

ABBREVIATIONS

AAP	American Academy of Pediatrics
ABR	Auditory Brainstem Response
ADHS	Arizona Department of Health Services
AHCCCS	Arizona Health Care Cost Containment System (Medicaid waiver program)
ASDB	Arizona State Schools for the Deaf and the Blind (A participating agency with AzEIP and Part C provider for children who are Deaf or Hard of Hearing)
AzEIP	Arizona Early Intervention Program (Umbrella organization for Part C of IDEA)
AzEHDI	Arizona Early Hearing Detection and Intervention
AzHV	Arizona Hands & Voices
BWCH	Bureau of Women's and Children's Health (Title V)
CDC	Center's for Disease Control and Prevention
CRS	Children's Rehabilitative Services
DHH	Deaf or Hard of Hearing
EFAz	The EAR Foundation of Arizona
EHDI	Early Hearing Detection and Intervention
EI	Early Intervention
GBYS	Guide-By-Your-Side a parent support program from Hands and Voices
HFK	HEAR for Kids a program of the EAR Foundation of Arizona
HV	Hands & Voices National
HIPAA	Health Insurance Portability and Accountability Act of 1996
IDEA	Individuals with Disabilities Education Act
MOU	Memorandum of Understanding
NICHQ	National Initiative for Children's Healthcare Quality
NCHAM	National Center for Hearing Assessment and Management
NICU	Neonatal Intensive Care Unit
NBS	Newborn Screening
OCSHCN	Office for Children with Special Health Care Needs
QIC	Quality Improvement Coordinator

INTRODUCTION

The goal of this initiative is to reduce the number of infants who are lost to follow up after a failed hearing screen. This project will be part of a collaborative effort with the Arizona Early Hearing Detection and Intervention (AzEHDI) program, which consists of state agencies, private providers, hospital screening programs, non-governmental agencies and others. This project has three primary approaches. The first approach is to increase the state Newborn Screening (NBS) program's capacity by hiring a High-Risk Follow-Up Coordinator to work with hospitals and ensure compliance with existing reporting mandates in order to reduce the number of infants lost to documentation. The second is to implement trained parent partners at hospital screening sites to improve communication with families and provide a consistent local resource to ensure families make it from screening to diagnostic evaluations and into early intervention. The third is to participate in the development of a parent directed video titled "Loss & Found" through the national Hands & Voices organization.

NEEDS ASSESSMENT

Arizona needs:

- *Additional capacity to ensure that those infants at highest risk for hearing loss are followed more closely*
- *Resources to bridge the gap between the screening process and the diagnostic testing and to provide information and support for parents*
- *Updated information available for parents before hospital discharge in both auditory/visual and written format*
- *Increased access to updated referral information, which includes emphasis on local resources in both English and Spanish for parents, caregivers and parent guides*
- *To educate providers regarding mandatory reporting and their role in ensuring families make it through the screening, diagnostic and intervention process in manner that is timely and supportive*

Arizona has geographic challenges. Although there are 15 counties, 77% of the state's population resides in either Maricopa County (Phoenix metropolitan area) or Pima County (Tucson area). Maricopa County is the third largest county in the United States. Three out of four Arizonans live in an urban area; one in five lives in a rural area and two percent of the population lives in frontier areas. Three percent of Arizona's population lives on one of the state's 21 Indian Reservations (tribal land). Approximately 18% of American Indians in Arizona reside on tribal lands, while 82% are urban. In Apache County, 77% of the residents are American Indian with 48% in Navajo County and 29% in Coconino County.

Arizona has language and cultural challenges. Four of the counties in southern Arizona border Mexico. Arizona has a large and increasing Hispanic population with an estimated 28% compared to 13% nationally. The number of births to Hispanic mothers has exceeded those of white, non-Hispanic every year since 2003. Arizona residents are more likely to speak a language other than English at home (26% compared to 18% nationally) and are more likely to report speaking English "less than very well" (11% compared to 8% nationally). Of those not

speaking English, 85% spoke Spanish while the other 15% spoke one of many other languages. Undocumented parents pose an additional challenge for follow up, as they may be less likely to give information that would allow them to be easily located and may be less likely to return phone calls or read mail from a government agency.

Arizona has budget challenges. The state budget anticipates a 4 billion dollar deficit resulting in very large cuts in health, social services and education. Fortunately, due to strong advocacy groups in the community and strong legislative support, the funding for the Arizona Department of Health Services (ADHS) Newborn Screening (NBS) program may be protected from cuts. The program requires a fee for service based on the bloodspot screen, it includes funds for the laboratory as well as hearing and bloodspot follow up. Unfortunately, the budget cuts have impacted some of the Arizona Early Hearing Detection and Intervention partners. Early intervention services, cochlear implants, hearing aids and genetic services have already been affected and it is anticipated that the 2010 budget will involve even greater cuts.

