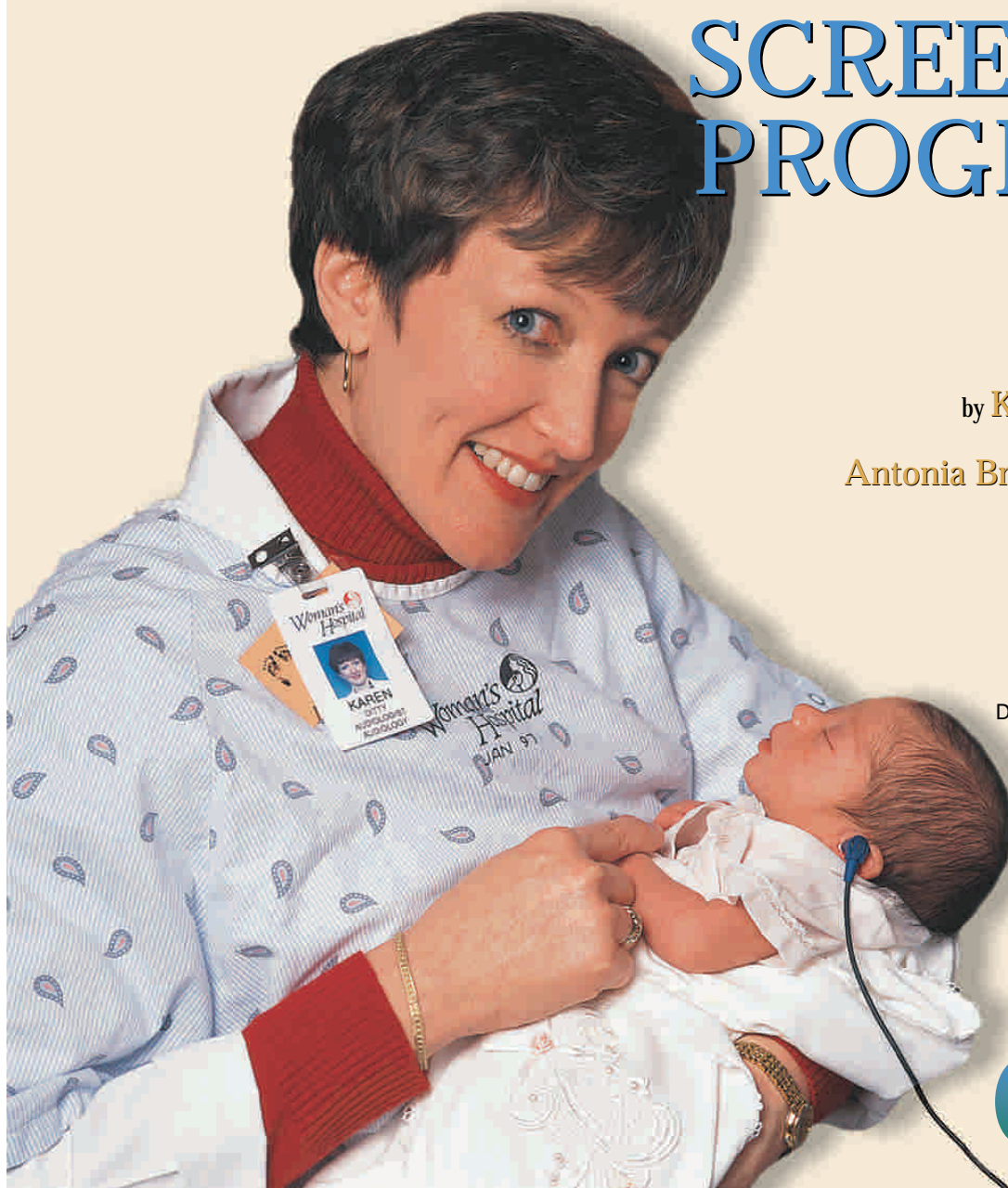


# EARLY IDENTIFICATION OF HEARING LOSS

## IMPLEMENTING UNIVERSAL NEWBORN HEARING SCREENING PROGRAMS



by **Karl R. White, Ph.D**  
Utah State University

**Antonia Brancia Maxon, Ph.D**  
University of Connecticut

Division of Services for Children  
with Special Health Needs



# CHECKLIST FOR IMPLEMENTING UNIVERSAL NEWBORN HEARING SCREENING PROGRAMS

**F**or over 50 years, there has been widespread acceptance of the need to identify hearing loss at an early age. Until just recently, however, very few hospitals were operating universal newborn hearing screening programs. Since 1993, hundreds of hospitals have implemented such programs. Based on the experiences and using materials from many of these pioneering hospitals, this booklet is organized around a “checklist” of 13 points that need to be addressed in implementing and operating a successful early identification of hearing loss program for newborns. The booklet provides a brief explanation of each activity in the checklist. In addition, the Appendices referred to in the text are available from NCHAM’s World Wide Web site ([www.usu.edu/~ncham](http://www.usu.edu/~ncham)) or in hard copy from NCHAM, the Marion Downs National Center for Infant Hearing, or the National Maternal and Child Health Clearinghouse.

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## ACKNOWLEDGEMENTS



he material in this booklet is based on the experience of staff at the National Center for Hearing Assessment and Management (NCHAM), who have directly or indirectly assisted with the implementation and successful operation of hundreds of hospital-based newborn hearing screening programs. Although NCHAM is responsible for assembling this information, it would not have been possible without the assistance of many different organizations and individuals who have graciously allowed the use of materials or contributed ideas. Particularly extensive contributions were made by staff at the Departments of Health in Texas, Michigan, Hawaii, Colorado, Connecticut, Utah, New York, Iowa, and Oregon. Coordinators of hospital-based newborn hearing screening programs in each of these states, as well as programs in Florida, Missouri, Illinois, and Washington, DC, and staff at the American Academy of Audiology, the American Speech-Language-Hearing Association, the Centers for Disease Control and Prevention, the American Academy of Pediatrics, the Health Resources and Services Administration (HRSA), the Directors of Speech and Hearing Programs in State Health and Welfare Agencies, and the Marion Downs National Center for Infant Hearing, also provided valuable material and made many helpful suggestions which substantially improved the final product.

Producing and distributing the booklet would not have been possible without financial support from the Maternal and Child Health Bureau of the Health Resources and Services Administration (HRSA/MCHB). The opinions expressed and positions advocated, however, are those of the authors and NCHAM and should not be interpreted as HRSA/MCHB policy. Readers should also note that some states have laws or regulations which take precedence over the suggestions made here. Therefore, anyone interested in implementing a hospital-based newborn hearing screening program should become informed about policies in their area and should coordinate their efforts with the State Department of Health, other state agencies, and existing hospital programs. Given the multifaceted needs of children with hearing loss, such coordination is invaluable in the development of effective early hearing detection and intervention programs. ☺

## PREFACE

**I**n 1988, when he was serving as Surgeon General of the United States, Dr. C. Everett Koop set a goal that all children with significant hearing loss would be identified before 12 months of age. At the time, it seemed like an unrealistic goal, given that the Commission on Education of the Deaf had just reported that the average age of identification of hearing loss in the United States was 2-1/2 to 3 years of age, and there were no proven methods for substantially improving the techniques then being used for newborn hearing screening. A short time later, that goal was incorporated into the *Healthy People 2000 Report* as a part of a national effort to improve the health of the nation's citizens by the Year 2000. At about that same time, the Maternal and Child Health Bureau of the Health Resources and Services Administration (HRSA/MCHB) convened an advisory group to recommend how HRSA/MCHB should respond to the recently issued report of the Commission on Education of the Deaf. Among other things, that advisory panel suggested that HRSA/MCHB fund some research and demonstration projects to improve the effectiveness of hospital-based newborn hearing screening programs.

Shortly thereafter, HRSA/MCHB began a series of initiatives, which has dramatically altered the way in which infants and young children with congenital hearing loss are identified and provided with early intervention services. Starting with a large clinical trial of universal newborn hearing screening conducted by Utah State University in conjunction with Women and Infants Hospital of Rhode Island (often referred to as the Rhode Island Hearing Assessment Project, or RIHAP), continuing with the National Consortium for Universal Newborn Hearing Screening, which operated from 1993-1996, and funding from 1996-2000 for the Marion Downs National Center for Infant Hearing, HRSA/MCHB has taken a leadership role in significantly reducing the age at which children with hearing loss are identified and ensuring that they receive appropriate medical, audiological, and early intervention services which are coordinated, family-centered, community-based, and comprehensive. During this time, the techniques and procedures for newborn hearing screening have continued to improve. In fact, the goal of identifying all children with hearing loss by 12 months of age, which was considered unrealistic in 1988, has been continually revised downward. Recently, the National Institutes of Health stated that children with congenital hearing loss should be identified early enough that intervention could start before 6 months of age.



Color copies of the above poster (12" x 17") are available from NCHAM for the cost of mailing.

As a result of various HRSA/MCHB efforts over the past 10 years, hundreds of hospitals are now operating successful universal newborn hearing screening programs, and at least six states are screening 90% or more of all births.



However, there is still a lot of work to be done as evidenced by the fact that more than 80% of all birthing hospitals are not yet doing universal newborn hearing screening. To assist hospitals which have not yet started, HRSA/MCHB is distributing this booklet about *Implementing Universal Newborn Hearing Screening Programs* to all birthing and children's hospitals in the United States.

The appendices referred to in the booklet and additional information and supporting materials for starting hospital-based newborn hearing screening programs are available from the National Center for Hearing Assessment and Management (NCHAM) at Utah State University, NCHAM's World Wide Web site ([www.usu.edu/~ncham](http://www.usu.edu/~ncham)), the Marion Downs National Center for Infant Hearing at the University of Colorado, or from the National Maternal and Child Health Clearinghouse. ☺



Utah State University  
2880 Old Main Hill  
Logan, UT 84322  
Phone 435.797.3589  
FAX 435.797.1448



University of Colorado at Boulder  
Campus Box 409  
Boulder, CO 80309-0409  
Phone 303.492.6283  
FAX 303.492.3274

**NATIONAL MATERNAL AND CHILD  
HEALTH CLEARINGHOUSE**

2070 Chain Bridge Road, Suite 450  
Vienna, VA 22182-2536  
Phone 703.356.1964



## POINT 1. ENLISTING SUPPORT FOR NEWBORN HEARING SCREENING



Although hundreds of hospitals have now implemented universal newborn hearing screening programs, thousands have yet to do so. The first step is usually persuading the various people associated with providing health care to infants that such programs are feasible, worthwhile, and affordable. The following information and strategies can be used to help these people understand the importance of newborn hearing screening.

