

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.

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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.

I Project Narrative

Abbreviations/Acronyms:

| | |
|--------|---|
| ADHS | Arizona Department of Health Services |
| AEC | Arizona Early Hearing Detection and Intervention State Coordinator |
| AHCCCS | Arizona Health Care Cost Containment System (Medicaid) |
| ASDB | Arizona State Schools for the Deaf and the Blind (Part C provider) |
| AzEHDI | Arizona Early Hearing Detection and Intervention |
| AzEIP | Arizona Early Intervention Program (umbrella agency for Part C) |
| AZHV | Arizona Chapter of Hands & Voices |
| AC | Audiology Consultant |
| CDC | Centers for Disease Control and Prevention |
| CRS | Children's Rehabilitative Services (Audiology provider for Medicaid children) |
| DHH | Deaf and/or Hard of Hearing |
| EC | Education Consultant |
| EFAz | The EAR Foundation of Arizona |
| EHDI | Early Hearing Detection and Intervention |
| EI | Early Intervention |
| FBF | Fax Back Form |
| GBYS | Guide By Your Side |
| HFk | HEAR for Kids (loaner and permanent hearing aids through EFAz) |
| LC | Learning Collaborative |
| NBHS | Newborn Hearing Screening |
| NBS | Newborn Screening Program (hearing and bloodspot) |
| NECAP | National Early Childhood Assessment Project |
| NICU | Newborn Intensive Care Unit |
| NCHAM | National Center for Hearing Assessment and Management |
| NHSTC | Newborn Hearing Screening Training Curriculum |
| OCSHCN | Office for Children with Special Health Care Needs |
| ONBS | Office of Newborn Screening (ADHS) |
| PS | Project Specialist |
| PDSA | Plan Do Study Act Quality Improvement Cycle |
| QI | Quality Improvement |
| TI | Tele-Intervention |
| TIC | Tele-Intervention Coordinator |
| WIC | Women's Infants Children |

INTRODUCTION

With the funding requested in this grant proposal the Arizona Early Hearing Detection and Intervention (AzEHDI) program intends to use quality improvement strategies to reduce loss to follow up by 15% over three years and to meet the following aims:

- 1 Month** Maintain the percentage of those screened at 98% while maintaining the timeliness of completing the screening process by 1 month of age at 97%
- 3 Month** Increase the number of children who have a diagnosis by 15% (5% per year) from 49 to 64% and increase the % who have a diagnosis by three months of age from 60% to 75%
- 6 Month** Increase the % of diagnosed children who are enrolled in Early Intervention Services from 71% to 85% and of those 85% (currently 70%) will be enrolled by six months of age.

Arizona

Arizona is the sixth largest state in the nation, with a total area of 114,000 square miles, about 400 miles long and 310 miles wide. Seventy five percent of the population lives in urban areas, where the population density is 673 people per square mile. Twenty-three percent of Arizona residents live in rural areas, where the density is 44 people per square mile, and 2 percent lives in areas that are considered to be frontier, in which there are less than 3 people per square mile.

Population:

The number of births in Arizona peaked in 2007 at 102,687 births, and declined by approximately 20% over the last few years. The birth rate appears to be stabilizing and in 2012 there were 87,274 occurrent births (which is approximately 18% less than 2007). This impacts the Arizona Early Hearing Detection and Intervention (AzEHDI) program as funding for the Office of Newborn Screening (ONBS) is fee based related to the blood spot test and as the birthrate decreased the revenue generated also decreased. The costs of the program, however, have not decreased at the same rate, which has resulted in a budget deficit for the program.

During the past decade the proportion of Hispanic births increased but has declined in recent years. The proportion of the population which is Hispanic in Arizona is twice that of the nation. In addition to having a higher proportion of those of Hispanic heritage, Arizona's population also differs from the nation in that there is a smaller proportion of African Americans (4.5 percent compared to 13.1 percent nationally) and a higher proportion of Native Americans (5.3 percent compared to 1.2 percent in the nation) according to the 2010 Census.

Currently approximately 2% of births are to parents who do not reside in Arizona. Unlike many states that have children born from other states, most non-resident births in Arizona are to parents who live out of the country which is a particular challenge for follow up.

Language Spoken

Arizona residents are more likely to speak a language other than English at home (28 percent in Arizona compared to 20% nationally), and more likely to report speaking English "less than very well" (12% in Arizona compared to 9% nationally). Among Arizona residents who spoke a language other than English, 78 percent spoke Spanish, while the other 22 percent spoke one of many other languages.

Economy

Although Arizona is slowly recovering, the state was hit hard by the recent economic recession. Arizona has experienced high rates of home foreclosures, poverty, and households on Supplemental Nutrition Assistance Program. Unemployment rates climbed to 9.5% in February 2010, not long after achieving a historic low of 3.7% in July of 2007. At the same time, Arizona experienced substantial declines in state revenue. In state fiscal year 2009, Arizona had the largest decrease (42.5%) in income tax revenue in the nation. The result of this economic crisis was a budget deficit projection in Arizona for 2010 of \$5 billion dollars, representing 52% of the total general fund budget. This is the second largest proportional state budget deficit in the nation. In response to the economic conditions the Arizona legislature instituted broad fund sweeps (significantly impacting the Office of Newborn Screening) and overall budget cuts that impacted all state agencies. The state budgets for both the Arizona Department of Education and Arizona Department of Economic Security were reduced by 20 percent between state fiscal years 2008 and 2011. Examples of program cuts that affect the maternal-child population include:

- A cap on KidsCare enrollment (the state's S-CHIP program)
- Elimination of preschool for 4,328 children
- Reduction of TANF cash assistance grants for 38,500 low-income families
- Stopped accepting new families in its child care assistance program in February, 2009
- Suspended enrollment in Children's Rehabilitative Services for more than 4,000 children who are not enrolled in Arizona Health Care Cost Containment Services (AHCCCS)
- Reduced approximately 8,800 home visits to newborns discharged from the Neonatal Intensive Care Unit (NICU)

The Arizona Department of Health Services (ADHS), State Laboratory, ONBS is the fiscal agent for this grant. ADHS has the statutory authority and expertise in active follow up and health surveillance programs. The AzEHDI is made up of multiple state agencies and organizations as well as private providers. This collaboration is led by the AzEHDI Coordinator (AEC), Lylis Olsen, MS, MPH, CCC-A, who is responsible for the leadership and partnerships needed for the activities in this grant proposal. The AEC works through the EAR Foundation of Arizona (EFAz), a key partner in many of the AzEHDI initiatives.

Background- Newborn Screening

Healthy People 2010, Objective ENT-VSL-1 (formerly 28-11a) addresses the need to increase the proportion of newborns screened for hearing loss by age one month, have audiological evaluation by three months of age and are enrolled in appropriate intervention services by age six months of age. This objective supports the national "1-3-6" goal.

By 2000 all birthing hospitals had universal newborn hearing screening programs in place with more than 90% of all births screened for hearing loss prior to hospital discharge. In 2005 Statute §36-693 was passed that mandated the hearing screening follow-up program within the ADHS. The program is currently located at the State Laboratory as part of the ONBS which includes blood spot screenings for 28 disorders and mandatory reporting of hearing screening results. Funding is based on a fee collected for the first and second blood spot screens. Statute requires:

- Mandatory reporting of hearing results to ADHS
- ADHS to maintain a central database of newborns and infants who are tested for hearing

- Active tracking and follow-up of infants that fail the newborn screen to encourage the child's family to access evaluation services, specialty care and early intervention services
- Education for parents, professionals and the public
- Advisory board meeting at least annually

Most newborn screening is conducted in the hospital with the Joint Committee on Newborn Hearing 2007 guidelines providing the best practice standard. The majority of hospitals use an Automated Auditory Brainstem Response (AABR) for inpatient screen with a small number that use Otoacoustic Emissions (OAEs) for the first screen followed by AABR for those that fail the OAE. All newborns in the NICU for more than five days are screened with AABR only, due to the higher risk of auditory neuropathy in that population. Any agency, organization or individual that screens or performs a subsequent test on infants through age 2 is required to report the results. The ADHS has recently transitioned to a web-enabled database (HI*Track 4) and hospital screening programs submit data through a secure web portal.