Current Status of Newborn Hearing Screening

For Babies Born in 2007:

- 95% of all newborns received a hearing screening, leaving 5,536, or 5%, lost to screening
- 3,467 or 3.5% of those screened did not pass the inpatient screen
- 1,415 or 1.4 % did not pass a final screening as defined by the Center's for Disease Control and Prevention (CDC) Early Hearing Detection and Intervention (EHDI) Hearing Screening and Follow-up Survey
- 1,031 or 26% did not return for the outpatient screen

In 2007, Arizona reported 104,516 births occurring in the state. More than 98% of these births occurred in birthing hospitals. Of the 1.08% of births that were not from birthing hospitals, 722 were home births. Of the occurrent births, less than 3% were without health insurance and were required to pay hospital expenses in full, 42% were covered by private insurance and 54% by public programs including Arizona Health Care Cost Containment System (AHCCCS), which is Arizona's medicaid program and Indian Health Services. In the Hispanic population, AHCCCS covered 73% of all births.

Arizona has a long history of newborn hearing screening as the standard of care with more than 90% of all infants screened since 2000. Data reported to the CDC in January 2009 for births in 2007 indicated that in Arizona, 95% of all newborns were screened for hearing loss. Although legislation mandates hospitals to report screening results, hearing screening is voluntary. For babies born in 2008, who were either not screened at the birthing hospital or were born outside of the hospital, only 17% obtained an outpatient screen according to the screening results reported to the NBS program.

All hospitals use equipment that can download the screening results directly into the local tracking database. Each of the birthing hospitals utilize the tracking software provided by the NBS program to record results, transmit data to the state, generate initial results letters and provide quality monitoring of their own screening program. The hospitals submit data each week via an encrypted file electronically mailed to the ADHS NBS program.

Hospitals encourage the families of babies who do not pass the inpatient hearing screen to obtain an outpatient rescreen within two weeks when discharged from the well-baby nursery or from a short stay (5 days or less) in the Neonatal Intensive Care Unit (NICU). Graduates of the NICU who have more than a five day stay are referred directly for diagnostic evaluation as recommended by the Joint Committee on Infant Hearing 2007 Position Statement.

Rescreening is generally available at the birthing hospitals; however, due to insurance issues and locations of families' residence, some infants are rescreened at other sites. Most hospitals have a reciprocal agreement with other hospitals to rescreen infants not born at their facility. In addition, nine community health centers have screening capability. Ear Nose and Throat specialists, otologists and audiologists also provide some follow-up screening.

Reporting from community health centers and private medical providers is not as comprehensive as that obtained from the hospital screening programs. Five weeks of age is the state's first follow-up checkpoint. At that time, the program sends a letter for high-risk infants who have not received a passing result to the parents and the medical home along with a list of available screening sites. If the infant is not high-risk, notification letters are sent at seven weeks of age.

As part of the Maternal and Child Health Bureau EHDI grant, AzEHDI is working on reducing loss to follow up through strategies developed by the Arizona National Initiative for Children's Health Care Quality (NICHQ) group. Our proposed plan to reduce and stabilize refer rates includes:

- Continued onsite training and review of policies and procedures
- Quarterly quality reports to hospital directors and screening coordinators
- Annual meetings to disseminate best practices
- Hospital screening program Compliance Scorecard (not yet implemented)
- Implementation of communication tools
- Implementation of standardized screener training developed jointly with the National Center for Hearing Assessment and Management (NCHAM)

Hospitals put forth a great deal of effort to make certain that babies who did not receive an inpatient hearing screen return for an outpatient screen. Although legislation does not mandate the reporting of babies who do not receive a screen, hospitals often include their information in the electronic data transfer to incorporate them in state follow up. Currently, active follow up is available to nearly all babies reported as having missed or failed the newborn hearing screen.

The screening brochure is approximately 10 years old and needs to be updated to incorporate new information. The referral lists distributed by the follow-up program are also outdated and need to be revised. Arizona needs a standardized way to deliver the urgency of follow up to parents in a friendly manner that is not dependent on the language, education or communication abilities of the screening personnel.

Current Status of Diagnostic Services

For those born in 2007, a total number of 97, or 27%, of the babies who referred on an outpatient screen or received a recommendation to forgo the outpatient screen and proceed directly to diagnostic testing, did not return and were lost at this stage of the process. Of the babies who

received an audiological diagnosis, approximately half of the evaluations occurred long after the optimal period of three months. Currently, Arizona's mechanism to substantiate the amount of time between screening and diagnosis is through the CDC's annual Hearing Screening and Follow-up Survey. The percentage of infants born in 2008 who have received a diagnostic evaluation after failing a two stage newborn screen is currently 56%.

In Arizona, the number of infants in the Neonatal Intensive Care Unit (NICU) for more than 5 days who do not pass the newborn screen and do not receive a diagnostic evaluation is a data point that we understand needs to be collected. This data acquisition is included in the workplan.

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. 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.