### SUPPORT FROM AUTHORITATIVE GROUPS

Government advisory panels, commissions, and task forces have been recommending for over 50 years that children with significant hearing loss be identified as early as possible. However, in the last decade, the frequency and urgency of such statements have become much more pronounced.

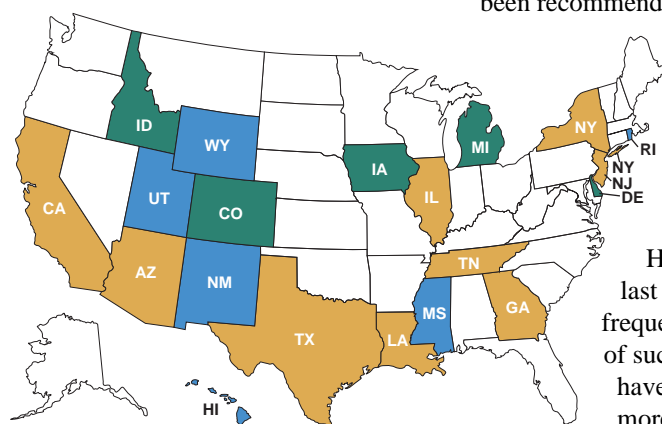
Some of the most convincing statements come from the National Institutes of Health Consensus Development Panel, the Joint Committee on Infant Hearing, the American Academy of Pediatrics, the American Academy of Audiology, the Commission on Education of the Deaf, and the *Healthy People 2000* report. (Complete references to each of these statements and a summary of the contents are included in Appendix 1.)

### MANY OTHER HOSPITALS ARE DOING IT SUCCESSFULLY

By the beginning of 1999, more than 550 hospitals in 46 different states were operating successful universal newborn hearing screening programs. Six states (Hawaii, Mississippi, New Mexico, Rhode Island, Utah, and Wyoming) have statewide programs (i.e., screening 90% or more of all births); others (e.g., Colorado, Delaware, Idaho, Iowa, and Michigan) are screening more than half of the births in their state; and several others (e.g., Arizona, California, Georgia, Illinois, Louisiana, New Jersey, New York, Tennessee, and Texas) are screening tens of thousands of babies each year. Appendix 1 includes a listing of names and addresses of coordinators for more than 100 different universal newborn hearing screening programs. Call some of the people on this list and talk with them about how they were able to do it. Those hospitals are no better, richer, or more dedicated than your hospital. If they can do it, your hospital can do it too.

### HAS NEWBORN HEARING SCREENING BECOME THE STANDARD OF CARE?

The fact that so many different authoritative groups have recommended newborn hearing screening, coupled with the existence of so many successful programs scattered all across the country and the ready availability of relatively inexpensive equipment and procedures, means that hospitals are running a significant liability risk if they do not do newborn hearing screening. Although this should not be the primary reason for starting a program, it is appropriate to make administrators



STATES OPERATING SUCCESSFUL UNIVERSAL NEWBORN HEARING SCREENING PROGRAMS:

- STATEWIDE NEWBORN HEARING SCREENING PROGRAMS.
- STATES SCREENING MORE THAN HALF OF ALL BIRTHS, BUT NOT YET STATEWIDE.
- STATES SCREENING MORE THAN 20,000 BIRTHS EACH YEAR.



aware of the liability risks and to meet with your hospital's risk manager concerning these issues (see references in Appendix 1).

### PHYSICIAN SUPPORT IS ESSENTIAL

It is important to have the support of two different groups of physicians. First, most hospitals have a pediatric committee, a medical policy committee, or other such group that makes decisions about what constitutes standard of care in that hospital. Make sure that the physicians in that group understand why newborn hearing screening should be the standard of care. Once they become convinced about the practicability and benefits of newborn hearing screening, a giant leap has been made toward it becoming a reality in your hospital.

Second, physicians in the community who care for babies need to understand why newborn hearing screening is important and how the process is supposed to work. Ideally, for each baby born, there should be a physician who knows that baby and its circumstances and is responsible for ensuring that it

receives consistent and appropriate health care. Often referred to as the baby's "medical home," the baby's primary care physician is the key to an effective early hearing detection and intervention program. Because the baby's primary care physician is responsible for the total health care of the baby, he or she needs to be assured that newborn hearing screening will not interfere with or complicate other health care activities. The physician at the baby's medical home is also extremely important in encouraging parents to keep appointments for follow-up screening and diagnostic procedures when it is necessary. You may need to use slightly different strategies to enlist the support of these two groups of physicians, but spending the necessary time in the beginning will pay huge dividends in the long run.

### IT WON'T HAPPEN WITHOUT SUPPORT FROM THE NURSING STAFF

Doctors may determine how medicine will be practiced, but babies live in the nursery while they are in the hospital. If nurses are not convinced that newborn hearing screening should be happening in your hospital, it will be almost impossible to have a successful program. If the nursing staff want newborn hearing screening, they can often convince the doctors and administrators to give it a try. In fact, some of the earliest successful hospital-based newborn hearing screening programs were started and largely operated by nursing staff. ☺



Photo courtesy of Bio-logic Systems Corp

## POINT 2. DETERMINING AN APPROPRIATE PROTOCOL FOR YOUR HOSPITAL

Once you decide to implement a screening program, one of the first decisions you will have to make is what equipment to use and what type of basic screening protocol to follow. The good news is that you have a lot of options, and almost all of those alternatives have been successfully implemented at one hospital or another. The bad news is that there are so many options, you might unnecessarily delay the implementation of the screening program to sort through them all. Our advice is to talk to some people who have tried different options; devote some brief, but intensive, study time to what type of equipment and protocol you want to use; and then make your choice and move ahead.



Photo courtesy of Madsen Electronics and University Hospital, Copenhagen

### WHICH EQUIPMENT IS BEST?

In the last 10 years, a variety of different types of equipment have been developed which can be used successfully in universal newborn hearing screening programs. Transient evoked otoacoustic emissions (TEOAE), distortion product otoacoustic emissions (DPOAE), and automated ABR (auditory brainstem response) equipment have all demonstrated their practicality and effectiveness in hospital-based newborn hearing screening programs. Each type of equipment has its proponents, and debates about which technique is best are sometimes quite energetic. It is clear, however, that the type of equipment you select is not the most important issue in whether the program will be successful.



Photo courtesy of Otodynamics Ltd

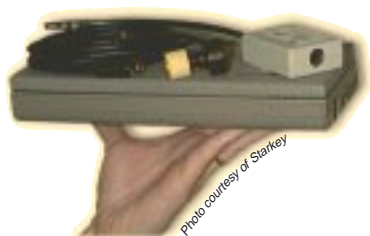


Photo courtesy of Starkey

THE EQUIPMENT CURRENTLY AVAILABLE IS MORE THAN ADEQUATE FOR OPERATING A SUCCESSFUL NEWBORN HEARING SCREENING PROGRAM.

Equipment continues to be modified and improved, and it is almost certain that better, faster, and easier-to-use equipment will become available on a regular basis. That is no reason, however, to delay implementing a program at the current time. The equipment currently available is more than adequate for operating a successful newborn hearing screening program. A brief summary of the issues to be considered in selecting equipment is included in Appendix 2, as well as a listing of names and addresses of various manufacturers.

### WOULDN'T IT BE BETTER TO WAIT FOR THE NEXT GENERATION OF SCREENING EQUIPMENT?

**Absolutely not!** Although it's easy to predict that newborn hearing screening equipment will continue to improve, there are two problems with waiting. First, no one can predict the timing of improvements. The next dramatic step forward in newborn hearing screening equipment may occur in 2 months or 5 years. Second, and most importantly, every day you wait, 33 babies are born in this country with sensorineural hearing loss. You don't want one of those to be born at your hospital and be undetected because you are waiting for even better, cheaper, and faster screening equipment than is now available. The equipment now on the market is effective, easy to use, and relatively inexpensive. Therefore, the best approach is to move ahead now with a newborn hearing screening program and then make your program even more efficient by purchasing the new and improved screening equipment when it becomes available.



### HOW MANY TESTS SHOULD BE INCLUDED IN THE SCREENING PROTOCOL?

The purpose of any screening program is to select a subgroup from the general population which

is at higher risk of having a particular condition so that a more in-depth diagnostic assessment can be done with members of that group. Therefore, it is expected that there will be some false positives (i.e., infants with normal hearing who do not pass the screening test) and occasional false negatives

(infants who pass the screening test but do have a hearing impairment). For hospitals who use only one screening test prior to the time the baby is discharged from the hospital, 2-10% of the infants will not pass prior to discharge.

Therefore, many hospitals have implemented a two-stage screening process. Sometimes this is done with the same type of equipment; sometimes with different types of equipment. Furthermore, some hospitals do a two-stage screening with different types of equipment before the baby is discharged from the hospital, while others do a single stage before the baby is discharged and then follow with an

outpatient screen several days later. Table 1 shows the many different kinds of protocols being used by hospitals in 1996.

You must decide which type of protocol is best for your situation based on factors such as the following:

- How long babies typically stay in the hospital before discharge.
- How difficult it is in your area to get parents to come back for rescreens.
- The availability of different types of equipment.
- Who is doing the screening.
- Personal preference.



Photo courtesy of Natus Medical

The fact that successful programs currently use such a variety of protocols suggests that no one protocol is really best for all situations. Regardless of the protocol you select, it is best to have a written document to guide the activities of all people associated with the program. Examples of several such written protocols are included in Appendix 2. ☞

### TABLE 1

#### Different Protocols Used in Universal Newborn Hearing Screening Programs<sup>a</sup>

Screening Procedure		
Before Hospital Discharge	After Hospital Discharge <sup>b</sup>	Number of Programs
OAE	OAE and ABR	44
OAE	OAE	5
ABR	ABR	24
ABR	OAE	2
OAE and ABR		8
OAE		7
ABR		30

<sup>a</sup> Based on universal newborn hearing screening programs that were operational as of January 1, 1996. The second technique listed for any protocol is only done if the infant does not pass the first technique.

<sup>b</sup> Only those screening techniques used **prior** to referral for a diagnostic evaluation are listed here.

## POINT 3. DEALING WITH PROCEDURAL ISSUES



**R**egardless of the technology selected or the protocol used, decisions have to be made about a number of procedural issues that are important for an efficient, successful program. It is often useful, and in fact, many hospitals require a written summary describing how the program typically addresses the following issues (see Appendix 3 for examples).

### WHO'S IN CHARGE?

If everyone is responsible for a task, it often remains unfinished. Hundreds of hospitals have now demonstrated that newborn hearing screening is relatively straight-forward and can easily be incorporated into the routine of a hospital. Just like any other procedure, however, it takes attention to detail and someone who is ultimately responsible to make sure that all of the specifics are done. The person responsible for day-to-day operation of the program needs to have good connections with the nursery, understand how screening happens, and most of all be committed to the success of the program. Instead of looking for reasons why newborn hearing screening won't work, that person needs to be committed to its success. Depending on how the program is organized, most hospitals find this person will require between 2 and 6 hours per week per thousand births to coordinate and manage the overall program.

