

## Abstract

**Arizona Early Hearing Detection and Intervention Organization: The EAR Foundation of Arizona**

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The purpose of the proposed project is to ensure that all of Arizona's children who are Deaf or Hard of Hearing are identified early and receive appropriate Early Intervention services in order to have the best possible opportunity to meet their potential. The goals are to ensure that parents are supported and educated about the decisions that they make, that best practices are followed and that there are standardized shared messages across the professionals in order to best facilitate and coordinate services and activities. The activities proposed support children in meeting their potential and parents being empowered and confident in parenting their children who are Deaf or Hard of Hearing.

Arizona Early Hearing Detection and Intervention (AzEHDI) has a long history of being a community-based program. Legislation was not introduced until 2005 at which time Arizona was already screening more than 98% of all births. This project proposes to engage the families and communities served in identifying and addressing needs, enhancing and improving the services throughout AzEHDI. Methodology includes promoting parent leadership in addressing legislation, policies and practices at all levels, moving parents from a seat at the table to the head of the table setting agendas and priorities.

Systems are in place for parent-to-parent support, there is active involvement with the Deaf community and Deaf Mentors. Systems to standardize, equip and train Head Start, Home Visiting, Early Intervention, Physician's office, Federal Community Health Centers and others to screen in early childhood beyond the newborn period are in place and expanding. As a result of legislation, a role for public health was established including standardized reporting, follow up, a mandate to provide education, the addition of parents and an audiologist to the state Newborn Screening advisory board and a sustainable base of funding for those services through the newborn blood spot screening fee. Existing services and funding will be leveraged to continue to sustain progress and this funding will continue to work with the professional communities to ensure that the needs are identified, addressed and best practices implemented

Quality improvement methodology will be used under the leadership of parents and local subject matter experts to move the percentage of timely diagnosis from <70% to 85% and improve timely enrollment in early intervention. Education and community-based approaches will be used to ensure that systems adhere to the best practices identified in the 2019 Joint Committee on Infant Hearing Position Statement.

AzEHDI values parents as the primary teachers and decision makers for their young children and Deaf and Hard of Hearing adults as a source of first-hand knowledge. The activities and funding in this grant reflect those values, embedding parents not only as participants at all levels of AzEHDI but actively working toward parents setting the agendas as leaders and decision makers in the EHDI system. Approximately 35% of the budget is dedicated to support Guide programs including Parent to Parent support, Deaf and Hard of Hearing Guides, the Deaf Mentor program, coordinating activities and events that bring together parents, children, the professionals that serve them and support for actively engaging parents in leadership positions across EHDI systems.

## Project Narrative

### Table of Acronyms

AAP	American Academy of Pediatrics
ASL	American Sign Language
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
AzEHDI	Arizona Early Hearing Detection and intervention
AzEIP	Arizona Early Intervention Program (umbrella organization for Part C of IDEA)
AZHV	Arizona Chapter of Hands & Voices
BASICS	Building a Screening Infrastructure for Children's Success (EFAz program)
CDC	Centers for Disease Control and Prevention
cCMV	Congenital Cytomegalovirus
DHH	Deaf and Hard of Hearing
DMP	Deaf Mentor Program (through ASDB)
EFAz	EAR Foundation of Arizona
EHDI	Early Hearing Detection and Intervention
EHDI-PALS	Early Hearing Detection and Intervention-Pediatric Links to Services
EI	Early Intervention
ELP	Early Learning Program (ASDB Part C of IDEA)
FL3	Family Leadership In Language and Learning
GBYS	Guide By Your Side (Parent to Parent Support through AZHV)
IDEA	Individuals with Disabilities Education Act
HRSA	Health Resources and Services Administration
HSFA	Hearing Screening and Follow-up survey submitted to CDC annually
JCIH	Joint Committee on Infant Hearing
LC	Learning Community
LEND	Leadership Education in Neurodevelopment and Related Disabilities
MCH	Maternal and Child Health
NCHAM	National Center for Hearing Assessment and Management
OAE	Otoacoustic emissions
OCSHCN	Office for Children with Special Health Care Needs
ONBS	Office of Newborn Screening
PALS	Pediatric Audiology Link to Services
PDSA	Plan Do Study Act QI approach to small tests of change
QI	Quality Improvement
RSK	Raising Special Kids (Family Voices funding recipient)
UNHS	Universal Newborn Hearing Screening
TI	Tele Intervention
U of A	University of Arizona

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## Introduction

The EAR Foundation of Arizona (EFAz) has a long history of providing leadership and collaboration with the many partners that make up Arizona Early Hearing Detection and Intervention (AzEHDI). AzEHDI is unique in that in the early years those partnerships and collaborations formed the community basis for moving newborn hearing screening program forward. Hospital screening was entirely voluntary prior to 2014 yet Arizona's screening rates have been greater than 95% since 2002. EFAz obtained grant funding to equip and support hospital screening programs across the state beginning in 1996. In 2005, EFAz began the parent support organization that would become Arizona Hands & Voices. Input from EFAz programs and AzEHDI from parents and Deaf and Hard of Hearing (DHH) adults has been in place since the beginning. A quarterly stakeholder's group meeting has been in place since 1994 to cooperatively discuss and address concerns across the many agencies, organizations and individuals that impact any aspect of the EHDI journey for families.

The EFAz approach is community based and parent/child focused. Parents are central to every decision and action taken with their child and AzEHDI feels that they should also be central to not only front-line provider decisions but also the policies and practices endorsed by the agencies and organizations in charge of legislating, regulating and oversight of all aspects of EHDI. Communities begin with parents and include those front-line providers that directly impact services. This grant proposal was developed with parents as partners in determining priorities, activities and methodology. Audiologists were polled to determine what they felt the gaps in knowledge and services are in AzEHDI, what they wished medical providers knew, what parents need and what audiologists in their community need to provide best practice in services. Early Interventionists were polled on similar questions and specifically, given the recent expansion of service providers (20 new hires in the previous year), asked what education and information they needed to provide the best possible services to families. The resulting proposal is founded on the premise that providers serving families are the key resource for best outcomes.

## Goal

The goal of the AZEHDI program is to ensure that infants are identified early, receive early, appropriate, evidence based, coordinated services so that families receive timely, meaningful and appropriate support, including access to DHH adults and that quality improvement is ongoing at all levels of the AzEHDI system.

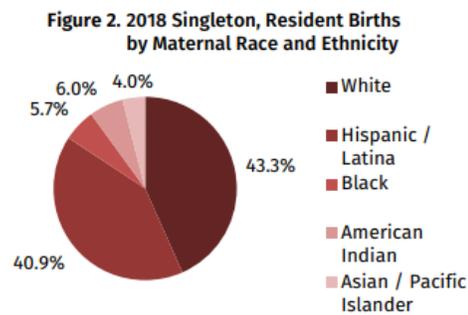
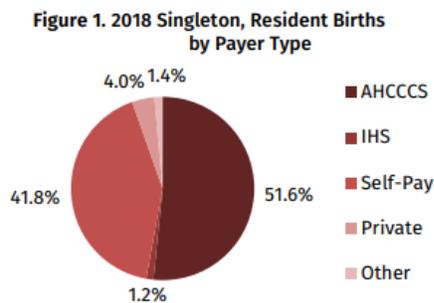
The focus of this proposal is to leverage parent leadership in an effort to increase the percentage of infants who complete a diagnostic evaluation by three months of age and enrollment in early intervention services by six months of age. The methodology will involve building a sustainable, statewide, data-driven approach to the critical system drivers to ensuring timely diagnosis and enrollment in early intervention services. A key aspect of the methodology is engagement, empowerment and education of individual parents early in the identification process to give them the support that they need meet the milestones.

## Needs Assessment

### State Level Data Related to Maternal and Child Health

Race, ethnicity, insurance coverage, care coordination, access to medical care and preterm birth all have an impact on early hearing detection and intervention. The following information is from the 2018 update to the Maternal and Child Health Needs Assessment (June 2019) and provides the most current information on these issues available for the Arizona population. Note AHCCCS is the Arizona Health Care Cost Containment System (Medicaid waiver program) and IHS is Indian Health Services. The document and original citation for primary data sources can be found at <https://azdhs.gov/documents/prevention/womens-childrens-health/reports-fact-sheets/title-v/fy2018-fy2020-title-v-needs-assessment-update-summary.pdf>

In 2018, there were 82,500 total live births in Arizona and 80,530 resident live births, with 51.6% paid by Medicaid [Figure 1]. Among women giving birth in 2018, 43.2% were non-Hispanic White, 41.2% were Hispanic/Latina, 5.7% were Black, 5.9% were American Indian, and 4.1% were Asian or Pacific Islander [Figure 2]. Over 60% of women who gave birth in 2018 had at least one previous live birth, and 30.2% had a live birth less than 18 months prior to getting pregnant with the 2018 birth.



Among 2018 resident singleton births in Arizona, 7.7% were born preterm, or before 37 weeks gestation, and 5.9% were born

low birth weight, or less than 2500 grams. Preterm births disproportionately affected Black babies (10.2%) and American Indian babies (9.6%) compared to White, non-Hispanic babies (6.9%). In addition, 10.0% of Black babies and 7.0% American Indian babies were born low birth weight compared to 5.1% of White, non-Hispanic babies.