Reporting diagnosed hearing loss is improving. 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. The correlation is very high. Children who complete a screening or diagnostic evaluation with a "normal" result are more frequently not reported. Considerable effort is made by the NBS follow-up program to track down these results. New providers, as well as those who do not have a large caseload of infants, need to be educated regarding the reporting process.

Current Status of Early Intervention

For babies born in 2007, four (5%) out of 142 with confirmed loss did not receive early intervention. Of these four children, one moved out of state, two refused and one expired. This represents a 0% loss to follow up between diagnosis and early intervention

Early Intervention (Part C of the Individuals with Disabilities Education Act of 2004 (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 in AZEIP and provides Early Intervention 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 primarily through home visits by interventionists. The majority of interventionists providing services to the families of children who are Deaf or Hearing Impaired are highly qualified in the area of Deaf Education. Some interventionists are audiologists or speech language pathologists.

Services are provided statewide by the Parent Outreach Program. 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 Early Intervention services are collected through a statewide web-based database. This database is populated and maintained by the Parent Outreach Program but is accessible to the

follow-up staff at the NBS program. This allows the NBS to ensure enrollment in EI and track completion of the Individual Family Service Plan.

Arizona participated in a pilot project called the National Early Child Assessment Project to collect standardized data on speech and language for children who are Deaf or Hard of Hearing. This project has moved beyond a pilot into full implementation. One component of the program is to contract with the University of Colorado to score and analyze assessments to provide both a data-driven approach to intervention and to contribute to a nationwide database. This allows the Arizona Early Hearing Detection and Intervention (AzEHDI) program to have access to outcome data from the entire EHDI process. Analyzing this data against the other program components will help determine if the systems are making a difference for children's development. The cost of participating in the project was included in a recent cooperative agreement proposal to the Center's for Disease Control and Prevention (CDC).

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. It is unclear if the American Recovery and Reinvestment Act of 2009 will provide additional funding.

Current Status of Access to Hearing Aids in Arizona

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 EHDI 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.

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). In Phoenix and Tucson, the sites contracted with CRS are not providing diagnostic services; but accept referrals after a hearing loss is diagnosed. Taking ear mold impressions at the time of diagnosis allows the hearing aid fitting within three weeks using the HFK program. 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.

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 Hear for Kids 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).

Parent to Parent Support

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. More than 200 people attended the Fall Expo in 2008. In the spring and the fall, the Arizona chapter holds family picnics in both Phoenix and Tucson. Event attendance continues to grow. Arizona Hands & Voices (AzHV) has a website, a brochure in English and Spanish and a toll-free message number that allows messages to be returned in English or in Spanish.

The AzHV was represented on the NICHQ team and their toll-free contact number is listed on the Family Checklist (Attachment 2) distributed at the outpatient screening appointment to those infants referred for diagnostic evaluation.

AzHV has been piloting a unique application of the Guide-By-Your-Side (GBYS) program with a birthing hospital. The GBYS program typically pairs a trained parent guide with the family of a child who has been newly identified as Deaf or Hard of Hearing. The implementation of a parent guide in the birthing hospital allows parents to be part of the team, starting with a referred screen, assisting parents through the outpatient screen, diagnosis and early intervention process. Of particular concern is the hand-off between screening and diagnosis. This model is expected to improve loss to follow up significantly as well as provide continuity of support.

Medical Home

The American Academy of Pediatrics (AAP) defines a medical home as “primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate and culturally effective.” Using this definition, in 2003, the National Survey of Children’s Health indicated that the percentage of children with a medical home is lower in Arizona than it is nationally (36% to 46%).

Since the state began active follow-up efforts in April 2006, an estimated 98% of all infants referring from the newborn screen and not receiving an outpatient screen by one month of age have had an identified medical provider. The provider identified at the time of the second bloodspot screen is more likely to be providing a place of ongoing care than is a provider documented during birth hospitalization. In Arizona, all infants are required to undergo a second bloodspot screen within five to ten days of birth. Of the infants receiving state follow-up services for a referred hearing screen, only 2% do not have an identified provider.

Brad Golner, MD is our American Academy of Pediatrics Chapter Champion for Newborn Hearing Screening and works with the AzEHDI program to educate medical home providers.

METHODOLOGY

The goal of the three-year grant is to reduce statewide loss to follow up between inpatient and outpatient screening and between screening and diagnosis by 50%. Estimates for 2008 loss to follow up between inpatient and outpatient are currently 23%, dropping 3% from 2007. Through this project, we are expecting to meet the goal of less than 12% loss between inpatient and

outpatient. Currently, loss to follow up between outpatient and diagnostic evaluation (not necessarily diagnosis) for births in 2008 is estimated at 44%. As 2008 data has not been closed for analysis, we anticipate that number may change. We expect to have the largest impact within this second group.

