



How Do We Support Families in 2010?

A look at family support in
newborn hearing screening and
follow up...`



Define 'Family Support'

- Family support is the provision of respectful collaboration to provide empowerment to the families to obtain the skills necessary to make informed choices for one's family based on access to unbiased options.



Family Support

- ---realizing that not all families are alike and that each family will have their own separate needs.
- This means that professionals will need to know what resources are available for families, understanding that families ultimately are the decision makers who need to be empowered.



Family Support

- Information provided in multiple modalities to acknowledge families have different needs, different learning styles and need different things to make decisions.



Family Support

- Train parents to make decisions/choices— understanding adult learners, different styles of learning.
- Unbiased/balanced options that are actually available
- Make them part of the process



Family Support

- Realize that hearing loss may only be one factor in this family and may not be the focus for the family because of the other and often more pressing issues in the home.
- Need to remember that you may need different strategies to get at information—verbally, written, take home surveys etc.



Family Support

- Involving family members e.g. spouses so that information is relayed accurately and to help all family members to be involved and supportive of what the child needs
- Culturally sensitive



History of family support in newborn hearing screening

- Before 1999-Newborn Hearing Screening (NHS) not part of routine practice
- 2000-2005-NHS rapidly being implemented throughout the US
- 2006- Now-NHS has now been in place for a few years and should be representative of current practices

Personal report, Karen Munoz, 2010



Pertinent Findings

- Increase from 14% to 36% of infants were scheduled for diagnostics by the nurses/hospital at the time of the screening.
- One of the top four themes from the 2006-2009 group was “*Positive experience: parents reported a positive experience throughout the NHS and diagnostic process.*”



Professional Organizational support

- ASHA has published guidelines on counseling....
- National Audiology Conference on EHDI
- NCHAM provides educational resources and workshops
 - States have provided funding for 400 audiologists to become trained in pediatric audiology and have become actively involved in the EHDI process.



EHDI eBook –NCHAM website

- EHDI eBook is a tool available to all universities....to incorporate into their pediatric audiology courses or to provide an stand alone course...



What the Professionals know now

- Historically education on family support, counseling and the EHDI programs were weak Audiology training programs
- In 2002, 27% of Audiology graduate programs required counseling courses.
- That has all been rapidly changing over the last several years.



Educating the Professionals

- Counseling is a research focus in 63% of Audiology doctoral programs, counseling courses are now offered, if not required in virtually all Audiology doctoral programs.
- Universal Newborn Hearing Screening (EHDI) is a research focus in 53% of Audiology doctoral programs



MA Survey Objectives

- To determine the levels of families' satisfaction and anxiety associated with the EHDI process
- To determine what factors affect families satisfaction levels with the EHDI process
- To assess whether or not a child's hearing status affects the levels of satisfaction

