## Missouri Project Narrative

## Introduction

To assure a newborn who is deaf or hard of hearing achieves communication skills comparable to those of her/his hearing peers, a follow-up process involving multiple providers must ensue. The Joint Committee on Infant Hearing (JCIH), a widely respected and endorsed organization composed of representatives from groups concerned for children with hearing loss, 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 receive intervention by six months of age. These goals are commonly referred to as the 1-3-6 early hearing detection and intervention (EHDI) model. Loss to follow-up/documentation (LTF/D) occurs when a baby fails to complete one step of this process, or when the results are not reported to the Missouri Department of Health and Senior Services' (DHSS) Newborn Hearing Screening Program (MNHSP) and, therefore, are not documented. The overarching goal of this grant proposal is to further improve progress toward meeting the 1-3-6 EHDI model. The primary aim of the grant proposal is to further reduce LTF/D after failure to pass the newborn hearing screening.

Through MNHSP efforts, reducing LTF/D occurs at two points – the MOHear Project managed by Missouri State University (MSU) through a contract with DHSS, and two DHSS MNHSP Follow-up Coordinators (FUPs). The MOHear Project, managed by an audiologist, is comprised of five professionals with expertise in hearing loss who study assigned regions of the state and use innovative and distinctive interventions to resolve and prevent LTF/D. Known as MOHears, these five professionals also assist the Missouri Department of Elementary and Secondary Education (DESE) with the Part C of the Individuals with Disabilities Education Act (IDEA) program of service coordination and early intervention (EI), First Steps. MOHears provide specialized service coordination for children diagnosed with permanent hearing loss to ensure parents receive unbiased information about language and EI opportunities in Missouri. The MNHSP FUPs track all babies born in Missouri who miss or fail the initial hearing screening, subsequent hearing screenings, and who are diagnosed with hearing loss following an audiologic evaluation. FUPs make follow-up contact with those infants' physicians and families in order to encourage adherence to follow-up recommendations. Additionally, FUPs refer all infants diagnosed with a permanent hearing loss to First Steps.

The MNHSP seeks to reduce LTF/D of infants who have not passed a physiologic newborn hearing screening examination prior to discharge from the newborn nursery by using specifically targeted and measurable interventions. The goal is to achieve a 5% per year reduction in LTF/D in years 2014 through 2017. To decrease LTF/D, the MNHSP proposes to utilize quality improvement (QI) methodology that will increase the numbers of infants who receive appropriate and timely follow-up at each stage of the EHDI process – the initial hearing screening, the audiologic evaluation, and enrollment into early intervention. This proposal describes the activities the MNHSP will take to reduce LTF/D at each level of the Missouri EHDI system and to achieve the 1-3-6 EHDI model using a QI team of stakeholders.

### **Needs Assessment**

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 metro areas, Kansas City and St. Louis, are located on the western and eastern borders respectively. Springfield is the third largest metro area and located in southwest Missouri. Audiological and early intervention services are centered in the St. Louis, Kansas City, Springfield, and mid-Missouri regions of the state.

The target population for this proposal is all babies born in Missouri and their families. Missouri State Vital Statistics recorded 77,135 babies born in Missouri in 2011. Of those births, 1,202 occurred out of a hospital. Mother's race was characterized as 75% white, 14% black, 11% other, with 5% of the population classified as Hispanic ethnicity. Individual hospital data pulled from Missouri Health Strategic Architectures and Information Cooperative (MOHSAIC), the MNHSP's electronic data management system, consistently shows that getting families from rural southeast Missouri and St. Louis City to find follow-up after failing the newborn hearing screening is challenging. The two hospitals with the highest amounts of LTF/D are found in St. Louis City and rural southeast Missouri, often referred to as the Missouri Bootheel. Both are clearly visible on the graph in Attachment 6. Poverty, high unemployment, and low education levels have been well-documented for years in St. Louis City and the Missouri Bootheel. The largest birth hospital in the Bootheel region does not have a rescreening program. Some local physicians and itinerant audiologists who provided rescreenings recently stopped providing those services because the Missouri Medicaid and Tricare reimbursement rate reportedly decreased by 60-70% over the past two years, making the practice unattractive to providers. Additionally, there is limited public transportation in the Bootheel. An analysis of LTF/D for babies born in 2008 identified larger percentages of LTF/D among infants born to mothers who were under 20 years old, non-Hispanic African-American, unmarried, in possession of less than 12 years of education, enrolled in Medicaid, the Special Supplemental Nutrition Program for Women, Infants and Children (WIC) or Temporary Assistance for Needy Families (TANF), and who received late or no prenatal care.

