Section 2: Narrative Description

A. Executive Summary

Staff and Organizational Update personnel changes

In 2013 the New Mexico Department of Health and the Family Heath Bureau had a number of staff changes. Retta Ward has replaced Catherine Torres as the Secretary of the Department of Health. The Family Health Bureau Chief Emelda Martinez retired and Denita Richards was promoted from Maternal Child Health Program Manager to Family Health Bureau Chief. Janis Gonzales has been promoted from CMS Medical Director to the Medical Director for the Family Health Bureau. She remains the AAP EHDI Chapter Champion.

Within the EHDI Program a new data manager Mario Lucero replaced Carolyn Romero in March.

There have been no political or policy changes.

There have been no legislative changes.

All contracts and contracted work was able to this year with no delays.

An administrative issue prevented the EHDI Advisory Committee from convening a face to face meeting but the work by the committees and individuals continued and communication was maintained by the EHDI Coordinator with all members through the interim. The EHDI Advisory Committee reconvened in person on 05/24/2013 and established an agenda for FY 2014.

Overall Progress:

The Needs Assessor submitted her recommendations to the program after a thorough assessment of data reporting activities by hospitals, midwives, Indian Health Services and audiologists. Based on the findings of the Needs Assessor the EHDI Program implemented some procedures with these providers and began to receive data on births and screening results on a monthly basis. The information is received by the program in different formats based on the capability of the individual providers. The various entities report by direct download into Challenger Soft, the CMS referral form or a nursery log. As of June 2013, 95% of providers were reporting data

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directly to the program using one of these formats. The data manager monitors and inputs this data and works with the MCH Epidemiologist linking to vital records data now received monthly. As part of quality assurance, reports are run by the data manager that compares the number of births per month by hospital to the number of records received by the program. We report this information back to the hospitals for validity. The Program has reconvened the Challenger Soft Work Group and meets at minimum quarterly or on an as needed basis to address overall issues around data collection and reporting and develop strategies to move forward. Members of this group include; the EHDI Coordinator, CMS Medical Director, MCH Epidemiologist, the Needs Assessor, Data Manager, Follow up Coordinators, the Challengersoft engineer, CMS Program Director and the Newborn/ Bloodspot Screening Program Manager. A new Division Director at Vital Records is in the process of being hired and will be invited to join these quarterly meetings. In addition, weekly phone conferences are convened by the EHDI Coordinator and the data manager with Challenger soft and any relevant members of the work group to review data and recommend needed enhancements and strategies to improve the data collecting, analysis and reporting. In addition, outreach plan had been developed and we reached out to 75 licensed midwives and 2 birthing centers with training and information about Newborn Hearing Screening and reporting now they have a mechanism to report as well. We identified there are approximately 300 home births per year. The EHDI Coordinator met with the Midwives Advisory Board and the New Mexico Midwives Association to develop a reporting form to capture the specific information on births attended by a midwive. This form is then faxed to the EHDI Coordinator who assists with follow-up and also provides the information to the Data Manager so information on these births may be recorded into Challenger Soft. Follow-up for these specific families does continue to be a challenge and the EHDI Coordinator has been working with the Midwives Association to develop some strategies to improve access to screening services.

B. Goals and Objectives

Objective Year Two: Provide education and training to hospitals and audiologists on correct data entry to improve reporting on the results of all newborn hearing screens from the initial hospital screen to referral to early intervention to reach 100% compliance.

Goal 1: Provide education and training to birthing hospitals on accurate and timely data reporting of the results of the initial hospital hearing screen into the electronic birth certificate.

This goal was changed based on the findings of the needs assessor as discussed above in the summary. Hospitals were not trained to enter information about hearing screening into birth record but instead were trained to provide information on the results of each a hearing screen, on each birth, directly to the Newborn Hearing Screening Program. Eight of 33 hospitals provide this information electronically to a secure website via Challenger Soft. Other hospitals are sending nursery logs or paper referrals that the data manager still enters manually. The data is cleaned and then analyzed by the Data Manager. Analysis includes linkages to vital records, bloodspot screening data, audiological diagnostic data and referral data. As of this report all hospitals have agreed to report directly but need continous communication from the EHDI Coordinator with reminders. Our goal is to have all hospitals reporting electronically by the end of year 3 if possible working within the limitations of some of our very rural hospitals and pending a legal agreement with the state's largest hospital. One possibility, which needs further exploration, was identified through the needs assessment. We learned that most hospitals have screening machines that have the capability to connect to the internet and maybe this information can be downloaded directly into the Challenger soft data base. The program will explore this further in the next year.

