

Project Narrative

Introduction:

The purpose of the proposed project is to ensure that Missouri families with newborns, infants, and young children up to the age of three who are deaf or hard-of-hearing (DHH) receive appropriate and timely services that include hearing screening, diagnosis, and intervention. The Joint Committee on Infant Hearing (JCIH) recommends that all infants be screened using a physiologic measure at no later than one month of age, that those infants who did not pass the initial hearing screening and the subsequent rescreening have an audiologic evaluation by three months of age, and that all infants diagnosed with a permanent hearing loss (PHL) receive early intervention (EI) by six months of age. These goals are referred to as the 1-3-6 early hearing detection and intervention (EHDI) model. The EHDI Act of 2017 expanded the target population for hearing screening to include children up to the age of three. Other important EHDI services include family support, DHH adult-to-family support, and provider engagement and education.

The Missouri Department of Health and Senior Services (DHSS) Newborn Hearing Screening Program (MNHSP) seeks to build upon its current efforts to meet the JCIH 1-3-6 recommendations, reduce loss to follow-up/loss to documentation (LTF/D), engage and support families, and educate and train health professionals by employing the following methods to system improvement:

- Lead efforts to engage and coordinate all stakeholders in the Missouri EHDI system to meet the goals of the program;
- Engage, educate, and train health professionals and service providers in the Missouri EHDI system;
- Strengthen capacity to provide family support and engage families with children who are DHH as well as adults who are DHH throughout the Missouri EHDI system;
- Facilitate improved coordination of care and services for families and children who are DHH; and
- Collaborate with Health Resources and Services Administration (HRSA) EHDI programs to implement project activities outlined in the work plan (see Attachment 1: Work Plan).

The five approaches to improvement listed above will serve to ensure that children who are DHH are identified through newborn, infant, and early childhood hearing screening and receive diagnosis and appropriate early intervention to optimize language, literacy, cognitive, social, and emotional development. The projected project outcomes are:

1. Maintain or increase by 1% from 96.15% (2017 Centers for Disease Control and Prevention [CDC] Hearing Screening and Follow-up Survey [HSFS] data; Denominator is total occurrent births for reporting year) per year, the number of infants that completed a newborn hearing screening no later than one month of age.
2. Increase by 10% from 62.90% (2017 CDC HSFS data; Denominator is total not pass most recent screen) or achieve a minimum rate of 85% over the duration of the project

period, the number of infants that completed a diagnostic audiological evaluation no later than three months of age.

3. Maintain or increase by 15% from 82.27% (2017 CDC HSFS data; Denominator is total enrolled in early intervention over the duration of the project period, the number of infants identified to be DHH that are enrolled in EI services no later than six months of age.
4. Increase by 20% from baseline data collected from year one of the project over the duration of the project period, the number of families enrolled in family-to-family support no later than six months of age in the first year of the project.
5. Increase by 10% from baseline data collected from year one of the project over the duration of the project period, the number of families enrolled in DHH adult-to-family support services by no later than nine months of age in the first year of the project.
6. Increase by 10% from baseline data collected from year one of the project over the duration of the project period, the number of health professionals and service providers trained on key aspects of the Missouri EHDI system in the first year of the project.

Needs Assessment

The target population for this proposal is Missouri children who are deaf or hard-of-hearing up to three years of age. The needs assessment describes the Missouri EHDI system, target population disparities, target population needs, Missouri EHDI system barriers, and summarizes project plans to overcome drawbacks to EHDI in Missouri.

Missouri EHDI System: Missouri is comprised of 114 counties and the independent City of St. Louis. The state is centrally located in the United States and shares borders with Arkansas, Kansas, Kentucky, Illinois, Iowa, Nebraska, Oklahoma, and Tennessee. Two large metropolitan areas, Kansas City and St. Louis, are located on the western and eastern borders, respectively, and are connected by Interstate 70. There are large differences in population distribution across Missouri, with the majority located near either St. Louis or Kansas City. Over half of the state's population (55%) falls inside these two cities, with St. Louis accounting for over 35% of the total state population and Kansas City accounting for nearly 20%. Six other Missouri cities with relatively high population density listed in order of size are: Springfield (southwest), Joplin (southwest), Columbia (central), Jefferson City (central), St. Joseph (northwest), and Cape Girardeau (southeast). Overall, Missouri is largely a rural state with 101 rural and 14 urban counties. The MNHSP is located in Jefferson City.

As required by state statute, newborn hearing screening programs in 64 hospitals and birth clinics statewide and five midwives regularly report newborn hearing screening to the MNHSP via the Missouri Electronic Vital Records (MoEVR) system. Those results are downloaded nightly into the Missouri Health Strategic Architectures and Information Cooperative (MOHSAIC), the MNHSP's data management system. In Missouri, hospitals determine how to proceed with audiological follow-up on an individual basis. Families may be referred to an outpatient screening at the birth hospital or to an audiology clinic for diagnostic evaluation.

Audiologists and/or audiology facilities that provide rescreening and evaluations for children from birth to age three following failure to pass the newborn hearing screening are located throughout the state, with the exception of the southeast region known as the Missouri Bootheel. Audiologists in rural areas of the state typically offer only rescreening services. Complete diagnostic evaluations are performed in nine clinics in the St. Louis (4), Kansas City (2), Columbia (1), and Springfield (2) areas. Each of these nine clinics employs four to twenty pediatric audiologists. All nine diagnostic facilities consistently report diagnostic results to the DHSS MNHSP.