The first objective of this project is to decrease the percentage of loss to follow up to 10% or less for those infants who fail the screen and who have a stay of five days or greater in the NICU. The definition for loss to follow up for this group is between the initial screen and the diagnostic evaluation. We currently do not have a baseline for this group; the work plan contains a strategy to ensure that we have accurate data that reflects this population. This objective will be accomplished through the hiring of a High-Risk Follow-Up Coordinator at the Arizona Department of Health Services, Newborn Screening Program. This additional staff will increase the capacity of the follow-up program to enable focus on the following activities:

- Work with discharge coordinators and case managers to identify babies with failed screens who have been in the NICU five days or greater
- Establish a liaison with hospital discharge coordinator/case manager
- Maintain timely follow up for all high-risk infants
- Update brochures and resource lists provided to families at the time of screening (in English and Spanish)
- Educate the medical home about referrals including development of a “pocket guide” for primary care providers
- Educate and enforce mandatory reporting requirements for audiologists, Arizona Early Intervention intake coordinators, medical home, community health care centers, early HeadStart, and other screening providers
- Liaise with the Guide-By-Your-Side coordinator and hospital guides
- Institute a small test of change to determine the best hours to call families for follow up, including evenings and weekends
- Provide bilingual/bicultural follow up for parents whose primary language is Spanish
- Broaden collaboration to other public health programs including Women Infants and Children, Neonatal Intensive Care Program, High Risk Perinatal Program, Best FIT, Smooth Transitions, Lay Midwives, Nurse Midwives and Community Health Nursing programs

The second objective of this project is to decrease the percentage of loss to follow up to less than 10% between inpatient and outpatient and between outpatient and diagnostic evaluation in 10 hospitals the first year by implementing a Guide-By-Your-Side follow-through program. This will increase to 20 hospitals by the second year. By the third year of the grant, the program will have decreased loss to follow up at 20 hospitals to less than 10% and will provide resource support to all remaining hospitals.

GBYS is a family support program that embodies the mission of Hands & Voices, which is to provide unbiased support to families with children who are Deaf or Hard of Hearing. GBYS does this through specially trained parents of children who are Deaf or Hard of Hearing who

work as guides with families who recently learned their child cannot hear, or whose child is at risk for hearing loss. For this project, the trained parent guides will be 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 outpatient screen. Currently, Arizona has eight guides who have been trained. A pilot birthing hospital follow-through program has been initiated at one hospital. Preliminary contact has also been made with two additional hospitals, as well as one company that provides outsourced hearing screening for 13 hospitals. In the pilot project, the parent guide is part of the screening team at the birthing hospital and received payment through the Arizona Hands & Voices Arizona Community Foundation Grant. The hospital position is a “volunteer” position dedicated to the newborn hearing screening program. As an official hospital volunteer, the parent guide completed training in Health Insurance Portability and Accountability Act and specific hospital policies and procedures including patient confidentiality.

We utilized the annual newborn hearing screening conference to introduce the hospital guide program to the screening programs. There was considerable interest and excitement expressed for the opportunity. The actual duties of the parent guide may vary depending on the hospital need. Some facilities have expressed an interest in having the parent guide intervene after the failed outpatient screen, others have shown a preference for assistance in supporting families between inpatient and outpatient screening. The actual configuration of the program will depend on the loss to follow-up rates in a given population at each stage of the screening, diagnostic and early intervention process. The implementation of the hospital guide program will require:

- Development of informed consent materials
- Working with the EFaz screening audiology consultant to meet with decision makers in the hospital screening programs
- Recruiting and training additional parent guides in communities outside Tucson (currently three trained guides are in Phoenix, eight reside in Tucson)
- Integration of educational materials for parents in the screening, diagnostic, intervention process

In order to implement a statewide program coordinated through birthing hospitals, the AzHV must collaborate with another organization that has the infrastructure to support the program. The EAR Foundation of Arizona has agreed to provide the support to contract with the parent guides and invoice the Arizona Department of Health Services to access the grant funds along with existing consulting contracts. The GBYS coordinator position will continue to be funded and managed through the AzHV. This will allow control of the program values and policies to remain with the parent support organization. A small amount of grant funds will go directly to AzHV to help with training and coordination needs.

The third objective is to provide supportive and effective information to parents early in the screening process through a collaboration that will develop a targeted parent-oriented DVD, aimed at empowering and motivating parents, thus improving follow up. This objective is specific to the first year of the grant and is a collaborative effort with Seaver Creative Services Inc. and other state EHDI programs. The Executive Director of the national Hands & Voices parent organization is an accomplished television producer and has proposed the concept of developing a short, targeted DVD that will bring parents who have “been there” directly in touch

with referred families before they leave the hospital. The use of the Hands & Voices Guide-By-Your-Side parent-to-parent model in the video “Loss & Found” will consistently deliver a strong, accurate, compelling message every time. The “Loss & Found” DVD can be viewed on an internal hospital television network, streaming on a website, and/or from a portable DVD player/monitor that can be brought to the parent’s room. Socio-economic status/ethnically-diverse parents of children who are Deaf or Hard of Hearing share stories of their child’s identification, and the importance of following through on testing and services. The overall tone is upbeat but serious, leaving the viewer with a sense of optimism and urgency. Encouragement and instructions from a warm, credible medical professional close the video with clear direction on how to take the next steps. The DVD will have closed captioning and Spanish language subtitles. The last portion of the DVD would be Arizona-specific with referral and follow-up information and resources. Additional information about Seaver Creative Inc can be found at www.seaver.xiostar.net. Information on the DVD can be found in Attachment 7.