Recent efforts have assisted in providing equipment, training and education to midwives to ensure that many of the out of hospital births are also screened. This has been a collaborative project between the ADHS and the EFAz. 38 non hospital providers are now reporting hearing screening. The AzEHDI program continues to work with hospitals to ensure quality screening in hearing screening programs, screening and refer rates are appropriate and policies and procedures to support screening and reporting are in place. The Centers for Disease Control and Prevention (CDC) cooperative agreement and State funding is used to contract with a consulting audiologist through EFAz, to provide the technical support to hospitals and midwives. Support includes training, site visits, assistance with data management and reporting, review of best practices and improving systems of care in hospitals involving multiple departments. The consulting audiologist is instrumental in the spread of best practices identified through previous Learning Collaboratives (LC). Best practices spread statewide include those that are thought to drive loss to follow up and delays in identification. These strategies have included:

- scripting the screener's message to parents,
- ascertaining the name of the infant's primary care provider,
- identifying a second point of contact for the family,
- making rescreening appointments for the infant at hospital discharge and
- telephone reminders for appointments
- faxing failed hearing screening results to the primary care provider

Arizona implemented a screening scorecard that gives birthing hospitals a quarterly "score" based on the following quality indicators:

- Screening rate compared to vital records
- Refer rate
- Number of babies not screened
- Reporting within one week as required by statute
- % of infants returning for an outpatient screen or diagnostic evaluation
- Reporting of mother's name and date of birth to facilitate record matching
- Participation of hospital screeners in use of the NHSTC

Issuing the scorecard resulted in a rapid and dramatic shift over the first quarter and continues to show improvement. The most significant impact of the scorecard was a better compliance in regards to timely submission of hearing results and providing mother's name and date of birth. The percentage of hearing results submitted timely went from 68% during the last quarter of 2009 up to 83% during the second quarter of 2010. During that same time period, the percentage of records containing mom's name and date of birth went from 73% up to 91%. Receiving hearing results on time, and being able to match records for transferred babies improve follow up activities by reducing delays to identify and locate infants who need further testing. In addition, subsequent to the release of the quarterly scorecard, hospitals are offered assistance to help improve their ratings in each of the areas. Site visits occur to address each area specifically. Different strategies are recommended depending on the quality indicator.

In order to maintain quality screening programs, use of the Newborn Hearing Screening Training Curriculum (NHSTC) is recommended for training all new screeners. 100% of the hospitals have used the NHSTC and continue to train with it. Site visits are provided to demonstrate the train the trainer approach using the NHSTC and incorporating hands-on competency based training.

In addition to quality training, providing ongoing technical assistance is integral to maintaining program quality and ensuring that screening, tracking and reporting issues are quickly addressed. Weekly data is monitored to identify potential technical breakdowns and training needs, (i.e. screening equipment or H*Track program or computer issues), reporting gaps due to staffing changes, etc. Refer rates and outpatient return rates are monitored and hospitals are contacted if spikes or changes are observed. Once a problem is identified, hospitals are contacted and strategies for improvement are recommended based on the hospitals specific program characteristics, for example average length of stay, population they are serving (well baby versus NICU), type of equipment, number of screeners, and hospital logistics.

The ADHS Newborn Screening Program provides tracking and follow-up for any child who is reported as missing the newborn hearing screening or who fails the hearing screening. Follow-up is based on the goals of 1-3-6.

Current follow up protocol for well babies (those who have not stayed in the NICU > 5 days) starts at 30 days of age allowing families to return to the birth hospital for their outpatient appointment. Initial follow up consists of locating primary care physician and verifying that the baby is established as a patient. From there, a Fax Back Form (FBF) is faxed to the Primary Care Physician (PCP) notifying them of screening results and asking where and when the baby will be referred for the outpatient screening. In addition, a letter is sent to the parents. Both the FBF and the parent-letters provide the link to EHDI-PALS (an online referral source for pediatric audiology services), enabling PCP and families to find resources locally. FBF are customized and reflect special circumstances such as cranio-facial anomalies.

Ongoing follow up calls with PCP and families are made until the case is resolved. The purpose of these calls is to find out the date and location where hearing testing will be done and to make sure that baby will be referred to a pediatric audiologist or appropriate specialist such as Otolaryngology or Ear Nose and Throat (ENT) physicians, if necessary.

Cases where the family did not return for further testing are reviewed and investigated by the team leader. The team leader will make sure that all options to reach family and PCP have been exhausted before closing the case as lost to follow up. The team leader will also take note of trends, and provide guidance to improve communications and follow up protocols for better turnaround time, and reduced loss to follow up.

ADHS has started a project with the Women's Infant's Children's (WIC) program to determine if the NBS program can leverage the WIC clinics to find infants in need of follow up. Preliminary data suggests that as many as 40% of those children, who are currently lost to follow up, may be enrolled in the WIC program.

Background-Beyond Newborn Screening

AzEHDI through the EAR Foundation of Arizona (EFAz) with funding from the Maternal and Child Health Bureau Block grant and the Office for Children with Special Health Care Needs (OCSHCN) has been involved in establishing screening programs beyond the newborn period with various community partners. Projects included:

- Community Health Centers
- Early Head Start/Head Start
- Arizona Early Intervention Program
- Pediatric Practices
- Home Visiting Programs
- Physician practices

In November 2006 Arizona voters passed Proposition 203; a citizen's initiative that funds quality early childhood development and health. The Proposition created a new state level board known as the Arizona Early Childhood Development & Health Board. The Board subsequently adopted the name First Things First (FTF). Regional councils determine the use of available funds. One of the priorities of some of the FTF regional councils is the need for additional hearing screening in early childhood populations around the state. The EFAz has worked with FTF to develop a tool kit and is working with them to ensure quality training, appropriate screening methodology and reporting. EFAz provides loaner equipment and has developed a training curriculum specific to early childhood screening. EFAz also has two FTF grants to provide early childhood hearing and vision screening throughout most of Central and North Phoenix.

Background-Diagnosis of Hearing Loss

Most pediatric diagnostic testing is done at one of six sites in the state. Two children's hospitals in Phoenix and one otology office have the staffing and equipment to do both sedated and unsedated Auditory Brainstem Response (ABR) testing for the Phoenix metropolitan area. A small number of infants are tested at sites that only have unsedated capability. These sites see a very small number of infants and routinely refer to one of the larger centers if hearing loss is not ruled out. Two hospitals in Tucson do the majority of the diagnostic testing for southern Arizona and one hospital in Flagstaff does the testing for northern Arizona. The University of Arizona and a team of stakeholders from Yuma are in the early stages of developing an audiology telemedicine project to address these needs. Funding for these efforts is being pursued outside this grant.

Pediatric audiology guidelines are in place. 21 audiologists, with the assistance of the AzEHDI program, have participated in the National Center for Hearing Assessment and Management's (NCHAM) audiology training program over several years with a large number completing the training this past year when it was offered locally.

Audiologists are required to report all screening and diagnostic testing through two years of age. All diagnostic reports are reviewed by an audiologist and entered into the HI*Track database. There are a small number of audiologists who work in hospitals and are able to enter the data themselves on the babies born in their hospitals. An audiologist consultant with the state monitors and reviews the data entered.

Background-Early Intervention

Early Intervention (Part C of the Individuals with Disabilities Education Act (IDEA)) is provided through the Arizona Early Intervention Program (AzEIP). The Arizona State Schools for the Deaf and the Blind (ASDB) is a partner agency with AzEIP and provides Early Intervention (EI) services to children who are Deaf or Hard of Hearing (DHH). Services are provided under a program called Parent Outreach. Parent Outreach consists of family-centered services delivered through home visits by interventionists. The majority of those providing services to the families of children who are DHH are highly qualified in the area of Deaf Education.