Activities:

a) Maintain contract with provider from Year One to coordinate implementation of reporting improvement activities with hospitals statewide.

Met. Ms. Reynolds contacted all birthing hospitals in New Mexico She created a list of who would be the contact person at each hospital site and what their capabilities were regarding reporting. The EHDI Coordinator and

Annual Progress Report for Budget Period July 1, 2012-June 30, 2013 New Mexico, 5UR3DD000807-03 Data Manager developed a protocol with hospitals to download and retrieve data on births and results of screening. The EHDI Program Coordinator sends all hospitals a monthly reminder with instructions about how to provide birth/screening information and follows-up with those hospitals that are missing data each month.

b) Provide training and technical assistance to appropriate personnel from the 33 birthing hospitals in the State on accurate and timely reporting of newborn hearing screening results into the electronic birth certificate.

Met. With changes. All hospital birthing providers have received training on the protocol, requirements and the information they need to begin reporting directly to the EHDI Program. This data is linked to vital birth records for comparative analysis. The EHDI Coordinator and Data manager continue to provide one to one training and technical assistance as needed to hospitals as staff change or problems arise with data management and collection. In June the only hospital without a plan for direct reporting was the largest hospital in the State, the University of New Mexico Hospital (UNMH). Negotiations took place between UNMH, Challenger Soft and the program to satisfy HIPAA and legal requirements by all parties. Just recently in August 2013, Challengersoft system was approved by UNMH as meeting all standards of industry compliance for HIPAA, security and Health Information protection and UNMH plans to begin the electronic download of data this fall. With over 3000 births per month this hospital is one of the State's largest facility and the acquisition of the data will greatly enhance the overall system.

c) Collaborate with Vital Records to begin process of establishing the newborn hearing results as required fields in the electronic birth certificate which could involve a rule change.

Discontinued this goal. This goal was changed during year two based on findings of needs assessment. The recommendation of the assessment was to collect data on all births and screening results directly from birthing providers either electronically through a download or direct data entry into Challenger Soft. Vital Records is still received and used for comparative analysis and to report on demographic statisitics.

d) Establish protocol for the CMS Data Manager to begin running monthly reports from data acquired from Vital Records on hospital reporting of newborn hearing results.

Met. The Bureau's Epidemiologist runs monthly reports from vital records. She cleans this data and provides this information to the Data Manager. He links this with data available in Challengersoft database (including Newborn/ Bloodspot Screening now downloaded from Oregon Health and entered into Challengersoft) The Data Manager runs comparative analysis with vital records cleaning any duplicate records and identifying any missing records. Reports are then provided to the EHDI Coordinator to send to the hospitals. We identify any missing data that should have been reported to the program.

Goal 2: Provide education and training to audiologists on data entry activates to improve accuracy and timeliness of reporting on the results of audiologic testing on newborns who did not pass the hospital newborn hearing screen.

Activities:

a) Maintain contract with provider selected in Year One to coordinate implementation of reporting improvement activities based on recommendation of the needs assessment in Year One.

Met- The summary from Needs Assessor was provided to EHDI Advisory Council and the Audiology Subcommittee. The reporting form to be used by audiologists was revised and field tested using the PDSA quality improvement process. The revised form is now protocol and was distributed to audiologists that provide services to children in the State. The Needs Assessor had identified and compiled a list of audiologists with contact information which the EHDI Coordiantor nows uses to communicate regulary with these professionals.

b) Maintain on-going communication with audiologists to trouble shoot challenges, provide technical assistance and monitor compliance with reporting.

Met-The EHDI Coordinator sends monthly reminders to Audiologists about submitting information to the program. The Challengersoft system can create reports to track referrals and number of audiological reports received. The Data manager manually enters all reports received from Audiologists and matches with hospital referrals to create a complete child record. The EHDI Coordinator and Data manager are available to respond to any concerns and provide technical assistance to audiologists. In addition the program has an improved ability to monitor compliance around reporting.

 Provide reports and updates on success and challenges to the Newborn Hearing Screening Advisory Council.

Met. Advisory Council Convened on May 24, 2013. Annual report delivered.

Goal 3: Continue to improve processes within ChallengerSoft to improve accuracy of data collection and ease of running reports.

Activities:

a) Monitor process improvement activities in regards to data collection into the tracking and surveillance database.