The following statistics show the status of LTF/D and 1-3-6 EHDI model goals in Missouri for the past 3 years of complete data:

	LTF/D	
Loss to follow-u	Loss to follow-up after	Loss to follow-up
after birth	final screening	after diagnosis
2009: 1.1%	2009: 58.8%	2009: 0.0%
2010: 1.2%	2010: 40.9%	2010: 3.0%
2011: 1.0%	2011: 34.7%	2011: 17.3%

	<u>1-3-6</u>	
Screened by	Evaluated by	Early Intervention by
1 month of age	3 months of age	6 months of age
2009: 98.3%	2009: 25.3%	2009: 62.0%
2010: 98.3%	2010: 39.0%	2010: 50.0%
2011: 98.2%	2011: 45.5%	2011: 53.4%

Clearly, Missouri needs to improve its LTF/D and 1-3-6 target rates. While LTF/D after birth and after the final hearing screening shows improvement over a three year period of focused efforts to reduce LTF/D at all stages of the EHDI system, LTF/D after diagnosis rates deteriorated. The 2011 data is less than desirable. Missouri reduced its LTF/D rate for babies born in 2011who failed their final hearing screening from 58.8% in 2009 to 34.7% in 2011 – a reduction of 24%. Although the reduction signals an improvement, of 1,344 babies born in 2011 who failed the final hearing screening, 467 babies may not have received appropriate follow-up. Additionally, the LTF/D rate for babies born in 2011 who received a diagnosis of permanent hearing loss increased from 0% in 2009 to 17.3% in 2011 – an increase of 17%. Possible causes include the family's lack of understanding about early intervention opportunities or errors that occur during the exchange of data between the MNHSP and First Steps when compiling statistics for the Centers for Disease Control and Prevention (CDC) EHDI Hearing Screening and Follow-up Survey (HSFS). While the increase likely implies a decline in documentation, out of 121 babies born in 2011 and diagnosed with permanent hearing loss, 21 babies may not have received intervention.

Similarly, Missouri's attempts to reach the goals of the 1-3-6 EHDI model met chiefly with improvement, but remained unsatisfactory. The proportion of babies who received a hearing screening by one month of age remained steady at about 98% from 2009 through 2011. Those who received an audiologic evaluation by three months of age improved from 25.3% in 2009 to 45.5% in 2011. However, those who received intervention by six months of age decreased from 62% in 2009 to 53.4% in 2011 – almost 10%. The decrease in the number enrolled in intervention by six months of age may be a result of a shortage of pediatric audiologists, leading to delays in receiving audiologic evaluations.

For the grant project period of April 1, 2014 through March 31, 2017, Missouri proposes the following aims:

- Aim I: By March 31, 2017, the MNHSP will use QI methodology so that LTF/D for infants who failed the final hearing screening as reported through the CDC annual EHDI HSFS is decreased from 34.7% (2011 data) to 20%.
- Aim II: By March 31, 2017, the MNHSP's MOHear Project will engage in efforts based upon QI methodology to decrease LTF/D at each stage of the EHDI process so that LTF/D as reported through the CDC's annual EHDI HSFS is decreased from 1% to 0.5% for infants LTF/D after birth, from 34.7% to 20% for infants LTF/D after the final hearing screening, and from 17.3% to 2% for infants LTF/D after diagnosis of a permanent hearing loss.

■ Aim III: By March 31, 2017, the MNHSP's FUPs will engage in efforts based upon QI methodology to achieve the 1-3-6 EHDI model so that 1-3-6 performance measures as reported through the CDC's annual EHDI HSFS increase from 98.2% to 99% screened by one month of age, from 45.5% to 60% evaluated by three months of age, and from 53.4% to 68% enrolled in early intervention by six months of age.

For Missouri LTF/D and 1-3-6 target rates to improve, EHDI-related practices and activities must improve. Through learning collaboratives with state EHDI teams, the National Initiative on Child Health Quality (NICHQ) identified ten promising strategies for reducing LTF/D. Based upon the results of QI projects, learning collaborative participants developed the following list of activities to aid EHDI systems seeking to reduce LTF/D: 1) script the screener's message to parents; 2) use fax-back forms between multiple providers; 3) ascertain the name of the infant's primary care provider (PCP); 4) identify a second point of contact for the family; 5) make rescreening and/or audiology appointments for the infant at hospital discharge; 6) make telephone reminders for appointments; 7) schedule two audiology appointments two weeks apart at hospital discharge; 8) streamline the EI referral process and obtain a consent for release of information; 9) improve data tracking systems; and 10) assign a dedicated follow-up coordinator. While the MNHSP and Missouri hospitals utilize some of these strategies to some degree, a number of practices are not in use at all while others function poorly as they are currently operated. For example, the MNHSP provides a "refer" brochure designed for parents of newborns who fail the final inpatient hearing screening that includes a fax-back page to indicate the time and place of the rescreening or audiologic evaluation. The MNHSP encourages hospitals to fax the information to the MNHSP so that the FUPs can make reminder phone calls prior to the appointment date. Out of 67 hospital hearing screening programs, only three regularly use this feature of the brochure. Statewide spread of the NICHQ-identified practices and other activities unique to the needs of the Missouri EHDI system would undoubtedly result in further reduction of LTF/D and increase of 1-3-6 target rates.