Over 75% of children ages 1-17 in Arizona had a preventative medical visit in the last year in 2017, and 70.6% received needed care coordination. However, 37.9% had inadequate health insurance or gaps in health insurance coverage, and only 44.0% had care within a medical home. Children with special health care needs (CSHCN) made up 15.5% of the children 1-17 in Arizona in 2017.

The 2018 MCH block grant submission also contains information specific to the status of Maternal and Child Health as well as current efforts by the Bureau of Women's and Children's Health and the Office for Children with Special Health Care Needs. A copy of the block grant application including primary sources can be found at <https://azdhs.gov/documents/prevention/womens-childrens-health/reports-fact-sheets/title-v/2017-block-grant-submission.pdf>

Arizona is the sixth largest state in the nation, located in the Southwest. One-quarter of the land in Arizona is home to 21 federally recognized Tribes and Nations. The Phoenix metropolitan area and Tucson are the primary urban areas of the state. About three-quarters of Arizona's population resides in urban areas and one-quarter resides in rural or frontier areas. Arizona has the fifth highest adult female poverty rate in the country.

Arizona has a higher percentage of residents living in poverty compared to the nation. In Arizona in 2015, 26 percent of children under 18 and 32 percent of those without a high school diploma lived below the poverty line. Poverty varies dramatically by county. The highest rates of poverty are in Apache and Navajo Counties with rates of 30 and 25 percent, respectively. In a five-year estimate for 2011-2015, 21 percent of families with children were below the poverty line in Arizona. Rates of poverty for families with children vary widely by ethnic background. The National Center for Children in Poverty reports that in Arizona in 2014, twelve and thirteen percent of Asian and White children, respectively, live in a poor family compared to 46 percent of Native American children, 36 percent of Hispanic children and 30 percent of Black children.

Arizona 1-3-6+

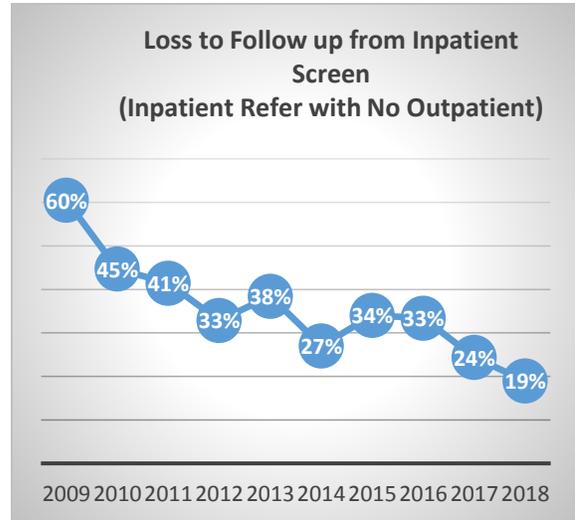
#### *1-Newborn Hearing Screening Status and Needs*

EAR Foundation has been the leader in Newborn Hearing Screening in Arizona since 1996 when they began providing equipment and audiology technical assistance to hospital screening programs. EFAz launched the newborn hearing screening program with local grant funding to purchase screening equipment for most of the birthing hospitals over a period of three years. EFAz first partnered with the Arizona Department of Health Services (ADHS) to begin collecting data on screening in 1998. All hospitals who received equipment through EFAz were required to send individual data to the ADHS Sensory Program. The ADHS Sensory Program, at that time, was managed by Lylis Olsen who is the current AzEHDI Coordinator. Since 1999 Ms Olsen has contracted with EFAz, managed the EFAz HEAR for Kids and provided grant writing and leadership in all aspects of AzEHDI. By 2002 more than 95% of all newborns were screened by one month of age voluntarily.

Legislation in 2005, promoted by EFAz, the March of Dimes, the Arizona Commission for the Deaf and the Hard of Hearing and championed by a team of dedicated parents, required reporting of all newborn screening and subsequent testing, maintenance of a statewide database for surveillance and active follow up, that parents, audiologist and specialty medical providers be included in the Newborn Screening Advisory Board and mandated education for all providers. In 2014, through advocacy by EFAz, hearing was added to the state panel of conditions screened for at birth to make hearing screening mandatory and consistent with the other mandated blood spot and congenital heart conditions included in the newborn panel.

Between 2002 and August 2019 EFAz had a contract with the ADHS Office of Newborn Screening (ONBS) program funded through fees collected with the blood spot, Health Resources and Services Administration (HRSA) prior to 2017 and CDC funding. EFAz provided audiology consulting, technical assistance and training to the hospitals, birth centers and midwives on screening practices, 1-3-6+ goals (+ parent to parent support), training on data collection and reporting and consulting with audiologists on reporting and best practices.

The ADHS ONBS provides follow up after one month of age for those who did not pass a newborn hearing screening. Due to Loss to Follow Up concerns, ADHS ONBS personnel shortages and a hiring freeze, ADHS outsourced follow up to EFAz from June 2017 through August 2019. EFAz follow up was able to bring loss to follow up at the time of screening down to less than 20% for 2018 births (the only birth cohort for which EFAz did all of the follow up). If contacted but unresponsive were not included the loss to follow up would be 8%. Similar results were achieved in loss to follow up at time of diagnosis.



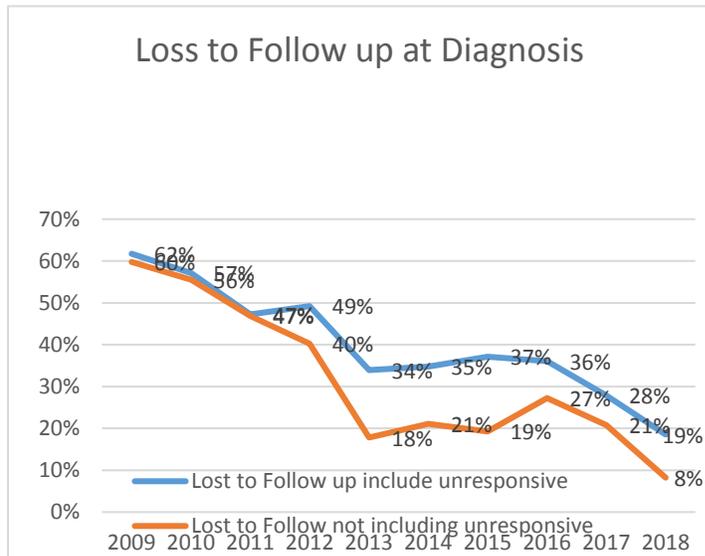
Although screening is well established and successful in Arizona there are ongoing concerns. The first is to maintain the high levels of screening in those hospitals that do not outsource their screening, especially in the smaller hospitals in rural areas. The second is to ensure that the practices in newborn screening support timely diagnosis. Based on data collected in Arizona over the past three years both parents and audiologists report that one of the primary reasons for late identification is that the hospital downplayed the seriousness of the referral blaming results on equipment, fluid and telling parents not to worry about the results. Screening programs need to stay engaged and focused on the outcomes of early identification of hearing loss not just maintaining screening numbers.

### 3-Diagnosis Status and Needs

Arizona has three areas of the state where diagnostic audiology providers are clustered. Southern Arizona is served primarily through one hospital based diagnostic center in Tucson that is staffed by the University of Arizona Audiologists. A small number of evaluations are performed at two other highly qualified locations, also in Tucson. In Central Arizona (the Phoenix metro area), there are two primary diagnostic centers based in Children’s hospitals, along with a small number of evaluations completed at private practice locations (including one associated with a neuro-otologist that is highly qualified). Phoenix Children’s Hospital has the largest pediatric audiology staff and diagnoses and fits well over half of those children identified in the state. Northern Arizona is served by a diagnostic center associated with the hospital in Flagstaff, and one in Kingman. Indian Health Services provides a small number of diagnostic evaluations in the Navajo Nation. This distribution of services requires extensive travel by some families. Immigration checkpoints deter families where parents of the child do not have documented immigration status which is common in Arizona.

EFAz has worked with the University of Arizona (UofA) Speech and Hearing Clinic and the Yuma Regional Medical Center to provide tele-audiology services. The equipment has been purchased and tested, the contract signed, and the project is awaiting completion of staff credentialing.

The AzEHDI program encourages providers to use the EHDI-Pediatric Audiology Link to Services (PALS) online database through the Centers for Disease Control and Prevention (CDC) to determine appropriate referrals for pediatric audiology services based on age, location and required level of diagnostic services. The AzEHDI coordinator is working with NCHAM on ensuring that audiology practices are updating and maintaining their information.

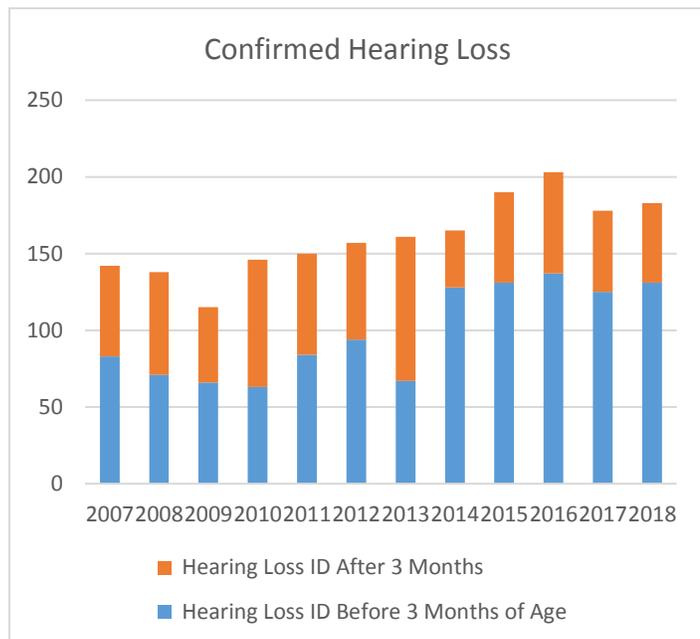


Loss to follow up at the time of diagnosis has shown significant improvement during the time that EFAz had the follow up contract. The previous grant cycle had a learning community that focused on improving follow up including a concerted effort to ensure that parents were contacted in the language of choice and physician referrals were actively facilitated.

