



THE EAR FOUNDATION[®]
OF ARIZONA

HEAR for Kids
Hearing Services for
Arizona's Children

Introduction

In 1999 a group of providers came together to talk about the unmet needs of children who are Deaf or Hard of Hearing in Arizona. With the help of St. Luke's Health Initiatives a collaborative program called HEAR for Kids (HFK) was created. The program is managed by the EAR Foundation of Arizona (EFAz) but the community of providers and parents continue to make decisions on the policies and practices of the program.

The group identified three areas where families needed assistance. The first was the need for a high quality pool of hearing aids that would help bridge the gap between diagnosis of hearing loss and obtaining permanent hearing aids. This gap is caused by a fragmented health care system, the need to obtain preauthorization, qualify for third party assistance or the confounding factors of difficulty in testing infants, frequent ear infections and possible progressive hearing losses. The second gap was those children whose parents had no financial resources to purchase hearing aids yet they did not qualify for state services. The third area was those children who needed an audiological or medical evaluation to determine hearing loss but did not have financial resources to obtain the evaluation and were "stuck" in a cycle of screening without a diagnosis.

The goal of the HFK is to fill the gaps so that all children in Arizona who are Deaf or Hard of Hearing have access to the services and technology that they need to be successful. Since the beginning of the program, almost ten years ago, more than 2000 children and their families have benefited from HFK. The average cost for each child assisted has been less than \$850. Services range from a set of earmolds (the custom made piece which fits in the ear and holds the hearing aid in place) to very high tech hearing aids that are worth up to \$4,000 apiece. The overall program has been found to be cost effective, efficient and serves a critical need at a time in the child's life when delays have life long consequences.

Since 1999 the program has provided:

- 1087 permanent hearing aids
- \$32,495 toward repair of hearing aids
- 871 vouchers for hearing related services totaling more then \$100,000
- loaner hearing aids for more than 800 children.
- 2376 earmolds (the custom made plastic piece that holds the hearing aid in place)

The report is divided into sections based on the type of services provided (loaner aids, permanent aid and vouchers), the results of a survey recently conducted and collaboration with the Arizona chapter of a parent support group called Hands and Voice and the Early Hearing Detection and Intervention program. Program changes, which will be described in each section of the report, are minimal and reflect overall satisfaction with the program both by providers and the parents of the children they serve.

Table of Contents

Introduction.....	1
Table of Contents.....	2
Loaner Hearing Aids.....	3
Program Overview.....	3
Changes to the Loaner Program.....	4
Baha®.....	4
Model Hearing Aid Loan Program.....	5
What Parents Say:.....	5
Permanent Hearing Aids.....	6
Population Served.....	6
Changes to the Program.....	7
What Parents Say:.....	7
Impact of Starkey “Mission”.....	7
Vouchers.....	8
Changes to the Program.....	8
Survey.....	9
Limitations:.....	9
Results.....	9
What Providers Liked.....	9
Opportunities and Suggested Changes.....	10
Arizona Hands and Voices.....	10
Early Hearing Detection and Intervention.....	11
Summary.....	12
What Parents Say:.....	12

Loaner Hearing Aids

The basis of the program is:

- *High quality, advanced technology hearing aids*
- *Requested online using a web-based system*
- *Available to any newly identified child*
- *For six months (longer as needed on case-by-case basis)*
- *Without cost to the family*
- *To allow fitting within two weeks of diagnosis*

Program Overview

Each year HFK loans approximately 200 hearing aids to children. Most of these are infants, with newly identified hearing losses, although some are older, trying out a new technology, or are in hearing aid trial prior to cochlear implantation. The normal loan period is six months, but is flexible depending on need.

The need for a statewide pool of loaner hearing aids is primarily due to the fragmented system of covering hearing aids for children and the nature of hearing loss in infants. Most infants are screened at birth and the average age of identification is less than six months of age. There are only eight diagnostic centers in the state. Currently, the diagnostic center in Flagstaff is the only one also associated with a Children's Rehabilitative Services clinic where half of the children will end up receiving services.