To meet its aims, Missouri proposes to use the same type of QI projects used by the NICHQ learning collaboratives. The Missouri EHDI Coordinator will convene a team of stakeholders who will use the Model for Improvement, developed by Associates in Process Improvement (API), to identify small programmatic changes with the potential to result in documented improvements in the LTF/D rate. The QI team will utilize the NICHQ-identified promising strategies to reduce LTF/D and create related tests of change that can be implemented within the MNHSP and throughout Missouri hospital hearing screening programs. Because urban St. Louis City and rural southeast Missouri have the highest LTF/D, the QI team will seek to create additional tests of change that meet the unique needs of these regions. By using a proven QI model to address its deficiencies, Missouri will achieve visible and measurable improvements in its EHDI system.

## Methodology

The overarching goal of the Missouri EHDI program is to strive to assure newborns are screened for hearing loss by one month of age, that those who fail to pass the final hearing screening are evaluated by an audiologist by three months of age, and that those who are diagnosed with a permanent hearing loss enter EI by six months of age. This is known as the EHDI 1-3-6 model.

By decreasing LTF/D, the MNHSP ensures that 1) a greater number of infants are adhering to recommendations for follow-up and 2) the program can precisely determine how well it is meeting the 1-3-6 model goal. To meet the needs of the Missouri EHDI system as outlined in the above needs assessment, the MNHSP proposes to use QI methodology using the API Model for Improvement, further increase efforts of the MOHear Project to reduce LTF/D at all stages of the Missouri EHDI system, and further increase efforts of the MNHSP FUPs to achieve the EHDI 1-3-6 model.

To incorporate use of the Model for Improvement into the Missouri EHDI system, the Missouri EHDI Coordinator, who is the MNHSP manager, will convene a group of stakeholders to assist in the QI work. In November 2013, the Missouri EHDI Coordinator solicited QI team members by specifically targeting the members and frequent participants of the MNHSP advisory committee, and the former team members of the Missouri NICHQ learning collaborative. To date, nine people have agreed to participate including one hospital hearing screening program manager, two pediatric audiologists, two representatives from EI (one from Part C and one from an auditory-oral approach school), one pediatrician, one parent of a deaf child and member of the family support group - Missouri Hands and Voices, one deaf adult, and one adult child of deaf parents. The EHDI Coordinator will continue to recruit in order to ensure a QI team that is representative of the Missouri system. MOHear staff will specifically target poorly performing hospitals from which to recruit more hospital-based hearing screening program managers. The Missouri EHDI Coordinator will also strive to include DHSS senior leadership in the QI process as the MNHSP mission to increase the likelihood that children with hearing loss achieve communication skills is closely aligned to DHSS' vision to improve the health and quality of life for Missourians of all ages. MOHear staff and MNHSP FUPs will participate in the QI team as they will be instrumental in testing and diffusing successful change strategies.

The next step in the MNHSP's QI work will be to set up a meeting schedule and offer educational opportunities to QI team members who are new to the Model of Improvement or who need a refresher course. The Health Resources and Services Administration's (HRSA) grant guidance for this proposal lists several QI videos available online and both the National Center for Hearing Assessment and Management (NCHAM) and NICHQ websites offer educational opportunities related to QI. Additionally, the experience of the Missouri NICHQ learning collaborative team can serve as both good advice and a cautionary tale to the new QI team. The outcomes of the Missouri NICHQ learning collaborative team's efforts are summarized in the accomplishment summary in Attachment 7.

A key responsibility of the QI team will be to craft an aim statement that explains what the team is trying to accomplish. The aim statement must address the gaps of the Missouri EHDI system as identified in the CDC's annual EHDI HSFS data as described above in the needs assessment. The aim statement must be specific, time-limited, and measurable in order to convey the basis for and the focus of the problem-solving effort. The aim statement will contain the process and outcome measures to be collected and tracked in order to evaluate progress and determine if the change is an improvement. A key focus will be the reduction of LTF/D at all stages of the Missouri EHDI system and especially at the time of failure to pass the final newborn hearing screening.

Next, the QI team will identify change strategies or ideas to be tested. These strategies will correlate to the identified needs of the Missouri EHDI system as made evident by the CDC's annual EHDI HSFS data. Additionally, the QI team will assess how well each hospital screening program is implementing the promising strategies identified by NICHQ. To do so, the QI team will examine individual hospital data available in MOHSAIC and develop surveys or questionnaires to determine the frequency with which the promising practices are used. The QI team will compare and contrast the best-performing programs to the poorest performing programs and analyze the differences. The QI team will identify change strategies to be tested at all stages in the Missouri EHDI system. The variety of backgrounds of the QI team members is a strength that will aid in identifying a wide range of needs and subsequent promising change strategies. Identifying change strategies will be an ongoing process.