WORKPLAN

Objectives	Activities/Steps	Data/Evaluation	Timeframe for Assessing Progress	Team Members Responsible
<p>Objective 1: Decrease the percentage of loss to follow up by at least 50% over three years for those:</p> <p>a. between inpatient and outpatient screen</p> <p>b. high-risk babies including those who have a stay of more than 5 days in the NICU</p> <p>c. who fail a two-stage screen</p> <p>d. who are lost to documentation</p>	Obtain approval for temporary High-Risk Follow-up Coordinator position	Position posted	August 2009 (in process)	Jacox
	Hire High-Risk Follow-up Coordinator	Position filled	September 2009	Jacox
	Establish liaison with Hospital Discharge Coordinators and/or Case Managers for follow up with infants who refer with a NICU stay >5 days	On-site meeting with every hospital with Level II or Level III NICU	October/November 2009	Dufour
	Educate screening programs about best practice and importance of reporting NICU status	# of NICU babies found without a documented nursery status	Reported Monthly	Dufour/ Winston
	Engage hospital case managers/discharge coordinators to report babies staying in NICU more than 5 days on a weekly basis to the NBS program specialist	Reports to track babies discharged with or without a screen including contact information for parents and medical home	Monthly report - ongoing	Dufour/ Winston
	Send quarterly newsletter to hospital case managers/discharge coordinators and audiologists showing improvement in the loss to follow up rate for “5+ days NICU babies” and providing tips and strategies to encourage parents to get their babies screened	Keep weekly stat reports for “5+ days NICU babies”	Quarterly newsletter	Dufour

Objectives	Activities/Steps	Data/Evaluation	Timeframe for Assessing Progress	Team Members Responsible
Objective 1 continued	During the first year, establish the baseline rate for loss to follow up for babies staying at NICU > 5 days	Keep Records in the tracking database	Monthly report	Dufour/ Taylor
	For babies leaving NICU after more than five days, maintain follow-up letters or calls within 5 days of due date to parents whose babies have failed the hearing screening	Monitor % of letters or calls made within 5 days of benchmark, report monthly to NBS team	Monthly report ongoing	Dufour
	Update the patient brochure in English and Spanish	Draft reviewed by team brochure printed	December 2009 January 2010	Dufour
	Educate audiologists on mandated reporting through licensure letters	# letters sent	Twice each year	Dufour
	Educate other providers such as community health centers and early HeadStart on reporting requirements	Active system of monitoring compliance in place	Ongoing	Dufour
	Complete onsite training for larger groups of providers	# of presentations # of providers educated	Reported monthly	Dufour/ Harmon
	Complete NICHQ test of change cycle on best time to call including weekends and evenings	Monitor completed/returned calls based on time of day	Track for 4 weeks beginning January 2010	Dufour
Objective 2: Decrease the loss to follow up by 50% between: <ul style="list-style-type: none"> ▪ inpatient and outpatient ▪ between outpatient and a diagnostic evaluation in 	Identify hospitals with high number of loss to follow up between inpatient and outpatient	List of top-ten hospitals with significant number of loss to follow up	August 2009	Taylor
	Provide Report Card to hospital discharge coordinator	# Sites visited	Starting Sept 2009 and on-going	Taylor/ Aponte
	Memorandum of Understanding (MOU) between AzHV and EFAz	MOU completed	August 2009	GBYS
	MOU between Arizona GBYS and HV	MOU competed	September 2009 (in process)	GBYS

Objectives	Activities/Steps	Data/Evaluation	Timeframe for Assessing Progress	Team Members Responsible
hospitals with GBYS	Work with Phoenix outsourcing group on a plan for implementing the GBYS second-stage referral model	MOU in place Policies and procedures developed Implement programs at first outsourced hospital	March 2010 April 2010	GBYS
	Implement in 2 Tucson hospitals with existing trained staff Implement in 1 Phoenix hospital with existing trained staff	Track by site # of referrals % return for rescreen % return for diagnostic	September 2009 October 2009	GBYS
	Develop and print supporting resource material for GBYS program	Printed forms	December 2009	GBYS
	Recruit and train up to 10 additional guides	# of guides trained	December 2009	GBYS
	Quarterly training for existing guides and semi-annual training for new guides	# of guides participating in quarterly training # of guides completing training for first time	Quarterly Twice a year ongoing	GBYS
	Parent Survey – mailed out within 1 month of contact	# of parents with positive responses to the parent survey	Ongoing	GBYS
Objective 3: Develop and implement use of the “Loss & Found” DVD in 10 hospitals the first year and 20 in second year	Purchase Order for Seaver Creative Inc	Purchase Order in place	September 2009	Jacox
	Development of Arizona specific content	Review by AzHV	January 2010	AzHV
	Implementation	# hospitals using DVD # parents responding positively to parent survey	Ongoing	GBYS

