

Early Hearing Detection and Intervention



Arizona Hospitals' Universal Newborn Hearing Screening 2001 Guidelines

Cooperatively developed by
hospitals and participating agencies
throughout the State of Arizona
in conjunction with:



Arizona Department of Health Services Sensory Program
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Making a Difference

Early Hearing Detection and Intervention makes a significant difference in the lives of children who are Deaf or Hard of Hearing and their families. Studies by Christine Yoshinaga-Itano and others have shown that the most significant predictor of normal language development, in children with significant hearing loss is detection and early intervention before six months of age. Hearing can be screened at any age using valid and reliable automated screening techniques. Universal newborn hearing screening is supported by national initiatives and policy statements such as Healthy People 2010, Maternal and Child Health Bureau objectives, the Joint Committee on Infant Hearing and the American Academy of Pediatrics.

Opportunity for Screening

The birth admission represents one of the few times when all but a small number of babies born outside of hospitals can be captured for screening. Arizona hospitals have recognized this opportunity and the need to identify hearing loss early. Hospital screening program form the basis for all statewide early hearing detection efforts and 98% of all hospitals in Arizona now provide universal newborn hearing screening as a standard of care.

Why Guidelines Matter

As programs have evolved, it has become apparent that there is a need for information and guidance to ensure that screening results are valid and that programs run efficiently and effectively. This document provides guidelines and information that will be helpful both in establishing and maintaining newborn hearing screening programs.

Who Developed the Guidelines

The guidelines on the following pages were developed by a task force facilitated by the EAR Foundation of Arizona in collaboration with the Arizona Department of Health Services Never Too Young Program. Funding was provided by St. Luke's Health Initiatives. A list of task force participants can be found in Appendix B

Minimal Screening Requirements

The minimal requirement of hospital based universal newborn hearing screening includes the following:

- ❖ Each hospital or birthing center should screen all births using a physiological hearing screening method prior to initial hospital discharge.
- ❖ Each hospital should provide outpatient rescreening for babies who were missed or are referred from the initial screen. Outpatient screening should be scheduled at the time of the initial discharge and completed between 2-6 weeks of age.
- ❖ When a baby refers from the inpatient and outpatient hearing screening, the hospital or birthing center's role should include linking the family to a medical home and appropriate audiological assessment.
- ❖ Each hospital should develop collaborative partnerships with the local AzEIP program coordinators and the audiology and early intervention community.

Program Coordinator Responsibilities

Newborn hearing screening programs are complex and involve the management of many different aspects including staffing, policies and procedures and communication with families, medical providers and government agencies. To accomplish the goals of your program, responsibility should be clearly defined and delegated. Assigning a Program Coordinator ensures that your program works more efficiently and effectively.

The Coordinator should be responsible for overseeing and managing (or delegating responsibility for) the various aspects of your program such as:

Training and Education

- ◆ Training screeners based on performance standards
- ◆ Establishing and monitoring performance based competency
- ◆ Communicating with community and health care providers
- ◆ Facilitating development and dissemination of culturally sensitive community/parent education materials

Quality Assurance

- ◆ Developing, maintaining and monitoring ongoing quality assurance
- ◆ Establishing benchmarks and quality indicators to ensure program efficacy
Benchmarks and quality indicators should be evaluated monthly and should be consistent with existing data such as those referenced in the American Academy of Pediatrics Newborn Hearing Screening Policy Statement and the Joint Committee on Infant Hearing 2000 Position Statement.
Benchmarks are used to evaluate progress by having identifiable goals that are useful in monitoring and evaluating a program. Benchmarks should include the following:
 - A minimum of 95% of all babies will be screened during their birth admission or prior to one month of age.
 - Refer rate should not exceed 10% and should average 1-4%.
 - Return for follow-up rate should be 70% or more.

Quality indicators are used to help ensure program efficacy, program consistency and stability and may include the following percentages:

- Babies screened during the birth admission
- Babies screened before one month of age
- Babies who do not pass the inpatient screen
- Babies who do not pass the outpatient screen
- ◆ Monitoring equipment calibration and ordering supplies.
- ◆ Developing, implementing and maintaining program policies and procedures.
- ◆ Ensuring that newborn hearing screening policies and procedures follow relevant state laws, JCAHO recommendations and hospital guidelines.

Tracking and Follow-up

- ◆ Ensuring outpatient rescreens are scheduled and the status of missed inpatient or outpatient screens are monitored.
- ◆ Serving as the contact person and providing information and data to the state coordinator, parents, attending physician, AzEIP and others.

