

Attachment 7 Summary Progress Report

Grant Number: H61MC00047

Project Title: UNIVERSAL NEWBORN HEARING SCREENING

Organization Name: Arizona Department of Health Services

Period covered: April 2011-March 2014

Abbreviations/Acronyms:

ADHS	Arizona Department of Health Services
ASDB	Arizona State Schools for the Deaf and the Blind (Part C of IDEA Provider)
EFAz	The EAR Foundation of Arizona
EHDI	Early Hearing Detection and Intervention
FBF	Fax Back Form
GBYS	Guide By Your Side (Parent to Parent through Az Hands & Voices)
HRC	High Risk Coordinator
NBS	Newborn Screening Program
OAE	Otoacoustic Emissions
OCSHCN	Office for Children with Special Health Care Needs
NICU	Neonatal Intensive Care Unit
PDSA	Plan, Do Study Act cycle

Goals

The project goal is to ensure that all infants born in Arizona are screened for hearing loss before one month of age, receive appropriate diagnostic evaluations before three months of age and are enrolled in appropriate early intervention services before six months of age. This grant proposed four objectives to be met over three years.

Objective 1

Maintain the percentage of those screened before one month of age at 97% and work to reduce overall loss to follow up at each stage of the process through implementation of best practices.

Measure the number of babies reported as screened by one month of age divided by the number of infants born according to vital records.

Birth Year	2008	2009	2010	2011	2012
% Screened	96%	97%	97%	98%	98%

*Preliminary data

Accomplishments

It is a significant accomplishment to maintain the high rate of screening. Arizona is one of the few states that have universal newborn screening without a legislative mandate and follow up efforts have been successful in ensuring that overall screening rate is 98% with approximately 2% screened after 1 month of age. Arizona has approximately 700 non-hospital births each year. AzEHDI efforts to ensure that non-hospital births also receive the opportunity to receive a newborn hearing screening have made progress. The EHDI team worked together with blood

spot screening program to provide in-services and site visits to 3 midwifery practices in the Northern Arizona region. The EAR Foundation of Arizona (EFAz) provided training on performing newborn hearing screening and loaned a piece of Otoacoustic Emissions (OAE) equipment to a group of midwives in Northern Arizona. Success has been noted through increased numbers of reported non hospital births.

The quality of screening programs is monitored monthly by the contracted audiologist and the data manager with technical assistance available as needed. Formal monitoring is shared with hospitals through the use of a quarterly scorecard. Each hospital is scored against best practice goals and the results are shared with screeners, program managers and hospital administrators. The scorecard is also used during site visits by the Arizona Perinatal Trust (a voluntary credentialing body) which does a formal evaluation of the Neonatal Intensive Care Unit (NICU) each year. The scores have improved from a state average of 71 points out of 100 possible in 2010 to 93 points out of 100 in the third quarter of 2013.

A priority identified by the stakeholders group is education, especially for providers. The Early Hearing Detection and Intervention (EHDI) team now has a part time consultant to help direct education efforts. The education team has worked on a comprehensive education plan which included the development of a pocket provider's guide and a packet of materials that covers both blood spot and hearing screening. The packet contains guidelines, parent materials and resources. Approximately 1500 combined packets and an additional 400 hearing only packets have been distributed. The education team has also provided site visits to 11 hospitals and clinics to promote best practices and hosted a regional EHDI meeting in Flagstaff. A statewide hearing screeners meeting was held in Phoenix in November 2012. This was an opportunity to ensure that best practices are promulgated and that hospital screeners and administrations have an opportunity to network.

The Audiology consultant worked with the Office for Children with Special Health Care Needs to provide the Newborn Hearing Screening Training Curriculum onto their eLearning Platform to monitor standardized training. Since 2012 more than 100 screeners have documented completion of the training and all but 5 hospitals have participated.