RESOLUTION OF CHALLENGES

Staffing

The state of Arizona is in an unprecedented budget crisis and hiring has been frozen for a year. Positions funded under federal grants have been exempted from the hiring freeze. The High-Risk Follow-Up Coordinator position will be created and filled expeditiously to resolve some of the staffing issue. The Office Chief of the Newborn Screening program has received assurances from the acting director of the ADHS that both the position created as part of the CDC cooperative agreement and the position proposed in this grant application will be expedited.

Data Challenges

The data system is currently outdated and needs to be transitioned to an online platform. A cooperative agreement proposal was submitted June 15th to accomplish this over the next two years. If this proposal is not funded, it is likely that it will be more difficult to obtain the data necessary for accurate and timely monitoring of the EHDI program. Implementation of the new data system populated through the hospital databases would greatly enhance the ability to track infants that are in the NICU and to know which infants did not receive any newborn hearing screening. Other grant funding will be pursued if the CDC cooperative agreement is not funded.

Sustainable Funding for the Guide-By-Your-Side Program

The GBYS program faces a sustainability issue. The GBYS program requires a paid coordinator and paid parent guides. The initial training will be several days and quarterly ongoing training is required. Although there is abundant initial enthusiasm for the program, ongoing funding will be critical for sustainability. 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 in the current economic crisis, ongoing support may be difficult to obtain. Funding through this grant would allow the program to have three years to develop a financial foundation and work with stakeholders on making the program self-sustaining. The EFAz has agreed to provide support for the guides during this time period. Keeping the coordinator position with AzHV should allow the AzHV to maintain control of the program policies, training and future direction.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

The program evaluation will be under the direction of the Quality Improvement Coordinator, Sondi Aponte and the Follow-up Supervisor Brigitte Dufour. Ms. Aponte has worked with the AzEHDI program for 6 years, initially in a screener capacity, then data management and now in a management position working on quality improvement for both bloodspot and hearing programs. Ms. Dufour is new to the position but has many years of management experience in public health programs. Her experience also includes a recent position working with compliance.

A recently submitted cooperative agreement submitted with the CDC proposes a move from the current outdated central database to a web version. This would have a significant impact on the follow-up program for the following reasons:

- Data entry would be in real time at the site of the screening or diagnostic evaluation
- The screening database would be populated with electronic records from the hospital which would ensure that all newborns would be tracked and would allow better identification of those newborns in the NICU.
- Data on standardized evaluations of speech, language and development every six months would be available to obtain true outcome measures of the AzEHDI program
- Difficulties with duplicate records for transferred babies should be resolved

This system will allow this project to closely track and measure progress on the goals and objectives. The program will measure overall project success by determining the number of infants who return for outpatient screen by one month of age, complete assessment by three months of age and those who are enrolled in early intervention by six months of age.

Formative evaluation will also be conducted throughout and beyond the grant period focusing on target activity outcomes identified in the Work Plan section of this application along with project process indicators listed below.

Technical support capacity includes collaboration both internally and with contractors. Collaboration with the Bureau of Women's and Children's Health and the Office for Children with Special Health Care Needs (both recipients of the Title V Maternal and Child Health Block grant) is expanding and includes:

- Collection and analysis of data on shared performance measures
- Shared epidemiology resources through the State Systems Development Initiative
- Movement toward greater data integration with CRS, Vital Records, Immunization, Birth Defects Registry and other public health databases

Contractors include two audiology consultants; Randi Winston, AuD who has 12 years experience in newborn, infant and child hearing screening program development and Lylis Olsen, MS, MPH who has 15 years experience coordinating the state EHDI program. Brad Golner, MD is the state Chapter Champion and a contracting medical home consultant for the NBS program. The national Hands & Voices chapter provides excellent technical assistance for all aspects of the GBYS program including onsite training, teleconferencing, email and phone support.

Evaluation High-Risk Follow Up Coordinator

Establishing a solid network between NBS, hospital discharge managers, EAR Foundation of AZ, and GYBS is the key to improve the loss to follow-up rate between inpatient and outpatient screenings, and between outpatient screening and diagnostic evaluation, particularly for babies staying more than five days in the NICU.

