



Health Resources and Services Administration
Maternal and Child Health Bureau

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UNIVERSAL NEWBORN HEARING SCREENING

Irene Forsman

March 2006

HISTORY

- Healthy People 2000
- 1988 Utah State University pilot in Rhode Island, Utah and Hawaii
- 1995 Technical Assistance by University of Colorado
- 1999 Legislation

HRSA Charge

- Develop and monitor the efficacy of statewide newborn and infant hearing screening, evaluation and intervention programs
 - (Early Intervention is defined in the law as referral to schools and agencies including community, consumer and parent-based agencies and programs mandated by Part C...)

HRSA Charge cont'd

- Collect data on screening, evaluation and intervention...systems that can be used for applied research, program evaluation and policy

HRSA's Program

Health Resources and Services Administration
Maternal and Child Health Bureau

- Universal newborn hearing screening prior to discharge
- Linkage to a medical home
- Audiologic diagnosis before 3 months
- Enrollment in a program of early intervention before 6 mos
- Linkage to family- to- family support

Collaboration

- Centers for Disease Control and Prevention
- National Institute of Deafness and Communication Disorders
- Dept of Education
- Administration on Children and Families'
Head Start Bureau
- American Academy of Pediatrics
- Family Voices



March 2006

Health Resources and Services Administration
Maternal and Child Health Bureau

- 55 States/Territories funded
- TA center continued

Other Activities

- Intra-Agency Agreement with CDC to examine reasons for loss to followup
- State Chapter "Champion" program with American Academy of Pediatrics
 - Head Start Screening Activities
 - Literacy contracts
 - JCIH 2006 Statement

Performance Measures

- 2005 All MCHB Discretionary Grant Programs report on selected performance measures
- Demographic and fiscal data

Purpose

- GPRA requirements
- Establish measurable goals
- Reported in budgetary process
- Link funding decisions with performance

Other Activities cont'd

- Series of targeted issues meetings
- Training grant targeted to audiologists
- Evaluation contract
- Learning Collaborative

Experience

- 93% of newborns are screened
- Data for about 40-50% of infants needing some f/up are missing
 - protocols for communication of screening results to parents uncertain
 - too few pediatric audiologists
 - health care professionals not all well informed of consequences of hearing loss
 - data and tracking systems not mature