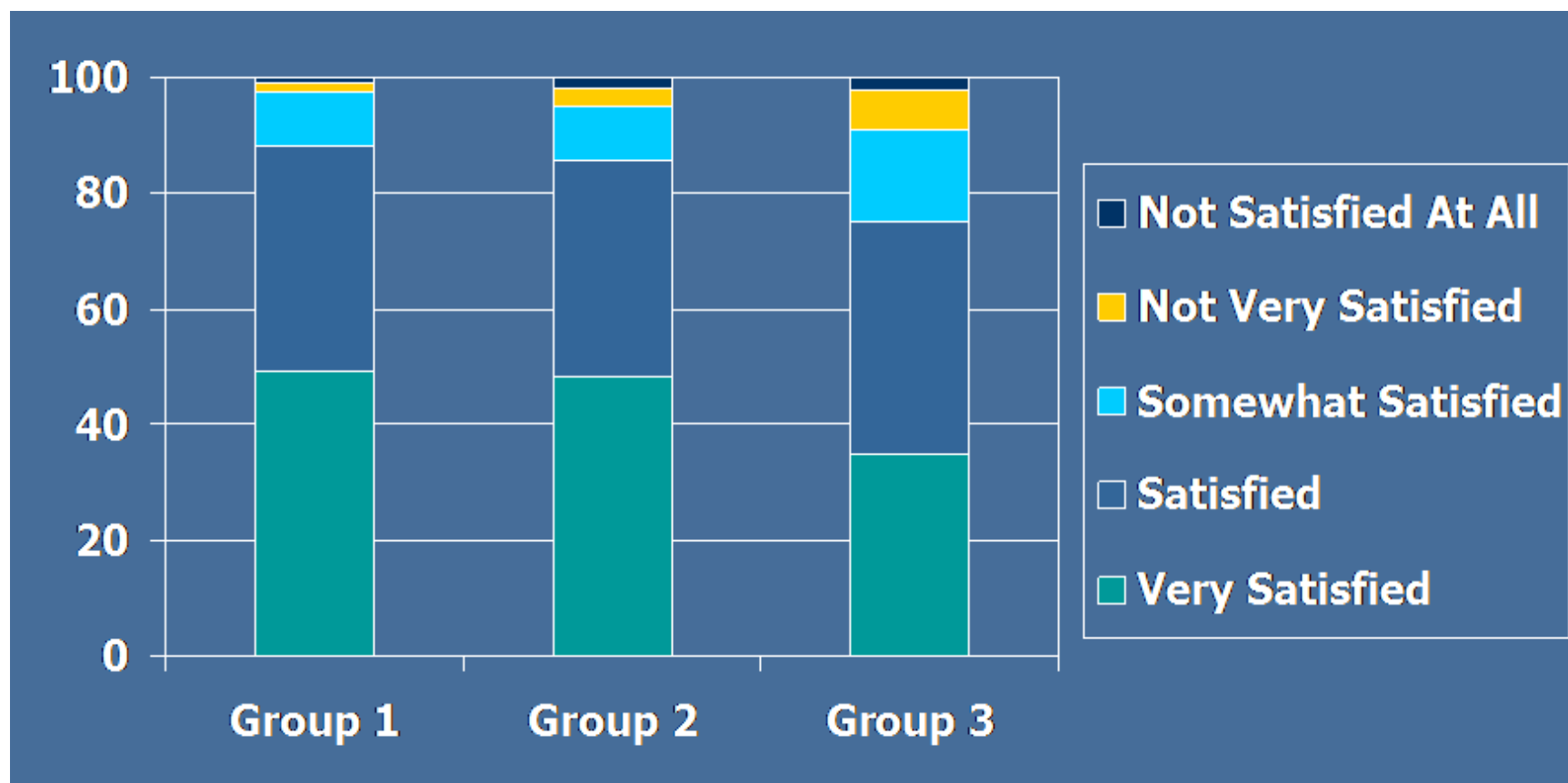


Groups

- Group 1: Families whose newborn passed their initial hearing screening
- Group 2: Families whose infants refer on their initial screening but subsequently pass on outpatient re-screen or diagnostic evaluation
- Group 3: Families whose infants are identified with permanent hearing loss

