

PROGRAM NARRATIVE

Experience To Date

The primary purpose of this grant project is to decrease South Carolina’s lost to follow-up rate for infants referred based on their hospital newborn hearing screening results. A secondary purpose is to continue moving *First Sound*, South Carolina’s Early Hearing Detection and Intervention (EHDI) program, towards meeting the American Academy of Pediatrics’ (AAP) quality assurance indicators for hearing screening programs.

This year has been especially challenging for South Carolina and, consequently, for *First Sound*. As in many other states, South Carolina has experienced state budgetary issues. The end result for *First Sound* was an approximate 18% reduction in the program’s state budget. As a result, South Carolina has realized some of its goals and continues to diligently work towards others, original timelines have been adjusted. One significant accomplishment was for *First Sound* to purchase eighteen Automated Auditory Brainstem Response (AABR) screeners for various hospitals. Many hospitals had equipment that was more than 10 years old and was outdated. Each of the 48 birthing hospitals had the opportunity to make application. Criteria for the equipment were based on age and condition of the current equipment and size of the hospital.

Progress on Goals and Objectives.

Goal #1: Increase the ability of <i>First Sound</i> staff to track infants and extract data for reporting and the evaluation of program performance.	
	Objective A: Increase accuracy and timeliness of audiology provider reporting by 10% by August 2011.
	Activity: Explore options (purchase existing software developed for newborn hearing screening vs. contractual use of consultants to develop a customized application) to enhance or replace the current data collection system for audiologists.

Objective B:

Expand data integration/sharing activities with at least one additional database by **August 2011**.

Activity: Explore the feasibility of direct data integration versus establishing a data sharing protocol with other DHEC programs containing information on the same population, such as immunizations, birth defects, Women Infants and Children (WIC), etc.

Objective C:

Develop a system to obtain detailed early intervention information to track outcomes by **August 2010**.

Activity: Collaborate with South Carolina School for the Deaf and Blind (SCSDB) to establish a systematic protocol to obtain outcome-based information on infants enrolled in early intervention as a direct referral from the *First Sound* process. This would include use of a release of information at first contact with Early Intervention so that information can be shared with DHEC in a way that would ensure compliance with Part C privacy regulations.

Goal 1 is the foundation for quantifying any measurements for other goals. We are able to continue to work towards implementing other goals; however it is difficult to accurately track progress without complete functionality of the data system. On April 1, 2008, the *First Sound* module of the Birth Data Exchange Engine (BEE) was launched. This module integrates information from Vital Records with newborn hearing screening systems by auto-populating demographic data from the electronic birth certificate to the *First Sound* module.

PROGRESS: Ongoing. The transition to the new Vital Records-integrated database for the hospitals has proven to be more challenging than anticipated. Staff has spent a great deal of time assisting the hospitals with the new data entry portal and protocol. We are now linked to the electronic birth certificate. Each user is required to have a background check as part of the application process to gain access. *First Sound* did not anticipate the time it would take for some hospitals to work through their administration to obtain the background checks. Hospitals that experienced a delay to getting access quickly got behind with data entry. *First Sound* staff assisted with the data entry. The delay has temporarily impacted the ability to report current

data. The link with Vital Records has proven to be extremely helpful in locating infants that audiologists needed to find in order to enter their data.

The next step is to redesign the web-based audiology data reporting system. Following a series of meetings, the decision was made to incorporate this redesign into the same system as the hospital module that integrates with the electronic birth certificate. The integrated module is managed by the Office of Public Health Statistics and Information Systems (PHSIS). The current audiology data reporting system is managed by the Bureau of Information Systems (BIS). Staff from *First Sound*, MCH, PHSIS and BIS worked together over several months to develop a statement of work to be put out on bid to hire consultants. Development is expected to be completed by July 2009, and then staff will test the system prior to releasing it for use. The audiologists will go through the same background check and application process as the hospitals. To avoid the delays we encountered for the hospitals, we plan to begin access assignment for the audiologists prior to June 2009.

First Sound has not yet begun to explore options to integrate with other DHEC programs. For the purposes of the total project period, it is more of a long-term goal but still remains a priority.

