. Rates are much higher for African American and American Indian babies and are more than twice that of Caucasians. For every 1,000 Michigan live births, almost seven infants die before reaching their first birthday. In 2017, 762 Michigan infants under the age of one year died, resulting in an infant mortality rate of 6.8 per 1,000 live births. There are also significant

¹³ National Zero to Three Organization. (2019). *State of Babies*, Michigan profile.

¹⁴ Figure 6 Poverty by Race. (2019) *State of Babies Yearbook 2019* - Michigan (https://stateofbabies.org/data/#/Michigan) Michigan compared to national average.

disparities that exist across race, with black infants 2.8 times more likely to die before their first birthday than white infants. Michigan experienced a significant decline in infant mortality during the early 1990s; but during the 2000s the infant mortality rates remained around 7.9 deaths per 1,000 births. The Michigan infant mortality rate continues to be higher than the rate for the United States, which was 5.9% in 2017, (as noted below in figures 7 and 8). 15,16

Figure 7: Infant Mortality Rates by Census Tracts.

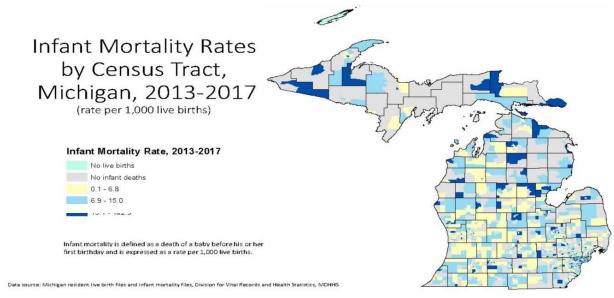
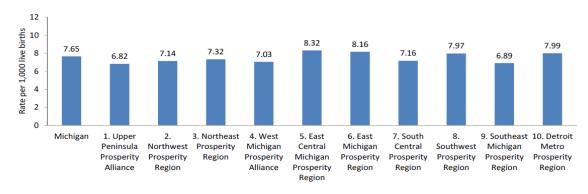


Figure 8: Infant Mortality by Prosperity Region.

Michigan Feto-Infant Mortality Rate by Prosperity Region: 2013-2017 (rate per 1,000 live births)

Feto-Infant Mortality Rate by Prosperity Region, Michigan, 2013-2017



¹⁵ Figure 7: Michigan Infant Mortality Rate by Census Tract, 2013-2017. (2019).

¹⁶ Figure 8 Michigan Department of Health and Human Services, Maternal and Child Health Epidemiology Section. (2019). *Fetal-infant mortality rate by Michigan prosperity region 2013-2017*.

MDHHS data also notes issues of disparity among fetal-infant mortality rate by Michigan prosperity region 2013-2017. Perinatal periods of risk (PPOR) uses a comprehensive approach to help communities use data to reduce infant mortality, including bringing stakeholders together to build consensus/partnership based on local data. ¹⁷ This community based partnership, developed through the Regional Prosperity Initiative, encourages local private, public and non-profit partners to create vibrant regional economies. Through collaborative efforts among business and non-profit representatives as well as representatives from local and regional economic development organizations, workforce boards, adult education providers and the higher education community, many communities are realizing positive impacts.

Special Populations

As populations become more diverse, and the structure of the family unit evolves from the nuclear parent model, a diverse mosaic of families emerges. Within this mosaic, are blended families, and families with members, who may be single parents, lesbian, gay, bisexual or transgender (LGBT), older, and whom may have disabilities.

According to the Fenway Institute (2018), the LGBT community is diverse. While L, G, B, and T are usually tied together as an acronym that suggests homogeneity, each letter represents a wide range of people of different races, ethnicities, ages, socioeconomic status and identities. What binds individuals together, as social and gender minorities, are common experiences of stigma and discrimination, the struggle of living at the intersection of many cultural backgrounds and trying to be a part of each. Specifically related to health care, Fenway notes a long history of discrimination and lack of awareness of health needs that persists. As a result, LGBT people face a common set of challenges in accessing culturally competent health services and achieving the highest possible level of health. In addition, it is difficult to define the size and distribution of the LGBT population. This is due to several factors, including: the heterogeneity of LGBT groups; the incomplete overlap between identity, behavior, and desire; the lack of research about LGBT people; and the reluctance of some individuals to answer survey questions about stigmatized identities and behaviors. However, in combining results from multiple population-based surveys, researchers in 2017 have estimated that approximately 4.5% of United States adults identify as lesbian, gay, or bisexual and that 0.3% of adults are transgender. This amounts to approximately 9 million individuals in the United States today. The expansion in the number (from 2015 3.9%) of Americans who identify as LGBT is driven primarily by the cohort of millennials, defined as those born between 1980 and 1999.¹⁸

The Michigan Behavioral Risk Factor Surveillance System (MiBRFSS) is composed of annual, state-level telephone surveys of Michigan residents, aged 18 years and older. The MiBRFSS is the only source of state-specific, population-based estimates of the prevalence of various behaviors, medical conditions, and preventive health care practices among adults. In 2015, the survey of 12,024 persons age 18 to 75 reported 176 (3%) persons identified as LGBT with 103 females and 73 males respectively, with the majority in the age range of 25- 54 years. Race was noted as 125 respondents identifying as white, 25 black, and 26 not reporting. ¹⁹

¹⁷ Michigan Department of Health and Human Services, Maternal and Child Health Epidemiology Section. (2019). *Fetal-infant mortality rate by Michigan prosperity region 2013-2017*.

¹⁸ Fenway Institute- The National LGBT Education Center. (2019). Fenway Health Reports to the Community.

¹⁹ Michigan Annual Reports. (2015). Behavioral Risk Factor Surveillance (MiBRFSS.)