Services are provided statewide by ASDB. In addition, Desert Voices provides EI services through their birth-to-three service program. Desert Voices is a non-profit organization providing oral communication training. All families who are enrolled in the Desert Voices program are also enrolled in the state Parent Outreach Program. Eligibility for Early Intervention services is based on a bilateral permanent hearing loss of any degree. At this time, children with unilateral losses do not receive statewide services, although in some parts of the state the program will provide a one-time home visit to educate and support families.

Data on EI services are collected through a statewide web-based database. This database is populated by ASDB and maintained by AzEIP. AzEIP recently transitioned to a new database that is used by all of the early intervention agencies.

Arizona participated in a pilot project called the National Early Childhood Assessment Project (NECAP) to collect standardized data on speech and language for children who are DHH. This project has moved into full implementation. One component of the program is a contract with the University of Colorado to score and analyze assessments to provide both a data-driven approach and to contribute to a nationwide database. This allows the AzEHDI program to have access to outcome data from the entire AzEHDI process. Analyzing this data against other program components determines if the systems are making a difference for children's development. The cost of participation is a shared cost between OCSHCN and ASDB.

The Phoenix metropolitan area has both the largest and the fastest growing population in the state. The population growth and the earlier identification of children who are DHH have challenged the ability of the early intervention program to continue to provide quality services. Not only has the federal funding through Part C of IDEA not increased, Arizona cut state funding considerably.

The individual infants enrolled in Early Intervention (EI) are compared to those reported to the state with bilateral permanent hearing loss to determine level of compliance with the reporting mandate and to ensure that all eligible children are referred for early EI.

Follow-up cases are not closed until diagnostic results are reviewed by the consulting audiologist. If an infant has a preliminary diagnosis of bilateral permanent childhood hearing loss, the follow-up team will work with the audiologist, the doctor and the family until the diagnosis is confirmed to the point that the child will qualify for enrollment in Early Intervention Services. In Arizona a child with unilateral or transient conductive loss does not qualify for Early Intervention Services.

The EAR Foundation of Arizona (EFAz) has a statewide HEAR for Kids (HFK) program, managed by one of the same audiologists providing consulting audiology services to the state AzEHDI program. The HFK program provides high-end digital hearing aids to any infant or child who is newly identified in Arizona with hearing loss, regardless of income. Generally, the loan of the hearing aid is for six months; extensions are granted if a family encounters financial difficulties, the child has a progressive loss or is a potential candidate for cochlear implantation. More than 200 hearing aids are available for loan (loaner pool), and if the pediatric audiologist requests an aid not currently available, the HFK program will purchase new hearing aids. HFK purchases between 30 and 50 new aids each year to maintain the supply of current technology. This program also provides vouchers for newborn hearing screening and both sedated and unsedated diagnostic testing if the family qualifies financially and either does not have insurance or has a high deductible plan. If a family does not have insurance or has insurance that does not cover hearing aids and they cannot afford to purchase hearing aids, the HFK program will purchase permanent hearing aids for the child. The HFK program purchases between 120-150 hearing aids each year for children of all ages. The audiologist chooses the aids most appropriate for the child. Due to private funding, the program is flexible with the criteria and occasionally purchases hearing aids for families who would not otherwise qualify if there are extenuating circumstances such as multiple family members in need of hearing aids or unusual financial circumstances (death, divorce or high medical bills). EFAz also funds repairs, parts and mapping for children with existing cochlear implants that are in financial need. In Arizona, more than half of the children who are Deaf or Hard of Hearing receive their permanent hearing aids through the Children's Rehabilitative Services (CRS). The loaner pool allows the diagnosing audiologist to fit loaner hearing aids, avoiding delays while the family qualifies for CRS services. Because there is no financial criterion for the loaners, the HFK program also allows immediate fitting of hearing aids for families who must meet insurance deductibles, pay out-of-pocket, or obtain pre-authorization.

The national Hands & Voices parent organization has an active chapter in Arizona. Partnering with the EFAz HEAR for Kids program has allowed notification of events and information to be shared with more than 800 families. The Arizona Chapter of Hands & Voices (AZHV) provides parent representation on learning collaborative teams and their toll-free contact number is listed on the Family Checklist distributed at the outpatient screening appointment to those infants referred for diagnostic evaluation. A representative of AZHV is on the AzEHDI stakeholders committee and AZHV.

The AZHV Guide By Your Side (GBYS) program typically pairs a trained parent guide with the family of a child who has been newly identified as DHH. There are 7 trained parent guides including one bilingual and one fluent in American Sign Language.

Despite the successes, it is readily apparent that there is considerable work to be done to ensure that children who do not pass the newborn hearing screening receive appropriate and timely diagnosis as well as linkages to early intervention services. In the following **Needs Assessment** section an overview of the qualitative and quantitative data that describes the current status of the AzEHDI program, the partners in AzEHDI as well as the needs identified for each program component will be discussed.

2 NEEDS ASSESSMENT

1 Month Screening Aims

Maintain the percentage of those screened at 98% while maintaining the timeliness of completing the screening process by 1 month of age at 97%

CDC Screening Data

| 2007 | 2008 | 2009 | 2010 | 2011 | 2012 |
|---|----------------|----------------|----------------|----------------|----------------|
| Total Occurent Births | | | | | |
| 104516 | 100088 | 93331 | 88100 | 86668 | 87292 |
| Total Screened (%) | | | | | |
| 98853 (95%) | 97886 (98%) | 91881 (98%) | 86679 (98%) | 84656 (98%) | 86033 (98%) |
| Total Passed by 1 mo (%) | | | | | |
| | 86783 88% | 90909 99% | 85809 99% | 82472 97% | 83874 97% |
| Total Passed between 1 mo and 3 mo | | | | | |
| 2359 | 1420 | 1256 | 1020 | 1098 | 1087 |
| Total Not Passed | | | | | |
| 1415 | 1104 | 972 | 870 | 820 | 837 |
| Not pass IP and NO OP Screen | | | | | |
| | | 588 | 389 | 311 | 231 |

Historical Arizona data, as reported to the Centers for Disease Control and Prevention (CDC), is presented on the left. It is clear from this data that Arizona has an excellent record of voluntary screening with a 98% screen rate with 99% of those completing the screening process by one month of age. The effectiveness of follow up is shown in the decrease in the number of children who pass after one month of age and the steady decrease in the number of children who overall do not pass the screening process.

The challenge over the next three years will be maintaining these gains in the face of known and unanticipated economic, political and other changes.

1. NEED TO REDUCE THE TIME TO COMPLETION OF THE SCREENING

Although not reflected in 2012 CDC data, recent events have shown that there has been a significant increase in the time to second screen at some hospitals. A focused look at three hospitals showed delayed outpatient screening in two of the three birthing hospitals.

| | 2012 3 rd Qtr average days IP to OP | 2013 3 rd Qtr Average Days IP to OP |
|------------|--|--|
| Hospital A | 26 | 34 |
| Hospital B | 19 | 38 |
| Hospital C | 30 | 14 |

Both hospitals A and B screening programs were acquired through a merger of two hearing screening outsourcing companies. Additional data is needed on each of the hospitals to determine what is causing the delays, how the delays might be addressed and what strategies Hospital C is using.

2. NEED TO SPREAD AND INSTITUTIONALIZE SCREENING BEST PRACTICES

The AzEHDI program continues to work with hospitals to ensure that quality screening is hearing screening programs, screening and refer rates are appropriate and policies and procedures to support screening and reporting are in place. Best practices spread statewide also include those that are thought to drive loss to follow up and delays in identification. These continue to be a need for both hospital and out of hospital screening programs and will be included in this grant cycle as well. These strategies have included:

- scripting the screener’s message to parents,
- ascertaining the name of the infant’s primary care provider,
- identifying a second point of contact for the family,
- making rescreening appointments for the infant at hospital discharge and
- telephone reminders for appointments
- faxing failed hearing screening results to the primary care provider
- new strategies to be determined

There is a need to institutionalize the use of these strategies and provide additional tools to both educators and hospitals trying to make these changes. This area will be targeted both through *Education and a Learning Collaborative Team* as described in the Methodology section of this proposal.