Contact Information

Health Resources and Services Administration
Maternal and Child Health Bureau

- Irene Forsman
- 301-443-9023
- Iforsman@hrsa.gov



The Status of EHDI Programs in the USA



presented by

Karl R. White

National Center for Hearing Assessment and Management

www.infanthearing.org

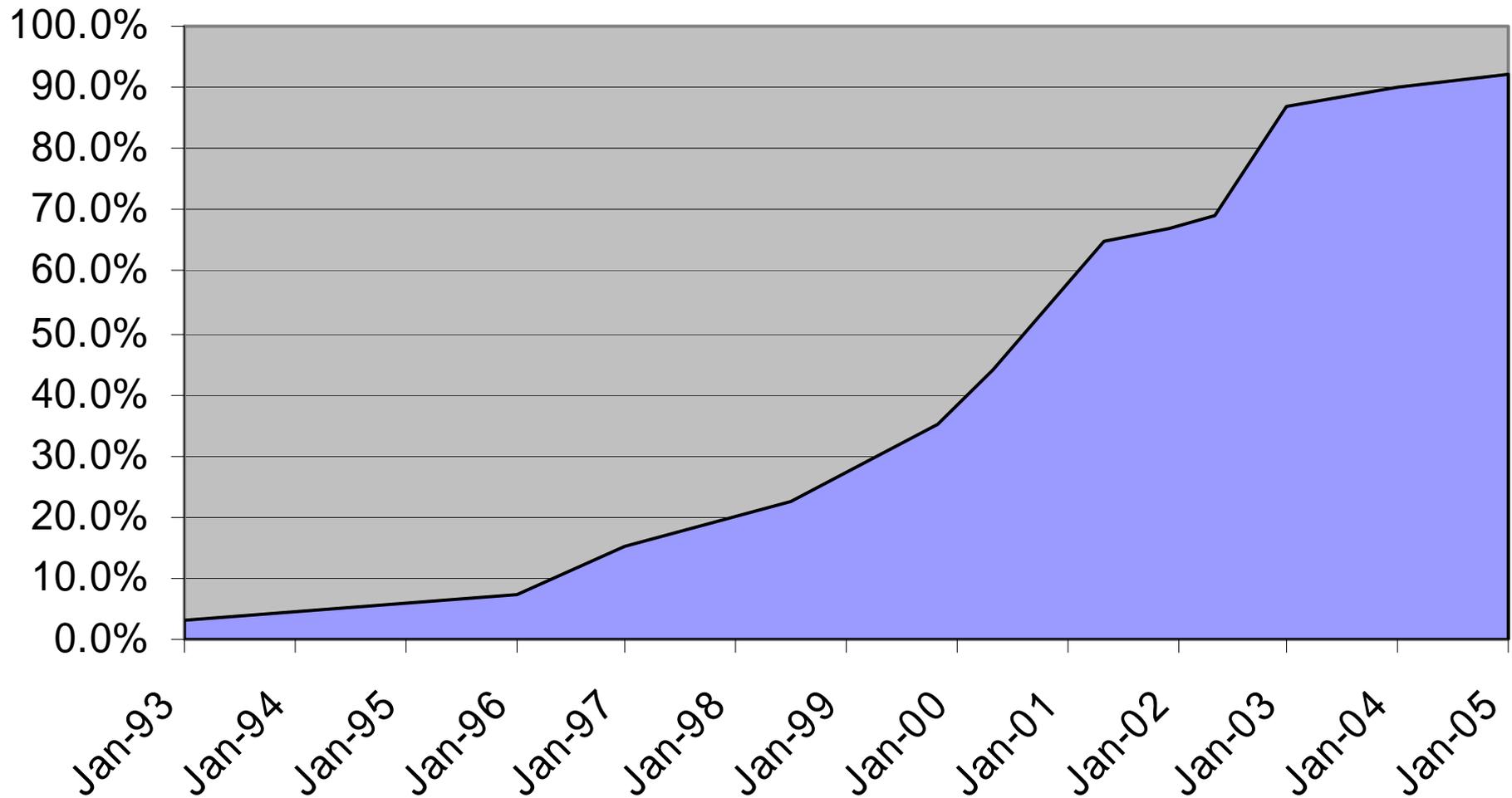
at

LEND Seminar on Newborn Hearing Screening

Logan, Utah

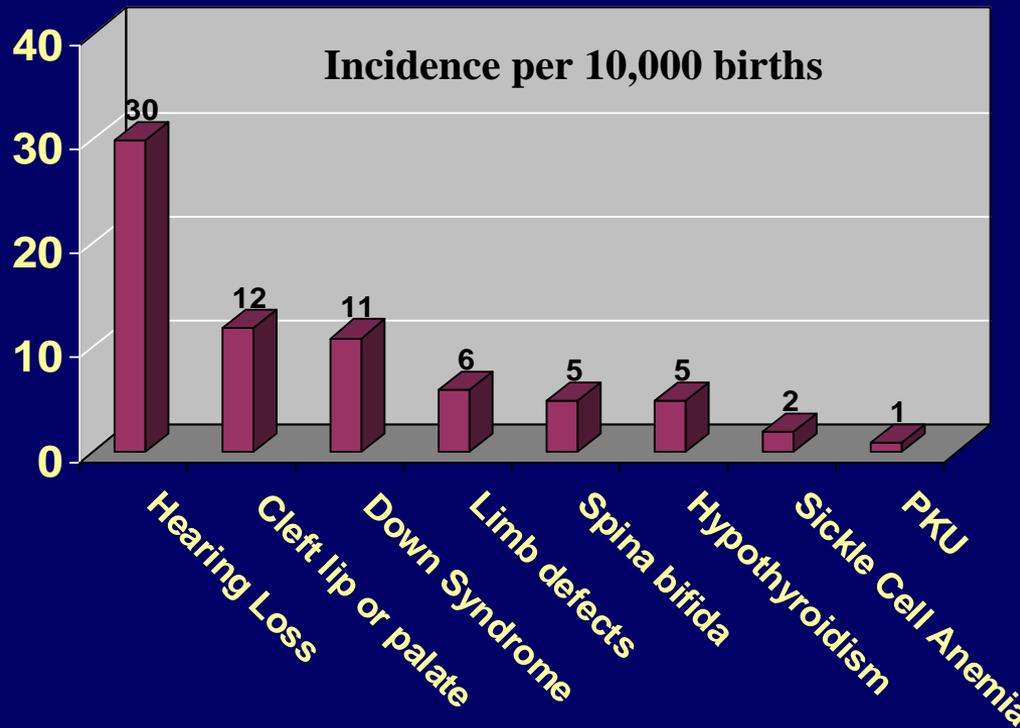
March 3, 2006

Percentage of Newborns Screened for Hearing in the United States



Why is Early Identification of Hearing Loss so Important?