The role of the High-Risk Follow-Up Coordinator is to foster communications between hospital discharge managers and NBS program. The High-Risk Follow-Up Coordinator will be responsible for:

- Establishing a liaison with Hospital Discharge Managers and/or Case Managers
- Engaging Hospital Case Managers/Discharge Coordinators to report babies staying in NICU for more than 5 days on a weekly basis to the NBS program specialist
- Maintaining follow-up letters or calls within 5 days of due date to parents whose babies have failed hearing screening
- Sending quarterly newsletters to Hospital Case Managers/Discharge Coordinators and audiologists showing improvement in the loss to follow up rates, including babies staying more than five days at the NICU
- Determining the baseline rate for loss to follow up for babies staying in the NICU for five days or greater (during the first year)

The High-Risk Follow-Up Coordinator will identify the top ten hospitals from the hearing database for which the loss to follow-up rate between inpatient and outpatient screenings and between outpatient and diagnostic evaluation are the highest. The coordinator will monitor these hospitals and ensure screening results are provided in a timely manner. In addition, they will be making direct contacts by phone, email or in person with discharge hospital coordinators needing additional support when the follow-up rate is not improving, and discuss areas where improvement is needed.

The High-Risk Follow-Up Coordinator will also provide positive feedback and public acknowledgement in the quarterly newsletter for hospitals showing significant improvement in the loss to follow-up rate.

The coordinator will develop new brochures and educational materials, educate audiologists about the mandatory requirements to report screening results to ADHS via licensure renewal letters, and provide training for large groups of providers. They will work with EAR Foundation of Arizona, and GBYS in order to educate audiologists, and encourage parents to schedule follow up appointments.

Monthly Report:

- Number of site visits at hospitals, including site visits for hospitals on the top ten list
- For each site visit, provide the date and time of the meeting, name of attendees, contact information for the discharge coordinator and a copy of the report card left to the discharge coordinator
- Number of contacts (phone, email and in-person) with discharge hospital coordinators not providing screening results in a timely manner
- Number of contacts (letters or calls) to parents
- Number of letters sent to audiologists on mandated reporting through licensure letters

Newsletter (quarterly):

- Provide data and graphs about statewide loss to follow-up rates

- Share success stories about hospitals showing significant improvement or having creative activities to encourage parents to return for a follow up screening and/or diagnostic
- Provide tips and strategies to encourage parents to get their babies screened
- Announce upcoming training or events about hearing screening

Baseline Report

- Determine the baseline for the loss to follow-up rate for babies staying at NICU for more than five days

Evaluation GBYS

The GBYS program has proven to be effective in several other states as implemented both after a child is identified with a hearing loss or as part of a loss to follow-up program.

In addition to the qualitative evaluation tools shown below, the GBYS Coordinator and the Follow-up program will be monitoring the loss to follow-up rates, median and mean age at completion of the screening, diagnosis and enrollment in early intervention for each guide and each screening site. The data will be compiled and analyzed quarterly for those hospitals with births less than 3000 births per year and monthly for those hospitals with a larger number of births.

Process indicators will also be monitored including:

- Number of trained guides
- Availability of guides fluent in Spanish and/or Sign
- Quantity and attendance at training events
- Numbers of hospitals participating in the guide program
- Number of hours guides work per screening site

The national Hands & Voices program has developed evaluation tools to provide qualitative assessment of the program. Two of the surveys have been developed to measure both the recipient (parents) experience of the guide and the input from the parent guide.

The parent satisfaction survey will be sent to every one the families of children identified with a hearing loss or who were part of the follow up between screening and diagnosis, and it will be sent to a random sample of those who were contacted as part of the follow through program from inpatient to outpatient screening. Copies of the survey tools can be found in Attachment 1.

Evaluation Loss & Found DVD

Process evaluation of the production and dissemination of the DVD will include:

- Purchase order awarded
- Script approval
- Completion of production
- # of hospitals implementing use of DVD

The AzHV will play a critical role in evaluating the scripts for the DVD, contributing to production and the Arizona specific content. A survey will be developed to provide qualitative data about the DVD and will be administered to those families who referred on an inpatient screen and saw the DVD prior to hospital discharge.

ORGANIZATIONAL INFORMATION

The NBS follow-up program is administered through the ADHS State Laboratory which includes bloodspot and hearing screening. The Maternal and Child Health EHDI grant is also administered through this program. The bloodspot program uses a case management system that has an automated link to the newborn hearing screening database. This allows the updated medical home data from the second bloodspot screening to be used, as well as providing additional contact information for active follow up.

The program maintains close ties with the Bureau of Women's and Children's Health (BWCH), which is the lead agency for the Title V block grant. Collaboration with BWCH programs includes the Arizona Perinatal Trust (multi-agency and non-governmental organization credentialing body for newborn intensive care units), the epidemiology/data section and midwife licensure.

NBS is working with BWCH and the Office of Children with Special Health Care Needs (OCSHCN) and is defining processes to identify newborns that test positive through the state's NBS program, refer them to appropriate staff within both offices and facilitate their enrollment into programs for care coordination and direct medical services, following Performance Measure # 31 of Title V. To track progress, BWCH and OCSHCN are collaborating to ensure children identified through the newborn screening process receive services through a BWCH or OCSHCN program, ensuring early and continuous care, following Title V Performance Measure #23. More than 50% of all children with hearing loss in Arizona are enrolled in audiological services and receive hearing aids, cochlear implants and/or specialty medical services (otology, genetics, ophthalmology and others) through CRS. Data elements from each of these services and providers will be available to the project in the future. NBS and OCSHCN are developing a care model including sharing web sites, brochures, and phone numbers with families to ensure a seamless continuity of care and provide a smooth transition for families who have been identified through newborn screening and qualify for OCSHCN.