Met- The Data Management Team now includes the MCH Epidemiologist. The team meets by phone weekly and through Webex. We discuss reports that need to be created, address challenges, fine tune processes to improve data collection and accuracy. See Data managers report attached appendix 2.

Section 3 Appendices for Annual Progress report for budget period July 1, 2012-June 30, 2013 New Mexico, 5UR3DD000807-03

Section 3 Table of Contents

- 1.2 spreadsheets of Hearing Screening Data collected from Hospitals from year 1 (20110-2011) and from year 2 (2011-2012) To demonstrate the increase (improvement in the number) in the data received from hospitals.
- 2. Summary report of Data Manager and the Challengersoft enhancements completed in year 2.
- 3. Report and findings from the Needs Assessment Coordinator.
- 4. NM PHD Organizational Chart

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Data Manager Report for FY year 2013- Changes to staff - Mario Lucero replaced Carolyn Romero

Challengersoft staff continue to be available for weekly scheduled WebEx trainings and hands on technical assistance. Also the SharePoint and Wiki sites are available to EHDI staff to post requests at anytime. Challengersoft engineers respond promptly to requests. The programmers continue to offer enhanced reports specific to Newborn Hearing Screening needs for data.

Mario Lucero trained/ worked with and then replaced Carolyn Romero as Data Manager beginning officially April 1, 2013. Carolyn and Challengersoft programmers worked to create a training program/site to assist Mario with some of the functions and reports needed for this transition. Also they created training site that includes modules for office staff as a general introduction for using Challengersoft this site to be used in conjunction with a SharePoint for EHDI staff using Challengersoft to share information. Carolyn has continued to be available to answer any details not included in this information.

Highlights

* All hospital are now required to report all births and hearing results directly to the NHS Program. As of June 2013 -29 of 33 birthing facilities are currently reporting.

*Midwives performing homebirth (about 300 births per year from 75 licensed midwives) are also now asked to report directly to the program.

*Vital Records Import File Created for:

- Those who were not screened for hearing
- Those that failed the hearing test
- Those with other conditions/risk factors
- Those transferred

*Merging Newborn Genetics Data with Newborn Hearing Screening Data

- Report to match those cases reporting using bloodspot to records received for newborn hearing screening hospital units that are now reporting directly. This report will help to identify any missing births that may not have been identified to the NHS Program
- Report to identify cases not reported to NHS
- Midwives now receive information from the NHS Program for reporting and to give to parents when they order Bloodspot Cards.

*Created a secure Challengersoft access/ link for hospitals to upload data directly

- 9 hospitals using this method to date
- Finalizing protocol to include in FY 2014 the Challengersoft access/ link to the largest hospital
 in the state UNMH
- Other hospitals submit Data on CD, password protected and sent by mail, nursery logs, or report birth and screening result using the referral form.
- 6 hospital managed by Pediatrix- Pediatrix uploads monthly to the Challengersoft secure link.

*Reports Created

- Spanish speaking data by hospital
- Number and demographic data for Open/ Active cases
- Report /access to Vital records merged with NHS and Genetics Records
- List of Records that include PCP will do follow up
- All Hospital results for Hearing Screening received that can be adjusted for a period

REPORT NEWBORN HEARING SCREENING BARRIERS AND PROCESSES TO IMPROVE REPORTING

TASK NO 1: PREPARE AND PRESENT A WRITTEN ASSESSMENT OF BARRIERS AND SOLUTIONS TO SCREENING BY MIDWIVES PRACTICING IN NEW MEXICO.

The State of New Mexico licenses to different midwife programs. The midwives who practice in hospitals have their births reported with all other births from the hospital they are associated with.

Home birth midwives have several barriers to overcome.

- 1. The reimbursement time for conduting the screening.
- 2. Access to a screening facility
- 3. Training to perform the screening
- 4. Understanding the reporting process

After speaking with approximately 70% of the homebirth midwives on the list provided to me, I learned what the barriers were and suggested that our NBHS coordinator meet with the group during a conference and present a training program and offer individual follow up with midwives as needed.

This has been a successful way to improve reporting. However, this group averages about 3 births per year and has a constantly changing active participation. For reporting to be successful continuous follow up with the leaders in the midwife program will be necessary.

Some equipment locations have been identified and will be used by the midwives. Parts of the state with limited resources are going to present a barrier to screening. Mothers who use home birth midwives are often reluctant to take their babies to hospitals for screening and those same hospitals may charge to high a fee if the mother does access them. The midwives themselves may be able to find equipment and places to screen if they work with the NBHS coordinator.