After change strategies have been identified, Plan Do Study Act (PDSA) cycles must be implemented. PDSA cycles are designed to provide a quick way to test and implement changes in a system. Planning refers to designing the test of a change and entails establishing a question to be answered, a prediction about what will happen, and a plan for collecting data. Doing refers to trying the change and entails the enactment of initial tests that are small in order to minimize risk and achieve buy-in. Eventually, the testing grows larger and occurs over a wide variety of conditions in order to determine its success. Studying refers to observing and analyzing the results. Analysis includes determining if more tests are still needed, if the test needs to be adjusted before adopting a change, or if the test needs to be discarded. Each test of change will have a varying number of cycles. Acting refers to taking steps to apply what has been learned. Ultimately, the PDSA reveals whether or not the change was an improvement and whether or not action should ensue.

When successful changes have been identified, they must be spread throughout the Missouri EHDI system. It is anticipated that successful changes will be spread by different approaches, depending upon the activity to be diffused. The QI team will assist in making such determinations. However, it is expected that MOHears and FUPs will play a large role in spreading change due to their contact with hospitals, audiologists, and First Steps service coordinators. MOHears and FUPs have relationships with these entities and, as such, understand the existing norms and barriers to change. Through their phone, email, and onsite interactions, MOHears and FUPs can spread the change strategies identified by the QI team.

As in the last project period, MOHear staff will continue to identify and enact successful activities to reduce LTF/D at every stage of the EHDI process. As noted above, MOHears will also spread proven change strategies as identified by the QI team in order to further reduce LTF/D. Likewise, FUPs will continue successful tracking activities in order to meet the 1-3-6 EHDI model goal. In addition, each FUP will be actively involved in identifying potential changes and spreading the proven change practices.

During the new project period, the MNHSP will capitalize on its linkages to other stakeholders including the MNHSP advisory committee, Early Head Start, Title V, and Home Visiting programs. The MNHSP advisory committee is a standing committee of the statute-mandated Missouri Genetic Advisory Committee. Membership in the committee is designed to represent a broad collaboration of persons and organizations that have an interest in the success of the

Missouri EHDI system. As such, committee membership consists of: 1) three persons who are deaf or hard-of-hearing; 2) one parent of a child with hearing loss; 3) two pediatric audiologists; 4) two pediatricians; 5) one pediatric geneticist; 6) one representative from an early intervention program for children with hearing loss; 7) one representative from the Missouri School for the Deaf; 8) one representative from a hospital hearing screening program; 9) one representative from the Missouri Commission for the Deaf and Hard of Hearing; 10) one representative from DHSS; 11) one representative from the Missouri Department of Elementary and Secondary Education (DESE); 12) one representative from the Missouri Department of Social Services; and 13) one representative from the Missouri Department of Insurance. Members serve a term of three years. The Missouri EHDI Coordinator attempts to recruit from every region of the state. New members are nominated and approved by current members. The committee meets at least once a year and more often if needed. The Missouri EHDI Coordinator recruited advisory committee members for the QI team with good results. Moreover, the Missouri EHDI Coordinator will seek advice and suggestions for tests of change by email from the entire committee throughout the project period.

The MNHSP is in the early stages of connecting to Early Head Start agencies throughout the state in order to ensure children enrolled in those programs are properly screened for hearing loss. At this time, memorandums of understanding (MOU) are in place with 40 Early Head Start and Head Start agencies that screen for hearing loss. Each MOU allows the agency access to the DHSS Public Health Profile (PHP) in order to view hearing screening records for children enrolled in their program. Knowing the results of the final hearing screening and the presence of associated risk factors for late-onset hearing loss assists the agency in knowing how to tailor their screening efforts and recommendations to parents or guardians. Further work needs to be accomplished in order for the MNHSP to obtain hearing screening results from the agencies.

The MNHSP works with a number of Title V programs to reduce LTF/D. The MNHSP works closely with the Newborn Bloodspot Screening Program and they assist each other with tracking, follow-up, and literature development. The Newborn Health Program provides education about newborn hearing screening and the importance of follow-up to parents through brochures and exhibits at health fairs, conferences, and conventions. The TEL-LINK information and referral line links parents to audiologists and health care providers. The DHSS Bureau of Special Health Care Needs shares information on coverage of hearing aids and frequency-modulated (FM) systems with the MNHSP. Most recently, the MNHSP and WIC collaborated in an effort to supply hearing rescreenings to WIC enrollees who the MNHSP considered lost to follow-up. The WIC staff makes MNHSP brochures available to its clients as well. Finally, the Title V Maternal and Child Health Block Grant (MCHBG) provides funding for some MNHSP staff.

Since the DHSS established the Home Visiting Program, the MNHSP has tried to be an active presence. The Missouri EHDI Coordinator has presented at one conference and two webinars in an attempt to teach home visitors to ask each family about the status of the newborn hearing screening and recommendations for follow-up and to offer assistance in making follow-up appointments when needed. The MNHSP produced "Missouri EHDI Resource Documents" individualized by county that provide home visitors with local options for rescreening, audiologic evaluation, and intervention. One home visitor uses an otoacoustic emissions (OAE) screener during her visits and sends her screening results to the DHSS. The home visitors have

access to the PHP to assist with offering relevant recommendations regarding follow-up to the families.