According to the CDC, over 61 million (26%) adults living in communities in the United States have a disability. Highest percentages are generally found in southern states and lowest are mostly in midwestern and Rocky Mountain States. Although anyone can have a disability, and a disability can occur at any point in a person's life, disability was more commonly reported by women (one in four), older people (65 or more years), and racial and ethnic minority groups (three in ten individuals). Although progress has been made since the passage of the Americans with Disabilities Act (ADA) giving people with disabilities better opportunities to achieve their potential, studies consistently show that people living with a disability have poorer health than people without a disability, and that many of the health issues related to this poor health are preventable.²⁰

In Michigan's 2016 MIBRFSS, of the 12,024 residents responding, 2,428 (27 percent) noted a disability. Of the respondents, the prevalence of disability was similar by gender and race/ethnicity, with 28% being female and 25% being male. The majority of the respondents were in the 55- to 74-year-old age range. Respondents by race/ethnicity were: 27% white, 27% black, 23% other, 18% Hispanic. An income of \$20,000 or less annually was reported by 49%.²¹

In 2018, the Michigan Department of Civil Rights, Division of Deaf, DeafBlind, and Hard of Hearing (MDCR-DODDBHH) conducted a randomized telephone survey of Michigan residents that are deaf or deafblind. The previous assessment occurred over thirty years ago. More than 739,000 residents identify under one of these labels, nearly double what was initially estimated in 2017. Nearly half of Michiganders who are deaf or deafblind or hard of hearing are reported to make less per household than their hearing counterparts, despite possessing the same levels of education.

Survey Results Highlights:

- About 633,000 people identify as hard of hearing. Nearly 46,000 identify as deaf, while just over 10,000 say they have little or no hearing or sight.
- Estimates that 7.4% of Michigan residents identify as deaf, hard of hearing and with little or no hearing or sight.
- ➤ The greatest percentage of households which have at least one person who identifies as deaf, deafblind or hard of hearing is in the rural Upper Peninsula at 22 percent.
- Access to physical and mental health care is another challenge disproportionately faced by members of the deaf, deafblind and hard of hearing community.
- ➤ Of the 739,000 residents, more than 44 percent of people who are deaf, 48 percent of people who are deafblind and 36 percent of people who are hard of hearing report making less than the state's median household income of \$52,668.
- The median individual earnings in Michigan for someone possessing a Bachelor of Science is \$65,534 and \$55,920 for a Bachelor of Arts.
- For the deaf and deafblind population that possess bachelor's degrees:
 - 18 percent make less than \$10,000 a year
 - 10 percent make less than \$15,000 per year
 - 18 percent make less than \$25,000 a year
 - 23 percent make less than \$35,000 per year

²⁰ Snapshot of Disability in the United States. (2018). Retrieved 9.8.19 from https://www.cdc.gov/ncbddd/disabilityandhealth/documents/disabilities impacts all of us.pdf

Michigan BRFS Annual Reports. (2016). Retrieved 10/10/2019 from https://www.michigan.gov/documents/mdhhs/2016 MiBRFS Annual Report 7.25.18 635618 7.pdf

Health Equity/Disparity

Michigan has taken significant steps to address inequities that result in health disparities, health at the state, local and MDHHS program levels. Achieving health equity for all citizens is a goal of public health work within Michigan and across the country. The MDHHS Diversity, Equity and Inclusion workgroup has operationalized the mission and vision as:

Mission-To promote and foster a culture that values diversity, equity, and inclusion throughout the Michigan Department of Health and Human Services and the diverse communities we serve in order to achieve our highest potential.

Vision-Diversity, as reflected in our leadership and throughout our workforce, offers a valuable range of experiences and perspectives. Our diverse workforce will be an essential asset for developing and providing health and human services that are culturally proficient to address existing and emerging health and social issues.

MDHHS has developed a three-prong approach to focus on transforming public health through equity education and action:

- ➤ Practices to Reduce Infant Mortality Through Equity (PRIME) initiative, which led efforts to change policies and practices within the state health department to ensure that Michigan residents have opportunities for their best health status. Through the PRIME training, MDHHS departments have participated in learning labs to facilitate staff knowledge.
- ➤ Health Disparities Reduction and Minority Health Program is responsible for the development, promotion, and administration of health promotion programs for populations of color, which include African Americans, Hispanic/Latinos, Arab/Chaldeans, American Indians, and Asian/Pacific Islanders. This effort is carried out primarily through grants to local health departments and community-based organizations. Funding supports highly targeted and evidenced-based prevention, health promotion, and screening services.
- Michigan's Mother Infant Health & Equity Improvement Plan (MIHEIP) released in September of 2019 –the plan aligns maternal and infant goals and strategies; facilitates collaboration among private and public stakeholders; and provides guidance on operationalizing a health equity lens to address social determinants of health and reduce racial disparities in maternal and infant health outcomes in Michigan. Partnerships with local health departments, community-based providers and health care systems act as the local "arm" of MCH activities. Other established partnerships include coordination with managed care plans, universities, Medicaid, Michigan Department of Education, and MDHHS program areas such as epidemiology, mental health and substance abuse, chronic disease, communicable disease, injury prevention, and public health preparedness. Michigan's MCH work is intended to impact health outcomes using clear performance measures coupled with evidence-based practices, innovative strategies, and program evaluation. MDHHS is also working to align objectives and goals across public and private systems to facilitate the vision of the Improvement Plan: Zero preventable deaths. Zero health disparities. 22

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²² Mother Infant Health & Equity Improvement Plan, 2020-2023 (2019). Division of Maternal and Infant Health. Retrieved 10/10/2019 https://www.michigan.gov/infantmortality/0,5312,7-306-88846---,00.html

Identification of Barriers and How They Will Be Addressed

Michigan has technically been out of the 2008 recession for several years; however, the slow recovery process has left many families behind with limited resources to reach their potential. While improvements have been realized, persistent challenges remain, many Michigan families continue to face challenges in employment, housing and deeply embedded systemic inequity, social biases, and related stressors that are closely associated with adverse health outcomes. African American and Native American families continue to face disparate outcomes as the result of inequity. In order to address root causes of underlying disparities, MI EHDI will leverage partners working on similar disparity issues and find ways to facilitate meeting the 1-3-6 goals and reducing Michigan's loss to follow-up rate.