TASK NO 2: PROVIDE & PRESENT A LIST OF HIS CLINICS THAT PROVIDE NBHS, EXPLAIN PROCESSES & EQUIPMENT USED. DISCUSS SOLUTIONS FOR COLLECTION DATA FROM THIS ENTITY.

The problem with reporting in this group was with Navajo hospitals and clinics. Other IHS entities use hospitals throughout the state and their numbers are reported along with all other hospital screens. This will make it impossible to identify all native populations being screened, but is not a barrier to screening itself.

All IHS hospitals and clinics reported after a single telephone call and follow up by the NBHS coordinator with one exception; Gallup Indian Hospital. After numerous attempts to talk with them and try to find a solution to their reporting problem, we have achieved cooperation.

The current Birth Defects MOU between Navajo Nation and the State of New Mexico is expired and a new MOU is "IN PROCESS". However, since the clinics and hospitals are cooperating and sending data, I suggest the program continue to work with the individual contacts and not worry about the MOU for the time being. The Gallup Hospital was not sending data because their machine was broken and they were not screening. That situation has been resolved.

This group of clinics and hospitals should be monitored and contacted monthly to keep data flowing.

TASK NO. 3: PREPARE AND PRESENT REPORT THAT IDENTIFIES LOCATIONS, EQUIPMENT &PROCESSES THAT COULD B USED BY MIDWIVES AND IHS CLINICS TO SCREEN.

This task is incorporated in Tasks 1 and 2.

TASK NO 4: PROVIDE A LIST OF AUDIOLOGIST AND ENTITIES THAT MAY SCREEN & EVALUATE NEWBORNS IN THE BORDERING STATES.

I attempted contact with various audiologists and early childhood entities in Texas, Colorado and Utah.

Colorado had cooperating audiologists in Durango and Pueblo and reported that they do screen any child referred to them.

Texas Tech in Lubbock cooperates and screens referred children but in El Paso I found it difficult to speak to audiologists and limited willingness. Cost and reimbursement seemed to be the biggest barrier. I did not receive a response from Utah or Arizona. Considering the parts of the states that are contiguous I believe accessing IHS services or going to Farmington, Albuquerque or Las Cruces is as easy as going to Arizona or Utah.

A list of cooperating audiologists was submitted to the NBHS Coordinator.

5. I was unable to determine the barriers and solutions for audiologists to accept patients for screening and report. The practices stated that they are willing to screen referred babies and they reported hearing loss. They are now aware that they are supposed to report all screens no matter the result.

One barrier that is not provable at this time could be lack of parental follow up. If the name of the audiologist to whom a family is referred is on the NBHS form

then the form could be flagged to determine if a corisponding form is received from the audiologist. If not a family follow up (or second follow up) could occur.

TASK NO 6: FINAL REPORT AND SPREADSHEET OF ALL NEEDED LOCATIONS, PERSONNEL AND METHODS.

The above tasks incorporate the report on the entities identified in the contract.

A NBHS Coordinator, data base manager and at least one clerk or analyst is needed to complete continued follow up, problem solving and reminders to submit data.

We have learned over time that turnover at hospitals and clinics is fairly frequent and those who leave do not list NBHS reporting as one of the duties for new personnel. Every time a gap occurs in reporting a telephone call should be made and the reason for the gap determined. Making these contacts is a labor-intensive task and needs a trained clerk or analyst assigned to assist the Coordinator if the Coordinator cannot regularly make the contacts.

Additionally, data entry and monthly monitoring of the submitted forms and the electronically submitted data is critical to keeping current. A part-time epidemiologist would greatly enhance the program by looking at the data for reporting to outside entities and for finding location gaps.

The data entry clerk or analyst should perform linking or matching of submitted data to the birth file regularly so that an epidemiologist can have a denominator (the birth file) to perform their analysis. Training and a system for comparing submitted data to the birth file may be necessary.

Barriers to NBHS Reporting

- 1. Hospital/midwife discharge does not include appointment to return for second screening.
- 2. Reports of screens sent on an apparently random schedule. Could be the result of changing personnel in nursery.
- 3. Disconnect with PCP's throughout the state.
- 4. Midwives still not reporting after births.
- 5. Still need places to test.
- 6. More tests are probably occurring than reports being sent.
- 7. Equipment may not be up-to date.
- 8. Unknown percentage of parents who refuse testing.
- 9. At Risk is not known by hospital discharge personnel.