MNHSP staff track screening and diagnostic results for all babies born in Missouri. Staff send letters and informational flyers, which stress the importance of follow-up, to families with infants who failed to pass or missed the newborn hearing screening, or have risk factors for late-onset hearing loss. Upon receipt of a diagnostic result indicating permanent hearing loss, the MNHSP Follow-up Coordinator (FUP) makes an official referral to the Part C of the Individuals with Disabilities Education Act (IDEA) EI program in Missouri, known as First Steps, and informs the parent of the referral. The FUP provides the family with information about family and professional support resources, the Family Partnership (FP) and the MOHear Project, respectively. In addition to English, the MNHSP supplies program literature in Arabic, Bosnian, Mandarin, Spanish, and Vietnamese.

The FP is a family-based organization located in the Missouri Department of Health and Senior Services (DHSS). Employed by the Family Partnership, the Family Partners DHH (FP-DHH) are parents of a child who is deaf or hard-of-hearing. The FP-DHH team offers parent-to-parent support to families with an infant newly diagnosed as deaf or hard-of-hearing. The FP-DHH can provide resource information, the opportunity to network with other families, and emotional support as only other parents/caregivers can offer.

The MOHear Project is a collaboration between the DHSS MNHSP and Missouri State University (MSU). MOHears are audiologists, speech-language pathologists, or educators of the DHH who can provide unbiased information to families with an infant newly diagnosed with permanent hearing loss (PHL). MOHears help parents understand their baby's diagnosis and early intervention options. A parent may be connected to a MOHear through their audiologist, their First Steps intake coordinator, or an FP-DHH.

First Steps confirms that the referral by the MNHSP Follow-up Coordinator was received. Additionally, each year First Steps shares the number of babies enrolled in EI through Part C based upon the MNHSP-generated PHL list by birth year. First Steps also seeks consent from parents of children enrolled in the program to share identifiable information connected to the date of the first signed Individualized Family Service Plan (IFSP) with the MNHSP.

While there is no system for total statewide periodic hearing screening for young children up to age three in Missouri, Early Head Start programs and First Steps require hearing screening of all children served in those programs. Additionally, children under the age of three may receive hearing screening from their primary care physician (PCP). There are 28 Early Head Start Programs in Missouri. In 2017, 3,028 children participated in Early Head Start. The First Steps

program served 6,599 children birth to three in a snapshot count of children served by the First Steps program on December 1, 2017. Screening results for children in these programs are not currently collected by the MNHSP.

There are no adult DHH mentorship programs for families with children who are DHH in Missouri. Additionally, targeted family-to-family support for families with children who are DHH is limited. Parent-based, non-professional support for families comes from the FP, family activities at schools for children who are DHH, and a local group in the Springfield area. While Missouri does have a Hands and Voices chapter, it is not yet fully functioning.

The Early Hearing Detection and Intervention Quality Improvement (EHDIQI) workgroup, the Missouri Genetic Advisory Committee's Newborn Hearing Screening Standing Committee (NHSSC), and the Kansas City Early Hearing Detection and Early Intervention-Learning Community (KCEHDI-LC) each contribute to the improvement of the Missouri EHDI system. The EHDIQI workgroup is made up of professionals and parents who access a shared spreadsheet to record Plan-Do-Study-Act (PDSA) quality improvement activities. The EHDIQI workgroup meets quarterly to provide feedback and develop new tests of change to reduce LTF/D at each point in the Missouri EHDI system. Serving as an advisory team comprised of Missouri EHDI stakeholders, the NHSSC meets twice a year to share updates and work on projects to move the MNHSP forward. The public is welcome, and many non-member stakeholders regularly attend and contribute. Members include:

- one adult who is DHH;
- two pediatric audiologists;
- one pediatrician who also serves as the American Academy of Pediatrics' (AAP) EHDI Chapter Champion;
- two parent representatives from the FP;
- one pediatric otolaryngologist;
- one representative from an early intervention program for children with hearing loss;
- one representative from a hospital newborn hearing screening program;
- one representative from the Missouri School for the Deaf (MSD);
- one representative from the Missouri Commission for the Deaf and Hard of Hearing (MCDHH);
- one representative from the Missouri DHSS; and
- the Missouri Part C Coordinator.

Similarly, parents and healthcare professionals who comprise the KCEHDI-LC seek to expand their knowledge of the Missouri EHDI system and foster projects specific to the Kansas City and northwestern region of the state.

Hearing screenings for children after the newborn hearing screening process is completed are not reported to the MNHSP. However, the MNHSP has 1-3-6 and LTF/D data for infants born in 2017 as illustrated in the figure below. Of the 73,839 occurrent births reported to the MNHSP in 2017, 71,000 (96.15%) were screened before one month of age. Of the 1,100 infants born in

2017 who did not pass the final hearing screening, 692 (62.90%) received a diagnosis by three months of age. Of the 113 who were diagnosed with a permanent hearing loss and referred to Missouri’s Part C EI, First Steps, 86 (76.10%) were referred before six months of age. Of the same 113, 65 (82.27%) were enrolled by six months of age.

However, of the 73,839 occurrent births, 471 (0.63%) were lost to follow-up or documentation (LTF/D). Of the 1,100 who did not pass the final hearing screening, 269 (24.45%) did not return for further audiological assessment or were lost to documentation. Of the 113 infants diagnosed with permanent hearing loss, 6 (5.30%) could not be contacted after diagnosis and are considered LTF/D.

1-3-6 Goals	Birth Year	Screened by 1 month	Diagnosed by 3 months	Early Intervention by 6 months
	2017	96.15% (71,000)	62.90% (692)	82.27% (65)

LTF/D	Birth Year	LTF/D following birth	LTF/D following final hearing screening	LTF/D following diagnosis
	2017	0.63% (471)	24.45% (269)	5.30% (6)

Disparities of the target population: Missouri State Vital Statistics recorded 73,839 babies born in Missouri in 2017. Mother’s race is characterized as 79% white, 14.5% black, 3% Asian, 0.5% American Indian or Alaskan Native, 1% unknown, and 2% other, with 3% of the population classified as Hispanic ethnicity. Mother’s education is characterized as 12% Less than High School, 24.75% High School Graduate or GED, 32% Some College or Associate of Arts/ Associate of Science degree, 31% College Graduate or above, and 0.25% unknown.