### WHO WILL DO THE SCREENING?

Reports from hundreds of operational programs provide clear evidence that newborn hearing screening can be done by a wide

variety of people, including nurses, audiologists, technicians, health care assistants, volunteers, and students (see Table 2). Some states have laws regarding who can screen for hearing and how they must be supervised; others do not. Regardless of who does the screening, make sure they are properly trained and supervised and keep data on how each screener is doing. Such data will enable you to give timely and appropriate training and assistance when it is needed.

**TABLE 2**

**People Doing Screening in 130 Newborn Hearing Screening Programs<sup>a</sup>**

Audiologists	34%
Technicians	27%
Nurses	60%
Volunteers	11%

<sup>a</sup>Percentages sum to more than 100%, because many sites have different groups of people doing screening. Data taken from a survey conducted in 1997 by the Marion Downs National Center for Infant Hearing.

### WHEN SHOULD SCREENING BE DONE?

All other things being equal, newborn hearing screening is faster and easier if babies are quiet and the environment is not too chaotic. Because of this, most screening is done in the early morning or during the night when there are fewer people wanting access to the baby (e.g., doctors, visiting relatives, nurses, parents, etc.). Even so, depending on who is screening, what other responsibilities they have, and how the hospital's nursery is organized, you may decide to do screening at



Photo courtesy of SonaMed Corp

some other time or continually throughout the day. Whatever you decide, there are dozens of other hospitals doing it at approximately the same time. The conclusion? There really is no wrong time to do newborn hearing screening.

#### **MAKING SURE EVERY BABY IS SCREENED**

If the hospital has accepted newborn hearing screening as the standard of care, there should be procedures to ensure that no babies are missed. Setting up a system to log the birth of every baby, making sure screeners are available to screen every baby prior to discharge, and incorporating the hearing screening into the discharge plan should all be considered. Because some hospitals discharge babies after very short stays, you will probably need 7-day-a-week coverage and people available to do screening whenever babies are likely to be discharged. Many hospitals have found that by incorporating screening duties into the job responsibilities of existing personnel, they have an easier time achieving 7-day-a-week coverage.

#### **SCORING**

Some types of equipment automatically produce pass/fail results, so no scoring is necessary. Other equipment requires someone to make a

pass/fail decision based on established criteria. With such equipment, you have to decide who will make those decisions and when they will be made. In most cases, this isn't a big deal, since it requires just a few seconds and many hospitals have the screening technician make the decision following established guidelines. Some states have laws or regulations governing such decisions, however, so make sure you are consistent with such requirements if they exist.

Even in those cases where the result is automatically produced, you need to make sure the results are written down or entered into a database. This will enable you to keep track of all of the results and make sure that infants referred from the screening program receive the appropriate diagnostic and, as necessary, intervention services.

#### **SHOULD SCREENING BE DONE WITH THE PARENTS PRESENT?**

You must decide whether or not you want to encourage parents to be present during the screening. If the parent is present for the screening, they will have questions and want to discuss the process. This is wonderful from an educational perspective, but it requires more time and, consequently, increases the cost of the screening program. If you can afford it and want to provide the extra education, it's a great thing to do, but be mindful of the extra time required. Even if you decide not to actively encourage parents to be present, if they ask to watch, you should certainly accommodate them. The important thing is to make sure parents are involved and supported at every opportunity.



### SHOULD PARENTS BE ASKED TO SIGN A PERMISSION FORM?

There are really two different, but related, questions here:

- First, should you have procedures to ensure that parents have a reasonable understanding of what happens during newborn hearing screening so they can decide whether they want their baby to be screened?
- Second, should parents be required to sign a written permission before their baby is screened?

The answer to the first question is definitely yes, while the answer to the second is probably no. With regard to the first question, every effort should be made to educate parents about newborn hearing screening prior to when it happens (what it is, why it is important, how it is done, etc.). This can be done with information in the preadmission materials, prenatal classes, media materials, or placed in the baby's crib. If, based on this information, parents do not want to have their baby screened, they have the right to refuse (it is a good idea to require that they give you a written documentation of that refusal, which is kept on file).

With regard to the second question, it is

important to remember that newborn hearing screening is not an experimental research procedure. If it were, written parental permission for every baby screened would be required. However, most people agree that if the medical procedures committee at the hospital has decided that newborn hearing screening is a standard of care, written parental permission is not necessary. Although it requires extra time (in some cases, more than the total time required to do screening), a few hospitals still obtain written permission from parents before screening the baby. As noted above, this does provide an opportunity to explain to parents exactly what the screening is and why it is important. It is also important to note that some states have laws or regulations regarding such issues. For example, in several states with legislative mandates for newborn hearing screening, parents may refuse screening for religious reasons. Therefore, it is important to know exactly what the situation is in your state. ☺



*Photo courtesy of Intelligent Hearing Systems*

## POINT 4. COMMUNICATING WITH PARENTS, PHYSICIANS. AND HOSPITAL STAFF



any people have a stake in the results of a newborn hearing screening program.

Making sure these people receive timely information is essential to the program's success. In many cases, it is also important to document that communication has occurred and to have a system in place to quickly and accurately retrieve information which has been communicated.

### COMMUNICATING WITH PARENTS

Parents are among the most important stakeholders in the results of a newborn hearing screening program, since they are the ones who have long-term responsibility for ensuring that the baby receives appropriate care. They are also the ones who have the strongest feelings (but usually limited experience) about what it means to have a child with a hearing loss.



*Photo courtesy of Otodynamics Ltd*

### RESULTS OF THE SCREENING TEST

For most parents, communicating the results of the screening test is more than just saying that the baby passed or was referred. Instead, parents need to know what the result means and what the next steps should be. Even when the baby passes a screening test, this is a great opportunity to help parents

understand the importance of monitoring language development and of being aware of the indicators of recurrent conductive or late-onset hearing loss.

Most successful newborn hearing screening programs use a variety of materials to educate, inform, and follow up with parents. For example, a 3-minute videotape explaining how newborn hearing screening is done, why it is important, what the results mean, and what should happen next is available in both English and Spanish from NCHAM. Such a video can be used during birthing classes so that mothers know what to expect when the screening is done. Other examples of parent information which can be copied or modified for use in your program are included in Appendix 4a. These include information pamphlets about the screening program, parent education materials, letters sent to parents when their baby does not pass, and cards used to make return appointments for rescreens or diagnostic evaluations. Use the ideas from other programs and then develop your own to meet your unique circumstances. If keeping costs as low as possible is important, acceptable print materials can be done with almost any word processing program. With a little extra money, they can be done in color with pictures and professional layout. The important thing, though, is to communicate the correct information to parents at a time when they can understand it and when they are likely to benefit from it.





#### WHEN TO COMMUNICATE THE RESULTS

If the logistics can be worked out, there are some real advantages to informing parents about the results of the newborn hearing screening test before the baby is discharged. Then, if there is a need to continue the screening procedure on an outpatient basis, it can be scheduled before they leave the hospital, and parents can have their questions answered and any misunderstandings clarified. For babies who pass the screening, most hospitals communicate results in writing because of the time involved in speaking individually with parents. Some hospitals, however, view this as an ideal educational opportunity and believe that it is worth the time it takes to spend a few minutes with each parent. At least for the babies who do not pass the screening test prior to discharge, it is highly desirable to make sure there is an opportunity for parents to have their questions answered when they are informed about the results of the inpatient screen.

You should also consider the opinions of the child's medical care provider. Some physicians feel keenly about their role in medical management and want to be the first to inform the parents. Therefore, make sure you have discussed your procedures for informing parents with representatives

from the medical community.

Whatever procedure and timing you select to inform parents, make sure that the health care team is aware of what has happened.

Some screening programs are not able to communicate results to parents before the baby is discharged. This is not so unusual. For example, most metabolic screening programs inform parents that if there is a problem, they will be contacted later. In most states, the parents of babies who pass the metabolic screening test receive no information at all. There's nothing wrong with operating the newborn hearing screening program in the same way, as long as it is clearly communicated to parents that this will be the case.

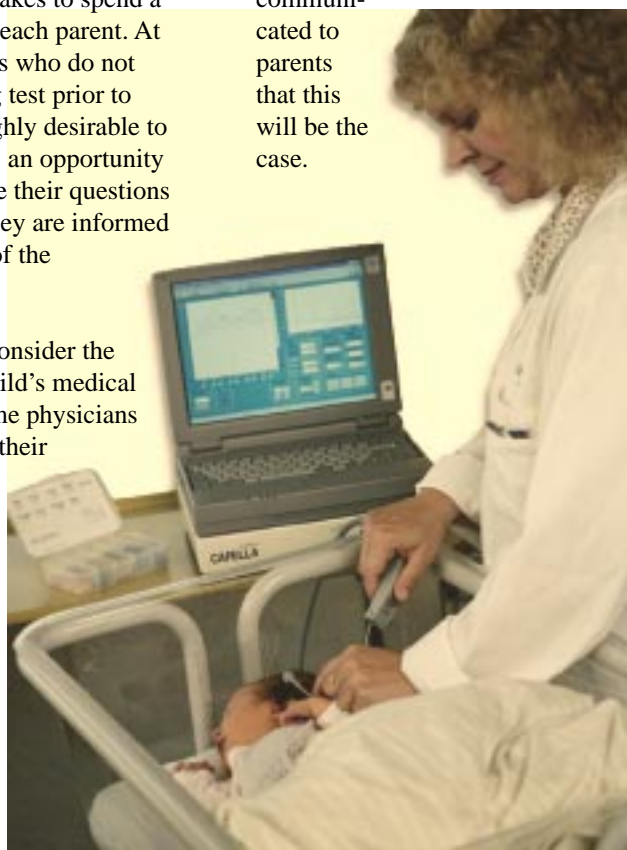


Photo courtesy of Madsen Electronics and University Hospital, Copenhagen



#### BEING SENSITIVE TO PARENTS' FEELINGS

Many people have worried about creating unnecessary anxiety in parents or disrupting family functioning, because most babies referred from an inpatient newborn hearing screening test will have normal hearing. There is no evidence that this is a frequent problem. The key to avoiding such anxiety or disruption of family functioning is to make sure parents understand that the screening test is not a diagnostic evaluation and that a referral for further testing does not mean that their infant has a hearing loss. Using the materials and activities described in the previous section can help to do this. Another simple, but effective, tool is to make sure that everyone associated with the screening program is careful about how information is communicated to parents. For example, it is much better to refer to babies who do not pass the screening as being **referred** for further evaluation, instead of as having **failed**.