The newborn screening follow up supervisor worked with the follow up team to develop an internal learning collaborative to explore how to make follow up more effective. Since 2010 several PDSA cycles have been completed. One test of change that was implemented included adding an additional step to the current follow up protocol by faxing the hearing screening results to the medical home and then calling to ensure the fax was received. Follow up coordinators have enhanced information provided to parents by giving explicit instructions to parents about sleep deprivation and delayed feeding to obtain optimal outcomes for both screening and diagnostic appointments.

Another PDSA cycle of change added an additional step to the current follow up protocol by calling the medical home to provide hearing screening results and clear instructions about the need to schedule another hearing screen, if needed. A measurable impact on the outpatient return rate was documented. The follow up protocol has been revised to include an initial call with the primary care provider.

Hospitals are now updating the state web-based data management system with Primary Care Provider information instead of attending physicians on babies that refer (inpatient or outpatient), are missed or refused. This will improve the quality of data needed for follow up

Objective 2

Decrease the loss to follow up between the final screen and diagnostic evaluation by 25% through implementation of known best practices and identify new best practices through a Learning Collaborative

Measure the number of infants who have a diagnostic outcome divided by the number of babies who did not pass the final screen (as defined by CDC report)

Birth Year	2008	2009	2010	2011	2012
% Completed	27 % (293/1104)	36% (354/972)	35% (296/841)	42% (322/758)	*47% (396/837)
Total not passed	1104	972	841	758	*837

*preliminary data

Accomplishments

Although the loss to follow up did not meet the objective of 25%, improvements were significant with 20% (73% to 53%) from 2008 to 2012. The numbers have improved by 12% in the last two years which suggests that the implemented changes are working and have made an impact. The Office of Newborn Screening implemented a successful small test of change to improve communication and feedback from healthcare providers. The small test of change involved the development and use of a Fax Back Form (FBF). The FBF indicates the infant's most recent hearing results and requires that the healthcare provider review and return the FBF with specific information regarding where and when a hearing test or diagnostic evaluation will take place. From there, the follow up team tracks and confirms with parents and the hearing testing facility that the evaluation occurred and ensures that the hearing results are obtained in a timely manner. The FBF enables the NBS Follow Up team to identify at an early stage, those families not returning to their healthcare providers, so other mechanisms can be utilized to reach the family.

Hospitals have also received extensive training on updating the data management system with comprehensive information on the status of babies, and any other pertinent information for follow-up. The state web-based data management system has been enhanced with a Primary Care Providers (PCPs) drop-down list through the vital records link, enabling screeners to report the name of the PCP more accurately. Hospital screeners now report the PCP on record for all babies that refer on the inpatient and outpatient screens, improving the quality of data needed for follow up.

The Pediatric Audiology Guidelines have been completed, distributed and posted on several websites. The guidelines are based on published national guidelines, position statements and best practices and references state and federal laws applicable to pediatric audiology. Bi-monthly conference-calls take place with the Guide by Your Side Follow-Through Program to review progress made with cases referred to their program and to discuss next steps. Cases are referred to the GBYS parent coordinator via Secure Email. From there, the parent coordinator accesses Hi*Track, reviews cases, and contacts parent(s)/caregiver(s). Assistance with

scheduling, reminders and support to the family through the process is provided. Each month between 20-25 families are being contacted by a parent guide. The parent guides successful in closing 20 cases with a normal screen or diagnosis of hearing loss. The Arizona chapter of Hands & Voices (AZHV) has developed an Arizona specific Parent manual with the assistance of the EHDI coordinator and audiologists and early intervention professionals.