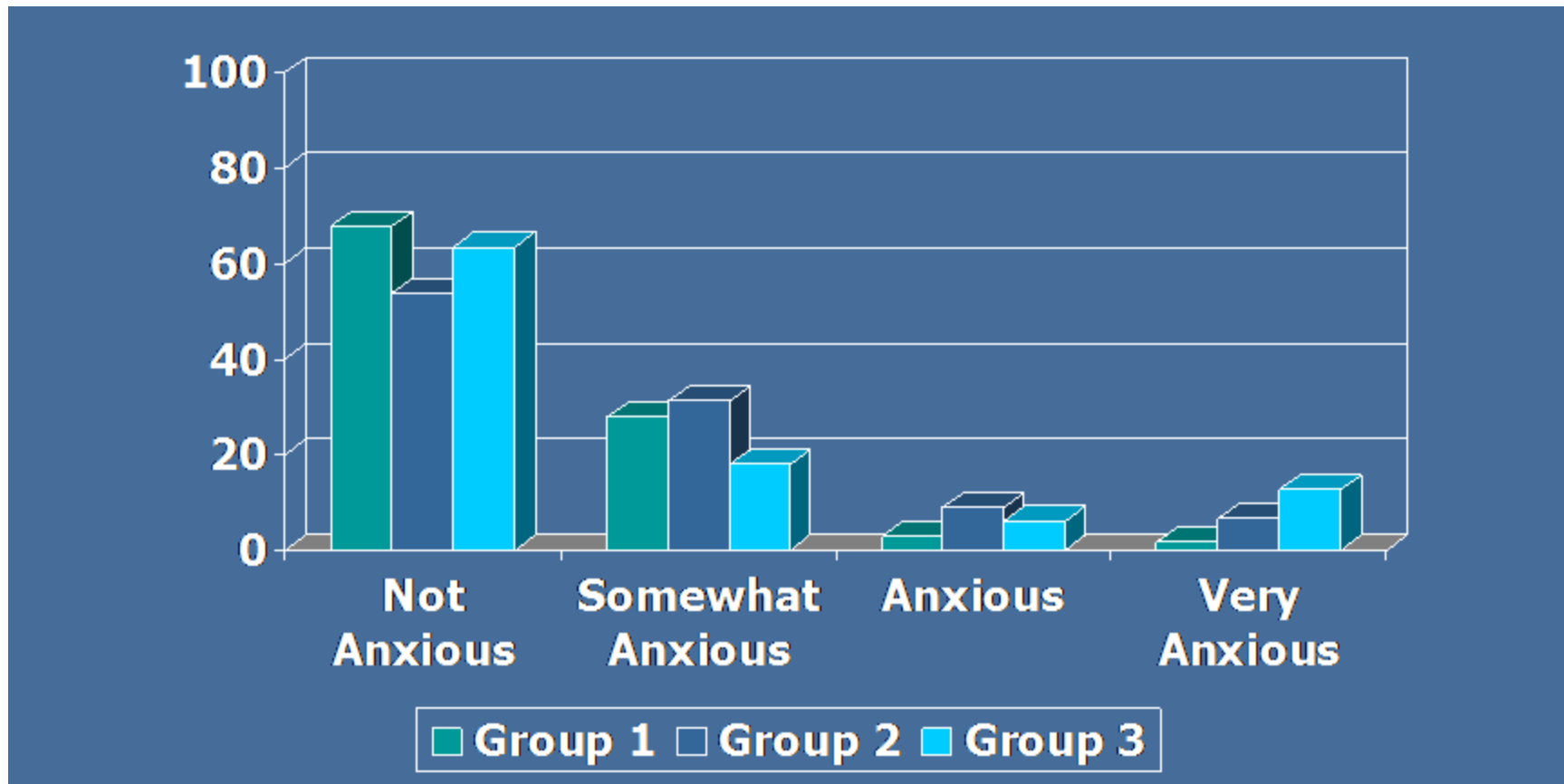


Satisfaction with Screening



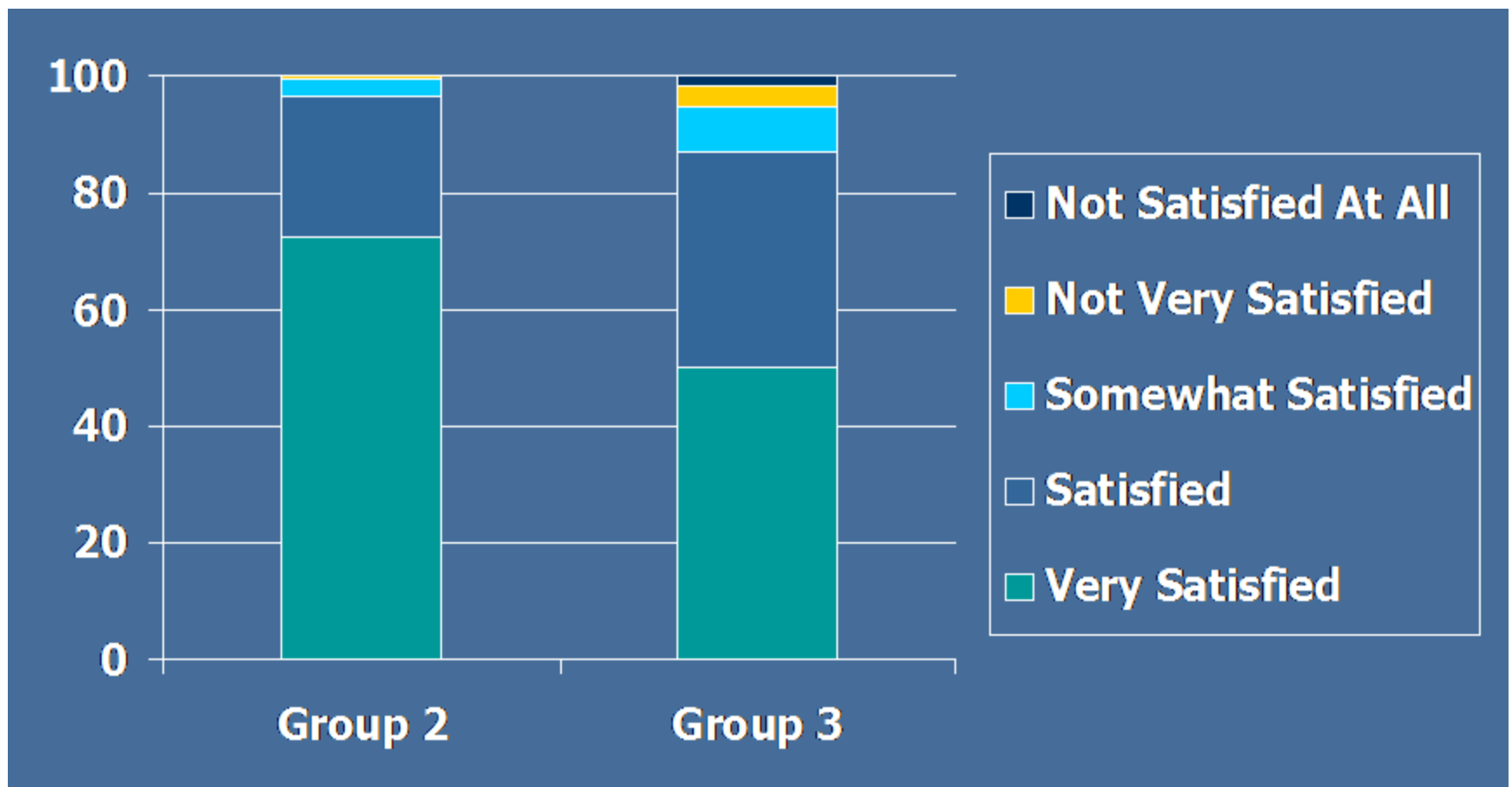


Level of Anxiety at the time of screening results



