Table of Contents

Missouri Department of Health and Senior Services
H61MC00071

Summary Progress Report
Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening
Budget Period: 4/1/2009 – 3/31/2010
Submitted: November 2009

The purpose of this application for continuation of grant funding for the Missouri Department of Health and Senior Services (DHSS) is to carry on the work begun on reducing the rate of loss to follow-up after failure to pass the initial hearing screening in Missouri. Following the determination of the highest rates of loss to follow-up, the Missouri Newborn Hearing Screening Program (MNHSP) recruited seven of those hospitals to participate in a pilot project that would incorporate new activities, based upon the National Initiative for Children's Healthcare Quality (NICHQ) learning collaborative, designed to reduce the rate of loss to follow-up after failure to pass newborn hearing screening. Additionally, the DHSS MNHSP received supplemental funding from Health Resources and Services Administration (HRSA) on August 21, 2009 to implement a program of rescreening newborns who do not pass the initial hearing screening and are born in communities where no rescreening program is available or in hospitals with large numbers of infants whose families do not return for rescreening. The program, known as MOHear, will also provide initial hearing screenings to infants known to have missed the initial screening. Additionally, the MOHear Program will provide for consultation with families whose newborn failed or missed the newborn hearing screening as well as those whose child has been diagnosed with a permanent hearing loss. The progress report will be composed of the following sections:

1. Brief summary of overall accomplishments including barriers to progress and strategies taken to overcome them;
2. Progress on specific goals and objectives ;
3. Current staffing;
4. Technical assistance needs; and
5. Linkages established with other programs.

Brief Summary of Overall Project Accomplishments, Barriers Encountered and Strategies Taken to Overcome Them: In the first project period year, 4/1/2008 - 3/31/2009, the Missouri Newborn Hearing Screening Program (MNHSP) manager, Ms. Cathy Harbison, and MNHSP audiologist consultant, Ms. Kris Grbac, conducted site visits to three Missouri hospitals determined to have high newborn hearing screening loss to follow-up rates and that had previously agreed to participate in a pilot program based on the NICHQ learning collaborative and aimed at reducing the rate of loss to follow-up following failure to pass the initial hearing screening. This program became known as the HRSA Pilot Project. Specifically, the MNHSP asked the hospitals to explain the importance of returning for a rescreening to the newborn's parent/guardian, make the appointment for the rescreening for the parent/guardian, obtain two contact phone numbers from the parent/guardian, determine the newborn's primary physician, inform the parent/guardian that the MNHSP would make a reminder phone call 24 hours prior to the appointment and use an MNHSP-developed appointment card to record the above information and give to the parent/guardian. The MNHSP requested each hospital to fax

a copy of the appointment card to the MNHSP. At that point, the MNHSP planned to immediately send a letter of notification to the newborn's physician and scheduled a phone call to the parent/guardian for 24 hours prior to the rescreening appointment. Located in the southeast corner of Missouri, the hospitals included: Southeast Missouri Hospital in Cape Girardeau, Pemiscot Memorial Hospital in Hayti, and Twin Rivers Medical Center in Kennett. Southeast Hospital failed to fully participate and the MNHSP eventually removed that hospital from the project.

In the current project period of 4/1/2009 to the present, Ms. Harbison and Ms. Grbac visited and recruited four additional hospitals ranging in size from small to large, and in areas from rural to urban. Some hospital screening programs included rescreening services, and some did not. At each hospital, the newborn hearing screening program manager was welcoming and receptive to the proposed changes to their program. Ms. Grbac offered technical assistance in the form of reviewing how to conduct a screening and how to record results. Ms. Harbison reviewed the specific requests of the pilot project. In collaboration with the the participating hospitals, changes were made to the appointment cards to better suit the procedures for follow-up screenings within each hospital. The hospitals began the changes in reporting "refer" results on September 1, 2009. The additional hospitals included: Fitzgibbon Hospital in Marshall, Texas County Memorial Hospital in Houston, Lake Regional Hospital in Osage Beach, and Barnes-Jewish Hospital in St. Louis.