#### AWARENESS OF LANGUAGE DEVELOPMENT MILESTONES

The activities associated with a newborn hearing screening program provide an ideal opportunity to help parents understand the importance of language development. Just because a child has passed a newborn hearing screening test doesn't mean that there will not be future problems with hearing or language development. Materials distributed in conjunction with the newborn hearing screening (such as those included in Appendix 4a) can help parents be more

aware of their child's language development and what they should do if the child does not achieve developmental milestones in a timely manner. The newborn hearing screening test provides information about the status of the infant's hearing at that time. However, common childhood diseases can later cause fluctuating or permanent hearing losses that will interfere with language development. As a part of the newborn hearing screening procedures, you should emphasize the importance of parents requesting another hearing evaluation if they have any concerns about their child's language development.

#### COMMUNICATING WITH PHYSICIANS

In recent years, there has been a major effort among health care professionals to make sure every child has a medical home. In other words, every child should have a primary health care provider who is aware of that child's needs and medical history so that the child receives appropriate and timely health care. Because of this emphasis, it is not surprising that one of the biggest concerns physicians have about newborn hearing screening programs is that they will not have sufficient input into making decisions about a medical issue for one of their patients. Such concerns are legitimate, and the program should be organized in such a way so this is not a problem.

#### GENERAL AWARENESS OF THE PROGRAM AND ITS IMPORTANCE

From the very beginning, physicians need to understand how newborn hearing screening relates to the care of their patients.



Photo courtesy of Logan Regional Hospital, Logan, Utah



Photo courtesy of Grason-Stadler, Inc

Presenting information to the hospital staff about newborn hearing screening or presenting to the pediatric committee are two effective strategies. If this is not possible when the program is being implemented,

you should distribute appropriate written materials to all pediatricians and family practice physicians who have babies at the hospital (see examples in Appendix 4b).

As the program is starting, it may be useful to do some screening of babies at the times physicians typically make their rounds. Be sure you don't interfere or take their babies while they are trying to examine them. Just being there and doing your work, however, will prompt a lot of questions and understanding of what is involved in newborn hearing screening. As babies with hearing loss are identified, be sure to communicate the results to that baby's physician. Periodically, you should use letters, reports to the hospital's pediatric committee, or a newsletter to inform the hospital's medical staff about the success of the program. Case histories and personal experiences of families whose babies have been helped by the program are particularly useful.

#### WHAT WERE THE RESULTS FOR THEIR PATIENTS?

Make sure you develop a mechanism to efficiently notify each of

the physicians who are responsible for babies in your hospital about the results for their patients. Although this is particularly important for babies who do not pass the initial screen, it is best if you can develop a system for giving them information about all of their patients. Some of the newborn hearing screening data management programs automatically print a monthly report which provides a summary for each physician of the results for all babies for which he/she is responsible. In those cases where babies do not pass the initial screen, it is particularly important that the primary care physician receive a timely written report of this result with a clear recommendation of what should happen next.

#### ENSURE THAT PHYSICIANS UNDERSTAND THE IMPORTANCE OF FOLLOW UP

Few things can undermine the success of a newborn hearing screening program as much as a physician telling the parent during a well-baby check that it is really not that important to follow up with the outpatient screen or diagnostic evaluation procedures. Some health care providers still have the mistaken idea that they can use some simple behavioral techniques during the well-baby check to determine whether the infant has a hearing loss. Actually, there is a wealth of well-documented information showing that using behavioral evaluation as the only way of assessing hearing loss in 1 to 3-month-old infants is extremely difficult, even for well-trained audiologists with a sound booth and all of the latest equipment. The best approach for a

physician is to encourage parents to follow through with the screening and appropriate diagnostic audiological procedures. In addition, if parents have concerns, they should be encouraged to see an audiologist who has experience in treating young babies.



Photo courtesy of Grason-Stadler, Inc

#### MEDICAL MANAGEMENT ISSUES

When a baby is referred from a screening program, medical evaluation is an essential part of the diagnostic process, and newborn hearing screening program staff must recognize and communicate to physicians that they are a critical part of that multidisciplinary team. It is also important that everyone involved in the baby's medical management understand how unfortunate it is when the diagnostic process drags out over several months, instead of being completed within a few weeks. For babies without other medical complications, there is no reason why amplification cannot be appropriately fitted and early intervention begun within a few

months. For that to happen, however, all members of the team have to recognize the importance of early diagnosis and intervention and then work together to make it happen as quickly as possible.

#### COMMUNICATING WITH THE HOSPITAL

Hospital administrators, risk managers, nursery supervisors, and community education staff, among others, also need to be kept informed about the newborn hearing screening program. If various people in the hospital are receiving the information they need on a timely basis, the continuation of the newborn hearing screening program is almost guaranteed, because the benefits will be well documented, and consequently, many different groups can work to support and improve the program.

#### RECORDING RESULTS IN THE CHILD'S MEDICAL RECORD

It is important to make sure that the results of the screening are a part of the child's permanent medical record maintained by the hospital. Many programs use a stamp in the baby's medical chart which indicates the results of the hearing screening. Some equipment and data management programs can print a label (showing name, date, type of test, and result) with sticky backing that can be affixed to the infant's medical chart.

#### DOCUMENTING THE SUCCESSES AND DIFFICULTIES OF THE PROGRAM

Hospital administrators at various levels want to know how the program is doing. Having an effective data management system



in place that can quickly compile information can be extremely useful, such as:

- The percentage of babies screened.
- The percentage of babies passed at discharge.
- The percentage of invalid tests.
- The percentage of babies who are referred from the initial screening who eventually receive diagnostic evaluations.
- The number of babies identified with sensorineural hearing losses.

Often, administrators need such information at a moment's notice for a particular time period you weren't expecting (e.g., last month, or the first quarter of this year, or year-to-date). If data is being maintained by a computer-based data management system, such requests are easy to meet. If not, you should try to anticipate

the type and timing of information administrators

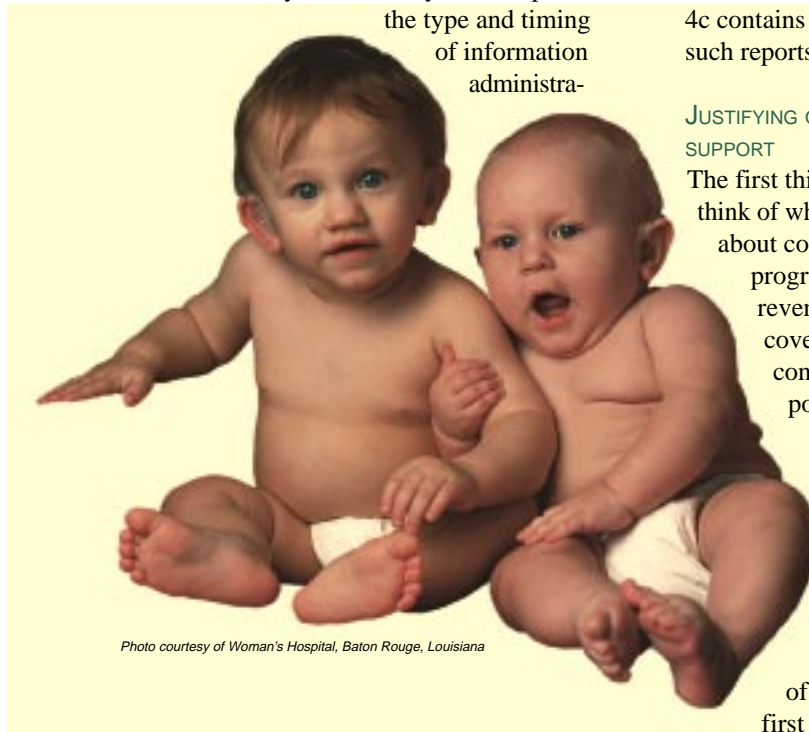
tors will want so you can arrange to produce the necessary reports.

#### REGULAR REPORTS TO HOSPITAL ADMINISTRATORS

In addition to statistical summaries, you should make sure that hospital administrators at various levels are regularly informed about the progress of the newborn hearing screening program. You don't want to burden yourself with creating reports which no one is reading. Depending upon the situation, however, you should summarize at least annually the successes of the program, the challenges which still need to be addressed, and the strategies for resolving those challenges. It is particularly important to highlight the human side of any success stories so administrators see that people's lives are better off as a result of this program. (Appendix 4c contains examples of several such reports.)

#### JUSTIFYING ONGOING PROGRAM SUPPORT

The first thing most administrators think of when faced with questions about continuing a particular program is whether the revenues generated have covered the costs. In this context, it is important to point out that many newborn hearing screening programs are implemented for just a few dollars per baby of "out-of-pocket costs." A simple, but complete, cost analysis of the program after the first year, and then at



*Photo courtesy of Woman's Hospital, Baton Rouge, Louisiana*





periodic intervals thereafter, can be extremely important information when it comes to decisions about continuation. Also, it is important to make sure that hospital administrators hear from people who are seeing the long-term benefits of newborn hearing screening (parents, audiologists, state department of health officials). For example, a letter sent each year

from the state department of health to hospitals where newborn hearing screening programs are functioning, which summarizes the success in the state during the past year and congratulates them on their foresight and commitment to making such a valuable service available to children born at their hospital, can have an extremely positive impact. ☺☺

## POINT 5. TRAINING NEWBORN HEARING SCREENERS

**G**iven enough time, you could probably figure out on your own everything involved in operating a successful universal newborn hearing screening program. However, it makes a lot more sense to learn from the experiences of others instead of using trial and error as your primary method of deciding how to operate a program efficiently.