Despite the challenges, MDHHS has a wealth of resources to assist Michigan families. MDHHS' underlying mission is to provide a persistent and continuing focus on assuring health equity and eliminating health disparities by aligning stakeholders around key goals to improve the health of mothers and babies. EHDI program staff has participated annually in program specific learning labs and trainings to address health disparities and inequities. EHDI will continue to participate in MDHHS efforts to support the three-prong approach to disparities and inequities. To improve maternal, infant and family health outcomes as noted above, the Michigan Department of Health and Human Services (MDHHS) released the *Mother Infant Health and Equity Improvement Plan* (MIHEP) with the backbone efforts of the MIHEIP being led by the Regional Perinatal Quality Collabortatives (RPQC). The RPQCs are made up of multi-sector partners, including family and community members. The RPQCs are overseen within the Division of Maternal and Infant Health. MI EHDI sits within this Division and will use a variety of strategies to forge new and continue collaborative partnerships to address barriers families face.

Methodology

This section includes MI EHDI proposed plans to maximize 1) Stakeholder and Professional Engagement, and 2) Family Engagement and Early Childhood Coordination, and Collaboration. It also outlines the proposed Work Plan to complete activities.

The goal of the Michigan EHDI program is to support the development of statewide programs and systems of care that ensure that infants and children, who are deaf or hard of hearing, are identified through infant hearing screening and receive evaluation, diagnosis, and appropriate intervention that optimize their language, literacy, cognitive and social-emotional development. EHDI will develop program methodology to address the issues identified in the unmet health care and barriers to services section. Through this HRSA funding opportunity, the Michigan EHDI system will seek to encompass a family-centered, culturally competent approach with seamless transitions and tracking of newborns from initial hearing screening to early intervention services.

This goal will be operationalized by focusing efforts on: 1) increasing health professionals' education and engagement within and knowledge of the EHDI system, 2) increasing capacity hearing screenings through three years of age, 3) improving family engagement, partnership, and leadership within the EHDI programs and systems, and 4) improving access to EI services and language acquisition.

Stakeholder and Professional Engagement

- A. Lead efforts to engage and coordinate all stakeholders in the state/territory EHDI system to meet the goals of this program.
- ➤ Since Michigan EHDI's inception in 2000, the program has developed a coordinated infrastructure to ensure that newborns are screened by one month of age, diagnosed by three months of age, and enrolled in EI by six months of age. The program will continue these efforts along with addressing loss to follow up by conducting individual provider visits and facilitating learning communities for quality improvement.
- ➤ To facilitate a state plan to expand infrastructure, (including data collection and reporting, for hearing screening for children up to age three), EHDI will continue the established partnership with the Early On® (EO) program and the coordinating MDHHS Preschool/School audiologist. Through these collaborations, Otoacoustic Emissions (OAE) hearing screening equipment has been disseminated throughout Michigan to early intervention programs and EHDI will assist with development of guidance documents for training and referrals. The coordinating audiologist has an extensive background in statewide training through a network of local public health departments, and Head Start, along with participating in the Early Childhood Hearing Outreach (ECHO) Initiative through the National Center for Hearing Assessment and Management at Utah State University.
- ➤ EHDI will establish and maintain relationships for referrals, training and information with various state stakeholders and organizations to include internal and external partners.
- EHDI will continue the advisory committee to advise on program objectives and strategies for quality program improvement. Since 2001, a variety of parents and professionals have contributed guidance to the Michigan program through this venue. Currently, over 25% of the committee is comprised of parents and professionals who are Deaf or Hard of Hearing. The EHDI American Academy of Pediatrics (AAP) Chapter Champion is a current advisory member providing guidance and expertise to the program. The current group of approximately 25 members meets biannually in April and October and is facilitated with interpreting and Real Time Captioning support. Members include a variety of professionals, including the State Part C Coordinator, Early Childhood Home Visiting Program Consultant, CSHCS physicians, LEND students, birth hospital, audiologists, Michigan Hands & Voices, and Michigan Department of Education Low Incidence Outreach and parent partners.
- To address diversity and inclusion in the EHDI system, the EHDI program will develop and implement a plan with a partner program. The EHDI program resides in the MDHHS Infant Health Unit with Infant Safe Sleep (ISS) and the Fetal Infant Mortality Review (FIMR) programs. The three programs partner regularly for joint objectives and activities to reach a shared audience of professionals and parents. In 2020, the FIMR program will release a culturally competent toolkit to address issues of health disparity, inequality, implicit bias, racial/gender discrimination and social justice. EHDI will utilize this toolkit to foster staff training and leadership development/coaching through our network of stakeholders. In addition, EHDI will work with the recently developed state Mother Infant Health Equity Plan (MIHEP). EHDI will incorporate both frameworks to educate stakeholders to address social determinants of health impacting issues related to loss to follow up.
- ➤ EHDI will utilize a variety of strategies to assess program performance to maintain quality improvement and address gaps/challenges during this grant period. Strategies that

will be evaluated will use the Plan-Do-Study-Act and the Lean Process Improvement Methodologies. Two quality improvement projects will be completed and focus on 1) family engagement/family support by increasing Guide by Your Side (GBYS) referrals and 2) early intervention referral and/or enrollment. These quality improvement focus areas were determined based on program needs with a plan for implementation to incorporate goals, methods, timelines for improvement, and stakeholders involved.

- > EHDI will continue to maintain, refine and promote its website, www.michigan.gov/ehdi.
- ➤ In addition, EHDI will promote the Michigan Hands & Voices website, http://www.mihandsandvoices.org/ to support a venue that is user friendly with accessible, culturally appropriate information for families and professionals. Both sites will be updated to assure that they are accurate, comprehensive, up-to-date, and evidence-based to allow families to make important decisions for their children in a timely manner.
- ➤ EHDI best practices, improvements in training and technology will foster program sustainability. The following key elements of the project will be sustained beyond the grant period using a quality improvement platform through various processes to include fostering family engagement, educating and engaging parents/professionals in the community, developing venues for Deaf and Hard of Hearing mentoring, focusing on care coordination via the medical home, and facilitating professional development for early intervention program staff. Financial sustainability is dependent on grant funding coupled with support from the newborn screening program blood card allocation.

