Reducing Loss to Follow-up in EHDI Programs and Special Projects By Meeting the Needs of Families

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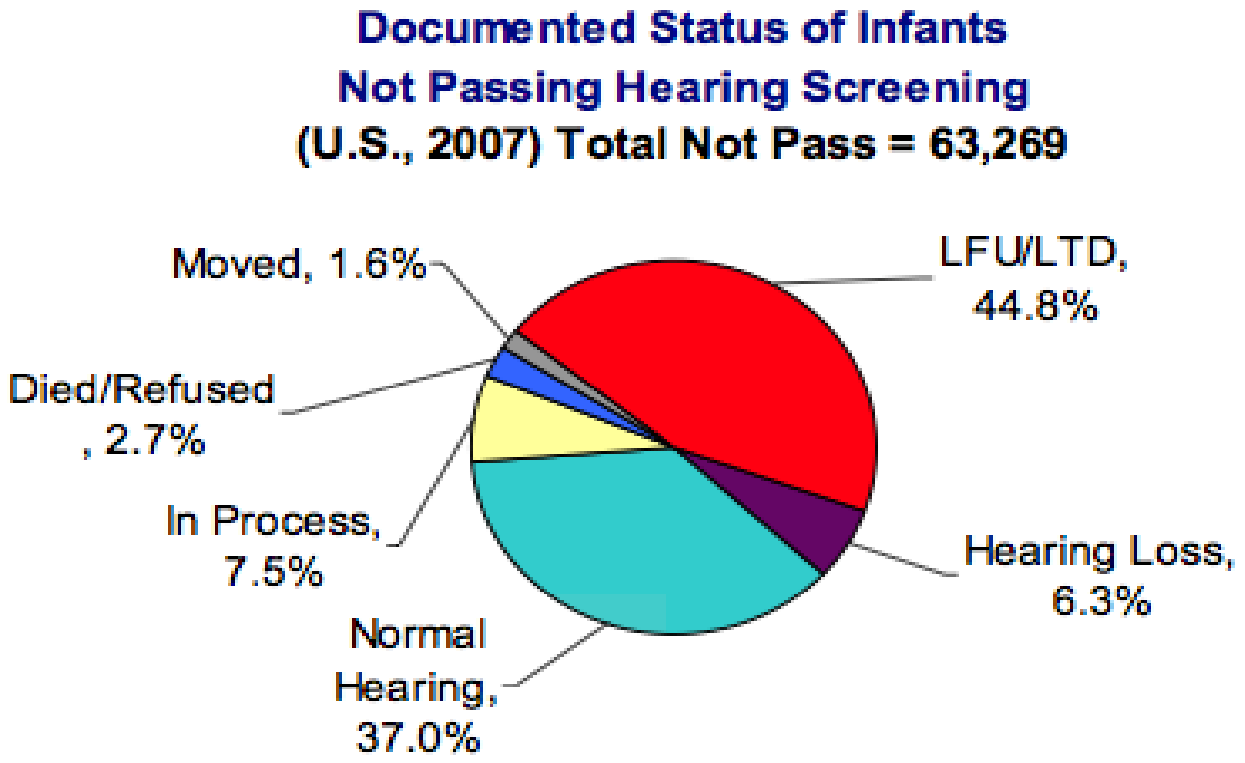
Barriers to Early Hearing Detection and Intervention (EHDI)