3 Month Diagnostic Aims

Increase the number of children who have a diagnosis by 15% (5% per year) from 49% to 64% and increase the % who have a diagnosis by three months of age from 60 to 75%

CDC Diagnostic Data

| 2007 | 2008 | 2009 | 2010 | 2011 | 2012 |
|--|------|------|------|------|------|
| Total Passed Screen | | | | | |
| 1415 | 1104 | 972 | 870 | 820 | 837 |
| Total Normal Hearing Diagnosis (%) | | | | | |
| 149 | 155 | 239 | 178 | 174 | 244 |
| Normal Diagnosis Before 3 mos | | | | | |
| 56 | 65 | 120 | 101 | 96 | 155 |
| Normal Diagnosis between 3 mo and 6 mo | | | | | |
| 22 | 21 | 74 | 40 | 5 | 55 |
| Total Hearing Loss Diagnosis | | | | | |
| 142 | 138 | 115 | 146 | 151 | 148 |
| Hearing Loss Diagnosis before 3 mo | | | | | |
| 83 | 71 | 66 | 63 | 82 | 91 |
| Diagnosis between 3 mo and 6 mo | | | | | |
| 29 | 32 | 30 | 41 | 33 | 35 |
| Total No Diagnosis | | | | | |
| | | | | 495 | 445 |

Historical data, as reported to the CDC, is presented on the left. The data shows that some incremental progress has been made in both improving the number of children who receive diagnostic testing and improving the timeliness of the testing.

It is this area that is the primary focus of the next three years for quality improvement. The strategies delineated in the methodology section describe how quality improvement measures will target many of the identified drivers of loss to follow up and delays in the diagnostic process. Additional real time data is described below to illustrate need in specific areas as well.

3. NEED TO COORDINATE FOLLOW UP EFFORTS BETWEEN ADHS AND SCREENING PROGRAMS

The majority of infants are screened by one company that provides outsourced screening services. This company provides considerable follow up services but both the company administrators and ADHS follow up team believe that their efforts could be better coordinated. It is often found that follow up efforts are duplicated or that one group has information that isn't available to the other that is critical to follow up efforts. It is anticipated that coordination of follow up efforts focused on improved documentation and improved communication strategies would result in improved loss to follow up. Preliminary discussions have resulted in a commitment to develop a *Learning Collaborative* Team approach to address these issues.

4. NEED TO IMPROVE AWARENESS, KNOWLEDGE AND RESPONSIVENESS OF PHYSICIANS

The physician survey completed by the National Center for Hearing Assessment and Management provided some insight into the knowledge and practices of physicians in Arizona. Only 10% of physicians surveyed responded so the results may not be representative of the whole but these results are interesting. Those responding indicated that they all have fair to complete trust in the newborn screening results and ~2/3 are aware that they have occasional to frequent communication with the state EHDI program. Fortunately more than 93% would refer to an audiologist if a parent had concerns about her child's hearing. The following chart shows the responses to the question "What is your best estimate of the earliest age at which":

| | <1 mo | 1-3 mo | 4-6 mo | 7-9 mo | 10-12 mo | >12 mo |
|---|-------|--------|--------|--------|----------|--------|
| A newborn not passing the hearing screening should receive additional testing | 56.5% | 39.2% | 2.9% | 1.4% | 0.0% | 0.0% |
| A child can be definitively diagnosed as having a permanent hearing loss | 24.2% | 38.7% | 17.7% | 1.7% | 12.9% | 4.8% |
| A child can begin wearing hearing aids | 12.9% | 29.0% | 25.8% | 3.3% | 17.7% | 11.3% |
| A child with permanent hearing loss should be referred to early intervention services | 34.8% | 24.3% | 25.7% | 6.1% | 4.6% | 4.5% |

More than 90% knew to refer to an ENT/Audiology but only 12.7% would refer to Genetics and only 1.4% would refer to Ophthalmology. Half reported that their training did not adequately prepare them to meet the needs of infants with permanent hearing loss. A summary of the survey is attached in Attachment 6.

The ADHS follow up team contacts the medical home practice to ensure appropriate and timely referrals are made for audiological evaluation. The follow up team has found that many referrals are made to Ear Nose and Throat doctors whose focus is on evaluating middle ear status and not ruling out underlying sensorineural or permanent conductive hearing loss. These cases are difficult for the follow up coordinators to deal with as the primary care practice is deferring to the medical specialist and the medical specialist may not be following best practice guidelines to

evaluate hearing status. There is a need to quantify the number of cases and work to change practice patterns to include hearing evaluation along with addressing medical issues. *The multifaceted approach to physician education and practices will be discussed further in the methodology section.*

5. NEED TO IMPROVE AUDIOLOGY PRACTICES RELATED TO REPORTING, TIME TO COMPLETION OF EVALUATION AND BEST PRACTICES

Only 44% of those identified with hearing loss in 2012 received a diagnostic evaluation before three months of age. Although considerable progress has been made in improving audiology practices there is still a need for improvement in the areas of

- Timely and complete reporting
- Timely Completion of evaluation

Preliminary data shows that some of those providers that identify themselves as providing services to this population have not submitted data to ADHS. Even one large provider that thinks that they are 100% compliant with the requirements has been shown to only submit within the 7 day timeframe 70% of the time. It is believed that improved compliance with reporting requirements will improve the efficiency of the follow up staff to focus on those children truly lost to follow up. *The methodology section will include a discussion of those strategies that will be used to improve reporting, quality and timeliness.*

6 Month Early Intervention Aims:

Increase the % of diagnosed children who are enrolled in Early Intervention Services from 71% to 85% and of those 85% (currently 70%) will be enrolled by six months of age.

CDC Early Intervention Data

| 2007 | 2008 | 2009 | 2010 | 2011 | 2012 |
|---|------|------|------|------|------|
| Cases of Hearing Loss | | | | | |
| 142 | 138 | 115 | 146 | 151 | 148 |
| Bilateral Losses | | | | | |
| 86 | 79 | 66 | 83 | 86 | 92 |
| Enrolled in EI | | | | | |
| 83 | 79 | 66 | 46 | 61 | n/a |
| Enrolled in EI before 6 mo | | | | | |
| 60 | 53 | 45 | 35 | 43 | n/a |
| Enrolled in EI between 6 mo and 1 year | | | | | |
| 17 | 14 | 12 | 11 | 14 | n/a |

Only those children who have bilateral permanent loss are eligible for early intervention services in Arizona. Data for 2012 won't be available until January 2014. ADHS and AzeIP are working on making data available in real time.

Timely enrollment in Early Intervention is the one area where Arizona has not only shown no improvement but the data shows that enrollment both in numbers and timeliness have declined significantly. Some of these may be due to a loss to documentation as they moved toward private pay providers when state services to families were no longer available at no cost.

6 NEED TO ENSURE FAMILY SUPPORT IS AVAILABLE TO FAMILIES WHEN THEY ARE MOST INTERESTED AND IN NEED

Arizona is committed to providing parent to parent support services but has, thus far, not been successful in integrating parent support with the AzeHDI program in a way that is effective for parents. GBYS is a family support program that embodies the mission of the Arizona AZHV which is to provide unbiased support to families with children who are DHH. GBYS does this through specially trained parents of children who are DHH who work as guides. In the past three years trained parent guides were paired with birthing hospitals to provide follow-up services to infants who either do not pass the newborn inpatient screen or in some programs; those do not pass the inpatient and outpatient screen. The number of successfully closed cases was only 20 in the past year. Both parents and hospital programs have expressed that parent to parent support during the screening process may not be the best timing for support and that connecting parents either during the diagnostic process or post diagnosis would be a better use of resources. The parent guides, hospital screening leaders and ADHS are committed to using small tests of change to determine how to best implement parent support. The Methodology section will discuss further using the *Learning Collaborative model*.