Final data for the HRSA pilot project for the time period 7/1/2008—6/30/2009 shows a reduction in loss to follow-up rates from 60.2% to 30% for Twin Rivers Hospital and a reduction from 68.7% to 32% for Pemiscot Memorial Hospital when compared to the same time frame a year earlier. For the newest hospitals, all of which began the project on September 1, 2009, statistics are insufficient for an accurate assessment of progress.

Finally, preparation for the MOHear Project is underway. To be funded with the supplemental HRSA funding and implemented via a contract with Missouri State University (MSU), the MOHear Program will involve development of a program for rescreening newborns who do not pass the initial hearing screening and are born in communities where no rescreening program is available or in hospitals with large numbers of infants whose families do not return for rescreening. It will also provide initial hearing screenings to infants known to have missed the initial screening. Additionally, the MOHear Program will provide for consultation with families whose newborn failed or missed the newborn hearing screening as well as those whose young child has been diagnosed with a permanent hearing loss. Since receiving the funding in late August 2009, the DHSS wrote and approved a contract for MSU, and Ms. Kris Grbac began work on the project. To date, Ms. Grbac has been involved in researching loss to follow-up in Missouri based on numerous demographic variables such as maternal age, maternal education and county of residence. Two Graduate Assistants, Mr. Ryan Bullock and Mr. Fadi Najem are helping Ms. Grbac. Position Descriptions and Biographical Sketches for the Graduate Assistants are found in Attachment 1 and Attachment 2, respectively, in the HRSA Electronic Handbook as directed in the application guidance.

Barriers:

- Scheduling conflicts caused delays in meeting original specified timeframes for making site visits to potential HRSA Pilot Project hospitals and establishing start dates for those who joined the project, affecting all subsequent goal dates.
- Some hospitals, from each time frame of HRSA Pilot Project participation, failed to send in appointment cards for all "refer" results.

Steps to Overcome Barriers:

- The MNHSP adjusted timeframes for initial site visits with potential HRSA Pilot Project hospitals as needed to meet individual scheduling requirements, thereby building rapport and trust with hospital representatives.
- The MNHSP offered assistance and consultation plus sent reminders and data showing that appointment cards for every "refer" result were not consistently submitted thereby generating swift adjustments to appointment card submission practices by the hospitals involved.

Progress on Specific Goals and Objectives:

HRSA Pilot Project (Implementation of NICHQ Strategies)

Goal 1: Enhance the Early Hearing Detection and Intervention (EHDI) system in Missouri to reduce loss to follow-up following a refer screening at all stages of the EHDI process.

Objective 1: Loss to follow-up rate is reduced from 36.7% to 1.0% of the total infants not passing their final hearing screening by March 31, 2011.
Objective 1 (revised; please see explanation below in discussion of progress.): Loss to follow-up rate is reduced from the Fiscal Year (FY) 2008 (July 1, 2007 – June 30, 2008) rate of 61.3% to 1.0% of the total infants not passing their final hearing screening by March 31, 2011.

Activities:

a) Compile data to determine loss to follow-up rates for birth hospitals and create report cards for Missouri birth hospitals with highest loss to follow-up rates indicating number of loss to follow-up cases.
b) Make site visits to those hospitals with highest loss to follow-up rates.
c) Assist those hospitals in creating a plan to reduce loss to follow-up.
d) Continue work with Missouri Department of Health and Senior Services (DHSS) Information Technology Services Division (ITSD) to ensure the data management system, Missouri Health Strategic Architectures and Information Cooperative (MOHSAIC), accurately reports the status of every occurrent birth throughout the EHDI system.