Recent efforts have focused on ensuring that diagnostic reports are submitted to ADHS ONBS within one week by audiologists to ensure timely

services are offered to families following diagnosis. EFAz follow up included contact with parents to determine if assessment had been done but not reported. Over two years, the data showed that lack of documentation for diagnostic testing was a rare event and more likely to be a faxing error than a site not reporting.

Despite successful efforts to reduce loss to follow, the number of cases of confirmed loss have not increased significantly. Timeliness (3-month benchmark) has also stalled at slightly less than 70%. Data demonstrates that the overall age of diagnosis continues to decrease making progress but 30% are still over the 3-month goal. In order to meet the 3-month target there is a need to improve engagement and focus at the screening level, to address physician delays in referrals, parental engagement/concern and rule out permanent hearing loss for those with middle ear disorders including children with other medical needs.



Our American Academy of Pediatrics (AAP) Chapter Champion has provided education to physicians including targeted efforts to ensure that those practices with a high rate of loss to follow up are providing appropriate and timely referrals. Results from several practices showed that referrals were being made but that the medical home was not aware if the family either did not make an appointment or did not show up for the appointment.

In online surveys September 2016 (all audiologists) and 2019 (audiologists serving 0-5), by the AzEHDI Coordinator, results continue to indicate concerns with parents and medical providers not understanding the importance of timely diagnosis. Minimizing concerns by the screeners and the physician are also significant barriers to timely diagnosis.

Most children born in Arizona have health insurance at the time of birth, although the number covered falls quickly after the newborn period. Most insurance covers diagnostic testing. EFAz HEAR for Kids program is able to cover either an unседated or an Auditory Brainstem Response under anesthesia as needed if insurance coverage is not available and the family is in financial need.

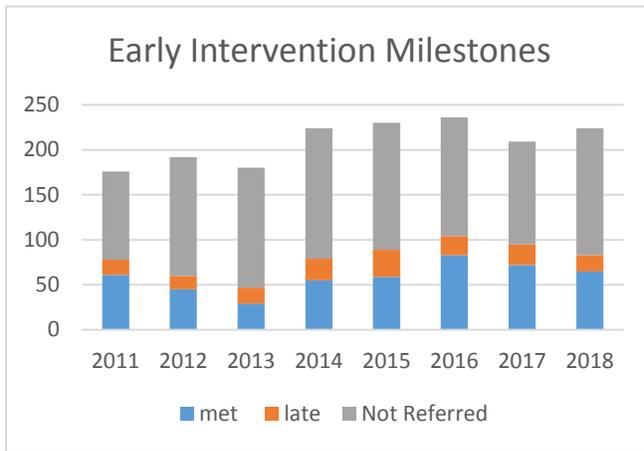
Audiologists serving pediatric patients and their families were polled and identified specific needs for continuing education on topics discussed in the methodology section.

#### *6-Early Intervention Status and Needs*

Early Intervention services for families in Arizona with a child who is DHH, 0-5 years of age, are primarily provided through the Arizona State Schools for the Deaf and the Blind (ASDB) Early Learning Program (ELP). Although the ELP program is the designated Individuals with Disabilities Education Act (IDEA) Part C provider for 0-3 both hearing and vision, less than 10% of their funding comes through Part C. The majority of funding for early intervention for DHH children in Arizona is through the state general fund. ASDB is one of the five agencies that make up the Arizona Early Intervention Program. AzEIP provides EI services for children with other disabilities and service coordination through contracted providers. ASDB ELP is responsible for providing services for all children who are DHH, Blind or Deaf Blind. They also provide consultation, direction and education on contracted services as well as policy and practice for Part C services for all children 0-5 years of age who are DHH or Blind. Since most of the funding does not come from Part C they set their own criteria for eligibility and service provision. This is advantageous as Arizona is a state that requires a 50% delay to be eligible for services which would exclude most of the DHH children until they are significantly older.

There is one private listening and spoken language school called Desert Voices in Phoenix and one private practice Speech Language Pathologist that provides additional services as well as contract services for ELP. ELP and Desert Voices offer preschool services as well as home visits and tele-intervention (TI) services. TI services are a joint venture coordinated by the EFAz over the past six years and funded through grants. EFAz continues to support the Zoom platform to make it available to ELP, private providers, The Arizona Hands & Voices (AZHV) Guide By Your Side (GBYS) parent to parent support, DHH Guides and the Deaf Mentor Program (DMP).

ELP services are provided by highly qualified teachers of the Deaf. In 2018, ASDB, EFAz and other AzeHDI stakeholders supported action by the legislature to provide funding for 20 addition ELP providers (both DHH and vision).



The chart on the left shows the current data for early intervention milestones. The large number of not referred is largely because only those children with significant bilateral hearing loss are currently eligible for ELP services and can only qualify for AzeIP if they have a 50% delay in language. ASDB is reevaluating the requirement for a bilateral loss and we expect to see families with a child with a unilateral loss receiving some level of services soon. As reported to the CDC for 2017 babies, 76% of those

enrolled made the 6 month goal. Of those children who were Deaf or Hard of Hearing bilaterally, 92/104 were enrolled in the ELP program which is an 88% enrollment rate for those qualified. ELP received a referral on 101 out of 104. Those not referred included children in hospice, those with residence outside of Arizona or unable to contact.

Between 2017 and August 2019, the EFAz follow up team along with AZHV GBYS program provided a safety net for referrals. Each month follow up contacted ELP to determine if they had referrals on the known bilateral losses and if a referral had not been received, contacted the audiologist to initiate a referral for Early Intervention (EI) services. Several are identified each year. Families that enroll in the Guides programs receive information and encouragement to enroll and utilize ELP services.

For the past 10 years referrals to ELP were made using the same faxed form that was sent to ADHS ONBS with diagnostic information. It was a jointly developed form that allowed audiologists to only have to send once and allowed some cross checks on referrals. The current The CDC cooperative agreement includes moving to an electronic referral form. ONBS is currently piloting an electronic referral that goes to both AzeIP and ELP. Concerns are that the referrals are not all getting to ELP and that the referral does not contain enough diagnostic information to confirm a loss and to determine eligibility. Discussions are ongoing to resolve these issues. Since more than 90% of funding comes from sources outside of Part C, ASDB ELP program has a significantly greater role in determining eligibility and service provision.

Loaner hearing aids are available to all children who are newly identified as DHH through EFAz HEAR for Kids program. Permanent aids are also available to those families in financial need who do not have adequate insurance coverage. This program has been in place for 20 years and it consistently scores the highest possible parent and audiology satisfaction scores on surveys (including the most recent in 2019). The program allows most children to be fit within 30 days of diagnosis. Those not making this milestone usually include parent choice, medical conditions or distance from services.

Early Interventionists were polled to determine education needs to improve best practices. Topics are included in the methodology section below. The ELP has added 20 new staff with additional funding. This extra staffing has created an opportunity to review and implement new practices and potentially expand change eligibility to include children with unilateral losses.

EFAz has a long-term collaborative project to ensure that quality early intervention services are available in all areas of the state. Over the past 7 years multiple grants have been used to train and implement tele-intervention services not only for ASDB ELP but private providers, parents and Deaf Mentors. There is a need to continue to fund the Zoom platform for this project.

#### *+Parent-to-Parent and Deaf Hard of Hearing Adults Status and Need*

ASDB also has a Deaf Mentor Program (DMP) that is available to all families with a child who has been identified as DHH. EFAz partnered with the DMP and AZHV to provide training to both the Deaf Mentors and the AZHV DHH Guides. DMP provides information about Deaf culture and teaches American Sign Language (ASL). The DHH guides provide parent support from both DHH adults without communication methodology bias. AZHV and DMP support and co-sponsor events to ensure that the two programs provide common messages to parents and provide additional opportunities for parents to have access to adults who are Deaf or Hard of Hearing. Currently 45 families are assigned a Deaf Mentor and 10 families have a DHH guide with additional families accessing Deaf and Hard of Hearing Adult support through events.

AZHV has been providing parent to parent support through the Guide By Your Side program for 10 years. Passive recruitment of parents through post cards given at failed first screening, flyers available through audiologists and EI were not successful. In 2017 a concerted effort was made to contact all parents of newly identified infants to offer parent to parent support in a timely manner. Follow up staff, who were also parents, called families and shared information about the program. This model was successful with 10-15 families enrolled in AZHV guide program each month. Since transitioning follow up back to ADHS only 2-4 families have enrolled each month. It is clear that the messaging from an AZHV parent is more effective than from the ADHS non-parent intermediary. ADHS ONBS has agreed to provide AZHV access to parents of babies who are newly identified as DHH. ONBS started the process to formally grant this access.