7. NEED TO ENSURE FAMILIES RECEIVE EARLY INTERVENTION SERVICES

The parent cost participation model was implemented to reduce costs to the state. Unfortunately this shift in costs has resulted in higher numbers of families who refuse or reduce the amount of early intervention services (for example Physical Therapy only rather than PT and Speech). Contributing factors include: moving to a team based model of service where providers are spending more time in meetings and less time in direct services, a lack of highly qualified providers in some parts of the state and other barriers such as weather, distance, illness and cancellations. The amount of actual early intervention service the average family receives has significantly decreased over the past three years. The EHDI stakeholders along with ASDB, AzeIP, the EFAz and the OCSHCN are actively working on both quantifying the results through the NECAP and addressing the drivers that can be addressed. One of the drivers is a lack of perceived value in early intervention due to costs and another is the availability of services from highly qualified providers. There is a need to provide free assessments for families to be informed about their decision making based on how their child is progressing. A copy of the most recent summary of Arizona Specific NECAP data is included in Attachment 8. *The NECAP and Tele-Intervention programs target to address these needs are described in the Methodology section.*

METHODOLOGY

1 Month Screening Aims:

Maintain the percentage of those screened at 98% while maintaining the timeliness of completing the screening process by 1 month of age at 97%.

REDUCE THE TIME TO COMPLETION OF THE SCREENING

Strategy 1-Pediatric Learning Collaborative Team

A Learning Collaborative (LC) team is proposed to address the amount of time between the initial inpatient screen and the second outpatient screen for those infants who are well babies (those spending five or more days in the neonatal intensive care unit are referred directly to diagnostic testing without an outpatient screen. This collaborative will focus on the hospitals

that have contracted to outsource their screening programs. A letter of collaboration is included in *Attachment Two from Pediatrix*, the outsourcing company. Preliminary data on two Pediatrix hospitals can be found in the needs assessment. Prior to initiating the project real time data for the rest of the Pediatrix hospitals from HI*Track will be analyzed. The data will determine which of the hospitals will be targeted first. The Learning Collaborative team will consist of:

- EHDI Coordinator for first PDSA cycle then as needed
- Pediatrix Coordinator
- Pediatrix Screener
- ADHS Follow up Team Representative
- Audiology Hospital Liaison Consultant
- Parent
- AAP Chapter Champion as needed

The LC team will begin to meet in April 2014 to fine tune the specific aim of the team, decide what changes they will test first and how to proceed. The EHDI Coordinator will meet with them to provide support for using this model of change and ensure progress is being made. ADHS will be responsible for collecting data on outcomes (time elapsed between inpatient and outpatient screen and communicating back to the team. It is anticipated that this LC will quickly move from testing to spread as the participants are already engaged, feel that they have a good idea what strategies will be successful (scheduling OP screen prior to discharge and phone calls to remind parents) and are eager to move forward. These strategies have a high likelihood of success. The model will be followed by trying the changes, collecting and analyzing the data, modifying as needed and implementing the changes. Spread with this team is also easier to accomplish as policies and procedures are standardized across the contracted hospitals with Pediatrix. Spread is also anticipated beyond Arizona as Pediatrix is a national company that is motivated and committed to improvement.

The ADHS team has begun a new strategy in collaboration with the WIC program. Preliminary comparison data for an area showed that 40% of those children who were in need of follow up were also enrolled in the WIC program. One of the strategies will be to complete the Plan Do Study Act (PDSA) process with the aim of leveraging the WIC visits to improve loss to follow up numbers. Additional data needs to be collected, the specific aims developed and a team established to pursue this potential collaboration. See *attachment 9* which contains a summary of this PDSA.

SPREAD AND INSTITUTIONALIZE SCREENING BEST PRACTICES

Strategy 2 Learning Collaborative Team and Education

It is anticipated that the same team will also be used in Strategy two to spread and institutionalize best practices following the same PDSA cycles. The initial time to OP screen will occur first but should be completed within the first 6-9 months of the first year of the grant. It is the intent of this proposal that this team continue throughout the grant to work on best practices in the hospital and out of hospital screening programs. The team will be responsible for developing specific aims related to decreasing loss to follow up both during the inpatient to outpatient screening process but also from screening to diagnostic evaluation. The specific aims will drive the data that is collected and analyzed and how the team will proceed.

Previous LCs have determined many of the best practices in screening programs including:

- scripting the screener's message to parents,
- ascertaining the name of the infant's primary care provider,
- identifying a second point of contact for the family,
- making rescreening appointments for the infant at hospital discharge and
- telephone reminders for appointments
- new strategies to be determined

For these strategies the focus is on both education to ensure that the strategies have been implemented and in developing tools to allow those that are conducting site visits to ensure that these strategies have been embedded in policies, procedure and practices at the screening hospitals. The Arizona Perinatal Trust (APT) is a voluntary organization that provides certification for birthing hospitals. This program has been a powerful collaborator in moving best practices since newborn hearing screening began in Arizona. The site visit team meets every other year with hospital leadership in a formal certification process. The ONBS team provides scorecard data to the APT team to drive best practices. This project proposes development and implementation of checklist and educational materials that can be used by both APT, the education team, the quarterly newsletter and screening meetings that can be used continue to spread and ensure continued compliance with best practices. Spreading best practices in some hospitals may require use of the PDSA methodology with the hospital.

3 Month Diagnostic Aims

Increase the number of children who have a diagnosis by 15% (5% per year) from 49% to 64% and increase the % who have a diagnosis by three months of age from 60% to 75%

COORDINATE FOLLOW UP EFFORTS

Strategy 3

The ONBS follow up team has been the most successful of the past LC Teams. They have experience with the methodology and will to continue with the internal team consisting of:

- Project Specialist
- Hearing Follow up Team Lead
- Follow up Coordinators
- Follow up Supervisor

The team will be joined by the Audiology consultants, parents, data specialist, epidemiologist and the chapter champion as needed. This team will continue to meet and work through PDSA cycles to fine tune the follow up process. Progress towards both reducing loss to follow up and delays has been made by changing the timing of follow up intervention, methods of communicating with the medical home and specific instructions given to the parents. The team meets bi-weekly and a portion of that meeting will focus on the current PDSA.

The second aspect of this strategy is to include the hospital screening programs to coordinate the follow up efforts. Independent hospitals and those contacting with Pediatrix have their own methods of follow up. The follow up team has determined that efforts are not as efficient if there is not coordination, adequate documentation and information sharing at each point of contact with parents and the medical home. Pediatrix and the follow up team have agreed to work together to determine the most effective sharing of information and coordination of efforts.

Some improvements will be changes in policies and practices but some may best be accomplished through the small test of change PDSA model. The Project Specialist (PS) will be the lead on these efforts with the support of the AzEHDI Coordinator. It is anticipated that this strategy will require several in person meetings and weekly phone calls until the changes are tested and implemented system wide. Data elements to track will be determined by the team.

IMPROVE AWARENESS, KNOWLEDGE AND RESPONSIVENESS OF PHYSICIANS

Strategy 4

The follow up team, along with the consulting audiologists, have met and are working through the aims for a PDSA related to providing the medical home with specific instructions by the audiologist. The follow up coordinators feel that they often are not able to get through to the physician and are not perceived as having the authority or expertise necessary to instruct the pediatrician or physician about next steps. This is especially the case when the physician has already referred to an ENT and the ENT is only addressing the middle ear conditions and not making progress on determining the presence or absence of a permanent hearing loss. One of the consulting audiologists is also in clinical practice and works one day a week at DHS to review diagnostic reports. This audiologist will work with ADHS follow up team on a specific PDSA to determine if involving a doctoral level audiologist to communicate with the medical home is feasible, how much time is involved, if the audiologist is able to speak directly with the physician and if the outcomes change with those cases where the audiologist is able to connect. Real time data from HI*Track will be used as well as fax logs.