### INITIAL TRAINING

Screening babies for hearing loss is like riding a bicycle—almost anyone can do it, but it is easier to learn how if you have some help in the beginning. Regardless of which screening equipment you decide to use, screeners will become proficient much faster if there is a hands-on, competency-based training session at the beginning. The best people to provide such training are those who are already successfully participating in a newborn hearing screening program. Sales representatives can show you how to operate their equipment, but the best training is usually delivered by people who have experience operating a newborn hearing screening program. Ideally, such training should include ample time screening real-

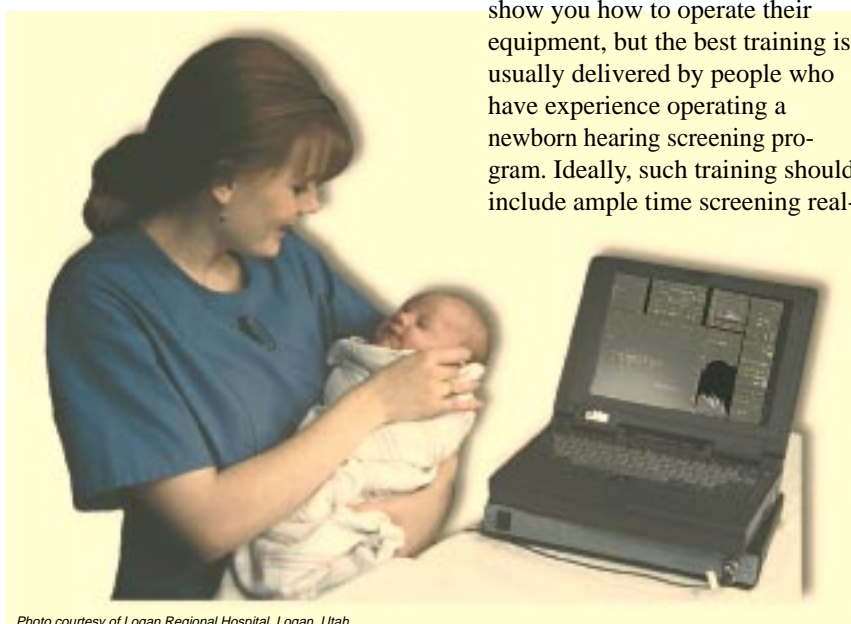
live babies in the same environment where the screening program will be conducted. Once a person acquires skill with the screening equipment, just like riding a bicycle, it is easily remembered.

### DON'T TRAIN MORE PEOPLE THAN NECESSARY

The number of screeners needed to operate a universal newborn hearing screening program depends on the annual number of births and how the program is organized. Because babies are often released just a few hours after being born, you will probably need 7-day-a-week coverage. However, the total amount of screening time is relatively small. Studies conducted by NCHAM suggest a range of 4 to 10 hours per week of screener time per thousand babies. Although you need to be sure to have enough people trained to achieve adequate coverage, many hospitals make the mistake of training too many people (e.g., all of the nursing staff). Not only does this require extra time for training and supervision, but it often results in a less efficient program because responsibility for screening babies is diffused and the quality of screening technique suffers.

### REGULAR SUPERVISION

It is often said that practice makes perfect. Actually, practice makes permanent. Consequently, it is important to provide timely feedback to people who are just learning to screen so you can correct errors before they become ingrained. Subsequently, there should be regular supervision and feedback regarding screening



*Photo courtesy of Logan Regional Hospital, Logan, Utah*



performance. One-on-one observation and instruction are the most effective and should be done periodically. A written checklist (see examples in Appendix 5) can be very useful. In addition, a regular report which shows the performance of each screener with regard to number of babies screened, number of babies passed, number of invalid tests, number of screens completed per hour of work, can be useful in identifying screeners who are having difficulty and need in-service instruction. Be careful to organize such supervision in such a way that screeners view it as a help instead of a punishment.

#### **RETRAINING TO ACCOMMODATE STAFF TURNOVER**

It is not unusual to experience a fair amount of turnover among those people responsible for screening babies (e.g., nurses, health care assistants, technicians, clerical staff). Therefore, it is important for you to plan from the beginning how new people will be trained and supervised. Once you have an operational program in place, this is usually accomplished quite easily by existing personnel.

Many program coordinators identify one of their most proficient screeners to be responsible for training new people. In some cases, state licensure laws or regulations will impact on how training must be done. Training is best when it is competency-based and requires trainees to actually demonstrate their proficiency in the same way as is required in the screening program. It is usually best to make the training intense enough so the new trainees can achieve and demonstrate proficiency within a few days and then have an opportunity to solidify the skills they have learned over the next several weeks. ☺☺



*Photo courtesy of Intelligent Hearing Systems*

## POINT 6. KEEPING REFER RATES LOW

**R**egardless of the type of technology or protocol used, the goal of newborn hearing screening is to create the smallest reasonable subset of the general population which still contains all of the infants with hearing loss. In other words, without missing any babies, it is generally best to minimize the number of infants referred from the screening process to a diagnostic evaluation (of course, this goal must be balanced by other factors, such as time and cost). Some strategies to reduce referral rates are applicable regardless of the technology being used, and others apply only to specific technologies.

### SCHEDULE SCREENING WHEN BABIES ARE IN THE BEST BEHAVIORAL STATE

Even though it is possible to screen babies who are awake and restless, screening happens much more quickly and the results are better if the screening is performed when the baby is quiet (or even asleep), happy, well fed, and comfortable. Therefore, if possible, you should schedule the majority of your screening activities when babies are most likely to be in this optimal state. When and where you do the screening will depend on other activities, routines, and available space at your hospital.

### MAKE A SECOND EFFORT PRIOR TO DISCHARGE TO SCREEN BABIES WHO DO NOT PASS AT FIRST

Most programs do not consider the initial screening to be complete until the baby leaves the hospital. Typically, the first attempt to screen the baby is made shortly after birth. It seems to work best to not spend too much time with the baby during this initial attempt. If the baby passes (as the majority will do), you are finished. If not, wait several hours and try again. Regardless of the equipment or protocol being used, these second efforts prior to discharge can substantially reduce the number of babies who need to come in for outpatient screens or diagnostic procedures. Instead of spending 30 minutes with the baby during an initial attempt, it is much more efficient to make a quick first attempt, followed by a second or even third attempt a few hours later. In other words, repeated short attempts are usually more successful than a single prolonged effort.

### MINIMIZE NOISE AND CONFUSION IN THE SCREENING AREA

None of the screening equipment requires extraordinary measures to make the screening area quiet. Newborn hearing screening is routinely being done in neonatal intensive care units and crowded and relatively noisy well-baby nurseries. However, all other things being equal, screening will be faster and more effective if you do what can sensibly be done to minimize noise and confusion in the screening area. In other words, where possible, do most of your screening when doctors are not



Photo courtesy of Madsen Electronics and University Hospital, Copenhagen



making their rounds, do not screen directly under a ventilator fan, and find an area to screen which is not adjacent to a bathroom where running water creates unnecessary noise. Where sensible and inexpensive modifications can be done to reduce noise (e.g., carpeting on the floor, curtains on windows, a portable room divider which provides some sound attenuation), they are worth considering to increase the efficiency of the screening program. However, it is certainly possible to operate a screening program without any such enhancements.

#### USE THE BEST PROTOCOL FOR YOUR SITUATION

In an effort to keep refer rates as low as possible, some hospitals use both OAE and ABR technology prior to discharge. In situations where it is difficult to get babies back for an outpatient screen, such a protocol can save time, money, and hassle for the program and families. The downside, of course, is the additional cost of using two types of equipment. Some manufacturers offer both OAE and AABR on the

same unit at substantially less than what it would cost to purchase both pieces independently.

#### HAVE BACKUP EQUIPMENT AND SUPPLIES READILY AVAILABLE

Because some babies are discharged after just a few hours in the nursery, it is essential to make sure your screening program has arranged for backup equipment in the event of a breakdown. Most newborn hearing screening equipment is extremely reliable. However, if your equipment unexpectedly stops operating and it takes you 3 days to get a replacement, you will probably miss 10% or more of the babies born at the hospital that month. Although you can have such babies come back for outpatient screening, it is extra work for everyone and unlikely to be completely successful. Therefore, you should make arrangements to obtain replacement or loan equipment within a very short time from the salesperson, a neighboring hospital, university, audiologist, or school district. It is also important to have sufficient supplies or replacements for consumable parts (e.g., probe tips, electrodes, probes).

#### FOR OAE PROCEDURES, PROBE FIT IS CRITICAL

If OAE technology is being used, the single most important factor in reducing refer rates is to make sure screeners understand how to achieve appropriate probe fit. Although this is relatively easy to learn, it may not be immediately obvious to screeners and usually has to be taught. A screening program whose personnel have not



*Photo courtesy of Intelligent Hearing Systems*



mastered the techniques of good probe fit will generally have refer rates at the time of hospital discharge two to four times higher than a program where screeners have mastered probe-fitting techniques.

**FOR AABR PROCEDURES,  
SCREEN WHEN MYOGENIC  
ACTIVITY IS LOW**

AABR screeners have artifact rejection systems built in so data are not included in the average

when myogenic activity is high. Myogenic activity is caused by muscle tension. If babies are tense, wiggly, or restless, myogenic activity will be higher, and it will substantially increase the screening time. It may even result in more babies who need to be brought back for rescreening or diagnostic procedures because a pass could not be obtained. Thus, it is best to do screening when babies are relaxed, happy, well fed, and, if possible, asleep. ☺



Photo courtesy of Natus Medical

## POINT 7. MANAGING DATA AND PATIENT INFORMATION

**T**he goal of a universal newborn hearing screening program is to identify babies with hearing loss and enroll them in appropriate intervention programs as early as possible. This will require coordination with the baby's medical home, one or more audiologists, and various state and local agencies who are responsible for providing services to infants and young children with hearing loss. The screening which happens prior to hospital discharge is only the first step. In fact, most screening program managers report that keeping track of what happens in the screening program and managing babies through the referral and diagnostic process is the most challenging part of an early hearing identification program. Data and patient information management includes keeping track of which babies have been screened, what screening or diagnostic procedures should happen next, and which babies have missed appointments and need to be located. It also involves generating reports for program management, accountability, and program continuation, and generating letters to parents and physicians concerning the outcome of various screening and evaluation procedures.

Not only is such data and patient information management complex, but if it is not handled appropriately, it can be much more time consuming than the actual screening. The most successful early identification programs are those which have a system in place to deal with all of these issues when they start the program. Data and patient information management is the kind of task that many people procrastinate (think of

how you keep track of all those records, business expenses, and donations needed for filing your income taxes each year). With a newborn hearing screening program, the amount of information you need to manage continues to multiply as more and more babies are born. If you don't have a system in place to efficiently manage the information when you first start, you will soon find that you are overwhelmed, and the whole system begins to collapse in piles of paper and yellow sticky notes.

### COMPUTER-BASED DATA MANAGEMENT

The information management tasks associated with an early detection of hearing loss program are well-suited to computer-based data management. Summarizing data from individuals into understandable reports, generating letters to parents and pediatricians at different times based on the most recent outcomes, and reminding you of upcoming and overdue screening and diagnostic activities are all easily done with a computer-based program. Information about several complete data and patient information packages which can be used by hospitals is summarized in Appendix 7.



**HI★TRACK PATIENT AND INFORMATION MANAGEMENT MODULE FROM NCHAM**



In some cases, the State Department of Health will have a data and patient information management system in place, which can be used by hospitals. In other cases, hospital-based systems may want to consider developing their own program.