- Hearing loss occurs more frequently than any other birth defect.



- Undetected hearing loss has serious negative consequences.
- There are dramatic benefits associated with early identification of hearing loss.



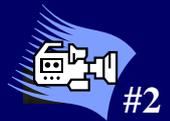
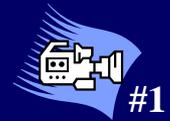
MONTREAL ORAL
SCHOOL
GROUP - 4
200-4 1977-78





Spring is my favorite season. The sun shines bright. The flowers begin to grow. I like spring.





How have we gotten from.....



There



Here?



**Earlier Identification
of Hearing Loss**

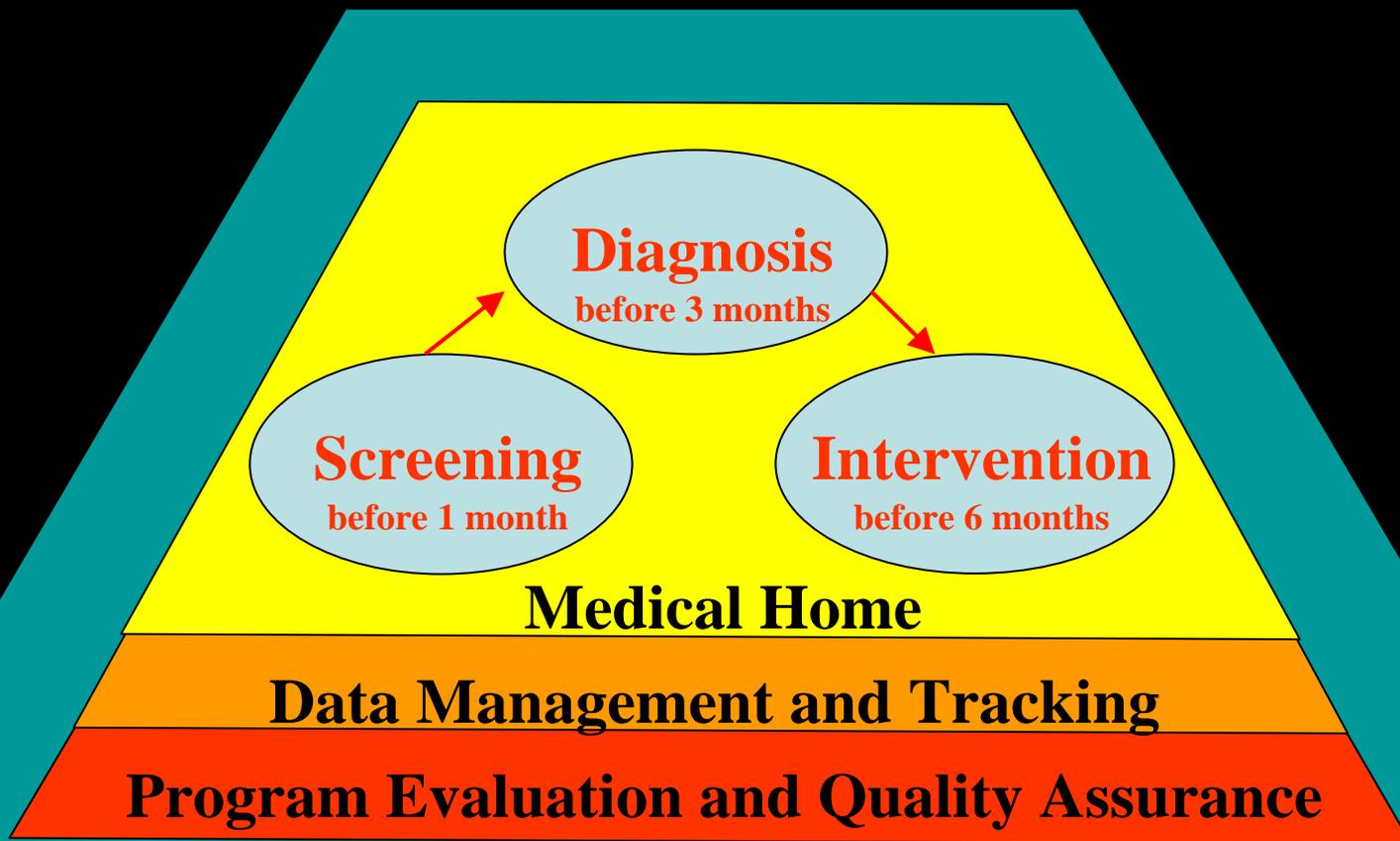
**Better Assistive
Listening Devices**

**Improved Methods
for Teaching
LANGUAGE**

**Increased Availability of
High Quality Early
Intervention Programs**



Essential Components of a Successful Early Hearing Detection and Intervention (EHDI) Programs



Family Support!!

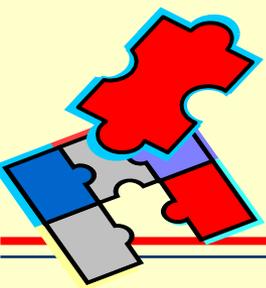


Status of EHDI Programs in the US

Universal Newborn Hearing Screening



- **With ~95% of infants screened, newborn hearing screening has become the accepted standard of care**
- **There are hundreds of excellent programs - - - regardless of the type of equipment or protocol used**
- **Some programs are still struggling with high refer rates and poor follow-up**
- **Only 40% of states have system to attempt screening of home births**
- **35% of states collect data on JCIH Risk factors**



Status of Hearing Screening Practices in “Head Start Programs



All children are supposed to receive a hearing screen within 45 days of enrollment; however:

- Most programs rely on subjective screening methods such as hand clapping, bell ringing, and parent questionnaires to screen children 0 – 3 years of age
- Most programs did not know that OAE technology existed or could be used with young children

The Hearing Head Start Project

- Feasibility study from 2001-2004
- 69 programs participated
- 3486 children screened



OAE Screening/Referral Outcomes

78 children identified with a hearing loss or disorder:

- 6 permanent hearing loss
- 63 serious otitis media requiring treatment
- 2 treated for occluded Pressure Equalization tubes
- 7 treated for excessive ear wax

Status of EHDI Programs in the US:

Audiological Diagnosis



- **Equipment and techniques for diagnosis of hearing loss in infants continues to improve**
- **Severe shortages in experienced pediatric audiologists delays confirmation of hearing loss**