Children who are covered under the Arizona Health Care Cost Containment System or KidsCare eventually receive their permanent hearing aids and specialty medical evaluations through the Children's Rehabilitative Program. However, these children can not begin the application process for CRS until a diagnosis is confirmed. Determining the type, configuration and potential for a hearing loss to be progressive in nature may take multiple visits to a pediatric audiologist.

The loaner hearing aid program allows high quality amplification to be fit while the funding, etiology, emotional issues and severity of hearing loss is being sorted out. Scientific evidence is now available that shows that the first months are critical for brain development related to hearing. Appropriate amplification and intervention before six months of age is likely to lead to speech and language development that remains within the normal range.

A Speech Language Pathologist describes the benefits:

Though not a parent I can attest that the difference these aids make for families is immense. Families are generally shocked with the diagnosis of hearing loss, especially if identified through newborn screening. They are struggling to deal with a lot of new information and grief. Having this program available allows parents to obtain aids for their children in an easier, less stressful manner, and gives them a buffer zone in which to deal with the emotional aspect of the diagnosis, while still providing listening opportunities for their children. They can take a bit of time to come up with the funds to purchase the hearing aids, and also have an opportunity to see the positive impact of the aids on their child, helping them to buy into the importance of amplification.

Changes to the Loaner Program

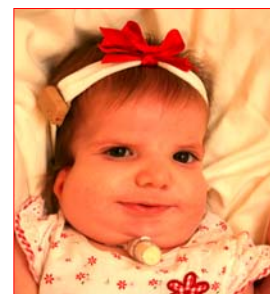
The primary change over the past nine years has been in the type of hearing aids in the loaner pool. In 1999, digital technology was still quite new and about half of the aids purchased were analog technology. Currently all of the loaner aids are digital.

The rapid changes in technology and need to upgrade the loaner pool are compounded by the fact that hearing aids worn by infants don't last long. The average lifespan for an adult hearing aid is five to seven years, for a child three to five years is more typical. For aids in our loaner pool, it is likely that they will last three or fewer years before they need to be repaired or replaced. Infants chew on their hearing aids, feed them to the dog and throw them. Toddlers are known for flushing them during those critical toilet training years. They are also known to hide them in silly putty or lose them in their back packs. Hearing aids are usually retired to an adult hearing aid program (such as the Community Hearing Aid Program) after five years.

The increased cost of new technology has been offset by the creativity and dedication of the audiologists in the community. They have been instrumental in maintaining the quality of the aids in the pool while containing costs. Our average cost of hearing aids is no greater than it was in 2001 despite increasing costs of some of the more advanced technology. The audiologists are not restricted in what is purchased and the replacement aids are purchased as they are needed/requested. If an audiologist does not see an aid in the existing loaner pool that is appropriate for their patient they request what they need (or want to try). They often use their own relationships with vendors and resources to get the best possible price on the aid that they want to fit.

Baha®

Baha® is an amplification device which is generally externally affixed to a titanium screw, which is osseointegrated into the skull and protrudes through the skin. This provides excellent conduction of sound and is the preferred practice for children with permanent conductive hearing losses. The surgery is not generally performed until age five due to anatomical development issues. Until surgery the external portion can be worn on a soft band.



Cicily and her Baha

Baha® is owned by Cochlear America who has generously provided five of the devices on an extended loan to be used in the loaner pool. There is no published evidence showing advantages for the device on the softband over a traditional analog device. It is accepted that the sound quality is better and there are clear advantages once it is implanted. Because of the lack of evidence and the cost (approximately 10x traditional bone conduction aids) HFK has been reluctant to purchase the aids.

The HFK is working on facilitating discussions to develop a study to be done by a researcher at the Arizona State University, funded by the manufacturer of Baha® to evaluate the qualitative (and eventually quantitative) differences that might be expected with the Baha® on a softband over the traditional bone conduction aid.

Model Hearing Aid Loan Program

The loaner hearing aid program has become a national model for how to ensure that infants and children receive appropriate amplification in a timely manner. HEAR for Kids has been presented at the National Early Hearing Detection and Intervention conference and the American Academy of Audiology annual convention. In 2006 the program manager was asked to sit on a national task force for hearing aid accessibility and represent the role that a quality statewide loaner bank plays in the EHDI process. As part of the process it was determined that Arizona had the only statewide loaner program with advanced technology hearing aids that was available to all children with newly identified loss. Most programs were patchwork with old aids available to only certain populations. Most states are also struggling with up to a year lag time between diagnosis and fitting. The program manager has worked with several states to help develop their own statewide loaner system and Virginia, Alaska, Washington DC, Maine and Minnesota all have programs using components of the HFK model.