Progress: Initial loss to follow-up data was compiled from 2006 data. Since the HRSA Pilot Project Hospitals began participation in the project on July 1, 2008, the MNHSP would like to revise Objective 1 to reflect the time dedicated to the changes in reporting and managing "refer" results. The revised objective is: "Loss to follow-up rate is reduced from the Fiscal Year (FY) 2008 (July 1, 2007 – June 30, 2008) rate of 61.3% to 1.0% of the total infants not passing their final hearing screening by March 31, 2011." The increase from 36.7% to 61.3% reflects the finding that a MOHSAIC report was counting diagnostic evaluations still in progress as permanent hearing losses and the same cases were also being subtracted from the number of final "refer" cases labeled as loss to follow-up when calculating the loss to follow-up percentage. Therefore, the statewide loss to follow-up data was skewed. This did not occur when researching rates for individual hospitals because the report described above was not used in this process. A plan to correct the report has been developed and will be in place by December 15, 2009. The statewide loss to follow-up rate following a final refer result decreased from 61.3% in FY08 to 58.3% in FY09.

The MNHSP continued to compile report cards for the hospitals with high loss to follow-up rates and contact those hospitals via phone calls, email, or site visits. In addition to refer rates and loss to follow-up rates, the MNHSP manager and audiologist consultant also discussed screening equipment, replacement of screening equipment, and hospital program procedures with nineteen hospitals other than the newly recruited HRSA Pilot Project hospitals. Site visits and contact with screening programs will continue into 2010.

Finally, the MNHSP continues to have a good working relationship with the DHSS Information Technology Services Division (ITSD), particularly the contractors assigned to maintain and repair, as needed, the data management system, Missouri Health Strategic Architectures and Information Cooperative (MOHSAIC). Repairs are made to the system as needed.

Objective 2: Loss to follow-up rate is reduced from 25.7% to 0% of the total infants diagnosed with a permanent hearing loss following a failed initial screening by March 31, 2011.

Activities:

a) Compile data to determine loss to follow-up rates for infants diagnosed with a permanent hearing loss and create report cards for all Missouri pediatric audiologists indicating number of loss to follow-up cases.
b) Make site visits to or other contact with those audiology clinics with high loss to follow-up rates.
c) Assist those clinics in creating a plan to reduce lost to follow-up.
d) Continue work with DHSS ITSD to ensure the data management system accurately reports the status of every occurrent birth throughout the EHDI system.
e) Continue collaboration with Missouri Department of Elementary and Secondary Education (DESE) in order to obtain personally identifiable Part C enrollment data.

Progress: The number of infants diagnosed with permanent hearing loss and reported to the MNHSP rose from 35 in 2006 to 133 in 2007. Along with that increase, the percentage of infants diagnosed with hearing loss who were not known to receive early intervention and were considered loss to follow-up rose from 25.7% to 47%. Both the higher number of reported hearing loss cases and the fact that the reported cases included 61 unilateral cases and 24 bilateral mild cases most likely account for the apparent decrease in the number of children receiving early intervention. In Missouri, mild losses and unilateral losses are frequently deemed ineligible for Part C due to the requirement that eligibility for early intervention services only includes children who have been determined to either (1) have a diagnosed physical or mental condition associated with developmental disabilities or have a high probability of resulting in a developmental delay or disability, or (2) be functioning at half the developmental level that would be expected for a child considered to be developing within normal limits and of equal age.

The MNHSP consultant audiologist, Ms. Grbac, compiled data to determine loss to follow-up rates for infants diagnosed with a permanent hearing loss and created report cards for all Missouri pediatric audiologists indicating loss to follow-up rates. In total, Ms. Grbac generated eight audiology reports that were followed by visits or other contact, as appropriate, between December 2008 and August 2009.

Additionally, the MNHSP continues to have a good working relationship with the DHSS ITSD, particularly the contractors assigned to maintain and repair, as needed, the data management system, MOHSAIC. Repairs and mandatory maintenance happen on a frequent basis.

Finally, the MNHSP continues to work with DESE to acquire personally identifiable Part C enrollment data of all children receiving services related to hearing loss. DESE relies on individual service coordinators to obtain parent permission to share this data. Some regions of the state are more successful at acquiring such consent and passing on

Individual Family Service Plan (IFSP) information. DESE consistently reports aggregate data on the numbers of children with hearing loss enrolled in Part C services.