The *First Sound* Program Manager has had a preliminary meeting with early intervention representatives from the South Carolina School for the Deaf and Blind regarding the plan to increase the scope of reporting early intervention data. As a result, we have seen a marginal increase in our informal exchange of information and the School for the Deaf and Blind is committed to working with us to establish a formal protocol. We plan to meet again once the test site where the information will be collected is available. At that time we will work on finalizing more formal protocols to collect additional data.

Goal #2: Decrease infants lost to follow up by implementing minor changes in protocol at all levels of the EHDI system.	
Objective A:	Decrease by 5% the number of no-shows to the initial hospital-scheduled audiology appointment by August 2010 .
Activity:	The Follow-Up Coordinator will place a reminder phone call and/or send a letter to parents prior to the appointment. The reminder will include brief information as to why follow-up is important.
Objective B:	Decrease lost to follow-up by 5% by August 2010 .
Activity 1:	Hospitals will be instructed to specifically ask parents the name of their intended primary care physician, or at least the practice name, rather than defaulting to reporting the attending physician's name.
Activity 2:	Hospitals will be instructed to obtain a second point of contact, such as a relative or friend, from parents whose infants fail their inpatient hearing screening. The alternate information will increase the potential of making contact with the families should the need arise.

South Carolina has been engaged in activities aimed at reducing lost to follow-up for the past three years. Lost to follow up rate peaked in 2005 at 43% in South Carolina, which is in line with the national average of 30 to 50 %. Funding from the Health Resources and Services Administration (HRSA) grant, has allowed *First Sound* to hire a Follow-Up Coordinator for the past two years. The Follow Up Coordinator has been effective in locating infants that do not show for their audiology appointments, tracking down audiologists to enter their data and resolving cases that are lost to documentation. *First Sound* now has a better accounting of cumulative confirmed hearing losses, which previously were below the national statistic of 1-3 per 1000 births, and our current lost to follow up rate (23.14%) is a better depiction of infants actually lost to follow up. Continued support for the Follow-Up Coordinator position is essential at minimum to maintain the improvement, but ideally to achieve continued reduction.

The work of the Follow-Up Coordinator has allowed us to anecdotally know a variety of scenarios that impact the follow-up portion of the Program. At the hospital level, there has been inaccurate demographic data, particularly related to contact information and identity of the

primary care physician. During the audiological evaluation level, infants can be lost to follow up due to the need for multiple appointments for definitive diagnosis or lack of parental follow up after diagnosis due to access to care issues for Medicaid recipients. Infants are lost to follow up at the early intervention level because they do not pursue (opt out of) services available to the infants through BabyNet (Part C). At the data collection level, *First Sound*'s current data tracking system is not capable of pinpointing the step(s) of the process in which lost to follow up occurs; this is being addressed through activities in Goal 1.

PROGRESS: Ongoing: The Program Manager worked with the Follow-Up Coordinator to develop a letter and establish specific protocols for mailing to parents whose babies have appointments with audiologists for follow up testing. The letter addresses the initial screening results, the appointment place and time, and the need to follow through with the appointment. The letter will be used more widely as we continue to work with the hospitals to help the hospital staff get accustomed to the new reporting methods and as the completion of the current database development and redesign is completed.

The objective to seek information from the hospital regarding a second point of contact and for the name of the primary care physician that they intended to use for medical care was delayed. *First Sound* asked seven hospitals to begin doing this effective February 1, 2009. Those hospitals are all complying with this request. After a period of six months of data collection, we will review the impact and plan statewide implementation.

In our original application, one of our activities was to encourage parents to participate in the *Early Childhood Deaf and Hard of Hearing Assessment Project* currently being conducted at the University of Colorado-Boulder, home of the Marion Downs National Infant Hearing Center. The grantor was marginally supportive of this activity only after requesting post-award

justification. In light of the marginal support by the grantor and further consideration by the Program, it was decided not to proceed with this particular activity.