AZHV works with Raising Special Kids (RSK) to share resources related to children with special needs. Although RSK has high quality training on IFSP and IEP as well as serves at the intake point for the Arizona Early Intervention Program (AzEIP) RSK does not have hearing specific resources or training. Currently RSK recognizes AZHV as the primary support for families with a child who is DHH.

The large number of parents requesting a guide has resulted in a need for recruitment and training of more parent and DHH guides. Although more than 30% of the previous grant was used by AZHV for these programs, the current need is approaching \$150,000 a year, exceeding the funding through this grant. AZHV leadership is new to grant writing and is not experienced in raising, managing and accounting for the large budget now needed. Funding sources have been reluctant to provide large grants to an organization without a history of larger budgets. Solutions involving using EFAz as a fiscal agent and collaborative projects are being explored.

## Hearing Screening Beyond Newborn

EFAz has a long history of screening, development of best practices, policy and equipment for hearing screening beyond the newborn period. In 1996 EFAz sponsored a study to determine the efficacy of OAE screening in school age children. This study has served as one of the sentinel studies showing behavioral testing remains the gold standard. EFAz obtained multiyear grants to provide equipment and training for the High Risk Perinatal program, AzEIP contractors, Head Start, Physician and Health Centers (including IHS). EFAz's Building a Screening Infrastructure for Children's Success (BASICS) program screens hearing and vision and provides monitoring for more than 4000 children between birth and five years of age since 2011. BASICS is the largest screening program in the state and is funded by a state agency, First Thing First.

EFAz audiologists and education staff have written curriculum for newborn and early childhood screening with sponsorship through the National Center for Hearing Assessment and Management, Office for Children with Special Health Care Needs, Bureau of Maternal and Child Health Sensory Program, University of Arizona Cooperative Extension and multiple grants obtained since 1997. Some of these grants also provided both equipment and technical assistance to various agencies and medical providers that screen throughout early childhood. AzEIP has built in objective screening into their provider contracts and most contractors have equipment and have been trained to screen by EFAz staff over the years. EFAz developed the best practices toolkit used statewide in the First Things First programs.

EFAz developed a curriculum for Otoacoustic Emissions (OAE) for use in the ADHS sponsored Train the Trainer program. When ADHS eliminated funding for the program EFAz provided a home for the training and continued to update the training curriculum called HEAR to Train. Recently ADHS OCSHCN expanded the school age sensory program to include training and reporting in early childhood. The program uses the ECHO model but has incorporated some of the training materials from HEAR to Train. OCSHCN has more than \$2M each year in Maternal and Child Health (MCH) funds as well as state funding for children with special health care needs and has designated funds to improve training, develop reporting mechanisms and support early childhood screening. EFAz is supportive of institutionalizing and ensuring that early childhood screening has the sustainability that it can achieve as part of the MCH program at ADHS and is no longer sponsoring the HEAR to Train program. Many providers, facilities and schools rely on the expertise of EFAz for continued technical assistance in screening and best practices including follow up.

## Methodology

### Objective One

The first objective is to continue to provide statewide leadership to engage and coordinate all stakeholders in the AzEHDI system to ensure that the AzEHDI goal is met. Engagement and outcomes will be measured through:

- 25% Parent, Deaf or Hard of Hearing adult participation in stakeholder meetings held at least 3 times each year (generally quarterly including national meeting).
- Solicit/invite new participants to join the stakeholder's meetings at least once each year
- Provide data related to each objective each year to the stakeholders committee

### *Collaboration in Assuring a Coordinated Infrastructure*

The EFAz has provided leadership from the very beginning of AzEHDI both in policy areas as well as in technical assistance and program/service implementation. Collaborations have been longstanding, diverse and comprehensive for all areas of needs assessment, policy, legislation and program implementation including:

- Equipped and trained hospitals to provide hearing screening
- Provided audiology technical assistance and training to all newborn and early childhood hearing screening programs across the state and nationally
- Developed best practice documents for newborn early childhood screening and diagnostic audiology
- Advocated for legislation to:
  - Mandate screening, referral for diagnosis and early intervention, surveillance, tracking and follow up
  - Expand funding for early intervention services staffing
- Provide loaner and permanent hearing aids and a voucher system to pay for screening and medical/audiological evaluations throughout childhood through HEAR for Kids
- Sponsored parent exploration of Parent-to-Parent support and establishing AZHV
- Provided equipment and training for Head Start, AzEIP contractors, HRP, Medical practices and federally funded clinics including Indian Health Services
- Screen and monitor more than 4000 children each year through the BASICS program
- Contracted with Arizona Commission for the Deaf and Hard of Hearing (ACDHH) on legislative recommendations, collaborate on needs assessment and legislation to mandate screening, follow up, surveillance, education and add parents, audiology, and early intervention to the state advisory committee
- Worked with state agencies and organizations on best practice tool kit, curriculum and implementation of screening programs from newborn to age five

The result of these efforts is that Arizona has an infrastructure that is sustainable and coordinated to assure that all infants are screened, diagnoses are reported, and families are referred for early intervention and parent to parent support. The maintenance of that infrastructure is a coordinated effort between multiple state agencies, private practices, hospital and health care systems and non-governmental organizations such as EFAz.

## *AzEHDI Stakeholders*

The AzEHDI program has had a comprehensive stakeholders committee for more than 30 years. The committee meets quarterly to share information and to help identify gaps in services. At this time the following participants have agreed to participate or have been long term participants:

- AZHV-Parents
  - Najwa Ghattas-AZHV Co-Executive Director
  - Heidi Klomhaus AZHV Co-Executive Director
  - Liliana Herrera, Spanish speaking Parent Guide
- Deaf and Hard of Hearing Community
  - Sherri Collins ACDHH
  - Astrid Goodstein
  - Heidi Klomhaus (also a parent)
  - Michelle Michaels ACDHH
  - Christina Vorreyer, ASDB DMP Program
  - Becca Bailey, ACDHH
  - Daisy Cartwright, Deaf Mentor
- Arizona Department of Health Services
  - Katharyn Levandowski, OCSHCN
  - Fran Altmaier, ONBS
  - Wendy McDonnell, ONBS
  - Sonia Samaniego OCSHCN
  - Jay Griffith, Audiology licensing
- Early Intervention
  - Dee Chapman-Desert Voices
  - Barb Schrag, former ELP coordinator
  - Kendra Benedict Statewide ASDB ELP coordinator
  - Jenee Sisroy, AzEIP Director
  - Carla Zimmerman, Private practice SLP
  - Jennifer Hensley, ASDB Director of Deaf Programs
- Physicians
  - Brad Golner, Pediatrician Chapter Champion
  - Nathan Page, Otolaryngology
  - Sidney Rice, LEND program
- LEND program
  - Mark Deruiter-The University of Arizona
  - Eileen McGrath- University of Arizona
- Early Head Start
  - Nicole Neal-City of Phoenix
- AHCCCS (Medicaid)
  - Eric Tack
- Hospital based Newborn Hearing Screening programs
  - Jeryl Barganski, Pediatric
  - Helen Castex, Sheridan
- Audiologists
  - Lylis Olsen
  - Shanna Dewsnap-(also a parent)
  - Deb Flynn, PCH
  - Alissa Nickerson, PCH
  - Randi Winston, NCHAM
- Raising Special Kids (family voices recipient)
  - Janna Murrell, Assistant Executive Director
- EAR Foundation of Arizona
  - Melissa Selbst-Executive Director
  - Lylis Olsen, AzEHDI Coordinator
- First Things First
  - Cheri Conte
- Katherine Muldoon, (CMV chair) parent

In addition to the people named above, an additional 25 people who do not routinely attend the meetings (mostly due to scheduling and availability) receive agendas and information. They request to stay on the list to be appraised of the agendas and outgoing information and will attend as they are able. Most of the meeting have 20-25 participants representing 18-20 organizations. Each meeting for the past three years (and longer) has had more than 25% of the attendees representing parents and/or Deaf or Hard of Hearing adults. Meetings are open and everyone that attends has a seat at the table and is able to openly join discussions. This has allowed open discussions of issues, solutions and networking. Recommendations are made and the individual

group members take recommendations and suggestions back to their own organizations for action. The meetings are held at a fully accessible location with interpreters, individual microphones, loop system and availability of CART if requested. Individuals can participate by phone to allow inclusion of those from other parts of the state. The location at the Arizona Commission for the Deaf and the Hard of Hearing also encourages members of the DHH community to participate. Agenda items are solicited on an ongoing basis with a final request for items at least one week prior to the meetings. While the AzEHDI Coordinator has facilitated past meetings, facilitation will now be a shared responsibility with Parent leaders.

Members of the group can submit suggestions for new participants at any time and at least once each year the members of the group are queried as to who else they would like to invite to the meetings. Other than ensuring adequate representation of parents and DHH adults there is no effort to limit participation in the group.