According to the American Community Survey (ACS), in 2015 Missouri's estimated population of women of childbearing ages (15-44 years) was 1,176,557. Children and youth with special health care needs (1-19 years) accounted for 252,734 of the population. Through the Missouri newborn hearing screening process, the MNHSP identified 121 infants with PHL in 2015, 100 infants with PHL 2016, and 113 infants with PHL in 2017.

Based on the United States Census Bureau’s 2013 - 2017 ACS 5-Year Data Profiles which provides information on the "ability to speak English for the Population 5 Years and Over", the most common languages spoken in Missouri – other than English – are Spanish, Chinese (including Mandarin and Cantonese), German, Vietnamese, French (including Cajun), Serbo-Croatian languages, Arabic, and Dutch (including Afrikaans and Pennsylvania Dutch). According to the ACS, Hispanics represent a small segment of the Missouri population, broadly

dispersed throughout the state. An estimated 149,022 (2.6%) Missourians use Spanish as the primary language at home. The primary language of birth mothers in Missouri is not available.

Geography and socio-economic status affect access to the Missouri EHDI system more significantly than any other disparity. Individual hospital data pulled from MOHSAIC consistently shows that families from rural southeast Missouri and St. Louis City are less likely to obtain audiological follow-up for an infant who failed the newborn hearing screening than families from the rest of the state. Poverty, high unemployment, and low education levels have been well-documented for years in St. Louis City and the Missouri Bootheel. Additionally, there is limited public transportation in the Bootheel. The MNHSP cannot determine geographical location for children diagnosed with PHL and enrolled in First Steps, due to a limited data sharing agreement between DHSS and the Missouri Department of Elementary and Secondary Education (DESE), where First Steps is housed (see Attachment 4). While First Steps provides the MNHSP with aggregate data, little individualized data based upon a signed release of information (ROI) by the parent reaches the MNHSP.

Needs of the Target Population: Missouri children who are DHH up to three years of age need:

- timely diagnosis for infants and children up to three years of age;
- access to family-to-family support services by no later than six months of age or at the time of diagnosis;
- DHH adult-to-family support services by nine months of age or at the time of diagnosis; and
- health professionals and service providers who are trained on key aspects of the EHDI system.

Barriers in the Missouri EHDI System: Barriers in the Missouri EHDI system include:

- limited access to diagnostic centers;
- limited family support services specifically for families with children who are DHH;
- lack of adult DHH mentorship for families with children who are DHH; and
- limited understanding of the importance of 1-3-6 recommendations and family support among health professionals and service providers.

Plans to Address and Overcome Drawbacks to the EHDI in Missouri: The MNHSP plans to overcome barriers using the methods and activities described in the Introduction, Methodology and Work Plan (See Attachment 1). The most significant activities will address:

- Infrastructure support that ensures 1-3-6 recommendations and reduces LTF/D;
- Infrastructure expansion that includes a plan to support hearing screening for children up to age three;
- Partnership improvement for information sharing, referral, and training to connect families with children who are DHH with access to family-to-family support services;
- Partnership improvement for information sharing, referral, and training to connect families with children who are DHH to adults who are DHH for mentorship and support;

- Outreach and education to Missouri health professionals and service providers about key aspects of the Missouri EHDI system;
- NHSSC expansion to increase the number of parents of children who are DHH and adults who are DHH;
- Diversity and inclusion development in the Missouri EHDI system to include issues of access for rural populations;
- EHDIQI workgroup focus on the identified needs of the Missouri EHDI system, particularly 1) the ability to maintain and improve the 1-3-6 recommendations – especially at the level of diagnosis, 2) family engagement and family support, and 3) provider outreach and education;
- Missouri EHDI and FP website improvement;
- Sustainability planning (a Sustainability Plan is found in the Methodology Section in Method 1, Activity 8);
- Family engagement in all aspects of the Missouri EHDI system;
- Partnership facilitation between families and professionals;
- Financial support for family engagement via the FP;
- Service improvement through coordination across early childhood programs; and
- Infrastructure strengthening via EHDI meeting attendance and collaboration with federal EHDI-partners – National Technical Resource Center for newborn Hearing Screening And Intervention (NTRC), Family Leadership in Language and Learning Program (FL3), National Resource Center for Patient/Family-Centered Medical Home (NRC-PFCMH), and the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) – Pediatric Audiology, as appropriate.

Methodology

The overarching program goal of the proposed project is to ensure that children who are DHH are identified through newborn, infant, and early childhood hearing screening and receive diagnosis and appropriate early intervention to optimize language, literacy, cognitive, social, and emotional development. To meet the needs of the Missouri EHDI system stated in the Needs Assessment, the MNHSP will address the project objectives listed in the Introduction by using the following methods and activities:

Method One: Lead efforts to engage and coordinate all stakeholders in the Missouri EHDI system to meet the goals of the program.

Activities:

1. Support infrastructure to ensure that all newborns are screened by one month of age, diagnosed by three months of age, and enrolled in EI by six months of age; and reduce LTF/D.
 - i) Continue MNHSP process of follow-up of families with infants who missed, failed to pass, or are identified with a risk factor for late-onset hearing loss.