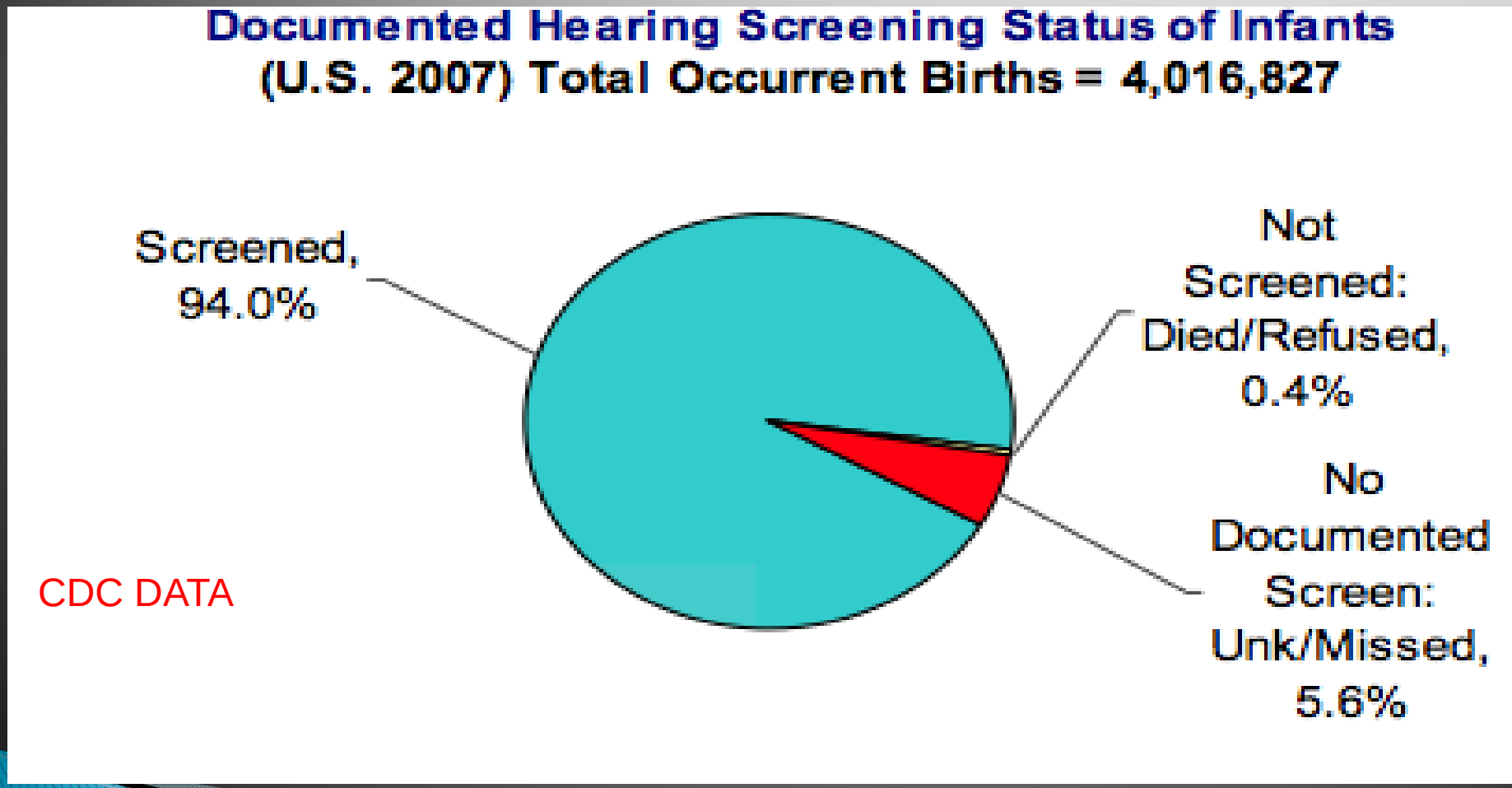
- >95% of all infants born in the United States receive a hearing screen at birth, yet in many areas only 50% of those that fail or miss their hearing screen return for follow-up. This loss to follow-up is complex and needs careful assessment and systematic planning for reduction to occur. All stakeholders have responsibility for addressing the plan.

44% of Infants Who Referred on Their Hospital **Screen** in 2007 Were Lost to Follow-up!



CDC Data

94% Screened in the US by 2007 According to CDC Data



CDC DATA

Retention of Babies and Their Families in the EHDI System

- It is important to minimize attrition so appropriate services can be provided
- Participants in a program who are lost are likely to be different from those who are retained
- The longer the follow-up period, the greater the likelihood of selective attrition (refusal to participate and inability to locate)

Why Do We Have Loss to Follow-up In the EHDI Program and Attrition in Projects?

- Birth of new baby is a life changing event
- Many activities, people and new information surround the birth of a baby, potentially leading to stress
- Hearing Screening is one component of a complex, time compressed period
- Best time to capture newborn hearing screening results,
- but Not best time to convey information about hearing screening results and needed follow-up

Why Do We Have Loss to Follow-Up in EHDI Programs and Attrition in Projects?