B. Engage, educate and train health professional and service providers in the EHDI system.

- ➤ EHDI will conduct outreach and education to health professionals and service providers to address 1-3-6 recommendations, and enrollment into EI services, medical home, evidenced-based care. EHDI will facilitate this work through the existing EHDI advisory, learning community networks and MHV.
 - New stakeholder relationships will be developed in designated prosperity regions through the Regional Perinatal Collaboratives.
 - EHDI has developed and will continue EHDI 1-3-6 overview for Ear, Nose and Throat, Otolaryngology (ENT) office presentations.
- To provide outreach and education EHDI activities will be shared through a variety of venues: conference presentations, hospital grand rounds and trainings, newsletters, webinars, workshops, web-based content, social media, texting and videos.
- The EHDI program will continue to collaborate with the Michigan Leadership Education in Neurodevelopmental and Other Related Disabilities (MI-LEND) program to promote the audiology training component. The MI-LEND program and the Pediatric Audiology Supplement is poised to significantly expand interdisciplinary leadership training opportunities for graduate-level audiology trainees to work with a wide variety of professional disciplines including medicine, psychology, behavior analysis, and special education. LEND trainees will be invited to participate in EHDI meetings at the state and national level. The goals of the audiology program will focus on 1) strengthening the focus on screening, treatment, and follow-up in infants and children who are deaf or hard-of-hearing, and/or have other related neurodevelopmental concerns, 2) building capacity by increasing the number of pediatric audiologists with clinical and leadership skills/expertise in delivering care to infants and young children, utilizing these unique

skills to work across disciplines to better serve children with hearing loss and their families, and 3) enhancing EI capacity to increase enrollment of infants/children with neurodevelopmental concerns who are deaf or hard of hearing.

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

- Family engagement improves the EHDI system across the 1-3-6 spectrum and beyond. EHDI will strengthen capacity to provide family support and engagement for families via partnerships with Michigan Hands and Voices (MHV), Children and Youth with Special Health Care Needs (CYSHCN)-Michigan Family to Family network and Michigan Coalition of Deaf, Hard of Hearing, and Deafblind People (MCDHHDBP).
- ➤ EHDI will partner with MHV to conduct outreach and education to inform families about opportunities to be involved in different roles within the EHDI system and collaborate with various leaders and policy makers in addressing the challenges to and providing solutions for the EHDI system. One way to support education and prepare families to be involved in the EHDI system is to support communication access at the annual Michigan Family Matters workshop. This one-day event provides resources and support for families.
- ➤ EHDI will facilitate the family engagement/family support initiatives of this grant opportunity with the continued partnership with MHV. The required 25% HRSA funding will be allocated to the MHV organization. The Guide By Your Side program originated within the MDHHS EHDI program in 2002. In 2017, the program was incorporated with MHV umbrella of services to provide management and oversight of the GBYS family support program.
 - a) The MHV/GBYS program coordinator will be responsible for the selection, training, evaluation and supervision of parent guides. A data sharing agreement and workplan has been operationalized by the EHDI program to facilitate understanding of program goals, objectives and contract deliverables. In addition, training of parents to be involved in the systems who serve them to encourage improvements in service will also be included.
 - b) Family to Family and DHH Adult Consumer-to-Family Support Preliminary planning will be initiated in concert with MHV to explore Deaf and Hard of Hearing mentor/support programs in 2020. Subsequent grant years of 2021 -2024 will be devoted to building on the successful operation and evaluation of the MHV GBYS program to facilitate expansion to the development of the Deaf/Hard of Hearing (DHH) Mentor program.
- MHV will begin the process with training of GBYS Parent Guides to educate their families on the benefits of meeting and interacting with adults who are DHH and to help families feel comfortable with individuals who are DHH. Alternatively, families may want to skip enrollment in GBYS and start their journeys by meeting with DHH Guides. MHV is committed to meeting families' personal needs because we understand each family is different. Next, families may either enroll in the MHV DHH Guide program or another organization's DHH Adult-to-Family program, and Parent Guides will record the enrollment and report on which program(s) each family is enrolled. To facilitate timely

- and accurate enrollment tracking, MHV will research and initiate use of a cost-effective and user-friendly customer relationship management program.
- MHV will explore the creation of a short video featuring Michigan DHH Guides to give families a feeling of what it might be like to interact with adults who are DHH and to explain the benefits. This video could also be used by professionals to promote the program and it will be posted on the MHV website.
- ➤ EHDI will also explore opportunities for DHH mentorship with other stakeholders to include: EHDI advisory group, EHDI learning community networks, Michigan Coalition for Deaf, Hard of Hearing, and Deafblind People, Michigan Department of Education-Low Incidence Outreach (MDE-LIO), Deaf-Blind Central (DBC) and Deaf Community Advocacy Network (Deaf CAN!).
 - c) Stipends will be provided to family leaders who have a child who is DHH to participate on the EHDI advisory.
 - d) Salary for family leaders who have a child who is DHH will be allocated to our GBYS coordinator and MHV management.
 - e) MHV has evolved their services with parents trained in the 1-3-6 model to share their story in a variety of settings: hospital meetings and trainings, community meetings and early intervention meetings. This 1-3-6 parent representative program will continue for this grant.
- ➤ EHDI will also continue to work with the National Center for Hearing Assessment and Management (NCHAM) as a partner in training and technical assistance regarding this grant opportunity. EHDI will also continue the collaboration with the HRSA Family Leadership in Language and Learning Center (FL3) for further program refinement and support. The Michigan EHDI Program consultant serves on the FL3 advisory board and anticipates continuing this role for 2020 to 2024.

D. Facilitate improved coordination of care and services for families and children who are DHH.

- ➤ EHDI will continue quarterly meetings with the state early intervention coordinator for Early On® (EO) to assess the status of coordination across early childhood programs and develop and implement a plan to improve coordination and care services.
- ➤ EHDI and EO will continue the agreement for annual data sharing initiated in 2015 and explore opportunities for more mechanisms for formal communication, training, referrals and/or data sharing between the state programs.
- ➤ EHDI will apply for the optional one-year HRSA funding to assess EO training and care coordination status in Michigan early intervention programs.
- ➤ EHDI will utilize information from the optional funding assessment to analyze the status of coordination across early intervention programs and develop a plan to improve coordination and care services.