- **State coordinators estimate only 62% “receive diagnostic evaluations by 3 months of age**

Status of EHDI Programs in the US:

Early Intervention



- **Current system designed to serve infants with bilateral severe/profound losses---but, majority of those identified have mild, moderate, and unilateral losses**
- **State EHDI Coordinators estimate:**
 - **Only 55% of infants with hearing loss are enrolled in EI programs before 6 months of age**
 - **Only 12% states notify EI system about screening results**
 - **Only 36% know whether hearing screening is done in early intervention programs**

Part C of the Individuals with Disabilities Act (IDEA, 1997)

a)...A statewide system...shall include, at minimum, the following components

1. **Definition of eligibility criteria**
2. Statewide policy to ensure services to all infants and toddlers
3. **Timely, comprehensive multidisciplinary evaluation**
4. An individualized family service plan (IFSP) for all identified children
5. **Comprehensive child find system**
6. Public awareness program
7. Central information directory of services
8. Comprehensive system of personnel development
9. A lead agency
10. Procedural safeguards
11. State interagency coordinating council

Federal regulations for IDEA require all states to provide Part C services to any child who:

- (i) is experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in one or more of the areas of cognitive development, physical development, communication development, social or emotional development, and adaptive development; or**
- (ii) has a diagnosed physical or mental condition which has a high probability of resulting in developmental delay.**

Are Children with Hearing Loss Eligible for Part C Service?

- **55 of 55 (100%)** indicated that services would be provided to a child who had a diagnosed physical or mental condition with a high probability of resulting in developmental delay.
- **37 of 55 (67%)** listed hearing loss, auditory impairment, deafness, or something similar as one of the specific conditions.
- **Only 7 of 55 (13%)** of the **State Plans** provided any kind of operational definition that could be used to determine if a specific child with hearing loss would be eligible.
- **Twelve other states (22%)** provided some type of operational definition for hearing loss in other documents.

What Is a Medical Home?