Objective 3: Three Missouri hospitals with the highest loss to follow-up rates will participate in a pilot project that utilizes the National Initiative for Children's Healthcare Quality (NICHQ) strategies found to be effective in reducing loss to follow-up by May 1, 2008. Up to 15 additional hospitals will join the project by February 2009.

Activities:

a) Review data to determine the Missouri birth hospitals with the highest loss to follow-up rates.
b) Recruit three hospitals with high loss to follow-up rates into a pilot project.
c) Create script for pilot hospital staff to use when discussing screening results with the parents of newborns who did not pass the initial hearing screening and forms/appointment cards for pilot hospitals to use to gather information from the same families including: second contact, confirmed name of baby's primary care physician (PCP) and date, place, time, and type of outpatient appointment.
d) Perform an initial consultation with each pilot hospital to set up new procedures and identify any other potentially helpful strategies to incorporate in the hospital screening and referral process.
e) Ensure that pilot hospitals initiate new procedures on May 1, 2008.
f) Begin new MNHSP tracking and follow-up activities. In addition to regular tracking and follow-up duties, MNHSP Follow-up Coordinators will contact families of newborns requiring outpatient screening or testing to remind them of their appointments and to stress the importance of keeping the appointment. Follow-up Coordinators will mail letters of notification to the identified PCPs as soon as the PCP information is received on the new information forms from the pilot hospitals.
g) Meet with pilot hospital representatives twice a month, via phone conference. Review most recent MOHSAIC data, discuss progress, and formulate solutions to identified barriers.
h) Evaluate pilot project. Make changes to procedures based upon outcome of evaluation.
i) Recruit at least 15 more hospitals to the project and repeat the above 8 action steps in the next project period.
j) Expand project to include statewide participation and repeat the above first nine action steps in the next project period.

Progress: In addition to high loss to follow-up rates, to better evaluate the effectiveness of the pilot project, the MNHSP considered size, location and type of screening program when recruiting new hospitals to the pilot project. Missouri is comprised of 114 counties and the City of St. Louis. Twenty four percent of all 2008 cases that are currently closed

as loss to follow-up reside in the City of St. Louis and St. Louis County. The county with the next highest percentage of cases closed as loss to follow-up is Jackson County with a 7% rate. There are 7 counties with 3% - 4% of cases closed as loss to follow-up. The remaining counties have 2% or less of cases closed as loss to follow-up.

Barnes-Jewish Hospital is a large birthing hospital in the City of St. Louis. The City of St. Louis has the highest number of cases closed as loss to follow-up. In addition, Barnes-Jewish Hospital is a hospital that typically has high numbers of cases closed as lost. For example, for 2008, 93 births of 233 that needed testing were closed as lost. By adding Barnes-Jewish Hospital to the HRSA Pilot Project, it was determined that a larger number of infants who could benefit from the NICHQ procedures designed to decrease loss to follow-up would actually be exposed to those procedures. The clinical nurse manager of the Barnes-Jewish obstetrics department reported that 90% of the maternity patients are Medicaid clients. Barnes-Jewish caters to numerous immigrant groups, including a high number of refugees. The hearing screening program provides rescreening services at the adjacent St. Louis Children's Hospital.

By adding Barnes-Jewish Hospital, MNHSP staff is contacting more families who need follow up than would have occurred if 10 smaller hospitals had been added in its place. It is hoped that the MNHSP's efforts towards reducing loss to follow-up will have a more dramatic effect by having added one of the state's largest birthing hospitals that also has one of the highest loss to follow-up rates.

The MNHSP also added three smaller hospitals to the pilot project. Each of the three smaller hospitals have higher percentages of cases closed as loss to follow-up, but each of the three hospitals are located in counties where birth rates are significantly lower than the more urban counties. The smaller hospitals include Fitzgibbons Hospital in Marshall, Lake Regional Hospital in Osage Beach, and Texas County Memorial Hospital in Houston.