Five positions in the NBS follow-up program have been recently filled including the supervisor, clinical educator and follow-up specialists. These are shared positions between hearing and bloodspot programs. This will allow one of the current follow-up staff to return to a data management role and the Quality Improvement Coordinator to focus on data analysis and on implementing data-based decisions.

This project will be the responsibility of the NBS Office Chief, Ward Jacox. Brigitte Dufour is the Follow-up Supervisor and will be in charge of the day-to-day operations of the project. Sondi Aponte is the Quality Improvement Coordinator and will have primary responsibility for the evaluation of the grant activities. Additional staff includes two follow-up specialists, a clinical educator, data manager and two audiology contractors who serve as hospital screening program liaison and AzEHDI Coordinator (Randi Winston, AuD and Lylis Olsen, MS, MPH).

The ADHS has statutory authority to maintain the centralized newborn and infant hearing screening database. 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 screening 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, and
- A committee to provide recommendations and advice to the department on at least an annual basis.

Administrative code 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.

Other Partners

Arizona Early Intervention Program (AzEIP)

AzEIP consists of five agencies and administers Part C of IDEA. As part of their intake process they use otoacoustic emissions to screen all children enrolling in the program regardless of disability. This data is reported to the state NBS program.

Arizona State Schools for the Deaf and the Blind

The Arizona State Schools for the Deaf and the Blind (ASDB) is the lead agency within the AzEIP providing services under Part C of IDEA for families whose infants are Deaf or Hard of Hearing. ASDB provides data for the AzEHDI program which includes all of the early intervention elements including; date of enrollment, Individual Family Service Plans, standardized outcomes, cochlear implantation or hearing aid usage and service units. Results of developmental evaluations performed every six months will also be available to provide outcome data from EI.

Non-Governmental Organizations

The EAR Foundation of Arizona (EFAz)

The EAR Foundation of Arizona (EFAz) is a not-for-profit organization that is also a contractual partner. The EFAz subcontracts with Lylis Olsen, MS, MPH and Randi Winston, AuD to provide audiology consultation to the AzEHDI program. Ms Olsen serves as the statewide EHDI coordinator and liaison between the state agencies, partners and contractors. Dr. Winston is the primary liaison between hospital screening programs and the NBS follow-up program. Dr. Winston also provides consulting services to the National Center for Hearing Assessment and

Management. Various projects funded by private foundations and administered by the EFAz are included in the statewide EHDI infrastructure. These projects include HEAR for Kids (loaner and permanent hearing aids for newborns) a technical assistance program that provides screening equipment and training to community-based health centers, medical homes and a community-based program for ages 0-5 as well as school hearing programs for children ages 0-5 in Maricopa County. Dr. Winston works with each of these programs to ensure compliance with state mandated reporting of screening results. EFAz is a partner in a proposal to develop a hearing, vision and developmental screening model for more than 27,000.

Audiologists

In Arizona, audiologists are required to be licensed. Through the licensing, they are notified of the requirement to report screening and diagnostic test results. Both audiology consults and the ADHS follow-up program have worked to ensure compliance with reporting. The largest pediatric providers are in full compliance, the smaller providers who may only see infants periodically still need to improve compliance with reporting all screens and diagnostic testing.

Specialty Medical Providers

For those children who qualify for the Arizona Health Care Cost Containment System or KidsCare (Medicaid waiver program and State Children's Health Insurance Program (SCHIP)), most specialty medical providers are covered under Children's Rehabilitative Services (CRS) programs and data elements are available through these sources. Data will need to be reported directly from providers for those children not covered by the CRS program (estimated at 40-50%). ADHS has established connections with medical providers in the state to allow information dissemination and encourage participation. Although there is a mandate for reporting hearing screening, specialty medical providers are not required to report services for otology, genetics, ophthalmology or other services beyond hearing screening and diagnosis.

Birthing Hospitals

Arizona has a long history of newborn hearing screening. All birthing hospitals have had the capacity to screen all births since 2000 with more 90% of all babies screened, and approximately 95% screened in recent years. All hospitals have the capacity and are mandated to report screening results electronically. Programs are based on the Joint Committee on Infant Hearing Screening 2007 position statement and subsequent clarifications. Most well babies are screened with a two-stage, otoacoustic emissions/automated auditory brainstem response screening. Some smaller birthing hospitals have either otoacoustic emissions or automated auditory brainstem response. Attachment 3 contains the curriculum vitae of key personnel, Attachment 2 contains job descriptions and Attachment 4 contains an organizational chart for the project.