Choosing Screening Method and Equipment

One of the most important decisions on implementing a screening program is the choice of screening method. Any screening method chosen should measure a physiological response. Currently, Otoacoustic Emissions (Transient and Distortion Product) and screening Auditory Brainstem Response are the methods used for universal newborn hearing screening programs. Your Program Coordinator should research the various equipment options based on the following:

- ◆ Initial cost
- ◆ Anticipated refer rates
- ◆ Ongoing costs
- ◆ Ease of use
- ◆ Availability of customer service and support
- ◆ Warranty and service contract

Other considerations for making technology choices include the following:

- ◆ Use of more than one technology
- ◆ Average length of stay
- ◆ Anticipated staffing patterns
- ◆ Goal in screening (detecting hearing loss vs. hearing loss and auditory neuropathy)
- ◆ Demographic characteristics of the community
- ◆ State and National Border community issues
- ◆ Likelihood of follow-up for other public health screenings (Metabolic/endocrine screening and immunizations)
- ◆ Anticipated follow-up rate

Several different types of screening equipment are available. Each of them can be part of a successful program although some characteristics may suit one program better than another. The per patient disposable costs are generally less for OAE programs but they often have higher initial refer rates, especially if length of stay is less than 24 hours. Hospitals serving remote areas where distance and transportation is an issue may need to implement procedures to ensure very low initial refer rates.

Some equipment may be easier to learn how to operate or less complicated with respect to maintenance of skills. Ease of use can be an important consideration in staffing patterns, especially for hospitals with low birth volumes or those who choose to train large numbers of staff as screeners.

Staffing and Training

Screenings can be successfully conducted by anyone who receives appropriate training and meets competency standards. Staffing should allow for all babies to be screened regardless of the day or time that they are born. Additional considerations for staffing and training are as follows:

- ◆ Staffing should ensure that no babies are missed: consider 7 days a week, 24 hour a day coverage.
- ◆ Training should be competency based and involve hand-on components.
- ◆ Training should be provided by your Program Coordinator or a designated trainer.
- ◆ Assessment of screeners skills should be done no less than annually or as indicated by quality monitoring.

Appropriate training of the screening staff to ensure infants are screened efficiently is vital to the success of a program. Your program coordinator should initiate the training and establish screener competency prior to allowing a screener to conduct the screenings. One-on-one instruction and observation are the most effective followed by periodic monitoring and observation of the screener. A competency checklist should be completed and signed off on when competencies are met. Additionally, a report showing screener performance should be reviewed monthly.

The number of screeners needed depends on the hospital birth rate and how your program is organized. For example, a hospital with a lower birthrate will need less screeners than a large birthing hospital, however, screener techniques are maximized with practice therefore, programs should determine a balance which will ensure that enough people are trained to provide adequate coverage and to maintain the skills needed.

Hospital Policies and Procedures

Each hospital in Arizona is unique in the way that they serve their community. Each hearing screening program should reflect this uniqueness in the way that the individual policies and procedures are implemented. Policies and Procedures should be developed in each of the following areas to reflect the practices of your hospital:

Screening protocols

- ◆ Who should screen, when and where
- ◆ How to prepare babies for screenings
- ◆ The number of screening attempts made
- ◆ How long should screeners wait to repeat screenings
- ◆ What to do when parents refuse screenings
- ◆ Infection control
- ◆ Documentation in the medical record, on the back of the immunization record or other location

Equipment

- ◆ Troubleshooting equipment
- ◆ What to do when equipment breaks down and who to contact.
- ◆ How to order supplies
- ◆ Calibration (annual) and routine maintenance

Quality Assurance

- ◆ Maintaining records
- ◆ Collecting appropriate documents and information when baby refers
- ◆ Establishing and maintaining method of tracking individual screener's performance
- ◆ Verifying that all babies were screened (cross reference with birth certificate)

Follow-up and tracking

- ◆ Follow-up procedures for babies referred, inconclusive or missed
- ◆ Ensure that contact information and primary care physician information is updated before discharge on all referred babies.
- ◆ Outpatient rescreens
 - Who schedules appointments
 - When and where rescreens are conducted
 - Reimbursement/preauthorization
 - Who should be contacted when a family doesn't return or refers from the outpatient rescreen
 - Determine if your facility can provide out-patient screening to babies born at other hospitals or birthing centers.

Referrals

- ◆ Communication with primary care providers, audiology assessment, early intervention
 - Phone calls, written report, referral forms
 - Babies referring from outpatient rescreen, make phone contact with the Primary Care Physician (PCP) and audiologist before family leaves hospital
- ◆ Consider incorporating a "safety net" into the discharge instructions such as a Sticker on the isolette, discharge summary, outside of chart.