- ii) Continue MNHSP process of referral of newborns diagnosed with PHL to First Steps EI.
 - iii) Continue MOHear Project process of assistance to families with newborns diagnosed with PHL to access EI and make informed choices regarding language opportunities.
 - iv) Continue MOHear Project process of contact of audiology centers for missing diagnostic results.
 - v) Explore use of FP-DHHs for the provision of education about 1-3-6 recommendations to parents with newborns who failed to pass the newborn hearing screening.
2. Develop a plan to expand infrastructure to include data collection and reporting for hearing screening for children up to age three by the end of year two of the project.
 - i) For planning purposes during years one and two of the project, research available resources, key stakeholders, potential partnerships (e.g. Title V, Early Head Start), potential collaborations with Maternal and Child Health programs, and necessary services (e.g. MOHSAIC) to implement the plan.
3. Establish and maintain partnerships for referral, training, and information sharing with stakeholder organizations and programs including, but not limited to, health professionals, service providers, birthing centers, and state organizations and programs to meet the needs of timely diagnosis of hearing loss, access to family-to-family support services, access to DHH adult-to-family support services, and health professionals and service providers who are trained on key aspects of the Missouri EHDI system.
 - i) By the end of year one, and revised annually, complete an assessment of current partnerships and identify key partners who could help address gaps and needs in the Missouri EHDI system.
4. Convene annually, at a minimum, the NHSSC to advise on programs, objectives, and strategies throughout the period of performance.
 - i) Expand current NHSSC membership to ensure 25% of the committee is comprised of parents of children who are DHH and adults who are DHH.
 - ii) Maintain current NHSSC membership of organizations that serve families of children who are DHH and expand membership to additional family organizations. Attempt to involve Home Visiting programs, the Training in Interdisciplinary Partnerships and Services (TIPS) for Kids, LEND program, the Missouri Family to Family (MOF2F) health information center, Missouri Family Voices, the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), Early Head Start, the Missouri Medicaid agency, and organizations with expertise in addressing diversity, health equity, and cultural competency.
5. By the end of year two of the project, develop a plan to address diversity and inclusion in the Missouri EHDI system to ensure that the activities are inclusive of and address the needs of the populations it serves. While geography and socio-economic status are known issues related to access in Missouri, also consider race, ethnicity, disability, gender, sexual orientation, and family structure.

6. Maintain the current EHDIQI workgroup to monitor and assess progress toward the project purpose and objectives through use of continuous quality improvement activities.
 - i) Use a PDSA approach to address, throughout the four-year project period, the identified needs in the Needs Assessment: 1) ability to maintain and improve the 1-3-6 recommendations – especially at the level of diagnosis, 2) family engagement and family support, and 3) provider outreach and education.
 - ii) Report annually to HRSA on progress towards addressing these issues using a PDSA approach including goals, methods, timelines for improvement, and stakeholders involved. For reporting, use the current EHDIQI workgroup shared PDSA spreadsheet as well as comments, concerns, and ideas gathered during quarterly EHDIQI workgroup meetings.
7. Improve the existing MNHSP website. Ensure website is user friendly and accessible. Ensure information for families and professionals is culturally appropriate, accurate, comprehensive, up-to-date, and evidence-based. Strive to include information that allows families to make important decisions for their children in a timely manner, including decisions with respect to the full ranges of assistive hearing technologies and communication modalities.
 - i) Work with the FP to update its website to include a page specifically for families with children who are DHH.
8. Plan for project sustainability (Sustainability Plan).
 - i) Determine which program elements do not rely on grant funding.
 - ii) Explore partnerships and collaborations with other organizations devoted to the success of young children who are DHH and their families.
 - iii) Explore other grant opportunities.
 - iv) Request HRSA project officer to provide ample notice prior to the conclusion of project funding.

Method Two: Engage, educate, and train health professionals and service providers in the Missouri EHDI system.

Activities:

1. Conduct outreach, in conjunction with the FP and the MOHear Project, and provide education to health professionals and service providers in the Missouri EHDI system about the following:
 - i) The 1-3-6 recommendations and the importance of timely screening, diagnosis, referral, and enrollment into EI services;
 - ii) The need for hearing screening up to age three to identify, diagnose, and enroll into EI those infants who pass a newborn screen but later develop hearing loss;
 - iii) The benefits of a patient/family-centered medical home and family engagement in the care of a child who is DHH;
 - iv) The importance of communicating accurate, comprehensive, up-to-date, evidence-based information to allow families to make important decisions for their children in a timely manner, including decisions with respect to the full range of assistive hearing technologies and communication modalities, as appropriate;

- v) The proper process for reporting initial hearing screening, rescreening, and diagnostic results to the MNHSP as well as who is expected to report such results;
 - vi) The opportunities available for family engagement in the MNHSP, such as the EHDIQI workgroup and the NHSSC; and
 - vii) The opportunities for family-to-family and DHH adult-to-family support services, as appropriate.
2. Research and utilize a combination of outreach and education activities. Consider use of webinars, workshops, hospital grand rounds, presentations at professional conferences, professional newsletters, web-based content, social media, list serves, and other communication channels, as appropriate.
- i) Collaborate, as appropriate, with federal EHDI partners (e.g. LEND, NTRC, FL3, and NRC-PFCMH). Explore ways to use partnerships to educate health professionals and service providers to help address program needs and meet project objectives.

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

Activities:

1. Engage families throughout all aspects of the project.
- i) Involve family members in development, implementation, and evaluation of the MNHSP through participation in the EHDIQI workgroup and the NHSSC.
 - ii) Encourage family members to develop relationships with other families in the Missouri EHDI system through the FP and other family organizations, as appropriate.
 - iii) Explore various communication avenues to reach families including email, social media, videos, and texting.
2. Facilitate partnerships among families, healthcare professionals, and service providers to ensure that providers understand the best strategies to engage families.
- i) Explore use of the FP-DHH staff to teach PCPs about family-support resources they can offer families with children who are DHH.
 - ii) Explore use of the FP-DHH staff to teach First Steps personnel about family-support resources they can offer families with children who are DHH.
3. Use 25% of funding for the statewide, family-based organization, Family Partnership, for the purpose of providing family support services to families with children who are DHH (see the FP Letter of Support in Attachment 7 and the Agreement between the Missouri DHSS Division of Community and Public Health's Section for Healthy Families and Youth's Bureau of Genetics and Healthy Childhood (GHC) and Section for Community Health Services and Initiatives' Bureau of Special Health Care Needs agreement in Attachment 4).
- i) Collaborate with the FP to provide direct family-to-family support by providing contact information of parents of infants who are newly diagnosed with PHL by the age of six months or at the time of diagnosis. Work with the FP to increase the

