

Newborn Hearing Screening Program Update (EHDI)

Responsibilities of the NM Newborn Hearing Screening Program and EHDI

The New Mexico Newborn Hearing Screening Program is designed to oversee the newborn hearing screenings, diagnostic evaluations and referrals to the early intervention process through a tracking system. The program assists in identifying those newborns with hearing loss, as soon as possible, so the ability to develop communication and social skills is obtained at the earliest stage.

Funding – the NM Newborn Hearing Screening Program receives federal funding through the CDC and HRSA. Funds were awarded to states to address the critical issue of the significant number of infants that are lost to follow-up. The New Mexico Program relies solely on this grant funding and receives no state monies.

The overall Goals of Early Hearing Detection and Intervention (EHDI) as stated by the CDC* are:

Goal 1: All newborns will be screened for hearing loss before one month of age, preferably before hospital discharge.

Goal 2: All infants who screen positive will have a diagnostic audiological evaluation before three months of age.

Goal 3: All infants identified with hearing loss will receive appropriate early intervention services before six months of age.

Goal 4: All infants and children with late onset, progressive, or acquired hearing loss will be identified at the earliest possible time.

Goal 5: All infants with Hearing loss will have a medical home.

Goal 6: Every state will have a complete EHDI Tracking and Surveillance system that will minimize loss to follow up.

Goal 7: Every State will have a comprehensive system that monitors and evaluated the progress towards the EHDI goals and objectives.

* these goals are taken from the CDC EHDI website:

<http://www.cdc.gov/ncbddd/hearingloss/ehdi-goals.html>

Facts about Hearing Loss:

Every day in the United States approximately one to three in 1000 newborns (or 33 babies a day) are born with permanent hearing loss. (American Speech and Hearing Association)

With a birthrate of about 26,000 babies New Mexico could have 78 babies born with hearing loss each year. (Approximate birthrate taken from Vital Statistics figures 2012)

Congenital hearing loss that is not detected within the first few months of life can significantly delay speech and language development.

Not all forms of hearing loss are expressed at birth and may be progressive or late onset.

Infants with hearing loss can be fitted with amplification as early as eight days of age.

Only half of babies born with hearing loss exhibit a risk factor. (American Speech and Hearing)

The first few months of life offer the critical “window of opportunity” for stimulating the neural pathways to the language processing areas of the brain necessary to help newborns, infants and children learn fundamental language, social, and cognitive skills.

Newborn hearing loss is 20 times more common than phenylketonuria (PKU) and is the number 1 birth condition in the U.S. (North Dakota Chapter of the American Academy of Pediatrics)

New Mexico EHDI program staff:

Tammy Voisine, LSW- NM EHDI Program Coordinator

Housed in Children’s Medical Services Newborn Screening Program in Santa Fe.

With grant monies from HRSA and CDC most of the work for Newborn Hearing Screening at the state level in New Mexico is performed by contractors:

Follow- up Coordinator- Suzanne Pope

Spanish speaking follow- up Coordinator- Sherry Burkart

Data Analyst- Mario Lucero

Needs Assessment – Connie Reynolds

EPICS- Rachael Sanchez

Hands and Voices- Marjorie Madsen Keilers

HRSA Grant

207,900.00- 23% less than last year

This grant pays the salary of the EHDI Coordinator, plus 1 full time follow up coordinator one part time contract for Spanish speaking follow up coordinator, EPICS and Hands and Voices contracts, travel, printing and supplies.

Goals of the HRSA Grant

Goal 1: Improve Access to diagnostic audiology services which are timely and meet standard of care.

Objective 1: Provide statewide training opportunities to audiologists through the Annual NMSHA Conference.

Objective 2: Participation in the NICHQ Learning Collaborative.

Objective 3: Obtain feedback from Audiologists on barriers and challenges.

Goal 2: Improve communication between the program, audiologist and the Medical Home.

Objective 1: Obtain feedback from stakeholders to determine challenges, barriers to be addressed.

Objective 2: Participate in the NICHQ Collaborative.

Goal 3: Provide culturally competent care to Native Americans families who have a child with hearing loss.

Objective 1: Work with Epics as the cultural broker to bridge communities

Objective 2: Deliver parent trainings on tribal locations on the importance of follow up after failure to pass hearing screen.

Objective 3: EPICS staff to attend annual EHDI meeting to increase knowledge base.

Goal 4: Implement a family to family support system for families who have a child with hearing loss.

Objective 1: Program will maintain affiliation with NM Hands and Voices.

Objective 2: Support Hands and Voices to expand their scope of work throughout the state.

Objective 3: Establish a Guide by Your Side program for New Mexico.

CDC Grant: 130,144.00

Goal 1: Develop and maintain the EHDI-IS to accurately identify, match and collect data that is unduplicated and individually identifiable through the EHDI process

Annual Objective 1.1: All new records will be assigned an unique identifier at entry in Challengersoft. The Challengersoft software engineer will create an automatic identifier. This will notify the person

entering data if a possible record duplication has occurred. But will still allow data manager to add additional information to an existing record.

Activity 2: All existing records will receive a unique identifier.

Activity 3: Data Manager will create a monthly report that will identify to the EHDl Coordinator birthing providers that have and have not reported.

Activity 4: Birthing Provider records will be linked to vital records quarterly and report provided quarterly by epidemiologist and report created indicating possible missing records.