E. Additional Items as Requested

- ➤ EHDI will provide monetary support with this funding opportunity for EHDI staff and one family leader to attend the national EHDI meetings in 2020 through 2024.
- ➤ EHDI will continue the partnerships with the National Center for Hearing Assessment and Management (NCHAM) and with the HRSA Family Leadership in Language and Learning Center (FL3) for further program refinement and support.

F. Optional Needs Assessment Project

EHDI is applying for the optional needs assessment as detailed in the attachment.

Work Plan

EHDI will develop and build program infrastructure focusing on the over-arching concepts of innovative, holistic care that is based on evidenced-based equitable frameworks. In concert with Michigan Hands and Voices, EHDI learning communities, EHDI advisory, federal partners and previously noted stakeholders, EHDI will facilitate the national 1-3-6 goals. These efforts will have a focus on the utilization of specific, measurable, achievable, and realistic and time bound (SMART) interventions.

This infrastructure and interventions will address the grant requirements in the objectives below, by March 2024:

- ➤ Objective 1. 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.
- ➤ Objective 2. 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.
- ➤ Objective 3. Increase by 15 percent from baseline, or achieve a minimum rate of 80 percent, the number of infants identified to be DHH that are enrolled in EI services no later than 6 months of age.

Using data collected from year 1 (2020) as baseline data:

- > Objective 4. 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.
- > Objective 5. Increase by 10 percent the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age.
- ➤ Objective 6. Increase by 10 percent the number of health professionals and service providers trained on key aspects of the EHDI Program.

Below lists the proposed timeline, activities, support, and collaborations required to successfully achieve each SMART objective.

Workplan Methodology

Objective 1: 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.

By the given definition for screening rate, which is number of infants screened for hearing loss by one month of age (105,053) divided by number of occurrent births (109,456), 96% of births were screened. With a deliverable of increasing 10% over this baseline or achieving at least 95 percent screening rate, the expectation has already been met. The CDC definition of screening rate is slightly different, as it divides the number of infants screened for hearing loss by one month of age by the total number of infants screened. The numerator and denominator are more closely related in this rate and Michigan EHDI would have a screening rate of 97% of newborns having a timely screen.

In 2017, EHDI had 105,053 (97%) of newborns receive a timely screening, no later than one month of age.

A regional approach will be implemented using Joint Committee on Infant Hearing (JCIH) guidelines to create an assessment of hospital baseline data, sharing parent stories and using the EHDI online training module via dyad teams of EHDI staff and parents. MHV has created an innovative approach to sharing parent stories based on the national 1-3-6 goals. A quality improvement approach will be implemented using the site visit rubric to assess hospital baseline data, screener training and parental messaging to facilities. EHDI will support hearing screening capacity in young children up to three years of age by partnering with MDE Early On® and MDHHS Pres-School/ School age audiologist.

Activity 1: By December 2020, using a parental engagement approach, EHDI will collaborate with MHV to create dyad teams to facilitate hospital screener visits and training.

Activity 2: By March 2021, EHDI will facilitate five hospital site visits for training and technical assistance with MHV Parent 1-3-6 representatives using the Plan-Do-Study-Act (PDSA) model for quality improvement.

Activity 3: By April 2022, EHDI will work to facilitate technology upgrades in data reporting for the implementation of the Health Level (HL) 7 interface, which will foster real-time reporting of hearing screening results. EHDI will work with current birthing hospitals to develop HL7 messaging pilot sites at two facilities in 2021. A QI focus will provide the background as the pilot sites implement and refine the HL7 messaging system to improve reporting time and subsequently diagnostic referrals.

Activity 4: By March 2024, the EHDI advisory committee will participate in an annual strategic planning process to identify opportunities to improve the EHDI system to maintain newborn hearing screens.

Objective 2: 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.

The HRSA and CDC definition for this objective are the same, the total number of infants who received a diagnostic test before three months of age divided by the total number of infants that did not pass the final screen. In 2017, EHDI had 287 (22.8%) of the 1,258 infants who failed their final hearing screen, received diagnostic testing no later than three months of age. With a deliverable of increasing 10% over this baseline, the expectation is that the state would reach a 25.1% timely diagnosis rate by the end of the 4-year period.

In 2017, EHDI had 96 (57%) of the 167 infants with hearing loss receive a timely diagnosis, no later than three months of age.

A collaborative approach with the Leadership in Neurodevelopmental Disorders (LEND) and Michigan Audiology Council will be implemented using Joint Committee on Infant Hearing (JCIH) Guidelines to facilitate audiology educational needs.

Activity 1: By June 2020, EHDI will develop an educational strategic plan (webinars and resource materials) to facilitate pediatric audiology training and reporting. This plan will identify what education will be provided, in what format, to which audiences and by whom.

Activity 2: By March 2021, EHDI will collaborate with the Wayne State University/LEND program to share EHDI program initiatives. During the grant period, up to three long-term MI-LEND audiology trainees will complete course work of combined didactic, clinical, community, and leadership activities in partnership with EHDI to attend advisory or learning community meetings and the national EHDI meetings.

Activity 3: By March 2024, EHDI will conduct individual provider site visits to educate the medical home on creating appropriate diagnostic referrals to the EHDI Pediatric Audiology facilities within the 3-month goal.

Objective 3: Increase by 15 percent from baseline, or achieve a minimum rate of 80 percent, the number of infants identified to be DHH who are enrolled in EI services no later than 6 months of age.

The HRSA definition for this objective is the total number of infants enrolled in EI before six months of age divided by the total number of infants enrolled in early intervention. In 2017, of the 167 infants identified with hearing loss and referred, 61 of 93 infants received services by six months of age for a total of 66%. The CDC definition of early intervention is slightly different, as it divides the total enrolled in EI before six months of age by the total diagnosed with permanent hearing loss. This means that 61 out of 167 infants received early intervention services by six months of age or 36.5%. With a deliverable of increasing 15% over this baseline, the expectation is that the state would reach a 42.0% timely enrollment in early intervention services by the end of the 4-year period.