Fitzgibbons Hospital is a 60 bed facility located in rural north central Missouri. The obstetrics floor delivers about 400 babies each year. The hearing screening program does not provide rescreening services. Lake Regional Hospital is a 116 bed facility in the Lake of the Ozarks region of central Missouri. The obstetrics floor delivers about 800 babies each year. The hearing screening program does not provide rescreening services. Parents of newborns who have "refer" results are instructed to contact their family physician or a local audiologist for a rescreening. Finally, Texas County Memorial Hospital is a 60 bed hospital in south central Missouri. The obstetrics floor delivers about 300 babies each year and offers rescreening services for babies that have "refer" results.

The strategies for the newly recruited hospitals remain the same: explaining the importance of returning for a rescreening to the newborn's parent/guardian based upon a script created by the MNHSP, making the appointment for the rescreening, obtaining two contact phone numbers from the parent/guardian, determining the newborn's primary physician and informing the parent/guardian that the MNHSP will make a reminder

phone call 24 hours prior to the appointment. The MNHSP also asked each hospital to fax a copy of the appointment card and the above information to the DHSS in order to allow the MNHSP to immediately send a letter of notification to the newborn's physician and make arrangements to call the parent 24 hours prior to the rescreening appointment.

Site visit scheduling conflicts prevented the current year project hospitals from starting the new processes until September 1, 2009. For that reason, final loss to follow-up rates will be compared to the 9/1/2008 – 8/30/2009 time period for each hospital. For that time period the loss to follow-up rates were: Barnes-Jewish Hospital - 75%, Fitzgibbons Hospital – 39%, Lake Regional Hospital – 56%, and Texas County Memorial Hospital: 44%.

As stated above, final data for the HRSA pilot project for the time period 7/1/2008 to 6/30/2009 shows a reduction in loss to follow-up rates from 60.2% to 30% for Twin Rivers Hospital and a reduction from 68.7% to 32% for Pemiscot Memorial Hospital when compared to the same time frame a year earlier. For the newest hospitals, all of which began the project on September 1, 2009, statistics are insufficient for an accurate assessment of progress. Records show that two hospitals have failed to send in appointment cards for all of their "refer" results. The MNHSP has been in contact with both regarding this situation. The MNHSP shared data, and offered consultation and assistance in any way either hospital felt was needed. It's important to remember that not all "refer" babies from this time period may have been able to obtain a rescreening as of the date of this writing in late October. Additionally, results for this time period may not have reached the DHSS as of this date.

Evaluation of this project has been planned and will include review of statistical data and a parent survey and a physician survey to examine the effectiveness of the specific strategies put in place by the pilot hospitals. Questionnaires will be mailed in late 2009.

Goal 2: Increase awareness and knowledge about the Missouri EHDI process among stakeholders including: hospital nursery staff, hospital administrators, physicians, audiologists, Part C service coordinators, and early intervention providers.

> Objective 1: Face-to-face meeting with pilot hospital representatives and regional stakeholders (physicians, audiologists, parent representatives, Part C representative, early intervention representative, a MNHSP Follow-up Coordinator, and the state American Academy of Pediatrics [AAP] Chapter Champion) to obtain stakeholder input for the development of quality improvement methods and strategies and to disseminate program information will be held by March 2009.

Activity:

a) Hold face-to-face meeting with all pilot hospital representatives. Include physicians and audiologists to whom newborns were referred, parent representatives, an early intervention representative, a MNHSP Follow-up Coordinator, and the state AAP Chapter Champion.

Progress: In the past year the MNHSP representatives have met with all pilot hospital representatives in face-to-face meetings. In some instances nursery physicians were present. Dissemination of Missouri EHDI process and information was accomplished in several different venues. MNHSP progress, including the HRSA Pilot Project, was described in the 2007 and 2008 Annual Newborn Screening Reports that were distributed to Genetics Advisory Committee members, delivered to birthing hospitals, and posted on the DHSS website. Additionally, the MNHSP presented at a Missouri First Steps (Part C) meeting in April 2009. Also in April 2009, the AAP Chapter Champion, Dr. Alan Grimes spoke about the EHDI process in Missouri at the DHSS sponsored conference "Newborn Screening: What Providers and Parents Need to Know." His session was attended by pediatricians, audiologists, and parents. At the same conference, the MNHSP Audiologist Consultant spoke at a breakout session geared toward parents. Pediatric audiologists also attended this session.