<p>Goal #3: Decrease the barriers to follow-up by fostering clear communications among providers and between providers and parents.</p>
<p>Objective A: Of those infants diagnosed with hearing loss, increase by 10% those diagnosed by three months of age by December 2010.</p>
<p>Objective B: Of those infants diagnosed with hearing loss, increase by 10% those in early intervention by six months of age by December 2010.</p>
<p>Activity 1: Develop a scripted message for hospital staff to deliver to parents whose infants failed the inpatient hearing screening.</p>
<p>Activity 2: Implement a fax-back procedure to alert the primary care physician of the screening results and the need for prompt follow up.</p>
<p>Activity 3: Develop an introduction to hearing screening brochure for obstetricians to give to their prenatal patients and to pediatricians for those parents that visit pediatricians prior to delivery.</p>

Lost to follow up occurs at various points of contact between initial screening and early intervention. Attempts of hospital staff to ease parental anxiety about the positive screening results may portray diminished need for the follow up appointment that is made for them prior to discharge. Primary care physicians could be excellent facilitators of follow-up by informing parents of the importance of the follow up audiology appointment that has been scheduled for their child, however a lack of accurate and timely information from the hospital prevents prompt notification of the PCP. Prenatal access to newborn hearing screening information will give the mother a familiarity with the process. Hopefully with increased knowledge a higher probability to follow through with the referral will be observed.

PROGRESS: Ongoing. *First Sound* asked the same seven hospitals to implement use of a scripted message to parents whose infants fail the inpatient screening. After a period of six

months, referrals will be evaluated and the scripted message will be implemented statewide if proven to be effective.

The pilot hospitals are specifically asking for PCP information, we continue to work with hospital staff to consistently provide this information in a timely manner. As a result we have not been able to begin effectively using the intended activity of sending faxes to the respective PCP office when a baby has failed the hearing screening and been referred for follow up. Reporting is anticipated to improve with the enhancements being made to the hospital data collection system in conjunction with the redesign of the audiology data collection system. Once we are better able to collect that piece of information we can implement this activity.

Most of the focus during this budget year has been devoted to working closely with the hospitals in transitioning to the new data collection system as well as outlining a scope of work for the enhancements to the hospital data collection system and the redesign of the audiology data collection system. *First Sound* has not completed the development of a brochure to be distributed through obstetricians' offices during the prenatal period. The Program Manager has collected samples of brochures used in other states for this purpose. The next step is to provide the Art Department with the facts we wish to include in ours and get a brochure designed for SC.

Goal #4: Establishment of a hearing loss specific parent support group.	
	Objective A: Recruit a minimum of four parents and four professionals to spearhead the establishment of a parent support group by December 2008. Completed
	Objective B: Refer 100% of parents of infants diagnosed with hearing loss to the established parent support group by August 2010.

Family support has been proven to be invaluable and extremely important for families embarking on the journey of managing a child with hearing loss. South Carolina has family

support options in place through Family Connection and PROParents (Parents Reaching Out to Parents) that provide parental support for children with disabilities. However, parents have requested support resources that are deaf and hard of hearing specific. A chapter of the Alexander Graham Bell Association for Deaf and Hard of Hearing (AG Bell) in is South Carolina but the AG Bell mission slants a definite bias towards oralism. Parents need to be provided information on all options available to help their child to develop language when a hearing loss is present. Hands and Voices is a parent-driven organization that supports all options for children with hearing loss. *First Sound* has received several inquiries and requests about Hands and Voices. *First Sound* will assist in getting a Hands and Voices chapter started in South Carolina by recruiting interested parents and professionals to spearhead this endeavor. The Follow-Up Coordinator is currently contacting potential stakeholders to set up a meeting to explain all that Hands and Voices can offer.

First Sound will develop a protocol for referring infants who have been confirmed with hearing loss. Hands and Voices also have a component to the organization called “Guide-By-Your-Side” which functions as a deaf mentor program. *First Sound* will attempt to develop “Guide-By-Your-Side” after the Hands and Voices chapter is stabilized.

PROGRESS: Ongoing. The Program Manager has recruited four parents and six professionals that are interested in spearheading the establishment of a Hands & Voices chapter in South Carolina. One of the parents has agreed to take on the leadership role as this is a parent-driven organization. The parent had the opportunity to attend the *Investing in Family Support* conference in Raleigh, NC in October 2008 and the *Early Hearing Detection and Intervention* conference in Dallas, TX in March 2009 and was inspired through her interactions with Hands & Voices leaders and members. The SC parents and professionals, including the *First Sound*

Program Manager will be meeting in June 2009 to begin the chapter application process.

Referral of parents to the support group is expected to begin in July 2010.