What Parents Say:

- *Loaner program was great-since our child had progressive loss and we had to try and change aids more often*
- *We got loaner hearing aids @ 3 months of age and wouldn't have been able to afford them otherwise*
- *HEAR for kids made it possible for my daughter to hear since 1 week of age. I am so appreciative of the service you provide.*
- *We found what a difference the CROS device made. Also that he would NOT wear it.*
- *It helped us get our son aided quickly and allowed us to get a grip on the situation*
- *The loaner really helped us determine if she needed it (unilateral loss), what kind she needed and we were able to get our finances together to purchase one.*
- *I am not sure my child would be at the level of hearing or understanding if we would not have had the aids so soon.*
- *My child was able to get access to sound at 5 weeks even when we weren't ready to fork out \$5K-\$10 for hearing aids*
- *Allowed our son to begin wearing his aids as soon as he was identified, rather than wait until insurance added coverage the following year*
- *They gave my 6 month old son access to sound. We won't know if he needs implants till about 12 months or so: so being able to loan til this decision needs to be made would be great.*
- *The program dramatically improves the speed with which a child starts hearing aid use and also reduces stress a great deal with parent know that they don't have to come up with thousands of dollars right at the time their grief and anxiety is the most intense.*



Corbin, 4 months of age, is wearing loaner hearing aids

Permanent Hearing Aids

Each year HFK buys between 120 and 150 permanent hearing aids for children who meet financial criteria. The criterion is based on the federal poverty guidelines with some allowed deductions (including rent/mortgage, un-reimbursed medical expenses and others). Some exceptions to the financial guidelines are made on a case by case basis. Most of the donations (funding other than St. Luke's Health Initiatives) are expended on these exceptional cases. Circumstances have included families with multiple family members in need of hearing aids, serious illness, divorce or other life surprises that may impact a family's ability to purchase hearing aids. Most insurance does not cover the cost of hearing aids and young families, regardless of income, are usually not prepared for the cost of hearing aids (which may exceed \$8000) with the birth of their newborn.

Because the cost of hearing aids is the majority of the budget, this is the place where restrictions have been made in the past when money was tight. We have been fortunate and have had to restrict the program once, for a little over a year and we chose to not provide permanent hearing aids for children over the age of 12. We have been able to lift that restriction and currently provide to age 18 (older if still in school).

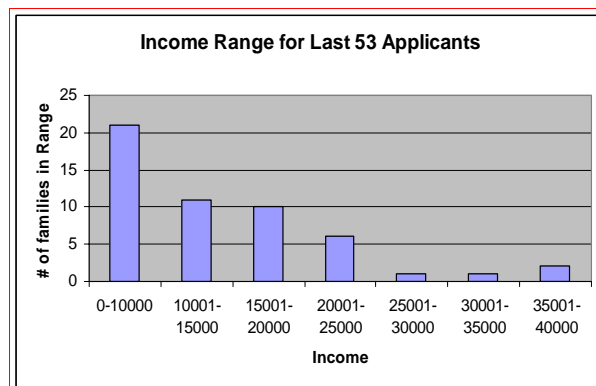
Population Served

Most (although not all) children receiving permanent hearing aids are older as most newborns are legal residents and have an identified source of insurance. The typical child is in school with a late identified hearing loss or hearing aids that are very old.

The HEAR for Kids program does not ask about the residency status beyond current place of residence in Arizona.

Of the past 53 applications for permanent hearing aids a birth city outside of the United States was listed on the application (includes Mexico, Burma, Korea, China, Philippines and Guatemala) for 21 of the children. An additional 17 had limited insurance that did not cover hearing aids including (Cigna, Blue Cross, Assurant, Humana, United Health and Aetna). The rest (15) were born in the United States, have no health insurance and were not eligible for Arizona Health Care Cost Containment System or KidsCare. It is NOT unusual for hearing aids to be excluded under insurance programs. AHCCCS and KidsCare only provide hearing aids for children through the CRS program and do not cover hearing aids for adults.