Screening Special Populations

Considerations for Well Babies with Risk Factors for Late Onset or Progressive Loss and visible malformations:

- Consult PCP prior to screening if infant has an abnormal appearance to the ear or skin tags.
 - Infants with visible malformations of the pinna or ear canal should not be screened and should be automatically referred for follow-up.
 - Notify PCP regarding babies with known risk factors for late onset or progressive hearing loss as noted in Appendix A.
 - Ensure that families receive informational material which discusses major milestones in normal early speech and language development and risk factors for hearing impairment.
- ◆ Ensure that babies transferred from other facilities have been screened prior to being discharged to go home. If the baby is being back-transferred to another facility or step-down unit, screening results should be communicated to ensure that the baby is screened before being discharged to home.
 - ◆ Babies who have long-term stays may be able to have a complete assessment and possibly fit with hearing aids if appropriate while they are still in-patients.
 - ◆ Screening for Auditory Neuropathy

As documented in the JCIH 2000 Position statement, babies in the NICU are thought to be at increased risk for Auditory Neuropathy. Although the prevalence is unknown, an increased number of cases have been documented and reported. This condition is described as abnormal neural conduction and is characterized by a combination of normal OAE's and absent ABR's.

At this time there is not enough empirical evidence to suggest which factors may indicate that a newborn is at risk for auditory neuropathy, although it appears that NICU graduates are more likely to be at risk than well babies. If a program chooses to screen for auditory neuropathy, in addition to screening for hearing loss, they should consider implementing a program in the NICU that utilizes either ABR or ABR and OAE. Screening programs may need to be revised as more published information becomes available.

Management of Infants

Screening infants requires the management and handling of infants. Hospitals may have specific policies, requirements or qualifications that must be met before a screener is able to conduct screenings. These policies should be reviewed and followed by the screening department to ensure the safety of every infant. Some infants may have special conditions that screeners should be made aware of prior to conducting the screening.

- ◆ Ensure there is a mechanism in place to inform screeners of any special physical conditions or anomalies that might require special handling or care.
- ◆ Consider consulting with the risk management department regarding qualifications necessary for handling babies.
- ◆ In order to maximize equipment performance, equipment manuals and manufacturer's specifications should be reviewed to ensure screeners are knowledgeable regarding appropriate and inappropriate physical and environmental conditions for screening.
- ◆ Infants with congenital malformations of the ear should not be screened but should be referred directly for further evaluation by an audiologist.

Communication with Families

Families that understand what is going to happen, are informed of the outcomes, and who understand the next steps are less likely to be overly concerned about the screening results and more likely to follow-up. Communications should be in the primary language of the home as well as be presented in a culturally competent manner.

Newborn hearing screening is relatively new and it is unlikely that the family is knowledgeable about the procedures or what the tests mean. There are several opportunities to ensure that families are informed before, during and after the screening.

Before Screening

Education prior to the screening may take the form of information distributed in the birthing classes, brochures in the admissions packet or a video on the closed circuit TV. No matter how it is done, the parents should be informed before the screening:

- ◆ What is going to be done, when and by whom
- ◆ Parental right to refuse newborn hearing screening
- ◆ The risks and benefits of screening and of choosing not to screen

During Screening

During the screening, and immediately after, it is *critical* that the screeners know exactly what they should and should not say. It is important that the screeners know who will tell the parents the results of the screen, when, where and how. It is usually not appropriate for screening technicians to explain the implications of the results unless they have scripted responses and can tell the families who to call for additional information.

After Screening

Soon after the screening is done, usually before discharge, the parents should know:

- ◆ The results of the screening
- ◆ What the results mean (screen not a diagnosis)
- ◆ What should happen next (ie: an appointment made for outpatient screening)
- ◆ Who is getting the results (hospitals should consider obtaining a signed consent for referrals to AzEIP)
- ◆ Information about normal development and risk factors for late onset or progressive hearing loss

Ensuring Follow-up

The most critical component of the early hearing detection and intervention program after the screening is completed, is ensuring that families are not lost to follow-up. Some of the factors that are believed to influence follow-up rates include:

- ◆ Parent's understanding of the meaning of the screening outcome and the next steps
- ◆ Length of time between birth screening and outpatient screen
- ◆ Refer rates
- ◆ Physician support and understanding of how to assist families in obtaining outpatient screen or audiology assessment
- ◆ Accuracy of contact information obtained at the time of discharge
- ◆ Method of communication
- ◆ Persistence of the screening program coordinator
- ◆ Health plans
- ◆ Awareness of early detection and intervention in the community
- ◆ Collaborate with the early care and intervention community.
- ◆ Consider establishing partnerships with health clinics and other local screening program/resources to ensure that follow-up is community based and accessible.