Grantees are expected to sustain key elements of their grant projects that result in the reduction of LTF/D and significant movement toward achieving the 1-3-6 EHDI model. The MNHSP will seek additional funding from the MCHBG to continue the work of the FUPs and the MOHear Project. If such funding is not possible, the MNHSP will look for other grant opportunities. To sustain specific improvements in the system, the MNHSP will assist stakeholders (e.g. hospital hearing screening programs, audiology clinics, EI service coordinators, etc.) to establish procedures, develop new job descriptions, and design staff trainings that maintain the new proven practices. Additionally, the MNHSP will use hospital hearing screening guidelines, brochures, newsletters, and other media outlets as able to convey best practices. All of the above strategies will involve utilizing the CDC's annual EHDI HSFS data, involving key stakeholders in identifying strategies for sustainability, and finding champions for the Missouri EHDI goals. Additionally, the MNHSP will strive toward continuation of the project's efforts to achieve the desired outcomes while understanding that the program may operate differently once in sustainability mode.

#### Work Plan

The overarching goals of the MNHSP are to strive to assure newborns are screened for hearing loss by one month of age, that those who fail to pass the final hearing screening are evaluated by an audiologist by three months of age, and that those who are determined to have a permanent hearing loss enter early intervention by six months of age. The primary aim of the upcoming grant project period is to reduce the LTF/D for infants who failed the final hearing screening from 34.7% (2011 data) to 20% as reported through the CDC's annual EHDI HSFS by March 31, 2017. The target is to achieve a 5% per year reduction in LTF/D in years 2014 through 2017. To accomplish this, the MNHSP will employ the assistance of a QI team, the MOHear Project, and the MNHSP FUPs.

The key stakeholders in planning, designing, and implementing the grant activities are listed below. Their job descriptions and biographical sketches are found in Attachments 2 and 3, respectively.

Role
Missouri EHDI Coordinator/MNHSP Manager
MOHear Project Manager
MNHSP Follow-up Coordinator
MNHSP Follow-up Coordinator
MOHear

Laura Campos	MOHear
Ilene Elmlinger	MOHear
Lisa Geier	MOHear
Megan Kelly	MOHear
To be determined (Currently includes one hospital hearing screening program manager, two pediatric audiologists, two representatives from EI (one from Part C and one from an auditory-oral approach school), one pediatrician, one parent of a deaf child who is also a member of the Missouri Hands and Voices chapter, one deaf adult, and one adult child of deaf parents)	Quality Improvement Team

The aims and activities that will be used to achieve the methodology can be measured to assess progress and thereby allow for expansion, adjustment, or discontinuation of a test of change. Project aims and activities are outlined below. A work plan in a table format that summarizes each year of the project and includes process and outcome measures is included in Attachment 1.

**Aim I**: By March 31, 2017, the MNHSP will use quality improvement methodology so that LTF/D for infants who failed the final hearing screening, as reported through the Centers for Disease Control and Prevention (CDC) annual EHDI survey, is decreased from 34.7% (2011) data to 20%.

Activity 1: Convene a team of stakeholders to be part of a QI team that will assist the MNHSP in reducing LTF/D using the QI methodology of the Model for Improvement. At a minimum, include Missouri EHDI Coordinator, a pediatric audiologist, a parent of a child with a hearing loss, a representative from EI, and a data person. Include a representative from the MOHear Project. Include representatives from each metro area and rural areas – especially southeast Missouri. Include leadership personnel.

Start Date: In progress

Estimated Completion Date: April 1, 2014

Lead Staff and partner Support: Missouri EHDI Coordinator

Activity 2: Develop a meeting schedule for the QI team based upon availability of team

members. Allow for flexibility. Start Date: March 1, 2014

Estimated Completion Date: April 1, 2014

Lead Staff and Partner Support: Missouri EHDI Coordinator

Activity 3: Develop an aim statement to focus purpose of QI team. Use data to inform decision making throughout process.

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Start Date: April 15, 2014

Estimated Completion Date: May 15, 2014

Lead Staff and Partner Support: Missouri EHDI Coordinator and QI team

Activity 4: Identify initial change strategies to be tested that meet the projects' goal and aims. Pull from the NICHQ-identified promising strategies and generate others based upon the unique needs of the Missouri EHDI system. Identification of change strategies will be ongoing throughout the project.

Start Date: April 15, 2014

Estimated Completion Date: April 30, 2014 (for initial change strategies) Lead Staff and Partner Support: Missouri EHDI Coordinator and QI team

Activity 5: Implement the initial PDSA cycles.

Start Date: May 15, 2014

Estimated Completion Date: August 15, 2014 (Dates will vary for individual PDSA cycles.)