Activity 5: This information will be used by the EHDl Coordinator to inform birthing providers and set quality improvement goals.

Activity 6: Needs assessor will help to contact any non complying providers in order to provide additional training, information or technical support.

Annual Objective 1. 2: Birthing Providers will report results of screening on all births.

Activity 1: Newborn Hearing Screening records will be compared to Newborn Genetic Records monthly.

Activity 2: Newborn Screen record received from hospitals will be compared to records from vital records quarterly.

Activity 3: Comparative analysis will be used to generate report to birthing providers for setting quality assurance measures and goals.

Activity 4: Needs Assessor and EHDl Coordinator will work with hospital providing technical assistance to improve reporting accuracy.

Annual Objective 1. 3: DOH with input from providers will develop a corrective action policy and plan to address ongoing non compliance issues for reporting from birthing providers or Audiologists that are consistently failing to report or providing inaccurate information.

Activity 1: Write rules for providers that clearly explain role and responsibilities for reporting screening and evaluation results.

Activity 2: Develop a corrective action plan.

Activity 3: Test and Evaluate process using PDSA Model

Annual Objective 1. 4: Develop an electronic management process and report in Challengesoft for providing information needed for follow up coordination.

Activity 1: Create report for follow up coordinator that identify the babies that did not pass final screening that can be provided weekly to follow up coordinator.

Activity 2: Create report to fax information to primary care provider officially notifying them of a baby in their practice that did not pass hearing screening and requesting follow up action.

Activity 3: Letter packet that includes family roadmap, reasons to follow up, instructions and list of audiologists will go to every family whose baby did not pass.

Activity 4: Using needs assessor evaluate work flow process and Challengersoft linkages.

Activity 5: Work with Challengersoft to create case management software unique to this process.

Goal 2: Collect and report individualized demographic data (as defined in HSF Annual survey) for every occurrent birth about the child's status and progress through the three components of the EHDI Process.

Annual Objective 2.1 By March 2014 submit 100% of requested data to the National CDC EHDI Hearing Screening and Follow- up Survey.

Activity 1: Data Manager and Epidemiologist will meet quarterly to link, analyze and review records from Vital statistics and those received directly from providers. Collecting information needed for annual survey.

Activity 2: Data manager will provider report to the EHDI coordinator and Challengersoft each quarter describing any missing information needed for accurate and timely EHDI Survey reporting.

Activity 3: Data Manager and Epidemiologist will complete annual survey.

Annual Objective 2.2 By June 30, 2014, develop and or implement a process for monitoring the quality and completeness of individualized demographic data (as defined by the HSF Survey) received from all reporting sources.

Activity 1: Collaborate with potential reporting sources to develop data collection and sharing agreements on individual unduplicated EHDI data.

Activity 2: Working with the Epidemiology Department develop an agreement for data sharing with Vital records for receiving all information needed for EHDI Survey and data analysis reports for Hospital and provider QA process.

Activity 3: Work with the Maternal Child Health Manager and Midwives association to develop policies and protocols for training Midwives and reporting.

Activity 4: renew data sharing agreement with the Genetics Program.

Activity 5: Renew data sharing agreement with Indian Health Services.

Activity 6: Evaluate and identify any addition areas of needs for accurately completing survey data.

Annual Objective 2.3 Review EHDl Data and collection process for 2012 (2011 data) and make changes needed for quality and completeness.

Activity 1: Data Manager, Epidemiologist, and EHDl Coordinator will evaluate current data collection processes with the survey results to identify any corrections needed to improve quality and completeness of the data. Develop a work plan to tackle this activity.

Activity 2: Challengesoft to install a software tickler system for notifying providers on a monthly basis to submit data.

Goal 3: Utilize findings from the analysis of the EHDl Data to guide the development and enhancement of EHDl-IS and educate stakeholders about the Programs successes, challenges and future opportunities.

Annual Objective 3: Convene an internal workgroup and external Advisory Council to achieve this goal.

Activity 1: EHDl Coordinator to convene an internal workgroup including the Medical Director, CMS Director, Data Manager, Epidemiologist, Screening Program Manager. Report on the website any new developments for stakeholders.

Activity 2: The EHDl Advisory Council will reconvene and meet quarterly. Advisory Council workgroups will meet as well. EHDl coordinator will report describing how the NM NHS Program is meeting goals based on the National Goals, Program Objectives and update Performance Measures for the EHDl Tracking and Surveillance Systems in an Annual Report to Stakeholders.

Goal 4: Strengthen EHDl –IS by developing and Implementing an evaluation plan and utilize findings to improve the system.

Annual Objective 4. 1 Improved reporting of data sets NHS, NGS, Vital Records and Part C.

Activity 1: Maternal Child Health Epidemiologist will review the quality of the data for accuracy of data entry and analysis quarterly.

Activity 2: Develop a new report to identify review the Challengesoft data to measure and set goals for improvement.

Activity 3: By report from Challengesoft all unscreened babies will be identified and referred for follow- up.

Activity 4: Follow –up Coordinator will receive a report from Challengesoft for all babies not currently followed by hospital programs and she will assist as needed with coordination of diagnostic evaluation.

Activity 5: Per agreement with NMSD Early Intervention Families that may have waiting period for evaluation and risk factor for hearing loss will be referred on a case by case basis to Part C.