Strategies to help your program ensure that families are not lost to follow-up may include the following:

- ◆ Communicate in written and verbal form in the primary language of the home.
- ◆ Ensure communications are culturally appropriate.
- ◆ Establish the outpatient screening appointment at the time of discharge.
- ◆ Outpatient Screen at 2 weeks (no later than 6 weeks)
- ◆ Coordinate appointments to first well child visit in some communities.
- ◆ Ensure parents understand what the screening means and what they need to do next.
- ◆ Ensure parents understand whom to contact for questions or further information.
- ◆ Ensure that the family is linked to a medical home.
- ◆ Provide the medical home with information about how to assist families in obtaining follow-up, referrals and/or preauthorization for insurance.

Ensuring Follow-up (continued)

A plan should be developed on what measures will be taken to find families who don't return for the outpatient screening. The plan may include:

- ◆ Contacting the PCP
- ◆ Coordinating with programs and providers already involved with the family to relay resource information and the importance of follow-up. This may include NICP, community health nurses, CRS, AzEIP, WIC, Early Head Start, Healthy Families, Health Start
- ◆ Sending notification letters by certified mail
- ◆ Referral to Community Health Nurses
- ◆ Using a Community and family centered approach to reinforce message

To ensure that families are not lost to follow-up, hospitals and the medical community must work as collaborative partners with Arizona Early Intervention Program (AzEIP). The essential elements of this partnership include public awareness about the importance of early detection and intervention for hearing loss, the identification of community resources for identifying, locating and evaluating eligible children, and linkages to ensure that children are not lost to the system.

It is also important that parents of babies who pass the hearing screening, do not leave the hospital with a false sense of security. Parents should understand that although their child may have passed the screening, there is no guarantee against a progressive loss or an acquired hearing loss at some future time. If they have concerns at any time, they should contact their PCP. It is helpful to have written information to hand to parents which includes:

- ◆ Information about the limits of the screening
- ◆ Developmental milestones
- ◆ Information on late onset and progressive hearing loss risk factors

Reporting Results and Tracking

Ensuring that the baby and family receive the necessary assessment and early intervention is a necessary part of the screening process. Without follow-up the screening may not result in early hearing detection and intervention. If a baby refers from an out-patient screen referrals should be made to:

- ◆ Medical Home (Primary care physician)
- ◆ Pediatric Audiologist

An important component of the tracking program is reporting data to the Arizona Department of Health Services, Never Too Young (NTY) Program. The NTY provides licensed software to any birthing hospital or center in Arizona. The software consists of a database of all births, their demographic and outcome data. Referral letters can be produced for parents and primary care physicians in English and Spanish. The quality improvement program can also collect data on individual screener performance. The NTY Program will also provide technical assistance to hospitals and birthing centers based on the data reported. Combined data is reported statewide and nationally (without individual or hospital identifiers). Reporting data enables the state program to access federal funding and your program to access technical assistance and participate in national benchmarking of best practices.

Some of the tracking issues that should be addressed include the following:

- ◆ Submitting data to the NTY program monthly, by the 5th of each month
- ◆ Updating files of referred infants on a regular basis
- ◆ Ensuring accurate demographic information
- ◆ Monitoring missed screens, no shows, transferred patients, and risk factors for late-onset or progressive hearing loss
- ◆ Incorporating outcome data from Audiologists on assessment
- ◆ Establishing and tracking quality assurance indicators such as:
 - Refer rates
 - Screener refer rates
 - Missed rate
 - Return rate/no shows

Appendix A

Risk Factors for Late Onset or Progressive Hearing Loss

The Joint Committee on Infant Hearing 2000 position statement suggests that the following indicators "...place an infant at risk for progressive or delayed-onset sensorineural and/or conductive hearing loss. Any infant with these risk indicators for progressive or delayed-onset hearing loss who has passed the birth screen should, nonetheless, receive audiologic monitoring every 6 months until age 3 years."

1. Parental or caregiver concern regarding hearing, speech, language and or developmental delay.
2. Family History of permanent childhood hearing loss
3. Stigmata or other findings associated with a syndrome know to include a sensorineural or conductive hearing loss or eustachian tube dysfunction.
4. Postnatal infections associated with sensorineural hearing loss including bacterial meningitis
5. In-utero infections such as cytomegalovirus, herpes, rubella, syphilis, and toxoplasmosis
6. Neonatal indicators specifically hyperbilirubinemia at a serum level requiring exchange transfusion, persistent pulmonary hypertension of the newborn associated with mechanical ventilation, and conditions requiring the use of extracorporeal membrane oxygenation (ECMO).
7. Syndromes associated with progressive hearing loss such as neurofibromatosis, osteopetrosis, and Usher's syndrome.
8. Neurodegenerative disorders, such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich's ataxia and Charcot-Marie-Tooth syndrome.
9. Head trauma
10. Recurrent or persistent otitis media with effusion for at least 3 months.

Appendix B Participants

Listed below are the participants who attended one or both Guidelines Development Meetings

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