A priority identified by the stakeholders group is education, especially for providers. The Early Hearing Detection and Intervention (EHDI) team now has a part time consultant to help direct education efforts. An education plan was developed and executed. In-services were provided to 3 large medical home practices to provide continuing education on appropriate follow-up steps. The Newborn Screening Program exhibited at the following conferences:

- The Arizona Chapter of the American Academy of Pediatrics annual conference
- Medical Assistants annual meeting
- EAR Foundation Audiology annual seminar
- Arizona Perinatal Trust Annual Conference
- Mead Johnson Nurses Conference
- High Risk Perinatal conference Annual Conference
- Neonatal/Perinatal meeting

The Office of Newborn Screening: Early Hearing Detection and Intervention (EHDI), in an effort to be more efficient, has changed the system it uses to communicate health-related information to EHDI partners. A “Constant Contact” list has been developed to be used for newsletters, upcoming events and updates; it does not replace but enhances the person to person contact EHDI partners have come to expect. Interested parties and stakeholders who register for this email communication will be kept up to date on information that supports their efforts to improve the health of all Arizonans.

Objective 3

Focus follow-up efforts on those at greater risk to decrease the loss to follow-up for those infants who have a stay of >5 days in the NICU to 10% or less

The intent was to measure the number of children who have reported diagnostic testing divided by the number of babies that refer on a hearing screen during a stay of >5 days in the NICU. The data was not collected this way and so the actual data shows the number of children who received a diagnosis divided by the number who referred after their final screen rather than the screen during their inpatient stay.

Birth Year	2008	2009	2010	2011	2012
% dx from NICU	25% (88/355)	35% (102/293)	39% (87/244)	73% (115/157)	88% (111/126)

Accomplishments

For 2010, 39 % of infants with a stay of > 5days had a diagnostic evaluation. For 2011, the percentage of infants with a stay of > 5days receiving a diagnostic evaluation improved to 73% and 77% in 2012. The primary change has been in the number of children who refer from the screening process. Previous HRSA reports indicate outpatient screening for NICU babies as a barrier and it continues to be; although, many of the NICU babies did have their O/P screening completed by an audiologist. Vital records merge was consistent for 2012 which lead to better

identification of NICU Babies. As the procedures were refined by the current HRC, for all babies who referred on the I/P screening, a hospital discharge summary was obtained to identify length of NICU stay and risk factors for hearing loss. Properly identifying length of stay resulted in 24 babies in 2012 who were identified to be <5 days in the NICU and therefore did not receive f/u by the HRC as they would have in 2011. In 2012, 209 babies referred on their inpatient screening. Of those, 10 died, 1 moved out of state and 72 passed an outpatient screening. Of the 126 expected to receive a diagnostic evaluation, 111 babies had diagnostic evaluation completed.

The HRC improved the documentation of the # of children who are in the NICU for more than five days. The JCIH 2007 position statement recommends the referral to an audiologist for these high risk children. A significant improvement in these numbers has been demonstrated. However, the way that the data is collected makes it appear that only the denominator has been impacted. This is because that unless frequency specific and ear specific testing is done, it is considered a screen rather than a diagnostic test and if the child passes, follow up is complete. For example: in 2012 70 babies had an outpatient screen pass and did not receive an actual full evaluation but are still considered to have passed and not be in need of follow up.

The HRC has also been successful in tracking babies that were transferred to hospitals in bordering states and across the country and requests hearing screening results so that they are not lost to documentation. The HRC has worked to collaborate with the Medical Home Audiologists and ENTs to acquire hearing screening and diagnostic results to reduce the number of babies lost to documentation and loss to follow up.

Vital records merge was consistent for 2012 which lead to better identification of NICU Babies. As the procedures were refined by the current HRC, for all babies who referred on the I/P screening, a hospital discharge summary was obtained to identify length of NICU stay and risk factors for hearing loss.

The HRC is collaborating with Home Visiting programs in Yuma and Maricopa Counties to assist families in following up on diagnostic testing. The HRC has made 2 site visits to train home visiting nurses on hearing screening and diagnostic basics to help families they see on a regular basis get scheduled for diagnostic testing in a timely manner. The HRC has participated in the quarterly Strong Families Az (MIECHV) meetings to increase collaboration with Home Visiting programs around the state. The HRC presented at the annual Strong Families Az Conference. The HRC is also participating in the "Smooth Way Home" pilot program. This is a program that provides collaboration with NICU's, Part C and home visiting programs to help babies transition successfully from NICU's to home.