The other strategy for this area of need is education. The education team is lead by a consultant who has high level experience with public health policy, education and quality improvement. This team has been responsible for developing a paired message with blood spot screening and has developed several marketing and educational materials for use with pediatricians. This team will continue to work closely with the American Academy of Pediatrics (AAP) Chapter champion and parents on ways to increase the awareness and knowledge base of physicians, particularly large pediatric practices.

IMPROVE AUDIOLOGY PRACTICES RELATED TO REPORTING, TIME TO COMPLETION OF EVALUATION AND BEST PRACTICES

Strategy 5

The ONBS along with the audiology consultant and the AzEHDI Coordinator are working on improving audiology practices. The first target is reporting compliance. By April 1 2014 an individualized report will be ready to share with audiologists. This report will serve a similar purpose as the screening scorecard as described in the introduction. The first iteration of the audiology report specifically addresses timeliness and completeness of reporting. Data has been collected through a fax log and is currently being finalized to show each audiologist (that self reports through EHDI PALS as providing services to the birth to three population) the following information:

- # of reports submitted
- How many of those reports were submitted within 7 days as required by statute and rule
- How many of those reports were submitted as a result of a request by ADHS after the 7 day benchmark
- How many reports were received through a 3rd party such as the medical home

As has been shown through the hospital screening report card, sharing information with audiologist and organizational administration, as well as providing technical assistance, results in positive change. The collection and analysis of the data will also provide information that will lead to targeted education and enforcement of reporting requirements. The approach that the team prefers is to provide information, education and support. Quality improvement techniques will be used as determined to be appropriate. Addressing compliance through licensure is a final resort approach only if the individual or facility is unwilling to comply.

The reporting is the first step in this strategy. It is anticipated that through the three years of the grant cycle that this audiology report will evolve to include measures of quality of assessment. Those areas which have been discussed for potential inclusion are:

- Reporting
- Time from initial appointment to diagnosis (completion of evaluation)
- Appropriate evaluation including tympanometry, OAEs and ear specific, frequency specific threshold determination
- Time to hearing aid fitting
- Appropriate and timely referrals

Technical assistance, training and educational opportunities will be developed as they are determined to be needed. Previous training has included the annual EAR Foundation audiology seminar speakers on hearing aid fittings, assistive devices, assessment, parent to parent support, Indian Health Services, Cytomegalovirus, Late onset and Progressive Loss, Language Outcomes and other topics. The AzEHDI program has also been a strong supporter of the NCHAM pediatric audiology workshops.

6 Month Early Intervention Aims:

Increase the % of diagnosed children who are enrolled in Early Intervention Services from 71% to 85% and of those 85% (currently 70%) will be enrolled by six months of age.

ENSURE FAMILY SUPPORT IS AVAILABLE TO FAMILIES WHEN THEY ARE MOST INTERESTED AND IN NEED

Strategy 6

The previous grant cycle included provision of parent to parent support through the screening process in conjunction with the hospital screening programs. This effort did not achieve an adequate measure of success and the follow up team and the AZHV GBYS program will be developing a new LC to determine the best strategy for ensuring that parents have the parent to parent support that they need when they need it. The members of this Learning Collaborative will include:

- AzEHDI Coordinator
- ADHS Follow up Representative
- AZHV Executive Director
- AZHV GBYS Coordinator
- Audiologist
- ASDB parent outreach (part C provider)

The overall aim of this Learning Collaborative is to determine the best time and method for introducing parent to parent support and developing systems to support this program. The team

will follow the PDSA cycle as well as develop tools and processes around parent to parent support within the EHDI process. One of the data elements that will be monitored will be enrollment in early intervention services as a part of the measures of success. ASDB is the source of this data. ASDB service coordinators will be the other strategy for ensuring that families are knowledgeable about the free services available to them.

MAKE EARLY INTERVENTION SERVICES MORE AVAILABLE TO FAMILIES

Strategy 7

As described in the Needs Assessment and Introduction, Early Intervention is the one area that has not improved in AzEHDI. Most of the drivers for this lack of improvement are beyond the control of the AzEHDI program and are the result of decisions made primarily to reduce costs. The two strategies that are being proposed are within the scope of the program to make improvements.

The first of these is to ensure that parents are aware of the services that are available to them free of charge and to ensure that they are making informed choices. Assessment of speech and language and service coordination is available to any family without being charged either directly through the family cost participation or through their insurance. Service coordination is also not billed. If a family chooses either to not receive billable services or to reduce the amount of billable service, coordination and assessment can still be available. Through the NECAP project in collaboration with ASDB Parent Outreach (part C services) and the OCSHCN, families can receive standardized assessment each six months free of charge that will give them information to determine if their child is progressing in their speech and language development. This information can be used to help families prioritize services that they receive or to reassess their choices.

The other part of this strategy is to decrease cost and improve access to highly qualified service providers through Tele-Intervention (TI). EFAz has submitted a community grant to provide equipment including cameras, tables and high speed internet access to a pilot group of parents and providers (both part C and private providers) to leverage access to highly qualified providers throughout Arizona. Barriers such as distance, illness (family, child and provider), weather and cost can all be addresses through tele-intervention. A stakeholder team has been meeting over the past year to explore development, a grant has been written to provide equipment and direct services and a coordinator hired. A small amount of funding through this grant will leverage this project to allow the coordinator to work on sustainability, data collection to determine cost, satisfaction with services and development of policies and procedures.

State Advisory Committee

By statute Arizona has a newborn screening (bloodspot and hearing) advisory committee to provide recommendations and advice to the department on at least an annual basis. Include the following members who are appointed by the director:

- Seven physicians who are licensed pursuant to title 32, chapter 13 or 17 and who represent the medical specialties of endocrinology, pediatrics, neonatology, family practice, otology and obstetrics.
- A neonatal nurse practitioner
- An audiologist (currently the AzEHDI Coordinator)
- A representative of an agency that provides services under part C of the individuals with

disabilities education act.

- At least one parent of a child with a hearing loss or a congenital disorder.
- A representative from the insurance industry familiar with health care reimbursement issues.
- The director of the AHCCCS or the director's designee.
- A representative of the hospital or health care industry.

This committee meets once per year and provides little or no direction or oversight to the AzEHDI program.

Stakeholders

The AzEHDI stakeholders committee is separate and functions as the advisory and oversight committee to the larger AzEHDI program which encompasses not only the newborn hearing screening and follow up but all of the agencies and organizations which are involved in early hearing screening diagnosis and intervention services in Arizona. The committee meets quarterly and is open to the public. The committee is chaired by the AzEHDI coordinator and active participants include:

- ADHS
- ONBS
- OCSHCN
- Bureau of Women's and Children's Health
- ASDB Parent outreach
- AzEIP
- Home Visiting Programs
- Arizona Commission for the Deaf and the Hard of Hearing
- University Audiology Training Programs
- Audiologists
- Early Interventionists
- The EAR Foundation of Arizona
- Consulting Audiologists
- Education Coordinator
- BASICS-Early Childhood Screening Program
- Children's Rehabilitative Services
- United Health Care (contractor under AHCCCS for CRS services)
- Members of the Deaf Community
- The Arizona Chapter of Hands & Voices
- Guide By Your Side
- Desert Voices Oral School
- Arizona Chapter of the American Academy of Pediatrics Chapter Champion
- Members of the public

The Stakeholders committee has been in place since before EHDI when the program was called Never Too Young and focused on high risk hearing screening. The program has always been highly collaborative and meetings are well attended with between 20-30 attendees each meeting. In January 2014, before the new grant cycle, the Stakeholders meeting will meet for a training

update on the quality improvement process, their specific role, how data is collected in real time and reported, how the results will be communicated with the group and the timeline for forming teams, developing aims, collecting data, small tests of change and evaluation of impact of change on outcomes. Many of the Stakeholders have either been on Learning Collaborative Teams or will be during this next grant cycle and this will be a refresher course. A face to face meeting is scheduled with the large group quarterly. Between meetings small groups meet or teleconference as needed. Information is provided via email, via the AzEHDI website, the quarterly newsletter or regularly scheduled small meetings. The AzEHDI Coordinator also meets with the ADHS and EFAz contractors every other week.