- Parents first time to hear about hearing screening
  - Screening results given in complex terminology
  - Written information provided is lengthy
  - Where is contact information for follow-up?
  - Trouble understanding without aid of interpreter
- Information overload, heard from the pediatrician, the nurse, the nutritionist, the lactation specialist, the pt, the neurologist, the neonatologist, and the baby in the isolet next to me- crying and unwilling to be comforted

Providing Information No One Wants to Hear

- Who has responsibility?
- Few screeners or audiologists have training or experience in counseling.
- Is a script or checklist needed?
- Avoid information overload
- Provide resources for later
- Listen/observe

Respect Parents Privacy: Provide Needed Information in Multiple Formats

- First Impressions are Important:
  - Time should be convenient
  - Information should be provided in native language
  - Materials should be succinct
  - Information provided should relate to parents' needs and questions, as well as be informative.
  - …

Conveying Information to Parents about HL and Establishing Positive Relationships

- Considerations for practitioners presentation method
  - Most parents have never heard about hearing loss, use basic information geared to the needs of the parents
  - Be straight forward/honest about need for special assistance that will be needed in intervention
  - Use latest research information
  - Listen to parents and allow ample time for questions
  - Guilt is common, convey information related to parents questions

Why Do We Have Loss to Follow-Up in EHDI Programs and Attrition in Projects?

- No primary care provider, not sure where we will get pediatric care for this baby.
- Single parent with a lot of responsibility
- No insurance
- Have to decide on the baby's name, but later perhaps, so names may change several times
- Living in multiple places – with mother, other relatives and sometimes with baby's father, telephone numbers are changed

Why Do We Have Loss to Follow-Up in EHDI Programs and Attrition in Projects?

- Not a priority
- Costs money
- Not needed
- My baby hears fine
- No one in my family has this problem
- I do not have transportation
- I do not have insurance coverage
- Don't know where the clinic is located
- My doctor/clinic will take care of all the baby needs
- I am too busy taking care of this baby

Multicenter Consortium on Identification of Neonatal Hearing Loss Retention Study

- 61% returned for follow up at 8 to 12 months later
- Retention ranged from 50% to 66% at the 6 sites

- Of Those Lost to Attrition
  - 51% unable to locate
  - 27% consent withdrawn
  - 22% included multiple reasons such as moving, health issues, death, etc.

Multicenter Consortium on Identification of Neonatal hearing Loss Retention Study

- Factors predicting attrition:
  - Nonwhite race
  - No insurance
  - Substance abuse
  - Young maternal age
  - More than 2 children in the home
  - Late onset of prenatal care

Action Steps

- Obtained family address and contact information
- Pediatrician contact information collected with letter to MD about study
- Parents received study information, names and #s of study personnel, information about hearing loss and language development
- Remember us Postcards sent at 2, 4, 6 and 7 months of age; letter(2), & phone calls made depending on site ; staff started calling to make the appt for audiologic testing at 8-12 months of age
- Reimbursement of $20 for visit

UAB Study

- Early in study, participants contacted by postcard one month prior to appointment, phone calls made sporadically, not recorded, participants received small compensation for time and travel
- Next retention plan implemented and more systematic effort for retention was implemented
- Evidence for pre and post results, measure success of system.

Retention Plan (Fowler)

- Short letter sent following each visit, thanks and enclosed stamped postcard for notification of project is address or phone # changed
- All corrections to address/telephone #s, contact information added in computer data base
- Reminder postcards sent 1 month before each visit
- Telephone contact attempted multiple times to schedule participant for follow-up. Transportation offered if transportation

Retention Plan (Fowler)

- Contact sheets developed for each participant with documentation of all contact attempts
- After appt. scheduled, reminder call made day before visit to confirm visit and address for cab fares
- Cab fare to and from clinic or parking fees paid for each visit
- At each visit, contact info reviewed, updated in computer data

Retention Plan (Fowler)

- Action Steps
  - Use directory assistance
  - Call other contact numbers
  - Send certified mail to last known address

Review results of retention efforts quarterly

Prêt racking results – 48 % on track for follow-up

Post retention plan – 81% follow-up rate

Less than 40% of hard to reach participants returned after intensive attempts at contacting them