#### *Expansion of infrastructure to include those up to age 3*

Methodology for this grant will address hearing screening beyond the newborn stage through:

- Education effort by parent leaders to implement an education plan and targeted QI aimed at those hospitals that either have a high refer rate or a low rate of timely completion of diagnostic evaluations to address meeting the 3 month diagnosis goal
- Supporting OCSHCN implementation of new rules regarding training and reporting early childhood hearing screening
- Continuing to provide loaner equipment to community providers
- EFAz BASICS screening program for Maricopa County early childhood sites

The plan to expand the AzEHDI program to age three is already underway. The EAR Foundation of Arizona with funding through grants and the Office for Children with Special Health Care Needs developed a model training program based on the ECHO initiative which included hands on and Arizona specific information more than 15 years ago. The Office for Children with Special Health Care Needs has responsibility for statewide school hearing and vision screening programs. OCSHCN recently completed updating the rules associated with the program to help close the gap between newborn hearing screening and school age including clarifying screening requirement for preschool programs. The new rules allow training, registration of trainers and reporting for not only school age but those beyond the Newborn Hearing Screening program as well. The advantage of this approach has allowed OCSHCN to work closely with other public health programs and agencies including the Office of Newborn Screening, Maternal and Child Health programs and other agencies such as AzEIP. ADHS OCSHCN now has the funding through state funds and the federal Maternal and Child Health grant as well as the authority through the newly passed rules to expand training of screeners, loaner equipment availability and the reporting of results past the newborn phase all the way through school age. The curriculum developed by EFAz has been offered to OCSHCN and forms the basis of their newly developed OAE curriculum both for early childhood and school age. The OCSHCN program manager is a certified EFAz HEAR to Train screening trainer as well as an ECHO program trainer.

EFAz also collaborated with AZEIP contractors and Early Head Start providers for the past 20 years to write grants to equip and train those screening in early childhood programs. EFAz has the largest early childhood hearing and vision screening program in the state, screening and monitoring more than 4000 children between the ages of 1 and 5 each year through First Things First funding in Maricopa County. This program has formed the basis for best practices statewide and has been presented as a model early childhood program in the state and nationally. EFAz continues to provide support and long-term equipment loans to community screening programs including midwives, physicians, clinics and other early childhood programs.

#### *Focused Quality Improvement (QI) efforts*

The four areas chosen for this effort include:

1. Moving parents from a seat at the table to the head of the table.
2. Providing outreach and education to targeted providers including:
  - a. Early Intervention
  - b. Medical Providers
  - c. Audiologists
3. Providing support for Deaf and Hard of Hearing Adults in family support
4. Quality Improvement and assessment of Parent to Parent support

#### 1. Parents

Moving parents to the head of the table in this grant cycle began with active parent leadership involved in the data collection for the needs assessment, analysis, determining goals, objectives, activities and methodology. Parents were involved in every aspect of developing this proposal. The goal is to move the AZEHDI state coordinator to a facilitator, mentor and coach position whenever possible and allow parents to take the lead. Measures will include the committees or workgroups chaired by parents, the collaborative projects engaging parents in any aspect of EHDI including and OCSHCN Learning Community, early childhood hearing screening trainers, education workgroups, and embedding parents in newborn hearing screening programs in their communities. Methodology for this QI activity will involve a diverse workgroup of providers led by a parent facilitator.

#### 2. Outreach and Education

EFAz is applying for funding for a supplemental needs assessment. This needs assessment will be implemented to identify and then provide targeted education to providers who interact with families in the EHDI process including medical home, audiologists and early intervention. Quality improvement efforts will focus on developing standardized shared messages across disciplines (including parent to parent support), developing a plan to implement educational activities led by parent leadership and measured through the number of individuals impacted and measured outcomes of education. Ultimately the outreach and education will impact age of identification and early intervention as well.

#### 3. Encourage Deaf and Hard of Hearing Adults in family support

Families benefit from exposure to DHH adults. This is accomplished through the Deaf Mentor Program, Deaf and Hard of Hearing Guides and through activities that include DHH adults networking with parents and DHH children at social, networking and educational events.

Quality improvement activities will include paid DHH Guides and Mentors at events (include jointly sponsored DMP and DHH Guides events), and paid DHH Guides providing individual services. Measurements will include the number of trained adults available, enrollment in programs and surveyed evaluation of events and services. Ongoing training and technical assistance will be included as needed as well as training for new DMP and DHH Guides.

#### 4. Quality Improvement and Assessment of Parent to Parent support

Families desire support from other parents of children who are DHH. Although support is available through RSK and OCSHCN, neither has the DHH specific training, expertise or DHH parents on staff. The AZHV board is more than 50% parent led allowing them EFAz to set their own direction and decision making based on what is best for their children and families. AZHV has had a GBYS program for more than 10 years. The program has seen tremendous growth in the past two years and needs to implement QI strategies to ensure that the program is meeting the needs of the families. The methodology will involve a workgroup to develop a Plan Do Study Act (PDSA) strategy for ongoing assessment the Guide programs and the events. Measurements will include the number of trained parent guides available, the enrollment in the guide programs, an evaluation plan, ongoing assessment of Guides and events. One of the first strategies will be to develop a plan to determine the timing and communication approach used for assessment.

#### *Website*

Past efforts related to an AzEHDI website included having an EHDI section of the ONBS website devoted to EHDI and having a separate website just for AzEHDI that could be maintained by multiple stakeholders involved in EHDI. There were disadvantages to each. The ADHS ONBS website is heavily skewed toward newborn hearing screening rather than the audiological evaluation, early intervention and parent support. ADHS ONBS is the only contributor. The advantage is that it is maintained and updated on a regular basis. The independent AzEHDI website was more inclusive but was not regularly maintained by the various stakeholders which made it less accurate and effective as well as less sustainable.

The methodology to address this will involve parent leadership and the AzEHDI stakeholder committee (possibly through a workgroup). They will assess the current options for not only the AzEHDI but also the ONBS and other agencies websites to determine:

- What information is needed
- Whether an independent, specific agency or mixed links on a website would best accomplish the goals for an AzEHDI website
- How to make the website sustainable, comprehensive, accurate, timely, unbiased and relevant to the needs of the state

EFAz, along with parent leaders, will facilitate the discussion and implement recommendations to ensure that by year two there is a plan and a process to implementation.

## Objective 2

Engage, educate, and train health professionals and service providers in the EHDI system about the 1-3-6+ recommendations; the need for hearing screening up to age 3, the benefits of a family-centered medical home and the importance of communicating accurate, comprehensive, up-to-date, evidence-based information to families to facilitate the parent in decision-making process.

Engaging, educating and training health professionals and service providers in the AzEHDI system is a key methodology in this proposal. Measurable outcomes include:

- Development of a written document for parents of those infants that fail the newborn hearing screening by AZHV
- Connection by local parents led by AZHV leadership and AzEHDI Coordinator/audiologist and AAP Chapter Champion to provide input, encouragement, motivation and training to at least 5 underperforming hospitals each year
- Increase by 10% the number of infants that complete a diagnostic evaluation by three months of age
- Leverage roles for existing partners in improving systems including:
  - ASDB ELP to train AzEIP providers on referrals, Service Coordination and base knowledge of hearing issues at least annually
  - Parent Leadership to work with AzAAP chapter champion, medical providers to identify and address specific messaging related to appropriate and timely referrals, late onset and progressive loss, deaf plus challenge and children with middle ear conditions including those with craniofacial anomalies with the outcome of a comprehensive plan
  - Support OCSHCN in expanding training and reporting into early childhood programs statewide
- Establish baseline and goals for the number of health professionals and providers trained on key aspects of the EHDI program

The AzEHDI is submitting a request for the supplement grant to address a needs assessment for providers. Preliminary data collected from Early Intervention, Pediatric Audiology and Parents surveyed identified the following needs for training/education:

- Best practices in diagnosis, fitting hearing aids and cochlear implants
- Cytomegalovirus/cCMV
- Assistive listening, safety and alerting devices
- Unilateral hearing loss
- Early Intervention and Special Education services
- Counseling and motivating parents

Arizona has a significant number of subject matter experts in many of the topics that were identified. EFaz has experience, through various grants and donations, providing workshops in the past to address best practices. The strategy to address the outreach and education needs is to leverage local talent and existing resources as well as promote common messaging and knowledge across disciplines. Some topics are discipline specific (such as Auditory Brainstem Response (ABR) and Hearing Aid fitting protocols) whereas others (such as CMV and hearing

loss secondary to craniofacial anomalies) are conducive to joint trainings and workshops for medical, audiology and early intervention. The workgroup will determine a plan for prioritizing and presenting educational opportunities and the best way to convey that information including promoting education that is already available through the National Center for Hearing Assessment and Management (NCHAM), Family Leadership in Language and Learning (FL3), national professional organizations and others. Specific training or expertise that is not readily available in the state will be brought in and hosted through workshops and webinars.

Arizona State School for the Deaf and the Blind is the subject matter expert for Part C of IDEA services in the state of Arizona for children who are DHH. This proposal will support ASDB's role in providing training, policy and practice guidance to the AzeIP through sponsoring education targeted to AzeIP service coordinators. EFAz along with other advocacy organizations will assist in educating and mentoring parents and professionals in advocacy, legislative process, policy and best practice implementation.