Objective 2: Face-to-face meeting with at least 15 pilot hospital representatives and regional stakeholders (physicians, audiologist, parent representatives, Part C representative, early intervention representative, a MNHSP Follow-up Coordinator, and the state AAP Chapter Champion) will be held by March 2010.

Activity:

a) Hold face-to-face meeting with all pilot hospital representatives. Include physicians and audiologists to whom newborns were referred, parent representatives, an early intervention representative, a MNHSP Follow-up Coordinator, and the state AAP Chapter Champion.

Progress: Plans for this meeting are in progress.

Objective 3: Face-to-face meeting with statewide hospital representatives and regional stakeholders (physicians, audiologist, parent representatives, Part C representative, early intervention representative, a MNHSP Follow-up Coordinator, and the state AAP Chapter Champion) will be held by March 2011.

Activity:

a) Hold face-to-face meeting with all pilot hospital representatives. Include physicians and audiologists to whom newborns were referred, parent representatives, an early intervention representative, an MNHSP Follow- Coordinator, and the state AAP Chapter Champion.

Progress: This meeting is planned for 2011.

Objective 4: Disseminate ongoing project results to Missouri stakeholders by August 2008 and annually through 2011.

Activities:

a) Include description of project and subsequent results in annual Missouri Newborn Screening Report.
b) Prepare "Best Practices" document based upon results of project. Distribute to hospitals and pediatric audiologists.

Progress: A description of the project and results to date was included in the Missouri Newborn Screening Report – 2007, published in November 2008. It will also be included in the report to be published in November 2009. The project was also addressed at the annual Missouri Newborn Hearing Screening Standing Advisory committee in November 2008 and will be presented at the Genetics Advisory Committee meeting scheduled for November 10, 2009. It is too soon to develop a "Best Practices" document.

MOHear Project

Goal 1: Decrease loss to follow-up following failure to pass the initial newborn hearing screening.

Objective 1: Establish a program of loss to follow-up coordination, known as the MOHear Project.

Activity 1: Establish a contract with Missouri State University (MSU) to provide a program of loss to follow-up coordination as part of the Missouri EHDI system by September 30, 2009.

Activity 2: Hire and train up to five professional and specialized loss to follow-up coordinators, known as MOHears by January 31, 2010.

Activity 3: Establish a method of sustainability for the MOHear Project by August 31, 2012.

Progress: The MNHSP received notice of the supplemental HRSA award in late August 2009. A contract was written and approved. As of this date, Ms. Grbac has hired two Graduate Assistants to work on the project and has begun research into the causes for high loss to follow-up rates in certain parts of the state.

Objective 2: Decrease the loss to follow-up for infants who failed the initial hearing screening to 33.6% (30% ↓) by August 31, 2010, to 19.2% (60%↓) by August 31,

2011 and to 4.8% (90% ↓) by August 31, 2012 as measured by the number of infants who are known to have failed the initial hearing screening but for whom there is no documentation of further assessment in the data management system Missouri Health Strategic Architectures and Information Cooperative (MOHSAIC) (719 or 48.2% in 2007).

Activity 1: Conduct hearing screenings for newborns referred on the initial hearing screening at hospitals, physicians' offices, county health departments, and/or other appropriate venues.

Activity 2: Report all rescreening results to DHSS via MOHSAIC.

Activity 3: Design, print, and distribute state-sponsored material for hospitals to use with families of newborns who refer on the initial hearing screening.