Change of telephone # 6 months after enrollment – 43.6 %

12 months after enrollment – 92.4%

Recommendations

- Maintain current address and telephone #s
- Obtaining contact information for relatives/friends
- Use computer database at sites to generate visits,
- Use follow-up tracking forms
- Document all contact with participants
- Stay in touch in the interval between visits, phone calls, post cards
- Establish positive relationships
- Reimbursement and small gift
- Review results on a regular basis (Quarterly)
- Potential LFU participants reviewed monthly/bimonthly with a plan for attempting contact

Retention of Babies and Their Families

- Maintain contact with family's primary care provider
- Obtain contact names and telephone numbers of relatives and friends
- Study personnel establish positive relationships with the participant and the family

Increased Funding for Best Practices and Research

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Health Resources and Services Administration

Maternal and Child Health Bureau

Universal Newborn Hearing Screening and Intervention

Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening
Competitive Supplemental Application Program Guidance
HRSA 09-241
Catalog of Federal Domestic Assistance (CFDA) No. 93.251

PROGRAM GUIDANCE

Fiscal Year 2009

Application Due Date: June 22, 2009

Release Date: May 22, 2009

Date of Issuance: May 21, 2009

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.

DVD VIDEO

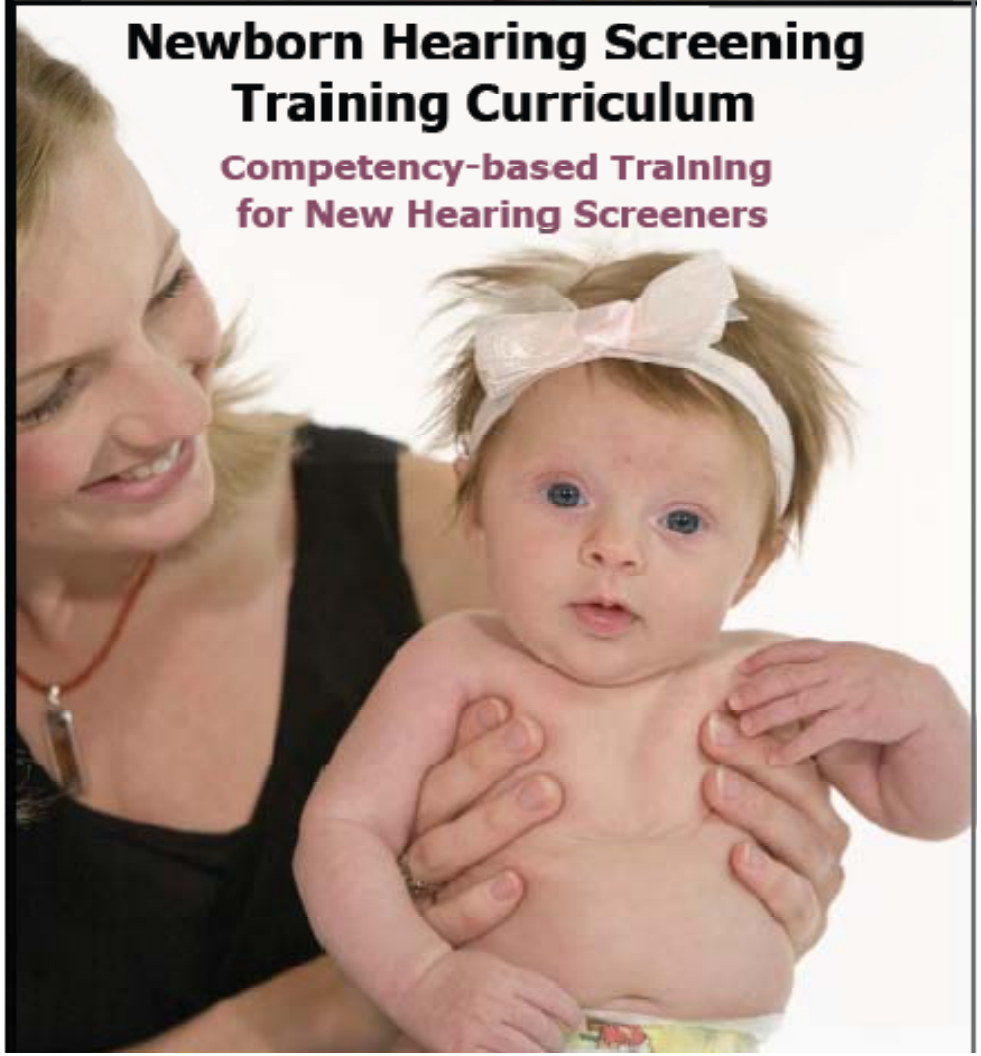
NCHAM
National Center for Hearing Assessment and Management
Utah State University™