Lead Staff and Partner Support: Missouri EHDI Coordinator and QI team

Activity 6: Spread successful changes throughout the Missouri EHDI system. The QI team will determine the method of diffusion based upon the type of change to be spread. MOHears and FUPs will play a large role in spreading change through their contact with hospitals, audiologists, and First Steps service coordinators via phone, email, and onsite interactions. Activities to spread change might include training, modeling, and assisting with policy and procedure development. All successful changes will be included in the guidelines for Missouri hospital hearing screening programs and will be available on the DHSS website. Updates to the guidelines will be mailed to hospital hearing screening program managers.

Start Date: August 15, 2014

Estimated Completion Date: March 31, 2015 (Dates will vary for different change strategies and may be ongoing.)

Lead Staff and Partner Support: Missouri EHDI Coordinator, MOHear Project Manager,

MOHears, and FUPs

Activity 7: Complete the spread of two change strategies successfully tested during the NICHQ learning collaborative – checklists for hospital hearing screening programs and checklists for audiology clinics.

Start Date: In progress

Estimated Completion Date: March 31, 2015

Lead Staff and Partner Support: Missouri EHDI Coordinator, MOHear Project Manager, and

**MOHears** 

Activity 8: Complete PDSA cycle to test use of a fax-back form between the MNHSP and the PCP following receipt of a result indicating failure to pass the newborn hearing screening.

Start Date: In progress

Estimated Completion Date: April 15, 2014

Lead Staff and Partner Support: Missouri EHDI Coordinator and FUPs

Activity 9: Complete PDSA cycle to test use of the MNHSP letter currently used as the final effort to find LTF/D infants as the second parent notification letter.

Start Date: In progress

Estimated Completion Date: April 15, 2014

Lead Staff and Partner Support: Missouri EHDI Coordinator and FUPs

Activity 10: Use a PDSA cycle to test whether or not a screener is able to ascertain the name of the correct PCP by individually asking each parent/guardian of infant being screened, "Who will be your baby's doctor?"

Start Date: May 15, 2014

Estimated Completion Date: August 15, 2014

Lead Staff and Partner Support: Missouri EHDI Coordinator, MOHear Project Manager, and

**MOHears** 

Activity 11: Develop a PDSA cycle to address issue of increased LTF/D after diagnosis. This will involve assessing current process for obtaining a release of information at the time of Individual Family Services Plan (IFSP) signature.

Start Date: May 15, 2014

Estimated Completion Date: November 15, 2014

Lead Staff and Partner Support: Missouri EHDI Coordinator and QI team

Activity 12: Utilize the support and collaboration of other stakeholders including the MNHSP advisory committee, the DHSS Home Visiting Program, the DHSS Newborn Bloodspot Screening Program, the Newborn Health Program, the TEL-LINK information and referral line, the DHSS Bureau of Special Health Care Needs, WIC, and Early Head Start programs to assist with QI methodology.

Start Date: April 1, 2014

Estimated Completion Date: Ongoing throughout project Lead Staff and Partner Support: Missouri EHDI Coordinator

Activity 13: Utilize MOHSAIC as the primary source of data used to determine needs/gaps of individual hospitals and audiology clinics and their success toward decreasing LTF/D and meeting the 1-3-6 EHDI model.

Start Date: April 1, 2014

Estimated Completion Date: Ongoing throughout project

Lead Staff and Partner Support: Missouri EHDI Coordinator and MOHear Project Manager

Activity 14: Ensure that data is collected and that process and outcome measurements are determined for each small test of change in order to accurately measure progress and quality of test results.

Start Date: April 1, 2014

Estimated Completion Date: Ongoing throughout project

Lead Staff and Partner Support: Missouri EHDI Coordinator and QI team

**Aim II**: By March 31, 2017, the MNHSP's MOHear Project will engage in efforts based upon QI methodology to decrease LTF/D at each stage of the EHDI process so that LTF/D, as reported through the CDC's annual EHDI HSFS, is decreased from 1% to 0.5% for infants LTF/D after

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birth, from 34.7% to 20% for infants LTF/D after the final hearing screening, and from 17.3% to 2% for infants LTF/D after diagnosis of a permanent hearing loss.

Activity 1: Continue to assess the needs of individual hospitals, audiology clinics, and communities related to LTF/D and, as appropriate, consult with hospitals and audiologists regarding procedures, provide follow through services to families with infants who miss or fail the hearing screening, perform rescreening clinics, conduct individual rescreenings in homes, and provide hospital staff in-services.

Start Date: April 1, 2014

Estimated Completion Date: March 31, 2015

Lead Staff and Partner Support: MOHear Project Manager and MOHears

Activity 2: Visit First Steps Service Coordinators to provide additional education about the MOHear Project in order to increase their use of MOHears as specialized service coordinators.

Start Date: In progress

Estimated Completion Date: October 1, 2014

Lead Staff and Partner Support: MOHear Project Manager and MOHears

Activity 3: Initiate contact with families of infants diagnosed with hearing loss as soon as the MNHSP is notified of the diagnosis in order to encourage entry into EI by six months of age or as soon as possible.

Start Date: In progress

Estimated Completion Date: Ongoing

Lead Staff and Partner Support: MOHear Project Manager and MOHears

Activity 4: Recruit hospitals and audiology clinics into small tests of change as part of the QI process described in Aim I.