### Objective Three

#### *Family Engagement and Education*

Families will be provided with information that is accurate, culturally and linguistically appropriate and timely. Methodology will include leveraging parent leadership at all levels of AzEHDI to review and revise communications with families from prenatal to enrollment in early intervention. A specific need has been identified to provide standardized information at the time of failure of the initial hearing screening. AZHV parents will work with FL3 to identify existing resources, develop Arizona specific materials, distribute and assist with implementation at the screening sites across the state. This process will also identify parents in the targeted communities who are willing to work towards a longer term relationship with the AzEHDI screening sites, agencies and organizations providing hearing screening diagnosis and early intervention in their community. This will result in a sustainable model of engagement that will be used to provide quality improvement initially to at least five sites identified as in need of improvement. Other family engagement and education activities and methodology can be found under the headings of Parent to Parent support and the involvement of DHH adults.

#### *Parent to Parent Support*

Parent to parent support through the AZHV Guide By Your Side program is offered to every family of a newly diagnosed child. The budget needed for this and the DHH Guide program exceeds what is available in this grant. AZHV is working toward sustainability and diversifying available funding for this program in excess of what is currently available. Part of the mentorship on behalf of EFAz is focused on increasing the capacity of AZHV to write community grants and raise funds to make the Guide programs, parent leadership activities and family activities more sustainable beyond the HRSA Universal Newborn Hearing Screening (UNHS) grant. The capacity of the Guide programs depends also on ongoing recruitment, training and support for the guides. Although data exists in Arizona on the number of families with guides and attending events, the first year of the grant will be used to determine how many families are enrolled by the time that their child is 6 months of age. Parent to parent support is also a targeted area for quality improvement related to assessment, timing, quality and parent satisfaction.

Measurable outcomes include:

- Establish baseline for referral and enrollment by six months of age
- Establish a quality improvement plan for parent to parent support and DHH family support including:
  - Time to first contact
  - Tracking of number and type of contact
  - Improve % of families that have regular contact with guide or mentor
  - Improve % of families who attend at least one event per year
  - Improve the % of respondents who can correctly identify the person and roles of the Early Interventionist, the Deaf Mentor, the DHH guide and the parent guide

#### *DHH Adult to Family support*

Arizona is privileged to have both a Deaf Mentor Program and a Deaf and Hard of Hearing Guide program through AZHV. Both programs are committed to working cooperatively to leverage opportunities for families to benefit from contact and mentorship with Deaf and Hard of Hearing Adults. The DHH Guide program ensures that paid, highly trained DHH Guides also regularly attend social, educational and networking events as well as 1:1 opportunities.

DMP/DHH Guides are also an area targeted for establishing a baseline and targeted quality improvement efforts to ensure that all families have opportunities that work for them and provide positive, useful experiences. It is expected that 100% of families will be offered DHH adult experiences. The first year of the grant will include establishing a baseline for how many (%) of families receive DHH adult to family support by the time their child is 9 months of age.

#### *Objective Four*

##### *Coordination of Care and Services*

The ADHS ONBS program is funded through the Centers for Disease Control and Prevention (CDC) Cooperative agreement to be working on establishing an electronic link for audiologists to both report assessment results and to refer to early intervention through a central portal. Educating medical providers on appropriate and timely referrals is also currently an ONBS follow up team activity for any child who does not pass the newborn hearing screening. Screening programs are required to report the primary care provider and ONBS follow up contacts the provider to facilitate referral to appropriate diagnostic sites for testing. ONBS is state funded through a statutory fee on the Newborn Screening Blood spot. EFAz and AzEHDI supports this role through education to screening facilities, audiologists and medical providers.

Arizona is fortunate that the newborn hearing screening results are available on the back of the immunization record. Previous Quality Improvement projects demonstrated that more than 80% of parents have the results with them on the immunization card at the first well child visit. The AAP Chapter Champion and AzEHDI Coordinator have provided ongoing education on finding results and providing appropriate and timely referrals. The education workgroup is expected to address the need for education on special populations such as CMV or those children with craniofacial anomalies that are often late identified. Engaged, educated and empowered parents are also key to timely diagnosis and early intervention. Efforts targeted at parents include the ONBS follow up and GBYS.

Methodology to assess the coordination of care across early childhood programs will focus on a parent led work group to determine what measures should be used for the assessment. The workgroup will incorporate those staff from ADHS Office for Newborn Screening (ONBS) and OCSHCN as well as stakeholders from AzeIP, ASDB, First Things First, Home Visiting and Early Head Start. Measurements will include participation by stakeholders in parent led meeting, development of a plan and progress towards executing that plan.

#### Objective 5

##### *Participate in EHDI meeting*

AzEHDI has actively participated in the national EHDI meeting since its inception. The program looks at areas in which the state excels and submits presentations or posters each year. In addition to funding a parent and the AzEHDI Coordinator each year, EFAz has partially funded attendance for our Chapter champion, DMP coordinator and early interventionists. ADHS ONBS follow up coordinator, OCSHCN staff, AzeIP, ASDB, private practitioners and others attend using other funding sources. EFAz proposes using HRSA grant funding to ensure that a parent, state coordinator and the chapter champion can attend and encouraging the use of other available funding to ensure additional parents and stakeholders are able to attend.

#### Objective 6 optional needs assessment

See Attachments 7-8

#### Objective 7

##### *National and State Leadership*

EFAz will continue to provide leadership, coordination, mentorship and advocacy within the state and representing AzEHDI at the national level. Lylis Olsen has served as the AzEHDI coordinator since 1994. She has and will continue to serve in state and national positions, on committees and workgroups to further EHDI objectives and provide input leaders.

As an EHDI Coordinator, Lylis along with Ginger Mullin, the Illinois Coordinator have facilitated an independent coalition that hosts teleconferences for EHDI coordinators called EHDI Chats. This group is entirely voluntary but routinely draws >30 participants representing the same number of states and territories. It serves as a safe place to share information, mentor, coach and coordinate between states in an open environment. Although many others have requested admittance, the group has made the decision to carefully limit membership only to those who are identified as the state EHDI Coordinator (usually one per state) to ensure that it remains a safe place. ADHS has documented agreement through a published letter to stakeholders and federal agencies that Lylis Olsen is the designated EHDI Coordinator for Arizona. It is anticipated that EHDI Chats will continue to support coordinators throughout the duration of this grant. Relevant information is shared to other programs and staff.

A primary role for the AzEHDI Coordinator is to facilitate cooperative efforts between agencies, organizations, not for profits and others. This role involves connecting groups with those either in state or nationally that have similar goals, working on related projects or implementing new strategies. This work is facilitated by the NCHAM and FL3 (see letters of collaboration) and EHDI chats

The focus for the next four years will be to improve the ability of AZHV to sustain their programs and diversify funding sources. AzEHDI has made significant progress in sustainability through the work of the ADHS ONBS and OCSHCN and efforts are ongoing. EFAz leadership is committed to mentor AZHV in grant writing, fund raising and advocacy. EFAz will also use its 23-year history of knowledge and collaboration with various governmental and non-governmental organizations to facilitate embedding parent leaders in all levels of AzEHDI.

EFAz leadership is also committed to re-engaging ADHS in community-based projects including education of providers as mandated through newborn screening statute, hearing screening in early childhood programs and connecting parents to other parents through follow up.

### Logic Model and Work Plan

See attachment 1 for work plan and logic model

### Resolution of Challenges

The previous grant application (2017) indicated that one of the challenges was the move of the grant administration from the ADHS to EFAz. The move was precipitated by both administrative difficulties in hiring, contracting and managing the grant as well as a change in focus of the grant from newborn hearing screening to diagnosis and early intervention. There was conflict between the community needs and grant focus and the ADHS ONBS desire to use funding to supplement the screening program, particularly follow up. For 15 years under previous ONBS leadership EFAz provided the lead on the direction, collaboration and writing of the HRSA UNHS grant. EFAz was the primary recipient of contract funding to complete the grant objectives with ONBS acting as fiscal agent.

The move to EFAz was successful in limiting overhead and indirect costs, expanding parent to parent support, continuing the focus on the community providers including audiologists and early intervention (ASDB-part C provider). This focus significantly improved both the support provided to families and the leadership of parents in the AzEHDI process and the growth of Deaf Mentors and Deaf and Hard of Hearing Guide programs. Overall, loss to follow up was reduced from 27% to less than 8% at the diagnostic stage and a similar amount at the screening stage. Most importantly the collaborative partnerships with audiologists, medical providers, screening programs, parents, the DHH community and other stakeholders were maintained and expanded along with community level control and priority setting for AzEHDI.

EFAz's control of the grant along with the newborn hearing screening follow up for the past two years provided a unique opportunity to fully implement the intent of the HRSA grant objectives. The HRSA EHDI funds are inherently the only dedicated funds for families with children who are DHH. Ensuring that the funds are used for that designated purpose is key to fully utilizing the ability to impact the AzEHDI system. Funds through the MCH Block grant and state blood spot screening funds are intended for those EHDI components related to public health surveillance, data collection and reporting. The data should be used to focus community efforts to improve services and outcomes for children and families. This includes supporting the EFAz and other partners in maintaining a community based, parent and child focused system.

EFAz recognizes the public health role of ADHS ONBS (and helped establish that role through legislation) in mandated screening, reporting, data collection and surveillance. EFAz supports that role as it forms the basis for all that follows in EHDI, however understand that the community focus and reduced indirect costs and overhead as well as flexibility the EFAz and other stakeholders can better implement a shared responsibility and accountability as well as control for AzEHDI.