Newborn Hearing Screening Training Curriculum

2 Disc Set

Newborn Hearing Screening Training Curriculum

Competency-based Training for New Hearing Screeners



Infant Hearing Guide

- Individual copies of the Infant Hearing Guide are available through the National Center for Hearing Assessment and Management (NCHAM) and can be ordered by visiting http://www.infanthearing.org

Helping Parents Understand

- The importance of Audiological Monitoring
- The probability of progressive and delayed onset hearing loss
- The importance of their role in monitoring for changes in their child's hearing and speech and language
  - Setting up routine "tests" of hearing
  - Observing their child's attention to auditory detail
  - Listening for changes in their child's speech and language

Helping Parents Become Partners in the Monitoring/Intervention Process

- Be straightforward
- Let parents know you are available to help
- Help parents understand how important their role is in obtaining the best services for their child
- Listen to concerns
- Answer questions by providing the best information research has to offer
- Have parents sign a friendly agreement with you that they will do everything they can to help their child

Parent Friendly Contract

- Have parents co-sign a friendly agreement with you that they will do everything they can to help their child:
- 1. Keep appointments, arrive on time, if unable to come, they will reschedule
- 2. Observe their child's speech, hearing, and language behaviors
- 3. Learn all they can about hearing, speech, and language development
- 4. Keep a record of their child's milestones
- 5. Contact you if they have concerns

Retention of Babies and Their Families

- Maintain contact with family's primary care provider
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Newborn Hearing Screening "Misses" May Lead to Invalid Assumptions Re HL

- Mild HL <30-40 dB HL
- Profound HL when early follow-up results confirm presence of middle ear dysfunction and cloud presence of sensory neural HL
- AN if use only OAE
- Some unusual configurations of HL
  - Low-frequency hearing loss (oae & abr)
  - Steeply sloping High frequency HL

    Mid frequency HL

    Profound

Additional Factors Leading to Invalid Assumptions About Hearing

- Inappropriate screening technique by screening staff lead to high referral rates or low referral rates when multiple retests are conducted until you get a pass
- Calibration/equipment problems
- Inappropriate diagnostic audiological protocol
  Munoz data – Audiologists do not use rec. eval. Components

“Misses”, Inappropriate Testing, and Delayed Onset Loss May Cloud the Picture

- Estimated that about 16 % of pediatric hearing loss is delayed in onset with CMV being primary cause, passed newborn screening with normal hearing, not a “Miss”
- Inappropriate testing may miss children with severe sn loss when there is conductive overlay and assumption is made that the loss is conductive
- Repeated screening will eventual pass a child with severe sn hearing loss

Audiologists Providing Services for Very Young Children Should….

- be experienced in evaluating children less than one year of age
- adhere to published guidelines
- have equipment available for recommended age appropriate assessment
- provide only those services for which they are trained
- write comprehensive professional reports
- have liability insurance
- be knowledgeable about etiology of hearing loss and case management of young children with HL

Making Our Job Easier in Managing Loss to Follow-up

- **Training** for all involved in EHDI Process; high level of turnover makes this an ongoing objective
  - Screening staff, refer rates carefully addressed
  - Pediatric audiologists use appropriate protocols
  - Interventionists can meet needs of families
  - Data management

Data Management System: Does it Meet Needs of the EHDI System for Reducing Loss to Follow-up?

- Define plan for retention
- Automate factors in plan if possibl: generate letters, generate lists to call, generate lists to send certified mail
- Generate monitoring reports, statistical reports
- Document all contacts
- Search other state databases for information
- Flexible, so added plan activities can be incorporated

Benchmarks are Guides, The Efficient EHDI Program Moves Quickly, Does Not Wait

- Birth Screening/rescreening
- By 3 Months Diagnostic
- By 6 Months Intervention

Inappropriate Waiting Leads to LFU

- For diagnostic assessment because of waiting list
- For a “complete audiogram”
- For otitis media to clear when there is documented SN HL
- For hearing aid purchase by agency
- For ear mold appointments
- Etc.

Reducing Loss to Follow-up and Changing Outcomes for Babies With Hearing Loss

- Questions and Discussion
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