Start Date: April 1, 2014

Estimated Completion Date: March 31, 2015

Lead Staff and Partner Support: MOHear Project Manager and MOHears

Activity 5: Spread promising changes as identified by the QI team during contact with hospitals and audiology clinics. Spread will be ongoing throughout project.

Start Date: August 15, 2014

Estimated Completion Date: March 31, 2015 (Dates will vary for different change strategies and may be ongoing.)

Lead Staff and Partner Support: MOHear Project Manager and MOHears

Activity 6: Complete the PDSAs in progress and currently planned as described above in Aim 1, Activities 7 and 10.

Start Date: In progress and April 15, 2014 respectively

Estimated Completion Date: March 30, 2015 and July 15, 2014 respectively Lead Staff and Partner Support: MOHear Project Manager and MOHears

**Aim III**: By March 31, 2017, the MNHSP's FUPs will engage in efforts based upon QI methodology to achieve the 1-3-6 EHDI model so that 1-3-6 performance measures as reported through the CDC's annual EHDI HSFS increase from 98% to 99% screened by one month of

age, from 45% to 60% evaluated by three months of age, and from 53% to 68% enrolled in early intervention by six months of age.

Activity 1: Continue current procedures to track Missouri babies who miss or fail the newborn hearing screening in an effort to meet EHDI 1-3-6 model goals and send appropriate notification letters to their families and PCPs. Contact hospitals, audiologists, PCPs and midwives as needed to secure documentation of screening and diagnostic results.

Start Date: April 1, 2014

Estimated Completion Date: March 31, 2015

Lead Staff and Partner Support: Missouri EHDI Coordinator and FUPs

Activity 2: Actively participate in QI team. Suggest change ideas, develop PDSAs, and carry out testing as appropriate within the MNHSP.

Start Date: April 1, 2014

Estimated Completion Date: March 31, 2015

Lead Staff and Partner Support: Missouri EHDI Coordinator and FUPs

Activity 3: Spread promising changes as identified by the QI team during contact with hospitals, audiology clinics, PCP offices, and midwife practices. Spread will be ongoing throughout project.

Start Date: August 15, 2014

Estimated Completion Date: March 31, 2015 (Dates will vary for different change strategies and

may be ongoing.)

Lead Staff and Partner Support: Missouri EHDI Coordinators and FUPs

Activity 4: Complete the PDSAs in progress as described above in Aim 1, Activities 8 and 9.

Start Date: In progress

Estimated Completion Date: April 15, 2014

Lead Staff and Partner Support: Missouri EHDI Coordinator and FUPs

# **Resolution of Challenges**

While most Missouri EHDI system stakeholders see the advantages of QI, challenges to implementing the work plan exist. Challenges include time constraints of QI team members, recruitment of hospitals that have the greatest need for QI, and knowledge gaps about the usefulness of QI methodology.

To address the time constraints of QI team members, the Missouri EHDI Coordinator will survey members to discern the most convenient meeting times. This may include meeting before or after normal work hours. The Missouri EHDI Coordinator will schedule meetings far in advance and will strive to facilitate meetings that result in concrete decision making about changes that demonstrate the most promise for significant improvement. The Missouri EHDI Coordinator will make use of emails and online surveys to advance communication between team members.

To date, only one hospital hearing screening program manager has joined the QI team. This team member - a former team member during the NICHQ learning collaborative - represents a hospital with a low LTF/D rate. In order to achieve the greatest impact, hospitals with high

LTF/D rates need to be involved. To achieve participation of hospitals in the PDSA process, the QI team will utilize the current hospital hearing screening program manager member's past success to assist with implementing change strategies. For example, the rural hospital this member represents successfully integrated the use of a hearing screening checklist into its electronic medical record (EMR). The MOHears will share this success story with other hospitals during onsite visits to targeted hospitals with high rates of LTF/D. Using the success story of another small, rural hospital combined with MOHSAIC data to show the areas of need may encourage broader hospital participation. Additionally, MOHears will attempt to meet with unit supervisors in order to achieve commitment to the QI testing process.

Knowledge gaps about the value and benefit of QI activities exist in some areas. The Missouri EHDI Coordinator will use the links to YouTube videos about the use of PDSAs provided in the guidance for this grant application and the NCHAM links to its webinar on QI as training tools for the QI team. Using champions of the cause, such as the Missouri American Academy of Pediatrics Missouri Chapter Champion or a parent of a child who successfully met the 1-3-6 model goals, to educate hospital stakeholders about the importance of QI work, may be beneficial. Emphasizing better patient outcomes as the primary benefit to QI activities is of primary importance.