If funded, EFAz and other AzEHDI partners will continue to work with ADHS to improve transparency so that all AzEHDI priorities can continue to be data driven and ADHS ONBS and OCSHCN efforts are supported, including their expanded role in early childhood screening. Along with providing training curriculum to OCSHCN, AzEHDI staff will apply to become early childhood trainers for the new Sensory program and EFAz will continue to provide early childhood screening to more than 4000 children each year including those children in home visiting, childcare centers, out of hospital births and others. In addition, EFAz's contract with AZHV will continue to support the Latino learning community led by OCSHCN and GBYS Latino DHH events. ADHS is a part of the AzEHDI stakeholders committee and Lylis Olsen, AzEHDI Coordinator is an ADHS director appointed member of the ADHS Newborn Screening Advisory Committee.

Another challenge is the result of the overwhelming success and rapid growth of the AZHV programs. 84% of all newly identified parents are interested in a Parent Guide and in participating in AZHV events. The Deaf and Hard of Hearing Guide program in collaboration with the ASDB Deaf Mentor program is experiencing similar growth. In the past three years AZHV has gone from 1 part time paid staff with a budget of less than \$20,000 to 13 part time staff and a budget greater than \$150,000. Although this grant proposes funding for parent to parent and adult DHH services significantly greater than the required 25%, the organization is now in need of significant additional funding to maintain and expand the level of services and to meet their goals of providing leadership at all levels of AzEHDI in all organization and agencies as well as a focus on sustainability EFAz and the AzEHDI Coordinator will continue to function in a mentoring role in community grant writing and leadership for AZHV. EFAz is willing to act as a fiscal agent for larger community grants that would otherwise be unavailable to AZHV due to their small size and previous budgets. Both AZHV and EFAz see this as a positive problem and will work together to address.

## Evaluation and Technical Support Capacity

### Evaluation

Two approaches will be used for evaluation. The first will be an ongoing real-time evaluation of each of the activities undertaken allowing for ongoing quality improvement. Most QI activities will use the small tests of change, PDSA approach that has been implemented previously. As described in the work plan and methodology sections, each grant activity has a component of evaluation embedded and all activities are data driven.

Annual evaluation will involve compiling the cumulative data on progress as well as evaluating the CDC Hearing Screening and Follow up Survey (HSFA) to determine progress on goals

related to diagnosis, timely referral and enrollment in EI services. Results will be shared and discussed at the stakeholders meeting and available to others interested in AzEHDI.

The new 2019 Joint Committee on Infant Hearing (JCIH) Position Statement will be reviewed and discussed at an upcoming stakeholders meeting in January 2020. At that meeting priorities will be determined based on feedback from the group. Early review shows that Arizona is not meeting some of the benchmarks such as:

- Lack of audiological oversight of the newborn hearing screening programs and ONBS
- Endorsement of OAE after ABR for well babies, if and how to incorporate into AzEHDI
- Infant mental health supports and how that fits into parent to parent support or EI
- Implementation of CMV protocols, education and potential legislation
- Implementation of evaluation intervals for specific risk factors per JCIH 2019
- Strengthening the link to timely referral for audiological evaluation and management after audiological evaluation

The stakeholder group will review the current status, prioritize and assign activities to be addressed by the collaborative agencies as appropriate, highlighting role and responsibilities. It is imperative to have collective buy in to AzEHDI goals to effectively and efficiently address issues. Activities by the non-profit partners, directed by boards and parents, do not have the constraints of large governmental systems or intermediaries delaying or impeding how or when to perform services which can eliminate interruption and delays.

The ASDB governing board is embarking on a strategic plan specific to Early Intervention Services to the age 0-5 population with the intent to focus resources on this group in order to impact long term outcomes. This effort will include an evaluation of the current services and has begun with the AzEHDI Coordinator working with the board to ensure that they understand the newborn hearing screening, evaluation and referral processes currently in place as well as the current status related to milestones and challenges in Arizona. This effort will be ongoing and a core part of evaluating early intervention services.

A significant area of evaluation and ongoing quality improvement efforts will focus on family to family support and exposure to Deaf and Hard of Hearing adults. An online survey of parents returned a disappointing number of results. AZHV acknowledges the need to obtain more timely satisfaction information from parents in order to provide data to improve timeliness, quality and content to their Guides. Small tests of change and data tracking will focus on using shorter assessments at more frequent intervals closely tied to services. How to communicate with young parents through social media, texting and other sources will also be systematically explored and implemented to ensure that services continue to improve and meeting the ongoing needs of families. A new audiology lead at our largest diagnostic center has experience in another state with assessing family needs through focus groups and surveys and has expressed an interest in facilitating this approach in Arizona through AZHV.

The Tele-Intervention (TI) program remains in place carried over from the previous HRSA and community grants as a useful way to serve families who may not otherwise have access to high quality early intervention, Guide and DMP services. TI will be evaluated to assess how many

parent guides and Deaf Mentors use the technology with families and how satisfied both the families served, and providers are with the use of technology for their interactions with families. Evaluation tools will include tracking of usage and parent and provider satisfaction surveys annually. As with other disciplines, the success of this method is expected to grow. Evaluation strategy will include tracking usage as well as parent and provider satisfaction.

Sustainability and leveraging of existing programs through education will be evaluated through process and outcome measures. Individual educational events will be tracked as well as satisfaction with each event. The number of potential providers impacted and the number of families impacted will be assessed.

Progress towards engaging parents in the process in a meaningful way, not just to participate but to take leadership roles, will be continually expanded and assessed through:

- the number of parents attending leadership training opportunities,
- the number of hours of leadership vs participation hours invoiced each month and
- an online survey which will assess the satisfaction of parent participants and leaders in their role and input.

Local parent participation on regional projects such as engaging birth hearing screening programs will also be tracked and monitored. Evaluation will address both the quantity of identified leaders with the parent and the DHH communities, the number of leadership roles assumed, the number participating in leadership training and mentoring and outcomes of training, including how comfortable each of them feels in taking on a leadership role.

#### Data

Data is currently tracked in several ways. The basis of the surveillance process is the Hi\*Track database that is supported by the ADHS ONBS. Hi\*Track captures data from all birthing hospitals from the initial newborn and subsequent screenings up to 24 months of age. It is used to capture not only the screening and diagnostic information but also referrals and enrollment in EI. Reporting to the CDC for the HSFS is completed by ADHS ONBS using Hi\*Track. Vital records data is merged into Hi\*Track and allows individual data on all births to be captured as well as the data to be analyzed for impact or outcomes with different cultural groups including race, ethnicity and language. Periodically data from Pediatrix Sound Data is merged to assist in tracking follow up efforts. Pediatrix as an outsourced screening company, screens approximately half of the state births and does extensive follow up through the initial and outpatient screen. ONBS follow up has access to the state AHCCCS (Medicaid waiver program), immunizations and blood spot databases which allows additional demographic data to be acquired to locate families and identify their medical home provider.

The Hi\*Track database is also used to guide quality improvement efforts and will be used to identify communities to target for community-based intervention. ADHS leadership staff including data management and epidemiology has previously committed to collaborate with EFAz to support data needs for this project. This program is publicly funded, and the expectation is that they will provide aggregate data for the Newborn Hearing Screening program and special reports as a component of oversight and specifically quality improvement needs.

OCSHCN has recently developed a reporting mechanism for hearing screening in early childhood programs. It is anticipated that this data will be made available to the AzEHDI stakeholders for program planning and evaluation. As another publicly funded program and subject to both open meeting laws and freedom of information requirements.

The AzEHDI Coordinator is responsible for maintaining sign in sheets for all stakeholder meetings and any meeting evaluations performed. A lead person (often a parent) for each community project or learning community will be identified and will be responsible for documentation of each meeting, participation, data collected, quality improvement measures implemented and outcomes.

### Capacity

See expanded organizational information for EFAz in the next section.

### Audiology

The EFAz AzEHDI Coordinator is a licensed audiologist with >30 years of experience in mostly administrative and policy roles. EFAz has contracted with experienced audiologists as needed to provide technical support over the past 23 years including Randi Winston, AuD and Melanie Moore AuD. An audiologist that is fluent in Mexican dialects of Spanish, Sara McLaws, AuD consults on an as needed basis to ensure that any bilingual communications regarding hearing are also accurate in Spanish for our large Latino population that is largely Mexican Spanish speaking.

### Parents

AZHV has co-executive directors, both of which have bachelor's degrees and experience. One is also a DHH adult, been through interpreter training in ASL and the other has two oral deaf children. One of the executive directors of AZHV has also been through the Raising Special Kids (family voices) leadership training. One parent on staff is also fluent in Spanish, has a Deaf plus child and is currently completing a degree in speech language pathology. There are 10 Guides currently employed with 3 DHH themselves, 4 Spanish speaking, 1 Arabic speaking and xx fluent in ASL.

### Sustainable Government Funding

The Arizona hearing screening rules were updated extending the reporting of school age hearing and vision screening data collection under ADHS OCSHCN and including training and reporting requirements for early childhood sensory screening. OCSHCN curriculum is largely based on ECHO and the former EFAz HEAR to Train program. Funding is available for both their screening, reporting, and equipment loan through both state and federal funds. Slightly less than \$2.5M is budgeted from the MCH block grant each year for OCSHCN with additional monies from the state general fund and other sources. AZHV has offered to provide the DHH specific parent perspective to their programs that they currently are lacking. AzEHDI chooses to support their efforts in expanding screening to the early childhood program as this will provide a sustainable infrastructure. HRSA funding will not be used to supplant the existing funding for these efforts.