- number of families who enroll in family-to-family support. Share data through monthly reports and in MOHSAIC.
- ii) Explore other collaboration opportunities between the MNHSP and the FP for providing family-to-family support, such as use of a shared Listserv, assistance with a parent retreat, development of literature, and other projects as appropriate.
 - iii) Assist the FP to establish relationships with other family support groups, hospitals, audiology clinics, and early interventionists for the purpose of promoting family engagement and conducting family support activities. Include a FP representative in meetings with the aforementioned groups and individuals.
 - iv) Unite with the FP to research and explore avenues for connecting families with children who are DHH to adults who are DHH for mentorship and support.
 - a. Examine availability and suitability of DHH adults from the following organizations: the Missouri Deafblind Technical Assistance Project, Ski Hi Deaf Mentor Program, the Missouri School for the Deaf Alumni Association, Deaf Inc., the MCDHH, and other organizations as appropriate.
 - b. Explore partnerships with DHH adult-to-family support organizations in other states or in national organizations.
 - c. Implement a program of DHH adult-to-family support, as appropriate.
4. Collaborate with the FL3 to strengthen infrastructure and capacity for family engagement and family support in Missouri.
- i) Utilize FL3 resources, technical assistance, training, and education for the MNHSP, FP, MOHear Project, and other stakeholders as appropriate.
 - ii) Distribute FL3 resources during community events and when conducting outreach to diagnostic centers and early interventionists, as appropriate.

Method Four: Facilitate improved coordination of care and services for families and children who are DHH.

Activities:

1. Assess and address coordination across early childhood programs in an effort to improve services – especially hearing screening and result reporting.
 - i) Review and research possibility of expanding and/or improving the effectiveness of the inter-agency data sharing agreement between the DHSS MNHSP and DESE First Steps.
 - ii) Review and research possibility of increasing coordination between the MNHSP and the GHC Home Visiting Unit for the purpose of improving LTF/D for infants who fail to pass the newborn hearing screening.
 - iii) Review and research possibility of partnering with Missouri Early Head Start programs to improve the system of hearing screening, referral to First Steps, and reporting for children up to the age of three.
 - iv) Review and research possibility of partnering with other early childhood programs in Missouri including, but not limited to, Parents as Teachers.

2. Develop a written plan that demonstrates evidence of planning, stakeholder engagement, and potential partnerships in efforts to improve support and services for children up to the age of three who require hearing screening, follow-up, and enrollment into EI, by the end of year one.
3. Demonstrate evidence of improvement in formal communication, training, referrals and/or data sharing with early childhood education partners, by the end of year two.

Method Five: Collaborate with HRSA EHDI-related programs' guidance and technical assistance to implement activities that will improve the Missouri system of care for newborns, infants, and young children up to the age of three who are DHH.

Activities:

1. Ensure attendance at the annual national EHDI meeting of one or two MNHSP staff and one family leader.
2. Utilize the guidance and expertise of the HRSA EHDI project officer throughout the length of the project.
3. Obtain technical assistance, training, education, quality improvement advice, and evaluation assistance from the NTRC throughout the length of the project.
4. Obtain technical assistance, education, and training opportunities from FL3 throughout the length of the project. Ensure the FP utilizes FL3 resources.
5. Collaborate with the FP to utilize NRC-PFCMH resources for the benefit of families with children with PHL up to age three.
6. Explore benefits of collaborating with Missouri's LEND program, known as TIPS for Kids, to provide education to health professionals and families about the EHDI system in Missouri. Note that Missouri is not a recipient of the Pediatric Audiology supplement.

Work Plan

The Work Plan and Logic Model are included in the application as Attachment 1. The Work Plan delineates the methods and activities that will help reach the project's objectives and overarching goal. It includes a timeline for activities and who is responsible for those activities. Additionally, the Work Plan indicates when Missouri EHDI system stakeholders will be involved with planning, designing, and implementing activities and at what points the MNHSP will collaborate with HRSA's national partners and project officers.

Resolution of Challenges

While many Missouri EHDI system stakeholders recognize the benefits of meeting 1-3-6 recommendations, increasing hearing screening opportunities for children up to age three, and enrollment of families with children who are DHH into family-to-family and DHH adult-to-family support services, challenges in implementing the work plan may exist. Challenges include time constraints of EHDI system stakeholders, reduced funding for the MOHear Project, and the challenge of convincing early childhood programs of the benefits of reporting hearing screening results to the MNHSP.

To address the time constraints of EHDIQI workgroup members, NHSSC members, and potential new members and participants in each group, the MNHSP manager will strive to determine the best times for meetings by surveys or individual contact. To meet the needs of busy parents and other EHDI stakeholders, meetings may occur before or after normal work hours. The MNHSP manager will schedule meetings far in advance, facilitate effective and efficient meetings, and help participants see the value in participation. The MNHSP manager will make use of emails and online surveys to advance communication between team members.

Reduced funding to the MSU MOHear Project is necessary to meet the requirement to use 25% of funding for family engagement and support. As the professional arm of MNHSP outreach to parents, health providers, and service providers, the MOHear Project provides unbiased information to parents prior to the IFSP and assists the MNHSP FUP with resolving LTF/D. MOHears reach out to audiologists and PCPs for missing results, provide training on reporting results to the MNSHP, and train hospital hearing screening programs to implement changes that will reduce high “refer” or failing hearing screening rates. The reduction in funding to MSU will result in fewer hours for the five regional MOHears who work with EHDI stakeholders in areas near their homes. The MNHSP program manager and MOHear Project Director will utilize PDSA activities to determine the MOHear activities that lead to the greatest improvement in LTF/D throughout the Missouri EHDI system. The MOHear Project Director will assign only the most beneficial activities to the MOHears.