### SHOULD YOU TRY TO DESIGN YOUR OWN SYSTEM?

Small hospitals with only a few births each month (less than 100 per year) may be able to keep track of all of the necessary information using a paper and pencil system. However, even if it is possible to do so, it often requires much more time and will probably result in a less efficient system than would be the case with a computer-based management system. Designing your own computer-based software is also an option. However, many hospitals who have tried to design their own comprehensive data management system have found that it is a much more difficult and time-consuming task than they anticipated. Some hospitals with newborn hearing screening programs, after spending several months and hundreds if not thousands of dollars, have decided that they ought to use one of the programs referenced in Appendix 7.

### CAN YOU MODIFY ONE OF THE DATABASES YOUR HOSPITAL ALREADY HAS?

Many hospitals already have a number of computer-based data management systems (for example, more and more hospitals are converting to computerized medical records and charting). However, in most cases, the data and reporting needs for a newborn

hearing screening program are too idiosyncratic for these systems to be of much use. For example, with metabolic screening programs, hospitals only need to provide a blood specimen and very limited demographic data for each child. If the baby fails the test, the name is given to the primary care physician, and the task is finished as far as the hospital is concerned. With most newborn hearing screening programs, however, hospital staff stay involved with outpatient screening and perhaps even into the diagnostic process. Therefore, the most successful early identification of hearing loss programs are using data management systems that are specifically tailored to their needs.



SCREENING AND INFORMATION MANAGEMENT SOLUTION (SIMS)  
FROM OZ SYSTEMS

### SAFEGUARDING YOUR DATA

The way in which computers store, process, and recall information is still somewhat of a mystery for most people. Even though a computer-based data management system can save you enormous amounts of time and result in a much more efficient program, they can also lose huge amounts of information if you are not careful. As with any computer-based



system, the information in your newborn hearing screening database needs to be backed up on a regular basis. The basic rule is that you should always have two copies of all important information. Computer viruses can also destroy or scramble data, making it unusable. Fortunately, most

hospitals have an information management office who can assist you in backing up your data on a regular basis and protecting against viruses. Often, a phone call to the staff of that office is all that is necessary to get onto their schedule to ensure that your data is safe and secure. ☞

## POINT 8. FINANCING THE PROGRAM



As pressures to contain rising health care costs increase, anyone interested in starting a new program will have to be concerned about costs. Even though everyone recognizes that newborn hearing screening is a wise investment, it is still necessary to find the dollars necessary to make that investment.

### HOW MUCH DOES IT REALLY COST?

Depending on how your program is organized, you can expect the total costs of the program to be

between \$8 and \$75 per baby. This includes all of the costs associated with personnel (including fringe benefits), equipment and supplies, and hospital overhead. These estimates are based on cost analyses conducted with actual programs and include all of the costs for activities related

to screening the babies prior to hospital discharge, outpatient screening, and tracking the babies into the diagnostic assessments. It does not include the costs of diagnosis or early intervention. (References on which these estimates are based are summarized briefly in Appendix 8.)



Photo courtesy of Natus Medical

### WILL INSURANCE PAY FOR NEWBORN HEARING SCREENING?

Some states have legislatively mandated that all health insurers must pay for newborn hearing screening (e.g., Massachusetts, Rhode Island, West Virginia). In other states, however, it depends on the insurer, and most programs have been reasonably successful in getting health insurers to pay. In many cases, however, it hasn't been automatic, and someone has had to spend a significant amount of time educating insurance company staff about the rationale for and benefits associated with newborn hearing screening. Programs which have tracked reimbursements have found that by working with the various insurance companies, they are able to achieve very respectable reimbursement rates.

### IS NEWBORN HEARING SCREENING COST BENEFICIAL?

There is fairly convincing data from cross-sectioned, correlational, and retrospective studies that children who are identified early will do much better in school and will generate many times the cost of the newborn hearing screening program in educational savings (summaries of such studies are included in Appendix 8). However, it is generally not very effective to try to convince health insurance companies that they will save money in the long-term by paying for newborn hearing screening. In fact, by identifying children earlier, it will probably cost the health insurance company more,



since there will be more and earlier visits to the doctor, more speech and language management, and earlier use of hearing aids. Nonetheless, many insurance companies are willing to reimburse for newborn hearing screening, because they recognize it is good health care policy.

### How do I convince the insurance companies to pay?

The best argument is that newborn hearing screening is the right thing to do and is a relatively small cost when compared to

other medical procedures. However, some insurance companies do not like to pay for universal screening procedures for low incidence conditions. It may be useful to point out to such companies that the alternative to universal newborn hearing screening is to do conventional ABR on the 10% of the population that exhibits high-risk indicators. Because that subgroup of the population has a condition which has long been recognized by the medical profession as being at higher risk for hearing loss, almost all insurance companies will pay for conventional ABR for those infants. Unfortunately, high risk-based hearing screening programs miss at least half of the babies with congenital hearing loss. Also, because the new screening technologies are so much more efficient, universal screening is actually less costly for the insurance company than doing conventional ABR on the high-risk population.

### Does Medicaid pay for newborn hearing screening?

Depending on where you live, Medicaid has been either very good or very bad about reimbursing for newborn hearing screening. In some cases, Medicaid has approved newborn hearing screening as a part of the first well-baby checkup in the EPSDT (Early and Periodic Screening, Diagnosis, and Treatment) program. Under EPSDT guidelines, Medicaid is then obligated to pay for the screening procedure (see a copy of the regulation from Utah in Appendix 8). In other cases, the Medicaid office ruled that newborn hearing screening would only



Photo courtesy of Otodynamics Ltd



be paid for if it occurred on an outpatient basis, which effectively eliminates Medicaid reimbursement for universal newborn hearing screening. The best advice about getting Medicaid to pay for newborn hearing screening is to find someone sympathetic to children's issues in the state Medicaid office and work with that person to find a way for Medicaid to pay the costs. Again, education and persistence are the keys.

#### USING EXISTING STATE RESOURCES

Every state has existing programs to provide some services to infants and toddlers with special health care needs. In addition to those funded directly by the state, the federal government requires states to operate several programs which can be used to make sure infants referred from newborn hearing screening programs receive timely and appropriate diagnostic and intervention services (e.g., IDEA—Individuals With Disabilities Education Act—or CHIP—Child Health Insurance Program). Taking advantage of these existing programs will substantially reduce your costs and improve the quality of services for participating families.

#### GRANTS, DONATIONS, AND COMMUNITY SUPPORT

In the early 1990s, federal research and demonstration grants were used to support a number of universal newborn hearing screening programs. Such grants are difficult to obtain now because federal agencies are hesitant to support the routine provision of health care. Because the concept of newborn hearing screening has now been endorsed by so many different federal agencies as being the desired standard of care, it is unlikely that you will find a federal grant to provide support for establishing a program. Private foundations and service clubs are a possibility, but will most likely limit their donations to the costs associated with establishing the program and not to the ongoing operation. Many hospitals have been successful in getting service clubs and auxiliary organizations, such as Quota Club, Lions Club, or Sertoma, to provide the money necessary to buy newborn hearing screening equipment for their hospital. Suggestions about foundations and other organizations who may be willing to fund such activities are included in Appendix 8. ☞

## POINT 9. CARING FOR EQUIPMENT AND SUPPLIES



All newborn hearing screening equipment uses a microprocessor, computer chip, or computer in some way. Such equipment will last for many years if proper attention is given to care and maintenance. In most cases, using common sense and taking advantage of services already offered by hospital support staff is all that is needed.



Photo courtesy of Natus Medical

### AN OUNCE OF PREVENTION IS WORTH A POUND OF CURE

The best way to avoid breakdowns in screening and computer equipment is to take care of it. Educate people so they don't eat or drink while using the equipment,

use a dust cover when the equipment is not in use, and get a surge protector to ensure consistent supply of electrical power.

Although most screening equipment is very durable, it

shouldn't be handled roughly, dropped, or exposed to temperature extremes. For example, leaving the screening unit in the trunk of your car on a freezing winter night or in the front



Photo courtesy of Otodynamics Ltd

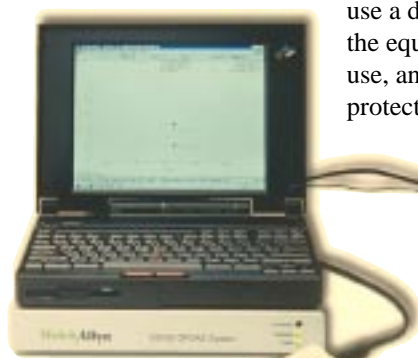


Photo courtesy of Grason-Stadler, Inc



Photo courtesy of Biologic Systems Corp

seat on a hot summer day could be the end of it. Also, make sure that people know that computer disks need to be handled sensibly. Don't get them wet, fiddle with the movable parts, or expose them to extreme temperatures. With common-sense care, screening equipment will last for many years.

### DON'T ASSUME PEOPLE KNOW HOW TO TAKE CARE OF COMPUTERS

Even though the guidelines for taking care of computers are common sense for most people, it is amazing how often they are violated. Many people have little or no experience with computers. Also, people are sometimes careless and forgetful. Diplomatically posting "rules for computer use" and making sure that everyone has been informed about those rules is very important.

### MOST HOSPITALS PROVIDE COMPUTER SUPPORT—ASK FOR IT

Hospitals have been using computers to process and store important information for many years. As a result, almost every hospital has someone responsible for information systems, data processing, or computer support. Generally, this person's job is to make sure that all of the computers and computer-related equipment in the hospital continue to function effectively and is available at no additional cost to your program. All you have to do is ask for help. ☞

## POINT 10. REPORTING



**M**any different people have an interest in the outcomes of an early identification of hearing loss program. As with any worthwhile program, a universal newborn hearing screening program will not manage itself. When you first implement the program, you need to decide who the most important stakeholders are, what information they need, and when they need it.

### GENERATING REGULAR REPORTS FOR PROGRAM MANAGEMENT AND IMPROVEMENT

The person in charge of the early identification of hearing loss program needs a continual flow of information, including:

- The number of babies born at the hospital.
- The percentage of babies successfully screened.
- The percentage of babies referred.
- The percentage of babies rescreened and/or diagnosed.
- The number of babies identified with hearing loss.
- How well each of the screeners is functioning.

Regular and timely summaries of such information is critical if the program is to be successful. At the beginning of the program, you should have a coordination meeting monthly, if not more often, to review such information. This meeting should be attended by the program coordinator, a representative of the screening staff, the nursery coordinator, an audiologist who is involved with the program, and a physician who cares for newborns at that hospital. The purpose of the meeting is to

review the functioning of the program during the previous time period to make sure that the goals of the program are being accomplished, such as:

- Why were only 80% of the babies screened last month?
- Are there any babies who have been referred for diagnostic evaluation who are still waiting after several months?
- Are some screeners performing significantly less well than others?