Activity 1: By April 2020, EHDI will develop a shared vision and plan with the state early intervention program coordinator to identify shared initiatives to facilitate EI enrollment for infants who are deaf or hard of hearing.

Activity 2: By March 2021, EHDI will collaborate with MDE to develop a needs assessment to identify educational/program needs for early intervention coordinators.

Activity 3: By April 2022, EHDI will collaborate with MDE to develop and conduct an assessment of other state EI/EHDI agreements for data sharing/identify opportunities. Results of the assessment will used to identify and implement a Michigan EHDI/MDE data sharing agreement.

Activity 4: By March 2024, EHDI will collaborate with MDE and develop a formal mechanism for communication, training, referrals, care coordination and data sharing with the Michigan Individuals with Disabilities Education Act (IDEA) Part C/Early On® program.

Objective 4: *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.*

Michigan will be defining this objective as the number of infants that received a Guide By Your Side (GBYS) visit no later than 6 months of age divided by the number of infants who are deaf and hard of hearing. In 2017, 21 out of 167 infants with hearing loss or 12.6% of infants received

a Guide visit no later than 6 months of age. Michigan does have a delay in diagnosis so if you evaluate the number of infants from 2017 that received a guide visit after 6 months of age that is another 22 infants. This means that 43 out of 167 or 25.7% of families received GBYS support. With a deliverable of increasing 20% over this baseline, the expectation is that the state would reach a 15.12% rate of infants receiving a GBYS visit no later than 6 months of age by the end of the 4-year period.

Activity 1: By April 2021, EHDI will collaborate with the Great Start Early Childhood Investment Corporation (ECIC) to conduct four community conversations with parents and early intervention partners via the EHDI learning communities to identify gaps in early intervention and family services.

Activity 2: By December 2021, EHDI will continue to collaborate with Michigan Hands & Voices, EHDI Advisory and Children Special Health Care Family to Family program to conduct outreach and education to inform families about opportunities to be involved in different roles within the state EHDI system using a variety of communication methods to include: social media, texting, videos, websites and other communication platforms.

Activity 3: By March 2024, EHDI will continue to refer all infants and children who are DHH to the Michigan Hands & Voices Guide By Your Side program for family to family support. Baseline data for year one will be used and analyzed to determine a quality improvement project to increase GBYS visits.

Objective 5: Increase by 10 percent the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age.

Activity 1: By April 2021, EHDI will explore with Michigan Hands & Voices opportunities to establish DHH adult to family support services. Other partners to provide feedback include the learning communities, Michigan Coalition for Deaf, Hard of Hearing, and Deafblind People, and the EHDI Advisory committee.

Activity 2: By March 2022, MHV will produce a cost analysis report to determine the costs required to maintain the DHH adult to family support services program and will investigate funding opportunities.

Activity 3: By March 2023, Michigan Hands & Voices and EHDI will collaborate with state and federal partners (NCHAM and FL3) to create an action plan that will be used to identify formal mechanisms to facilitate family enrollment in DHH adult mentor/family support services.

Objective 6: Increase by 10 percent the number of health professionals and service providers trained on key aspects of the EHDI Program

Activity 1: By April 2021, EHDI will collaborate with the MDHHS School age audiologist and MDE Early On® to develop training guidance and facilitate statewide county hearing screening trainings for children through age three.

Activity 2: By April 2021, EHDI will conduct *EHDI 101/1-3-6 Overview* presentations for designated Michigan ENT/OTO practices. To facilitate presentations EHDI will collaborate with Michigan Otolaryngology Society.

Activity 3: By July 2021, EHDI will establish a partnership with the Regional Perinatal Quality Collaborative to identify shared initiatives and create a regional and state level Michigan Loss to Follow-up intervention action plan. EHDI will work the Collaborative lead and Regional leads to create plans whereby regions, with EHDI support, will engage their members to address Loss to Follow-up.

Activity 4: By December 2021, EHDI will provide a LTF presentation for designated Regional Perinatal Collaboratives. Loss to follow-up data by region will be included in these presentations.

- ➤ Depending on the interest and success of these initial information meetings, other activities will be developed as follows. Ad hoc LTF committees will be formed to identify specific ways (create a loss to follow-up plan) regionally and locally high-risk residents who typically are categorized in loss to follow-up groups can be reached and provided with diagnostic and early intervention services. EHDI diagnostic and early intervention services will be a required component of the ad hoc committee to include in their plans.
- ➤ EHDI and the Regional Perinatal Quality Collaboratives will facilitate meetings and the loss to follow-up ad hoc committees will report on their progress and innovative regional and locally driven solutions to reach these high-risk families. Progress on state level solutions captured through this process will also be reported out to regions.
- A summary of each region's loss to follow-up plans, strategies identified, successes and barriers will be created and shared with each Regional Perinatal Quality Collaborative. In addition, successes and barriers related to state level strategies including activities associated with WIC, MIHP, and Early On® will also be documented as related to this activity.

Activity 5: By March 2022, EHDI will provide EHDI stakeholders with the FIMR program culturally competent toolkit to address issues of health disparity, inequality, implicit bias, racial/gender discrimination and social justice. EHDI will utilize this toolkit to conduct staff trainings and leadership development/coaching through our network of stakeholders.

Activity 6: By March 2024, EHDI will collaborate with MDHHS Preschool/School audiologist to develop a state/territory plan to expand infrastructure, including data collection and reporting, for hearing screening for children up to age 3.

Resolution of Challenges

EHDI continues to maintain internal program integrity despite challenges over the 19 year program history with staffing and funding fluctuations, and agency reorganizations. Agencies throughout the state face financial challenges related to low reimbursement rates and fluctuations in Medicaid health plan requirements, from providing transportation for clients to prior authorization requirements. Many families face a number of social determinants that impact them daily. These include lack of awareness of hearing loss and its effects on infant development, resources for hearing from screening and diagnostic follow up, lack of widespread public transportation, and difficulty in accessing hearing health care providers overall, especially in rural areas. Parents struggling to provide the basic necessities of life for their children are often overwhelmed and either reluctant or unable to take time from work to obtain follow-up hearing care for their infants and children.