## **Evaluation and Technical Support Capacity**

Evaluation of grant activities will be ongoing and include review and analysis of the annual CDC EHDI HSFS. Ongoing review of data will ensure the QI team can measure progress of the PDSA cycles toward the aims of the grant and make changes in strategies if needed. The annual outcome evaluation will consist of determining if the grant activities met the goal and aims of the grant as outlined in the methodology and work plan. Primary evaluation components are as follows:

- The number of newborns screened for hearing loss before one month of age.
- The number of infants referred from screening who have diagnostic evaluations before three months of age.
- The number of infants identified with hearing loss who receive appropriate medical, audiologic, and education intervention services before six months of age.
- The number of newborns lost to follow-up after birth.
- The number of infants lost to follow-up after the final screening.
- The number of infants lost to follow-up after diagnosis of a permanent hearing loss.

These data components are easily accessible to the Missouri EHDI Coordinator in MOHSAIC. Data collected by the MNHSP is entered into the MOHSAIC system. MOHSAIC is an integrated child health data system. MNHSP FUPs use MOHSAIC to manage their tracking and follow-up duties and the MNHSP manager relies upon MOHSAIC for data reports. The MNHSP works closely with the Information Technology Services Division (ITSD) to maintain the MOHSAIC newborn hearing screening data management system and produce accurate, pertinent statistical reports.

To ensure data is unduplicated and as current as possible, the MOHSAIC data management coordinator daily reviews and corrects data entered into MOHSAIC on the previous day. The MNHSP data management coordinator follows a process outlined by 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. In the past year, the ITSD added MOHSAIC reports that allow the demographic data needed for the CDC EHDI HSFS to be accessed without ITSD or Vital Records assistance. 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 MOHear Project Manager directs the MOHear staff to closely follow the hospitals in their regions via MOHSAIC data. Through constant surveillance, the MOHears know which hospitals to target for technical assistance in the form of consultation, training, equipment loans, or procedure audits. During the NICHQ learning collaborative, the MOHear Project Manager acted as the data person and became very adept at pulling information from MOHSAIC for the purpose of analyzing project progress. The Missouri EHDI Coordinator has experience in compiling the annual CDC data request and is responsible for submitting an annual internal evaluation of the MNHSP to the DHSS' Bureau of Genetics and Healthy Childhood (BGHC) Chief and Project Investigator, Dr. Sharmini Rogers.

Some obstacles exist. Resolution of duplicates can be slow when ITSD is understaffed or busy with projects considered more urgent. With funding from the CDC EHDI-IS grant, MNHSP is moving toward electronic entry of all hearing screening results through the electronic birth certificate, Missouri Electronic Vital Records (MoEVR). Use of MoEVR will reduce duplicates and allow for faster receipt of screening results into MOHSAIC. Another obstacle is the slowness with which the MNHSP receives identifiable information on children with permanent hearing loss who have enrolled in early intervention through First Steps, Missouri's early intervention program through Part C of the Individuals with Disabilities Education Act (IDEA). First Steps is housed in DESE. An inter-agency MOU is currently being reviewed that outlines a plan for improving the sharing of identifiable information – including the date the IFSP is signed and the specific interventions received per child.

## **Organizational Information**

Attachment 8 contains an organizational chart of the DHSS and Attachment 9 contains an organizational chart of the DHSS BGHC. The MNHSP is within the BGHC - part of DHSS's 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 and as written in its mission statement, the BGHC "...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 agreement from the Title V Director, Ms. Melinda Sanders, MSN, RN, reflects the commitment to these mission statements and the proposed project. Ms. Sanders' letter is found in Attachment 4.

The DHSS also supports the provision of culturally and linguistically competent and health literate services. In the MNHSP, brochures, notification letters, and informational enclosures are available in English, Spanish, Bosnian, and Vietnamese. MNHSP staff has 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.

The MNHSP staff, including the program manager/Missouri EHDI Coordinator and both FUPs, 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 MSU's Department of Communication Sciences and Disorders. Currently, the BGHC contracts with MSU for the services of the MOHear Project. A description of the role of the contractor and the contract deliverables is found in Attachment 4. The Department of Communication Sciences and Disorders Interim Department Head, Letitia White, Ph.D., wrote a letter of agreement that is found in Attachment 4. The MOHear Project manager is assisted by two graduate assistants (GA). GAs are graduate students in the Department of Communication Sciences and Disorders who are working toward Doctor of Audiology degrees. A job description for the GAs 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.

With past funding from past HRSA Universal Newborn Hearing Screening grant, the Missouri EHDI Coordinator, the MOHear Project manager, and two other stakeholders participated in a NICHQ EHDI learning collaborative as the "core team" from Missouri. An extended team consisting of hospital hearing screening program mangers, audiologists and EI providers made up the extended team. As a group, they actively developed and implemented PDSAs, participated in NICHQ webinars, and contributed to presentations about the use of QI methodology. Four of the original NICHQ team members will participate in the new QI team.

The Missouri early intervention Part C 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 early intervention services provided to children identified with hearing loss following newborn hearing screening. DESE sends individualized data, including the date an IFSP is signed and the specific services received, to the MNHSP if a parent signs a release of information.

A one-page figure that depicts the organizational structure of the proposed project is in Attachment 5.