Past attempts to partner with early childhood programs were not productive. The MNHSP supplied some Early Head Start programs with access to the Public Health Profile (PHP) in order to view newborn hearing screening results and risk factors for late-onset hearing loss, so as to identify children in their programs that may be at risk for hearing loss. The MNHSP asked those programs to report hearing screening results for the children who failed to pass the newborn hearing screening and never received diagnostic follow-up. However, early childhood programs rarely reported hearing screening results to the MNHSP. To avoid a repeat of the past, the MNHSP manager will utilize the following strategies to establish positive relationships with early childhood programs. The MNHSP manager will work with the NHSSC, FP, and the MOHears to educate early childhood programs about the importance of screening for hearing loss up to age three and demonstrate how the MNHSP can assist in ensuring that children who fail to pass a hearing screening obtain diagnostic evaluation and enroll in EI through First Steps. The EDHIQI workgroup will develop PDSAs related to determining the process for reporting early childhood hearing screening results to the MNHSP. Potential avenues include use of paper forms that may be faxed or mailed and provision of access to MOHSAIC for directly entering hearing screening results. Additionally, the MNHSP will invite early childhood program leaders to participate in the NHSSC and EHDIQI workgroup, and explore funding early childhood program leader attendance to the national EHDI meeting. Also, the MNHSP manager will encourage the family members involved in the FP to join boards and advisory committees of early childhood programs.

Evaluation and Technical Support Capacity:

An evaluation plan will be implemented and updated annually. The evaluation will determine if the grant activities met the overarching goal and objectives of the proposed project as outlined in the narrative's Introduction, Methodology, and Work Plan. The evaluation plan will address:

- the extent to which the six program objectives have been met;
- the extent to which program objective successes can be attributed to the project;
- the practices and procedures used for conducting the evaluation; and
- the process for collecting, analyzing, and tracking data.

Evaluation of grant activities will be ongoing and include review of the activities described in the Methodology and Work Plan, analysis of the annual CDC EHDI HSFS data for objectives one through three, and analysis of the baseline and subsequent data collected for objectives four through six. Ongoing review of data will ensure the MNHSP gauge progress and make changes in activities, if needed.

To implement the project, the MNHSP will use the following previously described inputs: MOHSAIC, MNHSP staff, MOHear Project, FP, NHSSC, EHDIQI workgroup, First Steps, Technical assistance from HRSA partners (EHDI NTRC, FL3, LEND, and the NRC-PFCMH), the HRSA EHDI grant project officer, and funding sources (HRSA grant, CDC grant, Maternal Child Health (MCH) Title V Block grant, and general revenue). Key processes will include monitoring 1-3-6 data, monitoring family enrollment into family-to-family programs and DHH adult-to-family services, and educational and training outreach to health professionals and service providers. The expected outcomes are to meet the objectives as stated:

1. Maintain or increase by 1% from 96.15% (2017 CDC HSFS data; Denominator is total occurrent births for reporting year), per year, the number of infants that completed a newborn hearing screening no later than one month of age.
2. Increase by 10% from 62.90% (2017 CDC HSFS data; Denominator is total not pass most recent screen) or achieve a minimum rate of 85%, over the duration of the project period, the number of infants that completed a diagnostic audiological evaluation no later than three months of age.
3. Maintain or increase by 15% from 82.27% (2017 CDC HSFS data; Denominator is total enrolled in EI.), over the duration of the project period, the number of infants identified to be DHH that are enrolled in EI services no later than six months of age.
4. Increase by 20% from baseline data collected from year one of the project, over the duration of the project period, the number of families enrolled in family-to-family support no later than six months of age in the first year of the project.
5. Increase by 10% from baseline data collected from year one of the project, over the duration of the project period, the number of families enrolled in DHH adult-to-family support services by no later than nine months of age in the first year of the project.

6. Increase by 10% from baseline data collected from year one of the project, over the duration of the project period, the number of health professionals and service providers trained on key aspects of the Missouri EHDI system in the first year of the project.

Measures to assess performance progress toward the objectives will include:

- On a quarterly basis, throughout the project period, review MOHSAIC 1-3-6 reports to monitor progress toward objectives one through three;
- On a quarterly basis, throughout the project period, use a “Family-to-family support” spreadsheet to gather data and establish the first year baseline enrollment of families into the FP, followed by regular review of enrollment data;
- On a quarterly basis, throughout the project period, use a “DHH adult-to-family support” spreadsheet to gather data and establish the first year baseline enrollment of families into DHH adult-to-family support services, followed by regular review of enrollment data;
- On a quarterly basis, throughout the project period, use an “Education and training” spreadsheet to gather data and establish the first year baseline number of health professionals and service providers trained on key aspects of the Missouri EHDI system, followed by regular review of ongoing training data; and
- On a quarterly basis, throughout the project period, use the targets stated in the objectives to gauge progress and make changes in activities if needed.

Data components used in evaluation are easily accessible to the MNHSP in MOHSAIC where screening, diagnostic, and early intervention data is stored. To ensure data is unduplicated and as current as possible, the MNHSP staff review and correct data daily that was entered into MOHSAIC on the previous day. MNHSP staff follow a process outlined by Information Technology Services Division (ITSD) to resolve duplicates that result from the integration of MOHSAIC with numerous other DHSS programs. Reports that provide aggregate or individualized data about the EHDI 1-3-6 model goals and LTF/D are available by individual hospital, region, or statewide at any time, and for any time period. Funding for the maintenance, repairs, and enhancements to the hearing screening portion of MOHSAIC comes from the CDC’s Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs grant. The MNHSP works closely with the ITSD to maintain the MOHSAIC newborn hearing screening data management system and produce accurate and pertinent statistical reports.