Activity 4: In addition to printed materials, provide families with newborns who do not pass the initial screening with a tangible reminder that their newborn needs a hearing check. This tangible reminder may be a refrigerator magnet or keychain or some such promotional type of item.

Activity 5: Use MOHSAIC to monitor numbers of newborns referred at Missouri hospitals and establish contact with each Missouri hospital to determine reasons for the missed hearing screenings and offer technical support.

Activity 6: Conduct additional search activities (evening and weekend phone calls) to families of cases that have been closed as loss to follow-up.

Progress: Work on these activities has not yet commenced.

Objective 3: Decrease the loss to follow-up for infants who missed the initial hearing screening to .91% (30% ↓) by August 31, 2010, to .52% (60% ↓) by August 31, 2011 and to .13% (90% ↓) by August 31, 2012 as measured by the number of infants who are known to have missed the initial hearing screening, did not die or did not decline the initial screening but for whom there is no documentation of later assessment in MOHSAIC (1,081 or 1.3% in 2007).

Activity 1: Conduct hearing screenings for newborns who missed the screening during the birth admission. The screenings will take place at hospitals, physicians' offices, county health departments and/or other appropriate venues.

Activity 2: Report all screening results to DHSS via MOHSAIC.

Activity 3: Use MOHSAIC to monitor numbers of newborns missed at Missouri hospitals and establish contact with each Missouri hospital to establish reasons for the missed hearing screenings and offer technical support.

Activity 4: Conduct additional search activities (evening and weekend phone calls) to families of cases that have been closed as loss to follow-up by BGHC Regional Representatives

Progress: Work on these activities has not yet commenced.

Objective 4: Decrease the loss to follow-up for infants diagnosed with a permanent hearing loss to 33.1% (30% ↓) by August 31, 2010, to 18.9% (60% ↓) by August 31, 2011 and 4.7% (90% ↓) by August 31, 2012 as measured by the number of infants who were diagnosed with permanent hearing loss, but for whom there is no documentation of enrollment in a program of intervention in MOHSAIC (63 or 47.4% in 2007).

Activity 1: Provide specialized service coordination to families of infants diagnosed with hearing loss regarding the importance of obtaining appropriate intervention services in conjunction with the System Point of Entry (SPOE) to the Part C program (Missouri First Steps)

Activity 2: Use MOHSAIC to monitor new diagnoses of hearing loss and monitor their referral into First Steps. If the case does not appear to be referred, MOHEAR will investigate the reason for the lack of referral.

Activity 3: Maintain continual, formal contact with the SPOE in order to identify cases of diagnosed hearing loss that are not evident in MOHSAIC. Seek to provide service coordination to those families and enter data into MOHSAIC. Investigate reasons why the case was not previously evident in MOHSAIC and report to MSU audiologist.

Progress: Work on these activities has not yet commenced.

Objective 5: Determine the feasibility of using the Vivosonic Integrity V500 as a traveling, intermediary component to Missouri's EHDI program in order to reduce loss to follow-up after failure to pass the initial newborn hearing screening.

Activity 1: Seek direct observation of this unit either through a trade show or by visiting a facility that uses it.

Activity 2: Interview three facilities using the unit for the newborn and infant population.

Activity 3: Obtain clinical trial information for the unit from manufacturer or distributor.

Activity 4: Explore whether laws in Missouri would enable or prohibit the Vivosonic's use by a technician with interpretation by an audiologist.

Progress: These activities are scheduled to take place in Year 2 of the MOHear Project.