Reviewing such information regularly is the key to enhancing program efficiency and success. Results from a computer-based data and patient information management program will provide all of the necessary data, but you still need to convene the meeting, take minutes, and follow up on assignments.

### DON'T EXPECT TO FIND A LOT OF BABIES WITH HEARING LOSS

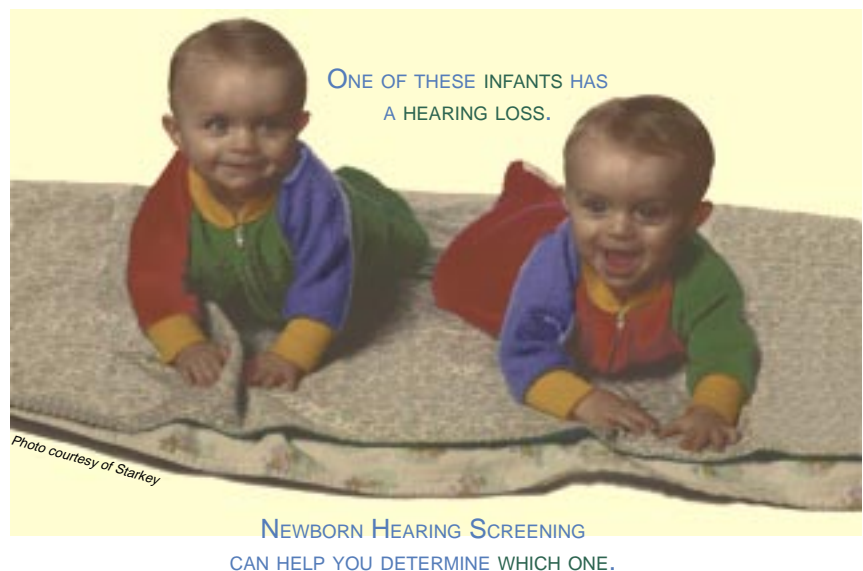
Over the long-term, an efficient hearing identification program will identify 3 to 4 infants per 1,000 with sensorineural hearing loss. However, because hearing loss is a low-incidence condition, it may take 10,000 babies before you hit that average (this is similar to newborn screening programs for metabolic disorders which have an even lower incidence rate). In other words, it is not unusual for a hospital to screen 1,000 babies and not find a single infant with a sensorineural hearing loss. That same hospital, however, may find 5 or 6 infants in the next 1,000. Therefore, don't be discouraged if it takes a while to identify your first baby with a hearing loss.



### MAKE PEOPLE AWARE OF YOUR SUCCESSES

Having convinced people that a newborn hearing identification program is important, you need to make sure they know about your successes. Whenever you find a baby with a hearing loss, make sure that physicians and hospital administrators are aware of your success and understand how much

better off the baby is because of having been identified early. Even if your hospital administration does not ask for regular statistical reports, you should generate them on at least a yearly basis and send them to key administrators. You should also consider involving the local news media to report about the successes of the program. ☺





## POINT II. COMPLETING AUDIOLOGICAL DIAGNOSIS AND FOLLOW UP

**T**he real goal of any screening program is to provide better health care services to people in need. Consequently, newborn hearing screening is only the first step. In many cases, developing an efficient network of diagnosis and intervention will require extensive input from the state department of health, the state Title V program, and/or the state's lead agency for serving infants and young children with disabilities. Even in cases where the hospital staff only participates indirectly in these efforts, you should know what needs to be done and how the system is supposed to function so you can be supportive.

### A GOOD SCREENING PROGRAM IS NOT ENOUGH!

Successfully screening all of the babies in your hospital is not very useful unless those babies who do not pass the screening complete a diagnostic evaluation, and the ones identified with hearing loss are enrolled in appropriate early intervention programs within a few weeks. Unfortunately, some "successful" newborn hearing screening programs are not effective in completing diagnostic evaluations and enrolling children in early intervention. Whether your hospital is responsible for doing diagnostic evaluations or whether you refer children to



*Photo courtesy of Mayo Clinic Scottsdale*

outside agencies or audiologists, it is important to develop a systematic mechanism to make sure children referred from the screening program receive a diagnostic evaluation. Such a system should produce periodic reports to tell you how well the real goal of the program is being accomplished.

#### **INVOLVE EXPERIENCED AUDIOLOGISTS**

Whether the hospital has its own audiologists or you refer to outside audiologists, it is important to have clearly established criteria to make referrals for audiological evaluation. Once a child is referred, there should be a tracking procedure to ensure that the referral has been followed. In addition, the audiologist to whom the baby is referred should be given as much information as possible about the referral (e.g.,

type of screening and refer criteria). Efficient newborn hearing screening programs are able to refer infants needing audiological evaluations within the first several weeks of life. Not all audiologists, however, have the appropriate experience and equipment to conduct the types of assessments that are needed to diagnose and confirm the nature and degree of hearing loss for infants and young children. It is a good idea to work with your state department of health or other licensing agency to identify those audiologists in your community who can and want to diagnose and fit amplification for very young infants so you can refer parents to those audiologists.

#### **USE APPROPRIATE DIAGNOSTIC PROCEDURES FOR INFANTS AND TODDLERS**

It is essential that the audiologists to whom babies are referred for diagnostic evaluations have experience using age-appropriate diagnostic techniques for such infants. Various organizations, such as the American Speech-Language-Hearing Association, have produced guidelines and recommendations that can be very helpful. (Examples of some of these are given in Appendix 11.) Typically, a combination of otoacoustic emissions and auditory brainstem response (ABR; including frequency-specific tone bursts, air conduction, and bone conduction measures) are used to diagnose hearing loss for children younger than 4 months of age. For such young children, behavioral observations in the sound field are typically used to support OAE and



*Photo courtesy of Mayo Clinic Scottsdale*



ABR results when amplification is recommended. After four months of age, ear-specific behavioral measures using visual reinforcement audiometry (VRA) should be considered. The diagnostic evaluation should also include middle ear measurements using electroacoustic immittance measurements. Tympanometry should be used carefully for infants who are younger than 4 months of age, because some methods produce misleading results for very young children. If an infant has middle ear disease, otological referral for evaluation and management must take place.

#### **MOVE AS QUICKLY AS POSSIBLE**

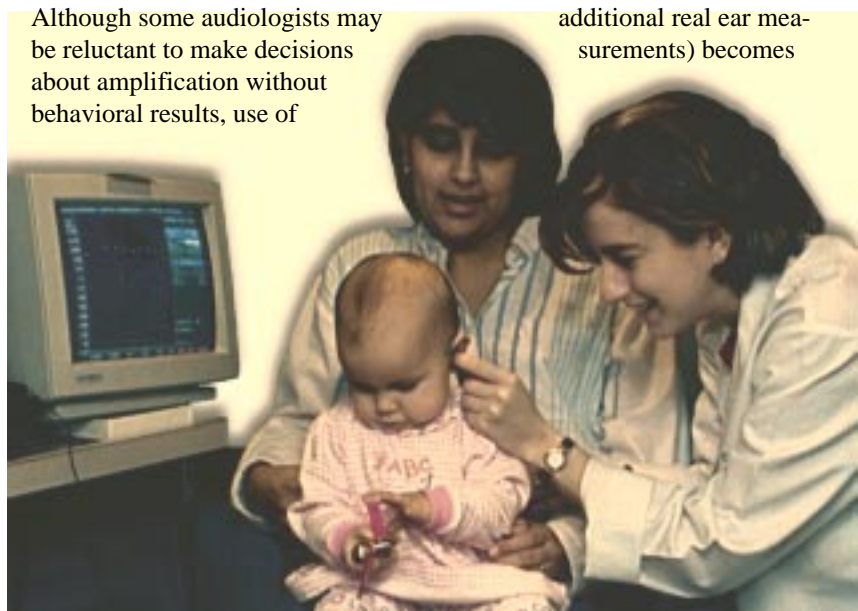
It is critical that the diagnostic process be completed as soon as possible. For many infants and toddlers, appropriate ear-specific, frequency-specific air and bone conduction ABR provides enough information to determine the type and degree of hearing loss.

Although some audiologists may be reluctant to make decisions about amplification without behavioral results, use of

frequency-specific tone bursts in ABR can ensure that amplification gain is appropriate (i.e., there is enough amplification, there is not over amplification, the frequency response characteristics are adequate). Monitoring the infant's auditory responses (through home-based and clinical methods) is also essential to continually refine the fitting. It is important to note that diagnostic techniques and equipment for infants continue to evolve and improve. Therefore, people responsible for ensuring timely and appropriate diagnosis of referred infants need to stay up-to-date with this rapidly changing area.

#### **MONITORING OF AMPLIFICATION**

Providing the first set of hearing aids is not the end of the process. Therefore, an audiologist with pediatric experience and expertise will fit the infant and then modify the fitting as more information (e.g., ear-specific behavioral and additional real ear measurements) becomes



*Photo courtesy of Mayo Clinic Scottsdale*



available. Additionally, the infant's behavioral responses, such as alerting to sound; responses to speech; or negative responses, such as flinching to moderately loud sounds, should be used in conjunction with clinical measures to ensure that the amplification is appropriate. The audiologist should not postpone amplification until a long-term amplification recommendation can be made. The goal should be to get the infant using amplification within a few

weeks of the diagnosis (even after accounting for the time necessary to obtain medical clearance for fitting hearing aids and fabricate earmolds). Often, loaner hearing aids are used as a way of getting amplification to the infant as soon as possible. ☺



Photo courtesy of Childhood Hearing Impairment Program (CHIP), University of Connecticut

## POINT 12. COORDINATING WITH STATE SYSTEMS

**E**very state already has a number of systems in place to provide services to children with disabilities and special health care needs. In addition to being a potential source of funding for infants and toddlers with hearing loss, it is essential for you to coordinate your efforts with these programs to ensure that services are delivered in a way which is efficient, family-friendly, minimally disruptive, and culturally appropriate. Because these systems are funded by a variety of different initiatives, each has its own rules, eligibility requirements, and procedures. Therefore, families often need help negotiating their way through the system. Although few, if any, are designed specifically for infants and toddlers with hearing loss, many are appropriate for such children. Because they are sometimes labeled differently in each state, it may take some research to find them, but the results can be well worth the effort.

### TIMELY, APPROPRIATE, FAMILY-CENTERED INTERVENTION IS THE REAL GOAL



Photo courtesy of Bio-logic Systems Corp

The infant diagnosed with hearing loss within the first few months of life has much greater potential of acquiring listening, language, and communicative skills at a rate that will prevent the negative effects of hearing loss. Even with amplification, the

infant (and the family) will need help to learn to make use of audition, stimulate communication, and develop language. Additionally, families will need information about the amplification and ways to optimize the listening and communication environment for the baby. Therefore, as soon as the hearing loss is diagnosed, an immediate referral to an early intervention program should be made so that intervention can begin. It is important that such referrals be coordinated with the infant's primary care physician (i.e., his or her medical home) so the total health care program can be appropriately coordinated). Several state agencies and other groups have developed excellent guides and booklets to assist parents of infants and young children identified with hearing loss. (Annotated references to several of these are available in Appendix 12.)