Sustainability

Arizona has made progress towards sustainability of the core functions of the programs that compose EHDI. The surveillance and follow up program is funded through the fee on the newborn bloodspot. The funds cover approximately 4.25 FTEs at the ADHS. An additional 2 FTEs at ADHS are funded by the HRSA grant and the CDC Cooperative Agreement. Other parts of the program are funded through community grants and funding raising by those partners that have a tax status of 501 (c)(3). These funds assist the Arizona chapter of Hands & Voices, EFAz, HEAR for Kids and partial funding for the Tele-Intervention program. The funding requested in this grant is focused on improving rather than maintaining the program.

3. WORK PLAN

The work plan can be found in Attachment 1

4. RESOLUTION OF CHALLENGES

The AzEHDI team does not foresee any challenges that would prevent completion of the activities in this grant proposal. The team including the AEC are all experienced and capable of meeting the challenges. Barriers listed below are considered possible but not expected to pose insurmountable challenges.

Sustainable Funding

Sustainable funding is always the goal of the EHDI program and considerable success has been achieved toward this goal. However, this grant is the only or primary source of funding for a couple of key elements of the program. The State Coordinator is primarily paid through this grant and is responsible for keeping the program collaborative and is largely responsible for grant writing, finding other funding and communicating with partners and collaborators. It is the intent that over time enough of the functions of the AEC will become institutionalized amongst the partners to allow the roles to be absorbed by others in the event that HRSA funding is no longer available. The other program that has limited outside funding is the GBYS program of Hands & Voices. The GBYS program requires a paid coordinator and paid parent guides. Arizona Hands & Voices is a young organization primarily consisting of a small core group of parents and a few professionals. Paid membership is currently less than 100 families and professionals. This group is probably not capable of the type of fundraising necessary to maintain the program. There have been discussions with other organizations about support for the program but sustainable funding has not been identified. The AZHV board is aware of this potential problem and is working on growing the program and membership while looking for opportunities for sustainable funding.

Learning Collaborative Challenges

Although a large diverse group of professionals working toward a common goal is beneficial, at times it delays the work-team process. A large group is great for a variety of ideas, viewpoints and opinions, but may delay the decision making process due to length of time it takes to discuss all opinions. By altering the initial format, the team found the smaller task group solved much of the issues, as those whose specialty pertained to a task were involved, and there were fewer schedule conflicts. Charging the task group with analyzing the issue and making decisions accomplishes the mission in a timely manner. The task group then reports to the work team to discuss findings, barriers and solutions.

5. EVALUATION AND TECHNICAL SUPPORT

The evaluation of the program is a shared responsibility between ADHS and the AzEHDI stakeholders. The Project Specialist reports to the Follow up Supervisor within the ADHS administrative structure. Performance review of the PS will include:

- Progress on meeting work plan process goals
 - Timeliness
 - Progress on Learning Collaboratives
 - completion of documentation
- success in obtaining diagnostic results on high risk infants
- quarterly publishing of newsletter

Ongoing data collection for both the Learning Collaboratives is the responsibility each LC team with the assistance of the ADHS data team under the direction of the Epidemiologist. The Epidemiologist and the data team services are provided in-kind by the ADHS. Qualifications for the Epidemiologist can be found in attachments two and three. The data goals for the Learning Collaboratives are to collect real time data that can be used to ensure that the proposed change is actually effective. The data collected will include process data that indicates if changes were actually implemented and if they are meeting the aim. Using strategy four as an example this may include things such how many calls were made to the physician by the audiologist, were the calls put through immediately or did the physician call back and was the follow up team able to document a timely evaluation. Outcome evaluations in the same example might include assessing if the change strategy actually shortened the time to evaluation over the baseline data. Documenting what data will be collected by whom, when and how it will be shared is a part of setting the specific aims and gathering the team. Documents such as that found in attachment 9 regarding the WIC PDSA will be used for other PDSAs. Summary documentation will be shared with stakeholders at quarterly meetings.

Evaluation of education efforts will consist of process measures such as documentation of the number of educational encounters such as workshops, site visits and participation at conferences. Each formal training or webinar will be accompanied by a qualitative evaluation to determine

satisfaction and need for further training. Training of screeners also includes hands-on competency and mandatory passing of a test before receiving a certification of completion. Early intervention services have been implementing a formal assessment of speech and language every six months. This information is part of the NECAP program described elsewhere in this proposal. This is considered a quantitative outcome measure. Analysis of the data is included in the program and results are shared with OCSHCN, the AzEHDI state coordinator, ASDB and AzEIP.

Tele-intervention is in phase two and the component that this grant will support is the assessment of the feasibility, desirability and cost effectiveness of this mode of providing early intervention services. A summary report will be provided to the stakeholders group by the end of the first year that describes cost of the pilot, cost to expand the program, anticipated need, feasibility and sustainability. Part of the evaluation will also include parent and provider satisfaction surveys. EFAz consultants and ADHS staff meet every other week to coordinate efforts. Progress on Learning Collaboratives, education and follow up are part of each meeting. The quarterly stakeholders meeting will also include reports on evaluation of the QI effort and solicit advice on new changes to try, areas of concern and direction.

The AzEHDI state coordinator is experienced in Quality Improvement (QI) and will provide support to all of the Learning Collaborative teams, the education team and the follow up team. The Audiology Consultant provides technical assistance to screening program regarding implementation of changes, tracking outcomes, data management and incorporating changes into policies, procedures and practices.

EFAz as a contracted consultant provide the ADHS with a monthly report which summarizes activities, concerns and upcoming activities. Part of this report includes the number of children screened, births as reported by vital records, the number of seconds screens and the refer rate. At each meeting a sign in form is used which includes the date and location of the meeting and all people attending.

The GBYS program is run according to the guidelines set up by the national Hands & Voices. The state chapter is responsible for training and managing their guides. AZHV has co-Executive Directors who are responsible for recruiting and supporting parents that serve on learning collaborative teams, attend stakeholders meetings and review materials.

6. ORGANIZATIONAL INFORMATION

This section of the grant application includes the mission and structure of the Arizona Department of Health Services and the statutory requirements for the program. Collaborative relationships have been established with intra-agency, inter-agency and nongovernmental organizations.

Mission and Structure

Janice K. Brewer became the 22nd person to take the oath of office as Governor of Arizona on

January 21, 2009 succeeding to Governor in mid-term. She was reelected in November 2010. The Arizona Department of Health Services (ADHS) is one of the executive agencies that report to the Governor. ADHS was established as the state public health agency in 1973 under A.R.S. Title 36 and is designated as Arizona's Title V MCH Block Grant administrator. The agency has four divisions: Public Health Services, Behavioral Health Services, Licensing Services, and Operations. The Office of Director includes a Native American Liaison, Local Health Liaison, Border Health, Public Information Office, and Legislative Services. An organizational chart that encompasses both the ADHS and the contracting organizations can be viewed in **Attachment 5**.

Will Humble was named Interim Director of the Arizona Department of Health Services on January 21, 2009, and was formally confirmed as Director in February 2010. Mr. Humble was most recently the Deputy Director of the Division of Public Health Services, and has been with ADHS since 1992. Mr. Humble holds a Master's Degree in Public Health with an emphasis in environmental science. He has served as chief of the Office of Environmental Health and was the Assistant Director of Public Health Preparedness in ADHS.

The Division of Public Health Services is organized into two primary service lines; Public Health Preparedness Services and Public Health Prevention Services. Public Health Preparedness Services includes the State Laboratory where the Office of Newborn Screening resides. Public Health Prevention Services includes Title V programs, Bureau of Women's & Children's Health, Office for Children with Special Health Care Needs, WIC, and Health Systems Development (includes Center for Health Disparities).

The Office of Newborn Screening includes both blood spot screening and hearing screening. The program is housed in the State Laboratory building and organizationally reports to the State Lab Director and administratively to the Public Health Preparedness division. Organization proximity with blood spot screening has allowed coordination with follow up coordinators, shared resources and exposure to proven follow up techniques. Paired QI message with bloodspot and hearing has been an effective tool used for site visits with hospital programs.