Likewise, AzeHDI supports the ADHS ONBS role in follow up, surveillance and oversight of the statute and rules pertaining to the newborn hearing screening system. The statute and rules were championed by EFAz in order to provide a sustainable infrastructure for the program. The ONBS receives more than \$7M each year to provide these services. HRSA funding for this project will not be used to supplant the existing state funding.

Early Intervention services through ASDB for DHH children ages 0-5 in Arizona is largely funded through the state. Less than 6% of the funding comes from Part C of IDEA although ASDB is the designated agency under the umbrella group called AzeIP. The ASDB board is working on a strategic plan, part of which is an effort to divert additional funding to early childhood programs in order to impact long term outcomes and to track those outcomes in a systematic way.

Programs such as the Head Start, Early Head Start, AzeIP, various Home Visiting programs and others are funded through state and federal funds and often include funding for equipment and training necessary to screen their program participants. EFAz has worked for the past 18 years to expand hearing screening in these programs.

#### Organizational Information

The EAR Foundation of Arizona, a 501c3, not for profit organization, is the lead organization for this grant and part of the group of many organizations, agencies and individuals that comprise the entity known as Arizona Early Hearing Detection and Intervention. EFAz has been active in Universal Newborn Hearing Screening efforts since 1996, a year after they were incorporated in Arizona. John Macias, MD, is the Board President and Founder of EFAz. He is a neuro-otologist based in Phoenix Arizona. An organizational chart is included in the attachments.

Early efforts in the area of newborn hearing screening included EFAz collaborating with the ADHS program (at that time under the lead of Lylis Olsen, MS, MPH, CCC-A at the ADHS sensory program) and funded through the Vitalyst Health Foundation to provide equipment and technical assistance for hospital newborn hearing screening. Part of that 3-year project included collecting data from hospital screening programs. Arizona served as a beta site for the National Center for Hearing Assessment and Management database called Hi\*Track.

Ms Olsen is a Pediatric Audiologist who has a Master's in Public Health with an emphasis on community health. She has 30 years of experience in program management including extensive quality improvement leadership roles. She served as a quality improvement mentor for two states through the National Center for Hearing Assessment and Management. She has served the American Speech Language and Hearing Association as elected member of the advisory council and as a member of the Medicaid committee. Ms Olsen was an elected officer of the Directors of Speech and Hearing Programs in State Health and Welfare Programs and served on the task force to develop a national data collection pilot program for newborn hearing screening. In 1999, Ms Olsen worked part time for EFAz managing the HEAR for Kids program and in 2000 she left the ADHS to work on AzeHDI projects through EFAz. Ms Olsen has served in the role of AzeHDI state coordinator since the inception of the program.

In 2005, as a public health student intern with Melissa Selbst, MPH, Director of Programs and Public Affairs at March of Dimes, (now Executive Director of EFAz), Ms Olsen worked with a group of stakeholders including parents to propose legislation to incorporate hearing screening into the blood spot screening legislation. This legislation did not mandate screening (hearing screening rates were already over 95% voluntarily) but mandated that if screening or diagnostic testing was completed subsequent to screening that the results would be reported to the ADHS ONBS. This legislation expanded the ADHS Newborn Screening Advisory Board to include parents, audiologist and ENT/Otology and established a requirement for follow up, education and surveillance (through the newborn hearing screening database). Ms Olsen currently serves as a director appointed member of this board.

Ms Selbst has a Master's in Public Health with an emphasis on education and is a registered lobbyist in the State of Arizona. Legislation passed in 2005, established the follow up program as well as provided stable funding for the surveillance, the statewide database, education and follow up staffing. In 2014 additional legislation championed by Ms Selbst, was passed to mandate hearing as one of the conditions on the newborn screening panel.

EFAz had a continuous contract with the ADHS ONBS program beginning in 2002 through August 2019 which was funded through a combination of state newborn screening blood spot fee fund, the cooperative agreement with the CDC and the HRSA Universal Newborn Hearing Screening grant. The contract funded between 300-400 hours each month of consulting including:

- Training for each hospital newborn hearing screening program
- Quality improvement activities
- AzEHDI State Coordinator activities
- Grant writing
- Education of physicians, parents, public health and education programs
- Collaboration between all of the agencies, organizations and individuals that comprise AzEHDI
- Data input and evaluation of Pediatric audiology diagnostic test results
- Technical assistance to pediatric audiologists
- Development of materials such as the pocket guide, roadmap, brochures etc
- Assisting AZHV in program development, board membership, recruitment of members, education and training
- System review and improvement

Between May 2017 and August 2019 EFAz was also contracted by ADHS to provide newborn hearing screening follow up services. The ADHS contract expired in August 2019 and ADHS stated that their decision to resume follow up internally was entirely financial and that they felt they could provide the services less expensively in house and were now able to hire and cross train additional staff.

EFAz programs include:

- BASICS
- HEAR for Kids
- HEAR to Assist
- AzEHDI

Building a Screening Infrastructure for Children's Success (BASICS) is a multi-year grant funded program within Maricopa County to screen hearing and vision for children ages 0-5, primarily in Child Care settings. The program employs 5 screeners and follow up staff and screens approximately 5000 children each year. This program has been running continuously since 2011. Three of the staff are parents of children who are DHH. Two staff members are bilingual English and Spanish speaking.

HEAR for Kids has been an EFAz program since 1999, with continuous funding through Vitalyst Health Foundation, other grants and private donations. Each year, between 120 and 180 hearing aids are purchased as loaners for newly identified children or as permanent aids for those children whose families do not have insurance coverage and are low income. In addition, the program provides earmolds, repairs and replacement of implanted devices and vouchers. The vouchers are used by the follow up program, school hearing screening programs, BASICS, Early Head Start, Home Visiting programs and others to ensure that children who have failed a community based screening are able to receive a diagnostic evaluation even if they are low income and do not have insurance coverage for audiology services.

HEAR to Assist is a volunteer led program to provide refurbished hearing aids to low income adults partnering with community-based audiologists.

HEAR to Train provided hearing screening training with curriculum that has been specifically developed for:

- Pure tone school hearing screening
- 0-3 OAE screening
- Tympanometry

The HEAR To Train previously certified trainers as well as provided community training for health care providers, Early Head Start, Arizona Early Intervention Program contractors, Home Visitors and others. The program was funded through fees for training. In the past the EFAz has also had grant funding to work with Federally Qualified Health Center to implement OAE screening. EFAz has served on agency work groups to develop policies, procedures and tool kits related to community based 0-5 and school-based hearing screening programs.

EFAz has worked extensively to assure that family support is available to all families. EFAz received a community grant to develop a family to family support organization that eventually created its own 501 (c)(3) status as the Arizona Chapter of Hands & Voices. EFAz employs three parents of children who are Deaf or Hard of Hearing and maintains an extensive database of more than 1500 families of children who are DHH. EFAz provides mailings and list serve notification for AZHV to recruit parents and notify them of AZHV events each year.

AzEHDI will attempt to engage both ONBS and OCSHN to leverage their mandate and funding to provide additional training for parents, access referrals for families of newly identified children who are DHH and to engage them in the education needs assessment as it is part of their legislative mandate that is currently not being implemented. They are active members of the AzEHDI Stakeholders group and regularly participate in the quarterly meetings. AzEHDI has had strong partnership in the past with both ONBS and OCSHCN and is expected to continue those as we have mutual goals for families in Arizona. ADHS ONBS was the fiscal agent for the HRSA grant prior to the most recent grant cycle with EFAz writing the grant and providing most of the services and oversight of the grant.

In 2017, with the agreement of ADHS, EFAz was the primary applicant for the UNHS HRSA grant. The award to EFAz allowed a much larger portion of the grant to be used for activities rather than indirect and allowed MOUs and subcontracts to be completed before the grant began rather than the lengthy process required by the state (currently more than two years for an MOU between ADHS ONBS and AzeIP). EFAz has a different approach and philosophy which is more community based. Providers, parents and other front-line stakeholders are regularly polled to determine their needs as well as their input on policy and practice. Parents are an active participant in writing the grant including determining priorities, methodology, activities and budget. EFAz has chosen to focus on collaborating with the ASDB ELP early intervention providers as they are the primary service providers, rather than the umbrella agency AzeIP. We have focused on partnering with AZHV rather than Raising Special Kids (the family voices recipient) for most projects as parents have expressed a very strong preference for parent to parent support specific to families who have children who are DHH. AzEHDI includes all of the agencies and organizations including Raising Special Kids (family voices) ADHS, AzeIP, Az Department of Education and other in the stakeholders meeting to ensure that networking occurs, information is shared and there continues to be a common mission and purpose across EHDI.

See the attachments for a copy of the position descriptions and biographical sketches of key personnel.

Both the Project Lead and the Executive Director have many years of experience in managing multimillion-dollar budgets and in working with multiple funding streams including federal, state and local grants. EFAz has an independent accounting firm that is responsible for bank reconciliation and report generation each month. Procedural safeguards and internal controls are in place to avoid account errors. The Project lead and the Executive Director as well as the subcontractors ZHV and Dr. Golner meet regularly. AZHV submits monthly reports and invoices and Dr Golner submits quarterly.