Current Staffing

The current *First Sound* Program Manager has served in this role for four years. She is a Master's audiologist who was in clinical practice for ten years prior to taking this role. Clinical experience was acquired in three non-profit United Way supported speech and hearing centers where there was a significant pediatric caseload. She also worked in an otolaryngology office with four locations. Her current role positions her to serve as audiology consultant to Children's Rehabilitative Services (CRS) and BabyNet (Part C) which are in the Division of Children with Special HealthCare Needs (CSHCN). Her responsibilities include serving as technical support and/or as resource to audiologists, hospital staff, deaf educators, pediatricians, parents and various other stakeholders. The Program Manager is accountable for applying for and managing grants; reporting to the SC Legislature annually; identifying areas in the Program that need improvement and effecting changes accordingly; supervision of the Follow-Up Coordinator and Data Manager and general oversight of the Program.

The current *First Sound* Data Manager has served in this role for two years. Her most recent experience prior to being with *First Sound* included data collection and management for DHEC's Division of HIV/STD Surveillance for approximately three years. Prior to that role she served as grant manager for the Community Access Program grant at New Horizon Family Health Services facility for three years. She has a Master's degree in Health Administration (MHA). Her responsibilities are: data collection, management, analysis and dissemination;

serving as technical liaison to PHSIS and BIS; serving as technical support to hospitals for data entry and managing user access to the data systems.

The current grant-funded Follow-Up Coordinator has served in this role for almost three years. Prior to transferring to *First Sound*, she served in a tracking and surveillance role for DHEC's Childhood Lead Poisoning Prevention program in the Division of Women and Children's Services (WCS) for twelve years. She has a Master's degree in Public Health. Her primary role is to identify infants that have been referred for follow up and ensuring that the follow up occurs. She searches the database daily for appointments to ensure that the audiologist has entered their data. She follows up with the audiological providers for appointments that do not have data entered, to facilitate timely entry. If a provider has a baby that never showed up for the appointment or if they are having difficulty getting the parent to come back for further appointments, the Follow Up Coordinator makes a referral to the respective DHEC Region to attempt contact with the parent. Letters are also sent directly to parents and primary care physicians.

The *First Sound* program is housed in the Division of Women and Children's Services (WCS) and is directly responsible to the Program Manager for the newborn metabolic screening program. She has been with the program for fifteen years. She has a Master's in Nutrition Sciences (MNS) and is a Registered Dietitian (RD). The leadership and guidance she provides to the newborn hearing screening program is invaluable.

Linkage With Other Programs

The Division of Women and Children's Services (WCS) is within the Maternal Child Health (MCH) Bureau.

Vital Records: *First Sound* has integrated data with Vital Records through the Birth Data Exchange Engine (BEE), is an attempt to develop an integrated child health data system. This linkage has been specific to data collected by the hospital but will soon incorporate a system for collecting data from audiologists and early interventionists as well.

Metabolic Screening: The fact that *First Sound* is housed in the same Division as the metabolic screening program and that the *First Sound* Program Manager is under direct supervision by the metabolic screening Program Manager has facilitated a simple mechanism for sharing data on the same population, allowing for coordination of needed services.

BabyNet (Part C): BabyNet has granted *First Sound* program staff access to the BabyTrac data system. This access allows seamless access to early intervention information.

Children's Rehabilitative Services (CRS): Many of the children who are diagnosed with hearing loss make application through CRS for assistance with the purchase of hearing aids. A protocol is in place for CRS to forward a copy of each application to *First Sound* who in turn uses it to cross check with their database to be sure the child is known to *First Sound* as a confirmed hearing loss.

Care Line: Recently, the Care Line was relocated into the Division of Women and Children's Services, allowing more direct collaboration with the program. The Care Line mission is to improve access to and utilization of health care and health-related services by identifying and addressing barriers for clients in need. Assistance and support is provided to callers in gaining access to family planning services, prenatal care, infant and child health care, care for children with special health care needs, and other related services.

Many challenges were confronted by *First Sound* staff during this grant period resulting in achieving some goals and amending timelines for others. Funding through this grant is critical for these activities to take place in order to reach our goals and objectives. Continued

employment of the Follow Up Coordinator who has been dedicated to determining an outcome for each infant is dependent upon the grant.