Hearing aids are selected and fit by a variety of community audiologists, including those in private practice, schools, hospital based and those employed by agencies such as the Arizona State Schools for the Deaf and the Blind. There are no restrictions on technology other than the same caveat as the loaner program that the audiologists strive to fit the most cost effective hearing aid to fit the needs of the individual child. Most aids are mid-range digital technology.



Changes to the Program

As discussed in the loaner section, the Baha® device is being evaluated for fitting children with permanent conductive hearing losses. HFK does not provide any of the surgical costs, but has been asked to help with the cost of the device pre-implant. This is currently being determined on a case by case basis due to the cost (approximately 10x that of a traditional bone conduction hearing aid).

An ongoing challenge is keeping up with new technology and incorporating data based decision making. We are fortunate to have one of the foremost researchers in the nation in the area of pediatric amplification, Andrea Pittman, PhD at Arizona State University. Dr Pittman has been a valuable resource for the HFK program and in educating pediatric audiologists in the state.



Brooke benefited from early amplification. She is learning to play the piano.

What Parents Say:

- *My first son received two hearing aids through this program. We were shocked to find out about our son's hearing loss at birth and even more shocked at the cost of hearing aids. Our son who is now two is talking up a storm and benefits on a daily basis from his aids.*
- *You purchased aids for my daughter that we could not afford*
- *HEAR for kids provided my daughter permanent hearing aids during a time of financial difficulty for us*

Impact of Starkey “Mission”

The Starkey Foundation completed a “Mission” associated with the 2008 Super Bowl. They have done missions in several other states and have had no problem meeting their limit of 300 children. Despite extensive marketing they were able to find less than 100 individuals (some adults) in Arizona.

Although they have not shared specific information, it is known that some children were fit who had coverage through CRS, had higher incomes than allowed under HFK or had hearing aids that were working but took the opportunity to replace their existing aids with the new technology that Starkey was offering.

The concern with the mission included the lack of pediatric audiologists to fit young children (they restricted to over age 3) and lack of coverage for follow-up services. Although there was much discussion of concerns among the community providers and with the Starkey Foundation, the impact appears to have been minimal. HFK provided two children with vouchers to obtain medical clearance and has helped coordinate follow-up care for two children who received the new aids but needed adjustments. The aids fit were high end digital hearing aids. HFK has not seen a net change in demand for permanent hearing aids, so far, as a result of the mission.

Vouchers

Approximately 120 vouchers are issued each year. Half are used to pay a nominal amount for fitting hearing aids. Although in the early years of the program this included only permanent hearing aid, the vouchers now also pay for the fitting of loaners on newborns for whom there are no other identified resource. In the past, vouchers have paid for one medical visit to receive medical clearance. The increased cost of the fittings have been somewhat offset by a decrease in use of the medical vouchers. This has been the result of a greater use of St. Vincent de Paul clinic both for medical clearance and for medical problems unrelated to an aidable hearing loss.

The other category of vouchers is for those children who are “stuck” in the screening cycle. These vouchers pay for a hearing assessment by a pediatric audiologist. The requests are primarily from school nurses, HeadStart programs, Arizona Early Intervention Program, Community Health Centers and from the St. Vincent de Paul clinic. Most of these are preschool or school age children who have failed hearing screenings whose families are not able to access audiology services on their own

The voucher program, even more so than the permanent hearing aids, is used by those with very low incomes. More than half of the last 40 applicants had an income less than \$10,000 per year for a median family size of five. None of the families had an income greater than \$20,000 per year.

Although it is a relative small part of the overall cost of the HFK program, the vouchers are labor intensive and generate the largest number of phone calls and emails. They also have resulted in some of the most dramatic stories. Each year several children are identified with serious medical conditions (including bilateral cholesteatoma tumors) or significant hearing loss that would not otherwise have been identified.

Changes to the Program

The reimbursement rate for the vouchers has not changed since the second year of the program and we have seen providers begin to refuse to see families with the vouchers. This creates additional problems when some families don't inform the provider when making the appointment that they have a HFK voucher. A very small number (less than 5 per year) are requested for sedated or un-sedated Auditory Brainstem Response testing. Currently there is no provider willing to accept the voucher for this service and two children who are currently waiting and meet the HFK income criteria. Discussions are ongoing to determine how to meet this need.