Statute and Rules

Arizona Revised Statute §36-694 was signed into law in May 2005. The statute included several provisions related to the AzEHDI program. The law requires:

- Initial screening results and subsequent hearing testing results reported to the ADHS
- An education program for the general public, the medical community, parents and professional groups,
- A central database of newborns and infants who are tested for hearing loss and congenital disorders that includes information required in rule.
- Follow-up services to encourage the child's family to access evaluation services, specialty care and early intervention services.
- A committee to provide recommendations and advice to the department on at least an annual basis. Include the following members who are appointed by the director:
 - Seven physicians who are licensed pursuant to title 32, chapter 13 or 17 and who represent the medical specialties of endocrinology, pediatrics, neonatology, family practice, otology and obstetrics.
 - A neonatal nurse practitioner
 - An audiologist (currently the AzEHDI Coordinator)

- A representative of an agency that provides services under part C of the individuals with disabilities education act.
- At least one parent of a child with a hearing loss or a congenital disorder.
- A representative from the insurance industry familiar with health care reimbursement issues.
- The director of the AHCCCS or the director's designee.
- A representative of the hospital or health care industry.

Administrative rule R9-13-207 became effective on April 4, 2006. The rules includes requirements for how, when and what information is to be reported to ADHS. Reports are required electronically within six days after the week in which the testing was completed. At this time data is accepted through an encrypted emailed file from each hospital screening site. Outpatient screening at the birth site is reported electronically and screening at other sites is reported through a faxed form. Diagnostic reporting is completed through a faxed form which is also faxed to the Early Intervention provider ensuring that reporting and referral are timely and avoids duplication of effort.

Additional state statutes authorize some maternal and child health programs or functions but are not specific to Title V. The statutory list of functions (A.R.S. 36-132) of ADHS includes: encourage and aide in coordinating local programs concerning maternal and child health, including midwifery, ante partum and postpartum care, infant and preschool health and the health of school children, including special fields such as the prevention of blindness and conservation of sight and hearing; encourage, administer and provide dental health care services and aid in coordinating local programs concerning dental public health, in cooperation with the Arizona dental association.

Intra Agency Collaboration

The AzEHDI program has a long history of collaboration with Title V programs. Those programs most integral to the success of EHDI include Bureau of Women's and Children's Health, Office for Children with Special Health Care Needs, Home Visiting programs (Health Start and High Risk Perinatal) and the midwife licensure program. **Letters of collaboration are included from WIC, BWCH and OCSHCN.** One of the Key EHDI partners, EFaz is working with OCSHCN on a needs assessment for the MCH Block grant related to hearing screening in early childhood, service availability, data collection and coordination.

CRS is a program is administered by the Arizona Health Care Cost Containment Services (Medicaid waiver program). CRS provides multi-specialty interdisciplinary care to children under age 21 with qualifying chronic and disabling health conditions. Permanent childhood hearing loss is a covered condition. Related conditions include cleft lip/palate, cranial-facial disorders, microsia/atresia and other syndromes that may cause hearing loss. Covered services include specialty medical including otology and genetics, cochlear implants, hearing aids and related audiological and rehabilitative services.

A component of the High Risk Perinatal Program/Newborn Intensive Care program is a home visiting service with community health nurses. Follow-up services support the family during transition from the hospital to home; conduct developmental, physical, and environmental assessments; provide education and guidance; and direct families to programs and services.

During home visits, community nurses also assess other children in the home to identify children at risk and screen mothers for postpartum wellness.

Health Start Health Start is another home visiting community based model that utilizes Community Health Workers or promotoras to identify, screen and enroll at risk pregnant or postpartum women and their families and assists them with obtaining early and consistent prenatal care, provides prenatal and postpartum education, information and referral services, advocacy and emphasizes timely immunizations and developmental assessments for their children. In 2009, the Health Start Program was provided in 100 targeted high risk communities in ten counties and provided services to 2,300 women and their families.

Arizona Department of Health Services houses the Arizona Health Disparities Center within the Bureau of Health Systems Development. The Arizona Health Disparities Center organizes frequent brown bag speakers that highlight the many cultures present in Arizona. The Arizona Health Disparities Center provides regular updates through email and through its website on news, funding opportunities, publications and events related to health disparities. Subscribers receive links/attachments to the latest resources identified by AHDC on their selected topic by email. ADHS has on integrated Culturally and Linguistically Appropriate Services (CLAS) standards into the orientation process required of all new employees.

Inter Agency

ADHS works particularly closely with the state's Medicaid agency, AHCCCS, participating in many AHCCCS Health Plan meetings. Health Start, Community Nursing, and Hotline staff all facilitate families enrollment in both Medicaid and SCHIP programs. OCSHCN staff assists families in understanding eligibility requirements and help with application processes for various programs that serve CSHCN.

The Department of Economic Security is the lead agency for the Arizona Early Intervention Program and is the part C provider for IDEA. AzeIP is composed of five state agencies with the Arizona State Schools for the Deaf and the Blind (ASDB) as lead agency/provider for children who are DHH and/or Blind. AzEHDI has a longstanding close collaborative relationship with ASDB. Previous grant funding has built on that relationship with joint projects related to training, data sharing and program development. ***A letter of collaboration from AzeIP is included in the attachments.*** Arizona Department of Education as one of the five partner agencies in AzEHDI and with the Head Start program has also been an EHDI partner.

Non-Governmental Organizations

The EAR Foundation of Arizona is one of the core AzEHDI partnerships. Leadership for AzEHDI coordination as well as technical assistance for screening programs and other aspects of the follow-up program is provided through a contract with EFAz. The HEAR for Kids is a program of EFAz that provides hearing evaluations, hearing aids and assistance with repairs of existing cochlear implants for families in financial need. EFAz is the lead organization for tele-intervention efforts. EFAz also has had grants and outside funding to develop screening programs beyond the newborn period impacting long term loss to follow-up for those children who are missed, lost or who have late onset or progressive hearing loss including home visiting programs, First Things First and the OCSHCN. ***A letter of collaboration from EFAz is included in the attachments.***

St. Luke's Health Initiatives is a not for profit foundation that provides funding for the HEAR for Kids program. SLHI was a key partner in establishing universal newborn hearing screening in Arizona. SLHI has provided funding for equipment purchases to initiate programs and provides ongoing funding for training and coordination.

The Arizona chapter of Hands & Voices is a parent to parent support system. One of the components to the AZHV is the Guide By Your Side program. Guide By Your Side Follow-Through is an extension of GBYS and works closely with NBS, particularly the NICU follow up coordinator to provide parent to parent support as early as possible in the EHDI process. *A letter of collaboration from AZHV is included in the attachments.*

Arizona chapter of the American Academy of Pediatrics is a longstanding partner in AzEHDI. Dr Brad Golner is the chapter champion. Dr Golner also serves as a consultant to the NBS program for blood spot as well as hearing screening programs. *A letter of collaboration from Dr Golner is included in the attachments.*

The Arizona Head Start Association is a new partner in the Early Childhood Screening project. First Thing First, established in 2008 as the result of a statewide voter initiative is also a new partner. They have taken the lead on assessing the home visiting programs and have indicated that they anticipate funding early childhood sensory screening throughout the state.

Other partners include the pediatric audiology providers, hospital and outpatient screening program and the specialty medical providers. *Additional information on staffing and qualifications for this project is found in Attachment 2 and Attachment 3.*

Experience in QI

As can be seen from the *biographical sketches in the attachments*, this is a very experienced EHDI team. Three of the members of the team have specific experience in the PDSA methodology and have successfully implemented changes that have been effective in the last three years. See the summary progress report for examples. The AzEHDI Coordinator has previous extensive experience with quality improvement having worked as a Re-engineering consulting for several hospital programs during previous employment as the Assistant Director of Rehabilitative Services. *See attachment two for additional information on the AzEHDI grant team.*