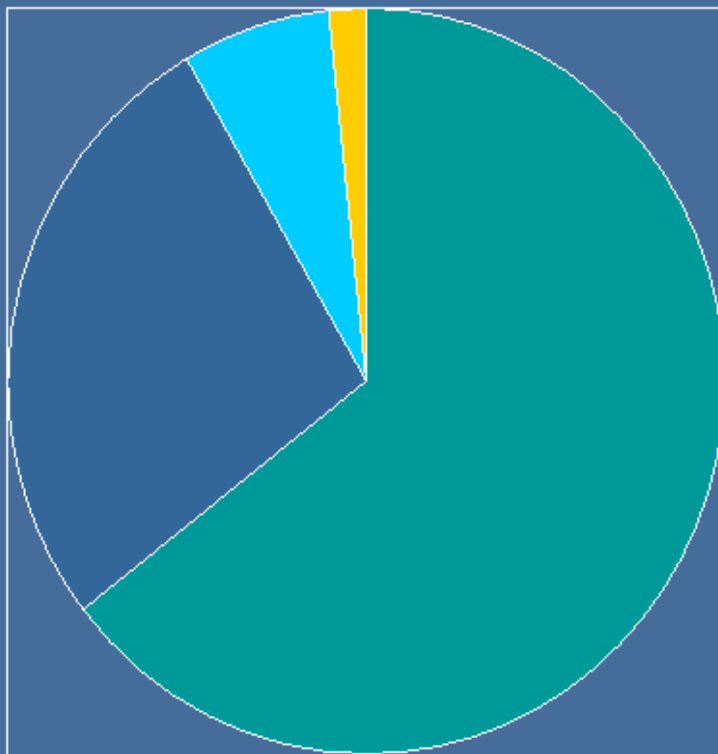


Satisfaction with Re-Screen





Looking back at the activities involved in finding out that your child had a hearing loss, did the benefits outweigh the negatives?