Originally the amount of the vouchers was loosely based on Medicaid reimbursement rates. There are ongoing discussions with the larger providers such as Phoenix Children's Hospital and Banner Health Systems to come to an agreement that would allow them to accept the vouchers. Parents and providers were asked about the possible inclusion of a co-payment and there is not consensus on the issue. Although the co-pay is probably feasible for the hearing aid fitting for some families, those families needing hearing assessments are very poor and a co-pay may be beyond their means.

Survey

In anticipation of the tenth year anniversary of the HEAR for Kids program a survey was sent out to parents and providers to evaluate the program and to elicit ideas for potential expansion or changes in the program. The survey is not intended to be scientifically valid. Some of the audiology practices completed one survey for the site rather than individual surveys. The parents were surveyed through a mailing by the parent support organization Hands and Voices (discussed later).

Limitations:

- Survey was only available in English
- Qualitative value only due to small numbers of responses
- Responses may be individual or groups of providers
- No responses from medical providers (other than St. Vincent de Paul)
- Although given the option of anonymity through faxed responses only one respondent submitted an actual anonymous survey

Results

Group	Method	# sent	# reply
Audiologists	Email	32	12
School nurses	Email	4	1
Parents	US Mail	668	30
Early Intervention	Email	8	6
Others	Email	2	2

All respondents said that we should keep each of the three elements of the program and were overall pleased with the program. Specific responses from parents are included in each relevant section of the report. In addition some of the responses to what they liked and didn't like about the program are included below.

What Providers Liked

- *HFK allows choice from wide range of manufacturer's with excellent hearing aids. Other resources are too restrictive for the needs of children*
- *The program is great! Easy to use and very quick so children don't have to wait for hearing aids*
- *For our patients, its great to get them loaner hearing aids while pending appointments*
- *Works extremely well for those of us requesting vouchers*
- *The online form is very convenient*
- *Many parents are freaked by the diagnosis and the cost of the "solution" that is all they are focusing on. Once I let them know they have time to sort that out it takes a huge load off*
- *Just peace of mind knowing that there is a program out there that cares about their children*

Opportunities and Suggested Changes

The program has never been marketed to the public but is primarily access through the providers. Several responders to the survey addressed the lack of information. Parents would like a consistent unbiased list of resources. They think we should get the word out to new parents, doctor's offices, Raising Special Kids and schools. The audiologists would also like assistance in making certain that the hearing aids are maintained and that parents have adequate information on the need for follow-up.

Other issues raised by providers are associated with the need for more documentation or better sharing of program components that are already available. Parents are given a starter kit with program provided through HKF and distributed through the Early Intervention program. FM systems are currently available for loan but rarely requested and hearing aids are purchased as they are requested, so more Baha® power aids, or other aids are available.

Occasionally the hearing aids are not working when they are received by the audiologist. Some retraining has been done recently to remind audiologists to check the aids before sending them back to put into the pool and to check them as soon as they receive them before the family comes in for a fitting. Cost of even once a year check by the manufacturer would add \$25,000-\$30,000 to the program. When aids fail a decision is now being made, based on the age and model whether it is worthwhile to repair or if they should be retired.

Arizona Hands and Voices

Many of the ideas generated from the survey are related to a desire for more opportunities for parent to parent interactions and support. In 2006 the EFAz received grant funding from the Arizona Community Foundation to help establish a parent to parent support program. The result is an independent Arizona chapter of Hands and Voices (AzHV). The group of parents and professionals received chapter status in November of 2006 and became incorporated in 2007. They are currently awaiting determination of non-profit status (submitted October 2007). The membership of AzHV is now 92 parents and professionals with more than 90% parents of a child who is Deaf or Hard of Hearing.

Hands and Voices is unique in its approach. Most organizations are focused on communication methodology (American Sign Language, Auditory Verbal, Oral, Cued speech). The philosophy of HV is that there is more that unites parents than methodology and *“what works for the child is what makes the choice right”*.