The spreadsheets created by the MNHSP manager for objectives four through six will be stored on a secure drive within the DHSS information system for the length of the project period. The ITSD directly supports the information technology needs of the DHSS by resolving technical issues and safeguarding the DHSS networks, systems, and data. The MNHSP manager will collaborate with the FP and the MOHear Project to obtain data for evaluation.

To collect, analyze, and track data for objectives one through three, the MNHSP manager will utilize the MOHSAIC 1-3-6 reports. For objectives four through six, the MNHSP manager will collect, enter, and manage the data. The MNHSP manager will collaborate with the FP and the MOHear Project to obtain data for evaluation. The MNHSP manager will gather enrollment

numbers from FP-DHHs who will conduct enrollment of families into the FP and connect families to DHH adult-to-family services. Data on health professional and service provider trainings will come primarily from, but not limited to, MOHears. MOHears will reach out by phone, email, and on-site visits to regionally-based providers to address education needs and training. Each connection made with a health professional or service provider for the purpose of training will be counted toward the baseline number. To establish the percentages in year two for objectives four, five, and six, the denominator will be the baseline established in year one and the numerator will be the number of new enrollments in FP, linkages to DHH adults, and connections made for education, respectively. The FP manager and the MOHear Project Director will compile MOHear data for the MNHSP manager to record in the appropriate spreadsheet. These activities are supported in the budget by categories for the Family Partnership and the MSU MOHear Project.

Analysis of data will inform project development and activities. If little improvement is seen during quarterly reviews of progress, activities will be reexamined among the funded programs (FP, MOHear Project, and the MNHSP) and the NHSSC. Changes will be enacted as appropriate. At such a juncture, PDSA activities led by the experienced EHDIQI workgroup will prove useful. Conversely, promising practices will be disseminated to the NHSSC, included in the annual GHC Newborn Screening Report, and shared with hospital hearing screening programs, pediatric audiologists, and early interventionists as appropriate.

A potential obstacle for implementing program performance evaluation is a lack of or delayed reporting by the FP and the MOHear Project to the MNHSP manager. The MNHSP will address this early in the project year with education about the importance of and the processes for collecting project data. Reminders will be delivered on a monthly basis to encourage front-line data gatherers to keep accurate records, follow project directives, and report data to the MNHSP manager.

Contributing FP and MOHear Project staff have honed their skills in providing data to the MNHSP manager via quarterly reports required during the years of the previous grant project. The MNHSP manager has experience in compiling the annual CDC HSFS and is responsible for submitting an annual internal evaluation of the MNHSP to the DHSS' GHC.

Organizational Information

The MNHSP is within the GHC - part of the DHSS Division of Community and Public Health (DCPH). As declared in its mission statement, the DHSS strives to be the leader in promoting, protecting, and partnering for health. As part of the DHSS structure, the GHC mission statement asserts that the GHC "...promotes and protects the health and safety of individuals and families based on their unique conditions, needs, and situations..." and "...accomplishes its mission in collaboration with families, health care providers, and other community, state, and national partners." The letter of support from the Missouri Title V Director, Ms. Martha J. Smith, MSN, RN, LNHA, reflects the commitment to these mission statements. Ms. Smith's letter of support is found in Attachment 7.

Funding for the MNHSP comes from the MCH Title V Block Grant, the EHDI-IS Grant from the CDC, the current HRSA Universal Newborn Hearing Screening Grant, and general revenue from the state of Missouri. The MNHSP staff, including the program manager and the FUP, have worked within the MNHSP for numerous years. Their biographical sketches are found in Attachment 3.

The MOHear Project manager is an audiologist employed by the MSU Department of Communication Sciences and Disorders. Currently, the DHSS contracts with MSU for the services of the MOHear Project. The Department of Communication Sciences and Disorders Department Head, Letitia White, Ph.D., wrote a letter of agreement that is found in Attachment 7. The MOHear Project Director is assisted by a graduate assistant (GA). The GA is a graduate student in the Department of Communication Sciences and Disorders who is working toward a Doctor of Audiology degree. A job description for the GA is found in Attachment 2. The five MOHears are professionals with degrees in audiology, speech pathology, or deaf education. Their job descriptions and biographical sketches are found in Attachments 2 and 3, respectively.

The Missouri Part C of the IDEA EI program, known as First Steps and housed in the DESE, is required to report annually to the DHSS. Since 2003, DESE has provided aggregate information on EI services provided to children identified with PHL following newborn hearing screening. DESE sends individualized data, including the date an IFSP is signed, to the MNHSP if a parent signs an ROI. An interagency agreement describes the expectations of each program and outlines data requirements and MOHear Project specialized service coordination expectations. The agreement is found in Attachment 4.

The unique needs of newborns and infants who are DHH and their families are routinely assessed by weekly review of incoming screening and evaluation results, comparison of birth certificates to the presence or absence of hearing screening results, monthly review of hospitals' LTF/D rates, and a biennial parent satisfaction survey. Identified issues that cannot be immediately met are addressed through quality improvement tests of change using the PDSA process. MNHSP staff, MOHear Project staff, FP staff, and external members of the EHDIQI workgroup document PDSA trials in PDSA logs placed on a SharePoint website. The EHDIQI workgroup meets quarterly to discuss current PDSAs, make suggestions for further tests of change, and identify new situations that may be improved by embarking on a new PDSA process. The MNHSP strives to engage parents and primary care providers in this process. Two physicians participate in the EHDIQI workgroup. Parents also contribute to the group. The MNHSP encourages all stakeholders who routinely participate in the EHDIQI workgroup and the NHSSC to reach out to families for the purpose of assisting the MNHSP and improving the Missouri EHDI system.