- Many more benefits than negatives
- Few more benefits than negatives
- Few more negatives than benefits
- Many more negatives than benefits



How do we support families today?

- Objectives:
 - Identify 2 ways to provide prenatal family support
 - Identify 3 significant improvements in the area of family support during the screening process
 - Identify at least 2 tools utilized by nurses and screeners to provide quality family support
 - Identify positive family support mechanisms to help the family through from referral by the screen to the diagnostic appointment



Time Line of Support Needed

- Prenatal Family Support
- Hearing Screening Family Support
 - 1st screen
 - 2nd screen
 - The referral to diagnostic
- Family support while waiting to get to audiology for diagnosis
- Family support at and after diagnosis--
ongoing



Prenatal Family Support

- Education
- Information
- What you need to know when you are expecting...



Have you seen prenatal family support in your state?

- Information on hearing loss in infants and children and newborn hearing screening during prenatal classes
- Hospital provided information on the standard of care you and your newborn will receive in the labor and delivery process
- Brochures in the OB/GYN clinic and other locations that prenatal care is obtained



Family Support during the screening process

- Training modules
- Hands & Voices involvement...
- Physician and pediatrician education on importance...



Barriers: Training of staff

- Training that is easily duplicated between sites and
 - updated over time.
- Side by side (shadowing) training provided by
 - knowledgeable staff.
- Clear expectations of procedures to be followed by the screeners and medical staff at each site.
- Lack of step by step procedures for equipment and troubleshooting of equipment issues.



Solutions: training issues

- Introductory information can be provided through screening modules.
- Screeners can shadow experienced screeners to have a better understanding of the “big picture”.
- Training be provided on Hospital specific procedures.
- Provision of a handbook outlining all of the above and step by step directions on use of the equipment.
- Cheat sheets on how to use equipment, troubleshooting scenarios in the nursery



All the critical information for quality newborn hearing screening.

The Curriculum Disc will play on a standard movie DVD player or on a computer with DVD movie player software.

- Insert the DVD into the player and choose the section from the menu that you want to view.
- After choosing a section you can:
 - Play Automatically
 - Play Manually (pause after each slide)
 - Thumbnails (preview each slide)
- For Manual Play and Thumbnails, use the "Next Chapter" button on your remote to advance to the next slide.
- Use the pause button on your player to pause the playback at any time.

The Resources Disc is a computer data disc. It can be used with either a Windows or Macintosh computer. The files on the disc are in Microsoft Word (.DOC) and Adobe Acrobat (.PDF) format. You may need to install the Adobe Acrobat Reader program in order to view the Acrobat PDF files.