Emmy was identified at birth, has bilateral cochlear implants and is mainstreamed. Emmy's mom is the president of AzHV

The program manager of HFK is one of three professionals that serves on the board of AzHV and maintains a collaborative relationship with the group. HFK has access to parents, especially those with children who are newly identified, primarily through the loaner program. The EFAz has paid for mailings to the families receiving HFK services (current addresses for approximately 650 families) to share current events hosted by AzHV.

The following responses to the survey have been shared with AzHV:

- *We wish we had more opportunity to be involved with other families*
- *We would like recreation and/or summer activities*
- *Offer more teen socializing centers, events, closed captioned movies*
- *My daughter gets so excited when she sees other kids with hearing aids, I think she would benefit from some sort of support group*
- *Information on different types of hearing aids, what features are available and of those features, what are appropriate for small children*

Early Hearing Detection and Intervention

The HFK program was significantly influenced by the success of efforts to identify hearing loss early. With the help of SLHI, the EAR Foundation of Arizona was able to partner with hospitals state agencies and other non-profit organizations to develop the Arizona Early Hearing Detection and Intervention (AzEHDI) program. In Arizona more than 97% of all newborns are screened for hearing loss prior to initial hospital discharge. HFK is part of the larger AzEHDI program.



Newborn hearing screening

Many states have struggled to fit amplification and serve families identified through newborn screening, reporting more than a year's delay in obtaining hearing aids after identification in many states. Arizona is fortunate to be able to ensure that the benefits of early detection are available by providing access to quality services during a time period which has proven to be critical for brain development.

The following responses to the survey will be shared with the AzEHDI program:

- *Partner with other agencies in town to not only provide technology, but therapy services as well, so that children and their parents can get the most out of the technology*
- *Keep educating doctors, and audiologists about what's available and the most economical fair ways to distribute resources.*
- *More experienced and highly qualified providers including speech pathologist, pediatric audiologists, early interventionists, physicians and therapists.*
- *More information on unilateral loss in children identified at birth*

Summary

Until 2003 all of the funding for the program was provided by St. Luke's Health Initiatives medical assistance program. Currently SLHI provides approximately 75% of the funding. The remainder is the result of grants, fund raising and donations from individuals. The program has been able to keep up with the demand for services with the current funding.

Some of the anticipated changes in the program will require a small amount of additional funds. It is anticipated that the change in reimbursement to providers for the voucher program may increase the cost by as much as \$10,000 per year. Support for Hands and Voices mailings to the HEAR for Kids families costs approximately \$1000 for one first class mailing per year and an additional \$500 for each of the other three quarterly mailings. The other area of need is educating parents and professionals about the HEAR for Kids program. The costs for this will be minimal other than the time to develop a brochure and find opportunities in the community to spread the word. It is anticipated that the additional costs for the program in the upcoming year will be between \$12,000 and \$15,000.

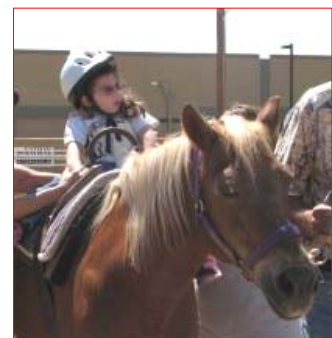
What Parents Say:

When asked how we should restrict services if we do not have the funding the responses were evenly divided between restricting by age and restricting by technology. However both of those options were outnumbered by a third response that we should not have to restrict services to children who need them. Here is what the parents have to say:

- *We must find a way to not have to restrict services at all.*
- *Our goal should be not to run out of money*
- *That is a hard questions to answer because every child that needs a hearing aid should have one*
- *I don't have any idea because needing hearing aids is a must*
- *It is hard to deny any child the chance to hear.*

The HEAR for Kids program has proven to be a valuable resource to the children who are Deaf or Hard of Hearing and their families. The program was created from needs identified primarily by the provider community and has evolved as a partnership between families, the professionals that serve them, agencies and non-governmental organizations. The program is a critical component to Early Hearing Detection and Intervention services in Arizona.

HEAR for Kids has been recognized as a model program for ensuring that children who are Deaf or Hard of Hearing receive the services and devices that they need when they need them. The achievements of these children are the true test of success!



Maria at Hippotherapy