Other challenges impacting families include lower level of educational attainment of some parents, lack of insurance coverage, limited time spent in the hospital, lack of a medical home, changing addresses, no phone, and transportation issues. These barriers all contribute to the social determinants of health challenges that we face in assisting families with health care resources. Challenges to our partner early intervention agency, Early On ®, include low enrollment as noted previously. According to the Michigan League for Public Policy (2019), currently 3.1% of infants and children age zero to two are being served; however, it is estimated that almost 8% of this age group are eligible to receive Early On® services. Ensuring that children start off on the right path with a healthy birth, early detection of hearing loss and access to coordinated healthcare are all necessary to enable children to thrive. With this funding opportunity, EHDI will have the expanded capacity to develop new collaborations and partnerships to facilitate hearing health care through increasing screening capacity through age three, improving family resources and support with access to Deaf and Hard of Hearing mentor opportunities, and addressing health disparities.

- Capacity/Access: Partnership with the Michigan LEND center will facilitate professional development for pediatric audiologists, and ultimately increasing access to care, especially in rural areas. EHDI will continue to work with CSHCS and Michigan Medicaid health plans to address the barriers and issues of provider reimbursement and client transportation. EHDI will also facilitate improving screening capacity with the MDHHS Pre-School/School audiologist.
- Family engagement: Partnerships with MI Hands & Voices and Great Start Collaboratives will ensure integration of family-centered perspectives into every level of the EHDI program including screening, diagnostics, and early intervention, in addition to the learning community curriculum development, training, and program evaluation.
- ➤ Early Intervention: Early intervention services help to ensure that children have better language outcomes in preparation for school. These services have also demonstrated a decrease in the cost of special education. EHDI will work to facilitate partnerships with Early On® Part C and Michigan Department of Education- Low Incidence Outreach to assess and refine professional development to foster EI services that support language acquisition.

Evaluation and Technical Support Capacity

Evaluation of all grant related activities will be ongoing, and completed on an annual basis. Program evaluation will implement the Specific, Measurable, Attainable, Realistic, Time Bound (SMART) approach to monitor and ensure the successful completion of the outlined goals/objectives of the project. Specific EHDI staff members will be assigned to take the lead on each activity and are responsible to the EHDI Coordinator and Infant Health Unit manager for continued progress, which will be reported as required by HRSA.

EHDI will continue to collaborate with the MDHHS Bureau of Population Health and Epidemiology to develop evaluation methodology of attainment toward the EHDI 1-3-6 Goals and quality program improvement initiatives. Through the Bureau and with funding from this grant, EHDI will support a half time epidemiology position. This position will assist with oversight for program planning, evaluation, and refinement of program deliverables including quality improvement activities. The epidemiologist has published two articles related to EHDI loss to follow-up and an overview of the EHDI midwifery screening project. MDE will provide in-kind staff support for analysis/evaluation of EI enrollment/IFSP data on a biannual basis.

The overall evaluation plan will also measure the impact and efficiency of proposed activities to include:

- ➤ Compilation of the annual CDC Hearing Screening and Follow-Up Survey (HSFS) to assess program outcomes for screening, diagnostic and early intervention enrollment
- ➤ Continuation of the data integration with the Newborn Metabolic screening program using Perkin- Elmer and Life Cycle software
- ➤ Implementation of the Health Level 7 (HL7) messaging via hospital test sites to foster efficient real time reporting
- Analysis and evaluation of the barrier and parent surveys with input from parents on the survey design/revision of questions
- ➤ Data analysis summary to identify gaps related to screening, diagnostic and early intervention processes, and to provide education to stakeholders about the program's successes, challenges, and future opportunities
- Analysis of data to assess/evaluate the outcomes of the statewide screening program for out-of-hospital and midwife-assisted births
- ➤ Data linkage analysis related to vital records to evaluate demographic data for all newborns including infants with hearing loss by year and county
- ➤ Continuation of data sharing/analysis agreement with the Early On® Part C program to evaluate biannually referral and enrollment for Infant Family Service Plans (IFSP) dates
- ➤ Implementation of a refined data sharing/analysis of individual infant early intervention data from Early On® to assess enrollment progress outcomes biannually by county
- > Development of new data sharing agreement with the WIC program
- ➤ Development of new data sharing analysis of families using Deaf and Hard of Hearing (DHH) mentors and resources

Health Information Technology

Data is critical to program evaluation and benchmark outcomes. Health information technology will play a pivotal role in care coordination and ease of reporting screening and diagnostic reporting to EHDI. EHDI plans to transform information and create a data platform for innovation using Health Level (HL7) messaging. The MDHHS Data Hub - Enterprise Service Bus (ESB) is the main entry point for traffic from the health care community (providers, hospitals, etc.) to internal MDHHS systems, as well as interconnecting MDHHS systems with each other. The ESB is primarily used for real-time clinical information or transactions going to or from MDHHS. It also provides interoperability between clinical electronic medical record (EMR) systems and EHDI systems for increased efficiency and better data quality. EHDI has worked diligently to facilitate upgrades in data reporting for the implementation of the HL7 interface, which will foster real-time reporting of hearing screening and diagnostic results, with hospital/audiology pilots. It is tentatively anticipated that HL7 messages will be operational and used by EHDI starting in in April 2021.

Quality Improvement

Another facet of the MI EHDI evaluation is to assess attainment of quality benchmarks. A quality improvement (QI) collaborative approach that focuses on adopting and adapting best practices across multiple settings and creating changes in organizations will be used. Two conceptual frameworks will be implemented with this grant: 1) Plan-Do-Study-Act (PDSA)

cycles are used to rapidly test changes in real work settings by planning a change, trying the change, observing the results, and acting on what is learned. The PDSA cycle guides the test of a change to determine if the change results in improvement, thus providing evidence for practice. The PDSA model of quality improvement will be shared among stakeholders to promote the delivery of effective interventions and services. 2) Lean Process Improvement (LPI) to enable the EHDI team to systematically find ways to deliver more value to the program and stakeholders. LPI uses a systematic, scientific approach to practicing continuous improvement as a part of daily work by identifying, planning, executing and reviewing through continuous improvement cycles. At a minimum, two PDSA cycles and one Lean Process Improvement will be completed. Lastly, EHDI will continue to participate in quality improvement (QI) opportunities supported and evaluated through the NCHAM regional QI advisors.