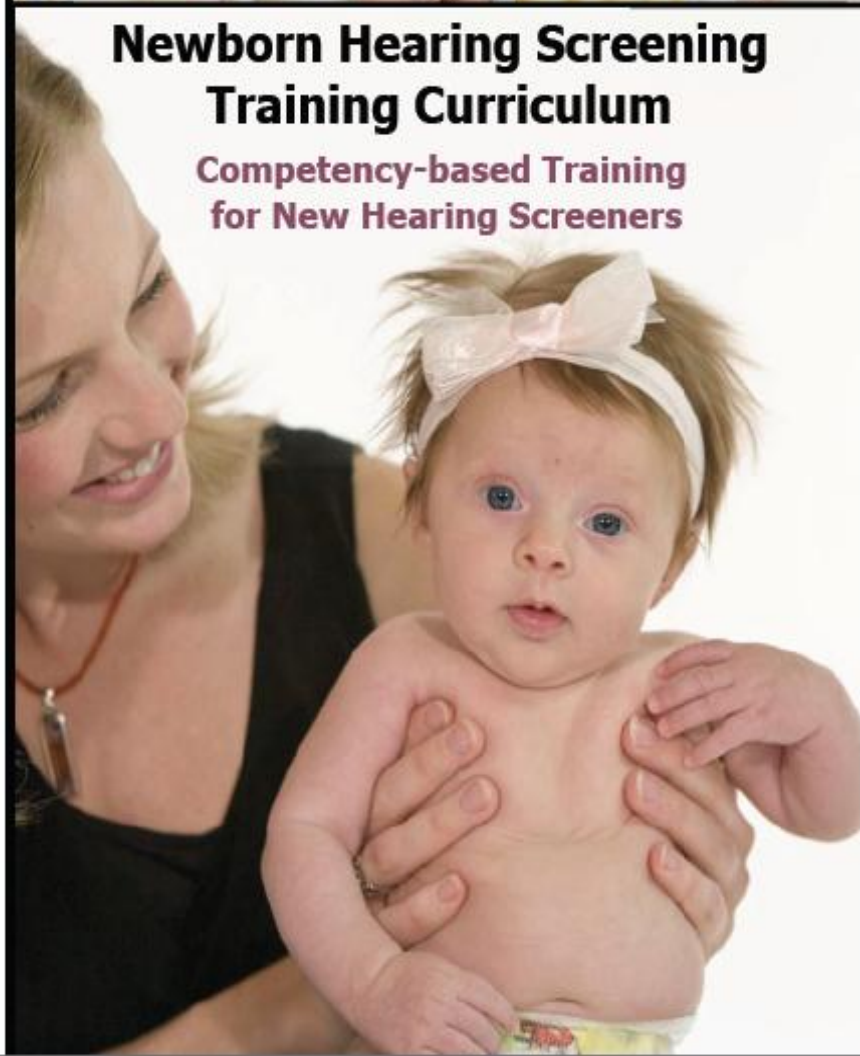
Newborn Hearing Screening Training Curriculum

2 Disc Set



Newborn Hearing Screening Training Curriculum

Competency-based Training for New Hearing Screeners





What does the curriculum consist of?

- Section 1: Intro to Newborn Hearing Screening
- Section 2: Getting reading to screen
- Section 3: Screening with Otoacoustic Emissions
- Section 4: Screening with Automated Auditory Brainstem Response
- Section 5: Completing the Screening Process
- Section 6: Communicating w/Parents and the Medical Providers
- Section 7: Screening Babies w/Risk Factors
- Section 8: Outpatient Screening/Re-Screening



Resource Disk

For Screeners

- Scripts for Screeners in English & Spanish
- Frequently asked Questions that parents may ask
- Glossary with definitions
- Links to related websites



Resource Disk

Program Manager

- Competency check lists for “hands-on screening” techniques
- Test questions, answers and test answer form
- JCIH 2007 Position Statement and Program checklist



Newborn Hearing Screening Curriculum

On the NCHAM website at
www.infanthearing.org

Specifically:

- http://www.infanthearing.org/nhstc_dvd/index.html



DVD



(((infanthearing.org





Passing

- Congratulations on the birth of your baby. We just completed the hearing screen; the results are a pass. Here is a brochure that talks about development of speech and language. It is always important to monitor the progress of your baby's development, especially their speech and language because your baby's hearing can change any time. If you are ever worried that your baby can't hear, talk to your baby's doctor right away and ask for a referral to an audiologist that is skilled at testing infants and young children.



Not Passing:

- Congratulations on the birth of your baby. We just finished screening your baby's hearing. Your baby did not pass the screen today. This does not necessarily mean that your baby has a permanent hearing loss, but without additional testing we can't be sure. The screening results will be provided to your baby's doctor. Please be sure you make or keep (depending on your hospital's protocol) the appointment for further hearing testing.



Not Passing Outpatient Rescreen:

- Your baby did not pass the second screen. The screening does not tell us whether your baby has a hearing loss; it just tells us that further testing should be done as soon as possible. The next step is to get a diagnostic ABR as soon as possible. This should be discussed immediately with your baby's doctor who may need to help you with obtaining a referral to a pediatric audiologist.



High Risk: Passing:

- Congratulations on the birth of your baby. We screened your baby's hearing and the results are a pass. However, because your baby has had some medical problems at birth, there is a chance that your baby can develop a hearing loss after you leave the hospital. Your baby's hearing is critical for normal speech and language development, so it is important that you speak to your baby's doctor who can help you in knowing when your baby should have further tests with a pediatric audiologist and can also help you to monitor for normal speech and language development.