The HRC has worked with Guide By Your Side to help reach families that need further diagnostic testing. In addition, there has been collaboration with Part C programs through the Arizona Division of Developmental Disabilities to reach out to families that have been lost to follow up and make sure that their Individual Family Service Plan team is addressing the need for diagnostic testing. The HRC presented to the Division of Developmental Disabilities Supervisors in Maricopa and Pinal counties regarding ensuring the high risk infants they serve are receiving the proper diagnostic testing and follow up.

The HRC has completed a 10 week online graduate course through Gallaudet University

“Genetics and Hearing Loss for EHDI Professionals”. This provided the HRC with a greater understanding of hearing loss and the genetic components related to hearing loss. The HRC has attended 2 Neonatal/Perinatal conferences (Phoenix and Tucson) to network with NICU nurses and educate on the importance of newborn hearing screenings. The Newborn Screening program has developed a quarterly newsletter that is distributed electronically to hospitals, stakeholders and others. The EHDI Coordinator, Parents, American Academy of Pediatrics Chapter Champion and members of the state EHDI team regularly contribute to the newsletter. Information about the AZHV GBYS follow through program is also included in the newsletter.

A pocket guide was developed and distributed to 15,000 medical home professionals including pediatricians, family practice, physician assistants and medical assistants. This guide provided information on the EHDI process, modifications for those infants who have spent more than 5 days in the NICU and the risk factors for late onset and progressive hearing loss.

The NICU coordinator put together a Standard Operating Procedure (SOP) for Special Care and High-Risk Infants. The objectives of the SOP are to define Special Care and High-Risks infants, establish a tracking system for those infants and determine the follow up steps.

Objective 4

Decrease the number lost to documentation by increasing the number of providers submitting timely diagnostic reports

Measure the number of providers submitting diagnostic reports and the % that are submitted within one week of the diagnostic test.

Year	2009	2010	2011	2012	2013
# Dx ctr reporting	407 reports 32 providers	894 36 providers	1317 Reports 34 Providers	1477	1381
# non hosp. reported	41	33	18	27	38
% reported on time	70.98%	81.87%	79.49%	82%	79.43

Accomplishments

An increase in the numbers of reports (up 42% from 2010-2011) resulted in a slight decrease in the percent of on time reporting. 2012 showed another slight increase in numbers of diagnostic reports received and increase to 82% for on time reporting. Loss to documentation is being more aggressively addressed through the newborn screening program. All hospital inpatient and outpatient sites report electronically and routinely 96% report within the one week mandate. Education efforts have focused on those screening sites beyond the newborn period who are conducting OAE screenings on children two years and under. Reporting mandates and forms have been integrated into the standardized training curriculum developed for the 0-5 year old population through the EFAz. The training is used by:

- Early Head Start
- Community Health Centers
- Arizona Early Intervention Program
- First Things First screening programs
- Parents as Teachers Programs

Reporting of Diagnostic evaluations by Audiologists has also been a targeted effort. Two webinars were held to answer questions from audiologists about reporting requirements. Site visits have been conducted and more of the diagnostic reports are being submitted by the audiologist rather than coming through the pediatrician. The number of diagnostic reports have increased significantly and they are received more timely through the audiologist rather than the pediatrician. This is also less labor intensive for the follow up staff. The education consultant and quality manager have conducted paired message: hearing and bloodspot, site visits. Although this deviates from the original work plan, combined newborn hearing and blood spot screening approach has been effective and efficient for both the newborn screening staff time and the hospital staff who have been able to review both hearing and blood spot in one site visit. Site visits to audiology practices have focused on compliance with reporting.