Impact

This project will impact the health care of infants and children with hearing loss through:

- Increasing family engagement
- > Increasing screening capacity
- ➤ Educating and engaging an expanded network of professions
- > Improving care coordination and developmental outcomes
- Applying systemic quality improvement in screening, diagnostics and early intervention
- > Improving access to hearing health care
- ➤ Developing innovative, efficient reporting technology via HL7 messaging.

Organizational Information

Resources and Capabilities

The EHDI program was created and is maintained, as an organizational component of the Michigan Department of Health and Human Services (MDHHS), which is comprised of of public health, mental health, and the Medicaid administrations. The Department strives to promote better health outcomes, reduce health risks, and support stable and safe families while encouraging self-sufficiency. As one of 18 departments of state government, MDHHS is responsible for health policy and management of the state's publicly funded health service systems. Services are planned and delivered through integration of these components. MDHHS is the Title V agency and EHDI is the agency's method of achieving the Maternal Child Health Block Grant and Healthy People 2020 early hearing screening and intervention objectives.

The EHDI program will have sufficient personnel to carry out the proposed goals and objectives. In addition to experienced newborn hearing screening personnel, there is also qualified staff working in other areas of MDHHS relevant to the project, including maternal and child health, CSHCS, vital statistics, and epidemiology, who will be contributing their expertise.

Capacity to Date - State and Program

Since 1997, the EHDI staff has worked with stakeholders to increase screening in Michigan from 5% to the current rate of 97%. This goal was accomplished by providing support and education to the community stakeholders and collaborating partners. Further, the 80-infant hearing screening programs in hospitals evolved voluntarily, prior to the legislative mandates for reporting and screening instituted in 2006. Correspondence occurs quarterly with the screening hospitals and midwives in a report containing referral statistics as well as a narrative section on program updates and training opportunities.

Two federal grants and state funding have supported the Michigan EHDI program for nearly 19 years. The current CDC Tracking and Surveillance grant was awarded in July 2017 and the HRSA/Maternal Child Health Bureau grant for implementation of Universal Newborn Hearing Screening was awarded in April 2017. Both grants have provided the opportunity to develop statewide infant hearing screening, data tracking and surveillance, a follow-up program, family support and two learning community networks.

The EHDI program and Michigan Hands and Voices staff attend the annual EHDI National and the National Hands & Voices Leadership conferences each year for program updates and refinements. Staff also participate in the CDC teleconferences on ad-hoc, data, and executive and special topic committees, in addition to the educational offerings from NCHAM and the FL3 on physician education, family issues, and hearing health care. Michigan will call upon technical centers available through both Maternal Child Health Bureau and Centers for Disease Control and Prevention for assistance in program refinement as well as state agencies.

The EHDI program currently provides a variety of educational materials that can be given to families and providers. Depending on the material, these resources are available in English, Spanish, and Arabic. EHDI recently partnered with the national *Talking Is Teaching* initiative through the Wayne County Great Start Collaborative to develop hospital and audiology clinic bulletin boards focusing on language acquisition. This initiative focuses on the importance of talking, reading, singing and signing daily with infants and young children. The EHDI program has the resources available through our publications department to translate educational materials to other languages depending on needs of the population. EHDI tries to ensure that educational materials are at a reading level to accommodate the public and provide a diverse representation of people in the materials. The EHDI program also has the ability to use a language phone line to communicate with families where English is not the primary language. The GBYS program will also utilize an interpreter as needed when providing home visits to the family. The GBYS program employs 14 parent guides statewide, including a native Spanish and a native Arabic speaker.

EHDI has been able to perform quality improvement projects by using the information gleaned from the barrier surveys. Implementing knowledge from the plan-do-study-act (PDSA) and Health Equity models, EHDI developed two projects to foster equity in service delivery to Michigan families with infants who needed screenings or rescreenings. The first project, with Wayne Children's Healthcare Access program (WCHAP), focused on improving loss to follow up for Detroit area families. Many Detroit families face daily issues of poverty and lack of transportation, which impact their ability to obtain follow up services for their infants. The WCHAP EHDI specialist contacted families via phone/letter to assist with hearing screening follow up appointments and transportation. In addition, many families utilize the free hearing screening clinic at Wayne State University.

The second project, a collaborative effort with Michigan Midwives Association (MMA), Michigan Coalition for Deaf, Hard of Hearing, and Deafblind People, Central Michigan University and The Carls Foundation, focuses on providing hearing screening equipment for families opting for out of hospital deliveries. The EHDI Program consultant was instrumental in developing this program and continues to provide day to day oversight. Carls Foundation funding was obtained in 2014 to support the initial purchase of hearing screening equipment for

the midwives throughout state for families residing in rural, underserved areas and Amish communities. In 2019, additional funding was secured for ten more screening units. To date nearly 100 midwives, doulas, and midwife students have been trained in this innovative program providing infant hearing screening services through a shared usage collaborative. EHDI continues to build on the lessons learned through these projects and the two learning communities to improve health access and programs for families with infants and children who are Deaf or Hard of Hearing.

Budget and Budget Narrative

Michigan EHDI is requesting \$235,000 per year over the four-year period (2020 to 2024) to plan, implement and evaluate the deliverables as outlined in this application. Please see the budget narrative file for the detailed budget and budget narrative descriptions which will follow HRSA budgetary guidelines. Funding from this grant opportunity will be allocated as follows to support EHDI program staff and projects as outlined below:

- ➤ EHDI Program Coordinator
- ➤ Michigan Hands & Voices to support a family organization and GBYS Coordinator
- ➤ Attendance to attend the annual EHDI conference for one EHDI staff and one family member
- ➤ Regional audiologist and screener/audiology training
- > EHDI epidemiologist for program evaluation and quality improvement