Frequently Asked Questions Parents May Ask (English and Spanish)

- ***Why screen my baby's hearing?***
- Hearing loss is one of the most common conditions present at birth. It is easy to miss hearing loss because you usually can't see anything different. Without screening, hearing loss is often not detected until the baby is 2 years old and not talking. Early identification and intervention means that your baby won't fall behind other children in speech and language development.
- ***¿Por qué hacerle una prueba auditiva a mi hijo?***
- La pérdida auditiva es una de las condiciones más comunes que se presentan en los recién nacidos. Es fácil no percatarse de su existencia porque uno no puede ver nada diferente en el bebé. Sin la prueba auditiva, es frecuente que la pérdida auditiva no se detecte hasta que el niño tiene 2 años y no habla. La identificación e intervención temprana hacen que su bebé no tenga un retraso en su habla y desarrollo del lenguaje.



Have you seen family support during the screening process?

- Training modules for screeners
- Role playing activities in training for screeners



Family support transitioning to diagnostics

- My child “failed” the screening now what?



Have you seen Family Support during transition from screening to diagnostic?

- Nurses or others schedule the appointments from the hospital
- Parent Professionals call to confirm, offer support, transportation



Family support transitioning to early intervention

- My child has a hearing loss--now what?



What is family support to you?

- Education?
- Road maps?
- Web sites?
- Brochures?
- Parent to parent contact?
- Physician guidance?
- Audiologist guidance?
- Early interventionists in your home?
- Support groups?
- Church?



When is family support provided?

- All the time and from everyone!



Informational Counseling

- Newborn Hearing Screening:
 - Audiologists (or someone carefully trained by an audiologist) should communicate with parents when a baby does not pass screening.
 - Parents given the opportunity and encouraged to ask questions
 - Recommendations/information for further testing
 - Presented in a positive manner
 - Emphasizes importance of further testing
 - Presented to parents confidentially
 - In a family focused manner
 - Free of technical jargon



Adjustment Counseling

- Newborn Hearing Screening:
 - WE are the professionals the parents NEVER hoped to meet!
 - We must LISTEN to fears and concerns expressed by families
 - We must support whatever decision the family makes regarding the screening process.
 - We must recognize that our manner of delivering screening results may interfere with parent-child bonding



Informational Counseling

- Confirmation of Hearing Loss
 - An audiologist is responsible for describing the hearing loss and its implications to the family
 - Initially, best to describe audiometric results to the family in functional terms
 - Parents questions and comments must guide the quantity of information and the level of detail provided
 - LISTEN, LISTEN, LISTEN, talk, LISTEN, LISTEN, LISTEN, LISTEN, LISTEN, talk, LISTEN, talk, LISTEN ETC.



Adjustment Counseling

- Confirmation of Hearing Loss:
 - MUST recognize the following:
 - The family's fragility during the EHDI process
 - The impact of diagnosis of hearing loss on the entire family, including extended family
 - The family will need to identify and seek the assistance of supports outside the audiological community
 - The family's strength and special needs within the context of their cultural and value system
 - The need for continuing emotional support of the family



Informational Counseling

- Intervention and Habilitation:
 - “Audiologists are responsible for providing families with unbiased information, recommendations, and appropriate educational and communication options based on family decisions and informed choices. As such, audiologists are responsible to families, not for families.”ASHA Guidelines



Adjustment Counseling

- Early Intervention
 - Consider the family's readiness to proceed
 - Coping skills
 - Support structures
 - Resources
 - Challenges
 - Facilitate knowledge of options and opportunities
 - Family to family support critical at this stage!



Adjustment Counseling

- Beyond Infancy:
 - Parents often form a deep bond with their first audiologist
 - Families often experience complex feelings through the grieving process at transitions throughout the active years of parenting
 - Emotional support needs change, but do not necessarily diminish, as the child ages



“Counseling in audiology has historically employed a medical model with an emphasis on providing content/informational counseling, and rarely providing emotional support”...ASHA Guidelines



...achieving benchmarks (i.e. positive language outcomes) in early detection is facilitated when family counseling and emotional support are actively infused into audiologic care with a systems-driven paradigm” ...ASHA guidelines