### COORDINATE WITH EARLY INTERVENTION PROGRAMS

The whole purpose of doing a universal newborn hearing screening program is to help infants with hearing loss get the assistance they need to maximize their development. Under federal law, every state is required to provide appropriate early intervention services to infants and toddlers with disabilities. Although every state establishes its own eligibility requirements, most, if not all, children with congenital hearing loss will qualify. (A list of contact people in each state is included in Appendix 12. You should coordinate with these people to make sure infants and young children





identified in your program receive the services they need.)

Although some hospitals are structured in such a way that they do not become involved in diagnosis and intervention, you should at least consider staying involved with infants through the entire process. Experience has shown that infants born in hospitals that remain involved through the entire process are much more likely to receive the services they need and to enjoy the benefits of early identification and intervention.

#### **DON'T WAIT TO START SCREENING UNTIL THE DIAGNOSTIC AND INTERVENTION SYSTEM IS PERFECTED**

Some people have delayed the implementation of a universal newborn hearing screening program because they felt there was not sufficient availability of high-quality diagnostic and early intervention services in their area. This is a mistake. The best way to expand the availability and improve the quality of diagnostic and early intervention programs is to identify more and more infants with hearing loss. As in other areas of social and health services, demand will drive supply. Whether or not the children are identified, they still exist, and the best way you can get needed services for infants and toddlers is to make public officials aware of the existence of positively diagnosed children. An

excellent strategy is to involve the parents of those children previously identified in efforts to expand and improve the quality of early intervention programs.

#### **COORDINATION WITH OTHER PUBLIC HEALTH INFORMATION DATABASES**

Most state departments of health already maintain a number of electronic databases (e.g., Vital Records, Immunizations, Metabolic Screening, Birth Defects, Follow Up of High-Risk Births). Developing a statewide electronic Early Hearing Detection and Intervention (EHDI) database and linking it to one or more of these existing databases has substantial advantages. For example, the Vital Records database could be compared to the EHDI database to make sure no newborns missed the screening test. If your state uses an Immunization database, when children come in to their health care provider for immunizations at 8 weeks of age, an electronic link with the EHDI database would show whether they needed a follow up related to newborn hearing screening. The potential for such linkages is enormous, and the technology is presently available. Although only a few states have started such linkages, you should keep such possibilities in mind as you design your EHDI system. ☞

## POINT 13. CONSIDERING LEGISLATIVE MANDATES

**T**wenty-one different states have legislative mandates related to early identification of hearing loss. Nine of those require universal newborn hearing screening, while the others are all targeted on high-risk groups. Unfortunately, some are unfunded and have not resulted in operational programs. However, more and more states are considering legislation which would mandate universal newborn hearing screening. In almost all cases where legislation has been passed, hospital-based people have been among the prime movers in making it happen.

### IS LEGISLATION A GOOD IDEA?

Although some states have had many hospitals implement newborn hearing screening programs without legislation (e.g., Iowa, Michigan, New Mexico, New York, Texas, Wyoming), most states which are screening more

than 90% of the babies have a legislative mandate (e.g., Hawaii, Mississippi, Rhode Island, Utah). A legislative mandate also ensures that newborn hearing screening programs will not be discontinued as a result of key people leaving the hospital or changes in hospital owner-

ship. Furthermore, a legislative mandate can be used to ensure that an effective statewide data and tracking system is created and that hospitals will participate in such a system.

### DON'T WAIT TO START UNTIL YOU HAVE A LEGISLATIVE MANDATE

Although it is often very helpful to have a legislative mandate, you shouldn't wait to initiate universal newborn hearing screening programs until a mandate has been passed. In fact, many legislators want to see evidence in their own state of some successful programs before they will even consider passing a legislative mandate. Furthermore, since it often requires 2 or 3 years to get a mandate passed, many children with hearing loss would not be identified if you waited to get a mandate before initiating programs. The best approach is to work simultaneously on implementing programs and getting a mandate in place.

### WHAT LEGISLATIVE ACTIVITIES ARE HAPPENING IN OTHER STATES?

In deciding what should be contained in a legislative mandate for your state, you should consult laws which have been passed or are being considered in other states. The complete text of those laws is available on NCHAM's Web site ([www.usu.edu/~ncham/](http://www.usu.edu/~ncham/)). Of course, you will want to tailor your legislation to the specific circumstances in your state, but the legislation from other states can give you a good head start. ☞



*Photo courtesy of Woman's Hospital, Baton Rouge, Louisiana*

## A FINAL NOTE



The 13 points included in this booklet's checklist will help you benefit from the experience of other hospitals as you design a universal newborn hearing screening program for your hospital. In completing the checklist, though, you should remember that each hospital and situation is unique, and the timing or the specific way in which the various activities are accomplished may have to be modified. Based on the hundreds of hospitals that are now operating successful universal newborn hearing screening programs, most, if not all, of the activities described in the checklist will have to be addressed. Remember that successful newborn hearing screening programs almost always involve a "team approach" with many stakeholders (e.g., audiologists, physicians, nurses, parents, etc.) being collaboratively involved.

Additional information about starting a universal newborn hearing screening program is available by contacting:



Utah State University  
2880 Old Main Hill  
Logan, UT 84322  
Phone 435.797.3589  
FAX 435.797.1448



University of Colorado at Boulder  
Campus Box 409  
Boulder, CO 80309-0409  
Phone 303.492.6283  
FAX 303.492.3274


A wealth of information can also be obtained from the following World Wide Web sites:

[www.usu.edu/~ncham](http://www.usu.edu/~ncham)

[www.hrsa.dhhs.gov](http://www.hrsa.dhhs.gov)

[www.colorado.edu/slhs/mdnc/](http://www.colorado.edu/slhs/mdnc/)

[www.cdc.gov/nceh/programs/edhi](http://www.cdc.gov/nceh/programs/edhi)

The appendices referred to throughout this booklet can be obtained from NCHAM, the Marion Downs National Center for Infant Hearing, the National Maternal and Child Health Clearinghouse, or on the World Wide Web at [www.usu.edu/~ncham](http://www.usu.edu/~ncham). 

## **IMPLEMENTATION CHECKLIST: UNIVERSAL NEWBORN HEARING SCREENING**

For over 50 years, there has been widespread acceptance of the need to identify hearing loss at an early age. Until just recently, however, very few hospitals were operating universal newborn hearing screening programs. Since 1993, hundreds of hospitals have implemented such programs. Based on the experiences and using materials from many of these pioneering hospitals, the following "checklist" was developed. This checklist includes the steps that typically must be addressed in implementing and operating a successful early identification of hearing loss program for newborns.

The 13 points included in this checklist will help you benefit from the experience of others as you design a universal newborn hearing screening program for your hospital. In completing the checklist, though, you should remember that each hospital and situation is unique, and the timing or the specific way in which the various activities are accomplished may have to be modified. Based on the hundreds of hospitals that are now operating successful universal newborn hearing screening programs, most, if not all, of the activities described in the checklist will have to be addressed. Remember that successful newborn hearing screening programs almost always involve a "team approach" with many stakeholders (e.g., audiologists, physicians, nurses, parents, etc.) being collaboratively involved. Additional information and concrete suggestions about how to address each item in the checklist is available in the rest of this web site or by contacting NCHAM ([nchamhelp@coe.usu.edu](mailto:nchamhelp@coe.usu.edu)).

### **Point 1. Enlisting Support for Newborn Hearing Screening**

- Support from authoritative groups.
- Many other hospitals are doing it successfully.
- Has newborn hearing screening become the standard of care?
- Physician support is essential.
- It won't happen without support from the nursing staff.

### **Point 2. Determining an Appropriate Protocol for Your Hospital**

- Which equipment is best for your situation?
- Wouldn't it be better to wait for the next generation of screening equipment?
- How many tests should be included in the screening protocol?

### **Point 3. Dealing with Procedural Issues**

- Who's in charge?
- Who will do the screening?
- When should screening be done?
- Making sure every baby is screened.
- Should screening be done with the parents present?
- Should parents be asked to sign a permission form?

### **Point 4. Communicating with Parents, Physicians, and Hospital Staff**

- Communicating with parents: What, when, and how?
- Communicating with physicians.
  - General awareness of the program and its importance.
  - What were the results for their parents?
- Ensure that the physicians understand the importance of follow up.
  - Medical management issues.
- Communicating with hospital administrators.
- Justifying ongoing program support.

### **Point 5. Training Newborn Hearing Screeners**

- Initial Training.
- Don't train more people than necessary.
- Regular supervision.
- Retraining to accommodate staff turnover.

**Point 6. Keeping Referral Rates Low**

- Schedule screening when babies are in the best behavioral state.
- Make a second effort prior to discharge to screen babies who do not pass at first.
- Minimize noise and confusion in the screening area.
- Use the best protocol for your situation.
- Have backup equipment and supplies readily available.
- For OAE procedures, probe fit is critical.
- For AABR procedures, screen when myogenic activity is low.

**Point 7. Managing Data and patient Information**

- Computer-based data management.
- Should you try to design your own system?
- Can you modify one of the databases your hospital already has?
- Safeguarding your data.

**Point 8. Financing the Program**

- How much does it really cost?
- Will insurance pay for newborn hearing screening?
- Is newborn hearing screening cost beneficial?
- How do I convince the insurance companies to pay?
- Does Medicaid pay for newborn hearing screening?
- Using existing state resources.
- Grants, donations, and community support.

**Point 9. Caring for Equipment and Supplies**

- An ounce of prevention is worth a pound of cure.
- Don't assume people know how to take care of computers.
- Most hospitals provide computer support-ask for it.

**Point 10. Reporting**

- Generating regular reports for program management and improvement.
- Don't expect to find a lot of babies with hearing loss.
- Make people aware of your successes.

**Point 11. Completing Audiological Diagnosis and Follow Up**

- A good screening program is not enough!
- Involve experienced audiologists.
- Use appropriate diagnostic procedures for infants and toddlers.
- Move as quickly as possible.
- Monitoring of amplification.

**Point 12. Coordinating with State Systems**

- Timely, appropriate, family-centered intervention is the real goal.
- Coordinate with early intervention programs.
- Don't wait to start screening until the diagnostic and intervention system is perfected.
- Coordination with other public health information databases.

**Point 13. Considering Legislative Mandates**

- Is legislation a good idea?
- Don't wait to start until you have a legislative mandate.
- What legislative activities are happening in other states?