Current Staffing:

MNHSP staff includes:

1. Ms. Catherine Harbison, Program Manager – Ms. Harbison manages the consultant audiologist contract, maintains the HRSA and CDC grants, prepares administrative reports, examines data and prepares statistical reports, develops and maintains relationships with stakeholders, develops program materials, evaluates program activities, and performs supervisory functions. She will oversee the MOHear Contract.
2. Ms. Linda Krogstad, Data Management Coordinator – Ms. Krogstad validates MOHSAIC data and actions through a process of deduplication and extensive spot checking, compiles data reports, and prepares GIS maps as needed.
3. Ms. Marie Duggan, Follow-up Coordinator (formerly known as Regional Representative) – Ms. Duggan tracks Missouri-born newborns who missed or failed the initial hearing screening, prepares and mails letters of notification to parents/guardians of newborns who missed or failed the initial screening, and responds to inquires from parents and providers. She assists the Program Manager with special projects as needed. For the HRSA Pilot Project, she sends a letter of notification to the newborn's physician immediately upon notification of the "refer" and makes appointment reminder phone calls to the parent/guardian one day prior to the appointment. She utilizes a translation service as needed. Additionally, Ms. Duggan records the results of her attempts to reach the family in a prescribed spreadsheet and in MOHSAIC.
4. Ms. Laura Lewis, Follow-up Coordinator (formerly known as Regional Representative) – Ms. Lewis tracks Missouri-born newborns who missed or failed the initial hearing screening, prepares and mails letters of notification to parents/guardians of newborns who missed or failed the initial screening, and responds to inquires from parents and providers. She assists the Program Manager with special projects as needed. For the HRSA Pilot Project, she sends a letter of notification to the newborn's physician immediately upon notification of the "refer" and makes appointment reminder phone calls to the parent/guardian one day prior to the appointment. She utilizes a translation service as needed. Additionally, Ms. Lewis records the results of her attempts to reach the family in a prescribed spreadsheet and in MOHSAIC.
5. Ms. Sally Streeter, Data Entry – Ms. Streeter enters hearing screening results into MOHSAIC and assists with clerical duties.
6. Ms. Kelly Welch, Clerical Support – Ms. Welch provides clerical support to the MNHSP.
7. Ms. Lori Gillmore, Data Entry (part-time) – Ms. Gillmore enters hearing screening results into MOHSAIC two days per week.
8. Ms. Kris Grbac, Audiologist Consultant and MOHear Project Manager – Ms. Grbac provides consultative and technical assistance to the MNHSP,

Missouri newborn hearing screening programs, and pediatric audiologists. She will manage the MOHear Project.

9. Mr. Ryan Bullock, MSU Graduate Assistant – Mr. Bullock assists Ms. Grbac with the MOHear Project including, but not limited to, monitoring hospital loss to follow-up rates.
10. Mr. Fadi Najem, MSU Graduate Assistant – Mr. Najem assists Ms. Grbac with the MOHear Project including, but not limited to, monitoring hospital loss to follow-up rates.

There have been no difficulties in hiring or retaining staff. Mr. Bullock's and Mr. Najem's position descriptions are found in the Attachment 1 and their biographical sketches are found in Attachment 2. Both attachments are found in the HRSA Electronic Handbook as specified in the grant application guidance.

Technical Assistance Needs:

Information technology assistance is available to the MNHSP from the DHSS Information Technology Services Division (ITSD). The MNHSP works closely with personnel assigned to improve and maintain MOHSAIC.

Any audiological technical assistance requested by or assessed to be necessary for the pilot hospitals is provided by the MNHSP consultant audiologist, Ms. Kris Grbac. Likewise, Ms. Grbac offers technical expertise at all site visits, including those not involved in the pilot. As the MOHear Project Administrator, Ms. Grbac will provide and/or arrange for training of the MOHears who will be performing rescreenings, parent consultations, and service coordination.

Linkages Established With Other Programs:

The MNHSP currently benefits from linkages to databases (vital records and newborn bloodspot screening), stakeholders (birth hospital newborn hearing screening managers, primary care providers, audiologists, Part C personnel and standing advisory committee members) and the Missouri State University contract audiologist consultant and MOHear Project Administrator. Recently, the DHSS Children with Special Health Care Needs (CSHCN) Program manager worked with the MNHSP to identify children who have received hearing aids through the CSHCN Program. This allows the MNHSP to obtain a more complete picture of outcomes for children diagnosed with a permanent hearing loss. Finally, the MNHSP worked with a MSU audiology student to develop and distribute the parent surveys in 2009.