The FP offers peer support to families of children and youth with special health care needs. The MNHSP provides fiscal support to the FP as required by the HRSA Universal Newborn Hearing Screening grant. The FP employs two Family Partners who work with families with children who are DHH. These Family Partners are known as FP-DHHs. To date, the FP-DHHs recruit families to attend the annual Family Partnership Retreat, provide parent-to-parent support to

families with infants newly diagnosed with PHL, and actively participate in QI activities aimed at reducing LTF/D at the diagnostic level.

The KCEHDI-LC exists to promote a regional, comprehensive, and coordinated system of care that ensures newborns and infants receive appropriate and timely services including screening, evaluation, diagnosis, and EI. Missouri, St. Louis, and neighboring regions possess a strong EHDI system that includes major audiologic diagnostic centers and several high-quality EI options. The Kansas City area has fewer of these resources, but have many devoted EHDI professionals who want to explore and address the needs and challenges of its EHDI system and utilize the dedicated EHDI stakeholders in the area. In the current project period, the KCEHDI-LC identified its region's greatest needs and worked to develop a "Parent Binder" that could be shared with parents at the time of diagnosis. The "Parent Binder" will be placed on the MNHSP website and is currently under review at the DHSS. KCEHDI-LC members also participate in a variety of learning opportunities related to the EHDI system and potential resources for the EHDI system.

The DHSS supports the provision of culturally and linguistically competent, health literate services. In the MNHSP, brochures, notification letters, and informational enclosures are available in Arabic, Bosnian, English, Mandarin, Spanish, and Vietnamese. MNHSP staff have access to a telephone interpreting service which allows them to communicate with parents whose primary language is not English. The DHSS has contracts with several American Sign Language interpreters, and the MNHSP is able to obtain those services as needed.

While all these elements contribute to the MNHSP's ability to meet project requirements, the MNHSP also relies on HRSA project officers, the National Center for Hearing Assessment and Management (NCHAM), and FL3 for technical assistance and educational opportunities. In the past project period, the MNHSP provided education to LEND students and home visitors about the EHDI process and how to help parents complete recommended follow-up after their newborn fails to pass the newborn hearing screening. The FP utilizes technical assistance from the National Resource Center for Patient/Family-Centered Medical Home (PFCMH) to educate families about the importance of the medical home. A one-page figure that depicts the organizational structure of the proposed project is in Attachment 5.

In order to implement the approved plan of the next project period, the MNHSP manager will meet, at least every other month, with the FP manager to discuss current and future activities aimed at meeting the project's stated needs, successes, challenges, and plans to address needed change. Similarly, the MNHSP manager will meet with the MOHear Project Manager at least every other month to review current work toward improving 1-3-6 goals, education of health professionals and service providers on the key aspects of the EHDI system in Missouri, successes, challenges, and how to address need for change in activities. Likewise, the MNHSP will meet with the FUP every other week to discuss progress toward 1-3-6 recommendations. The EHDIQI workgroup will play an important role in assisting the key project players in developing small tests of change through PDSA activities that could improve progress toward the project objectives.

The MHNSP will account for the federal funds with the assistance of a partnership with the DHSS Office of Financial & Budget Services (OFABS). Per DHSS Financial Policy 3.2, OFABS follows 2 Code of Federal Regulations (CFR) Part 200 Uniform Administrative Requirements, Cost Principles, and Audit Requirements for Federal Awards, issued by the U.S. Office of Management and Budget (OMB) and associated federal regulations when administering federal programs. All department staff responsible for managing federal funds are expected to be familiar with the provisions of 2 CFR Part 200.

The MNHSP plans to routinely assess and improve conditions related to the needs of the target populations. This includes expanding hearing screening reporting, tracking, and referral to EI of all children up to the age of three. As the MNHSP successfully establishes a screening program in one early childhood program, it will approach additional programs and propose the same successful activities that previously brought about change. Similarly, the MNHSP plans to conduct in-depth research to ensure effective and safe linkages of families with DHH adult-to-family programs. With no DHH adult mentorship program currently available in Missouri, the MNHSP and its partners will be the initiators of a Missouri program. DHH adult mentors must meet certain requirements including, but not limited to, fluency in American Sign Language (ASL), the ability to communicate and develop rapport with families, non-biased support for all types of communication needs, and an unblemished background check. On an ongoing basis, FP-DHHS will identify families who may benefit from linkage to a DHH adult-to-family program through MNHSP referrals to the FP and contact with current families involved in the FP. Likewise, on an on-going basis, the MOHear Project director and the MNHSP manager will monitor 1-3-6 goals via MOHSAIC and offer training and educational opportunities to health professionals and service providers in the regions where the 1-3-6 goals fail to improve.

The MNHSP and its partners are adept at facilitating partnerships and engaging families, health professionals, and service providers. The MNHSP has contact information for all families with infants who are diagnosed with PHL, health professionals who attend to the primary care of children with PHL, and Part C/First Steps service providers throughout the state. The FUP is in regular contact with pediatricians across the state, and the MNHSP manager is able to communicate to Part C service providers via the Part C coordinator at any time. Also, the early interventionists with the largest population of children who are DHH in the state are also regular attendees of the NHSSC and the EHDIQI workgroup. The FP-DHHS are in direct contact, usually via telephone, with the parents of infants newly diagnosed with PHL. Additionally, the FP-DHHS meet other families with children who are DHH through their work with the annual FP retreat. Finally, the MOHears are familiar with their regional EHDI resources, EHDI-related health professionals, and EHDI service providers. MOHears have met with and trained health professionals, including hospital screeners, midwives, audiologists, and PCPs. MOHears also know local First Steps service coordinators through their involvement with families during the IFSP process. These connections ensure the ability to facilitate the needed relationships and partnerships for the proposed project.