- **A primary care physician provides care which is:**
 - **Accessible**
 - **Family-centered**
 - **Comprehensive**
 - **Continuous**
 - **Coordinated**
 - **Compassionate**
 - **Culturally effective**

American Academy
of Pediatrics

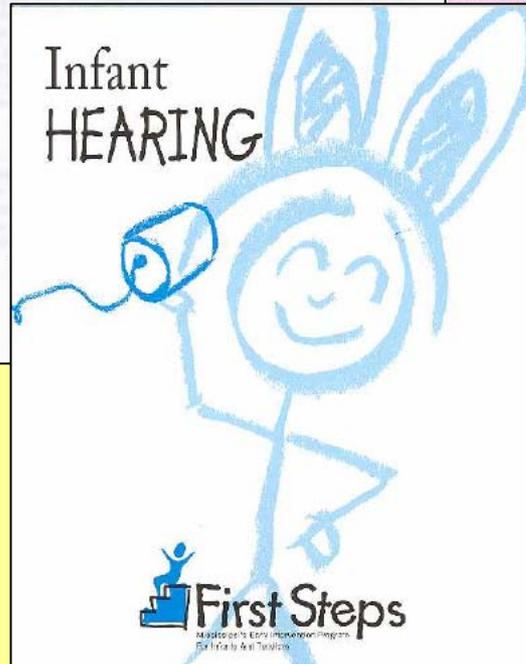
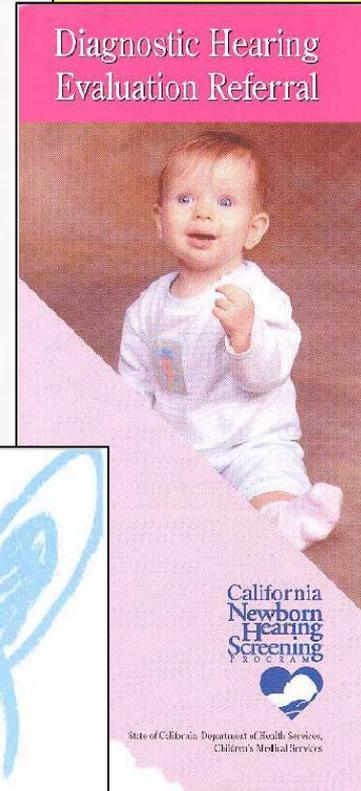
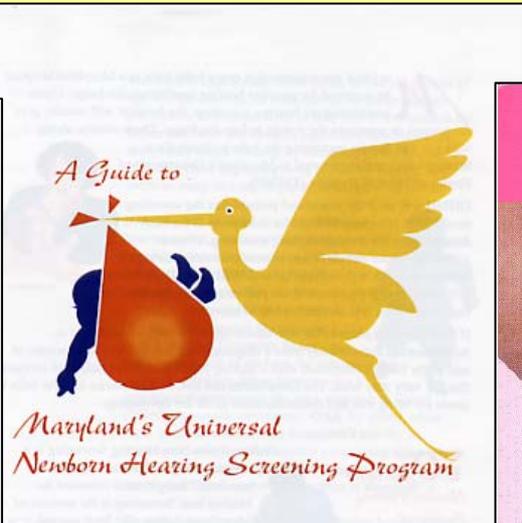
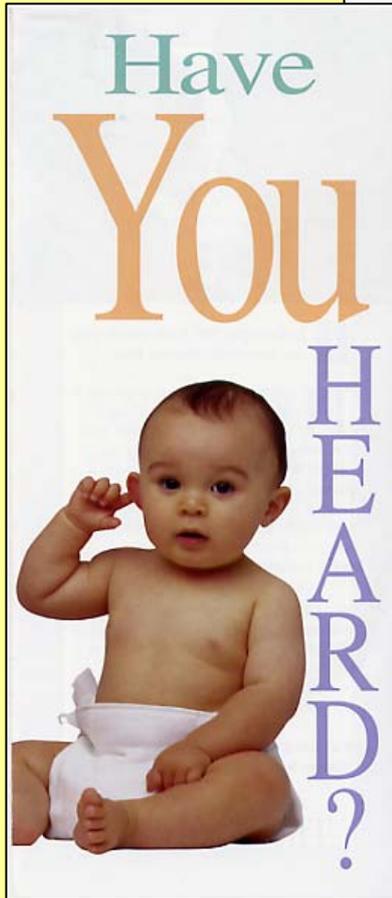


DEDICATED TO THE HEALTH OF ALL CHILDREN™

Status of EHDI Programs in the United States

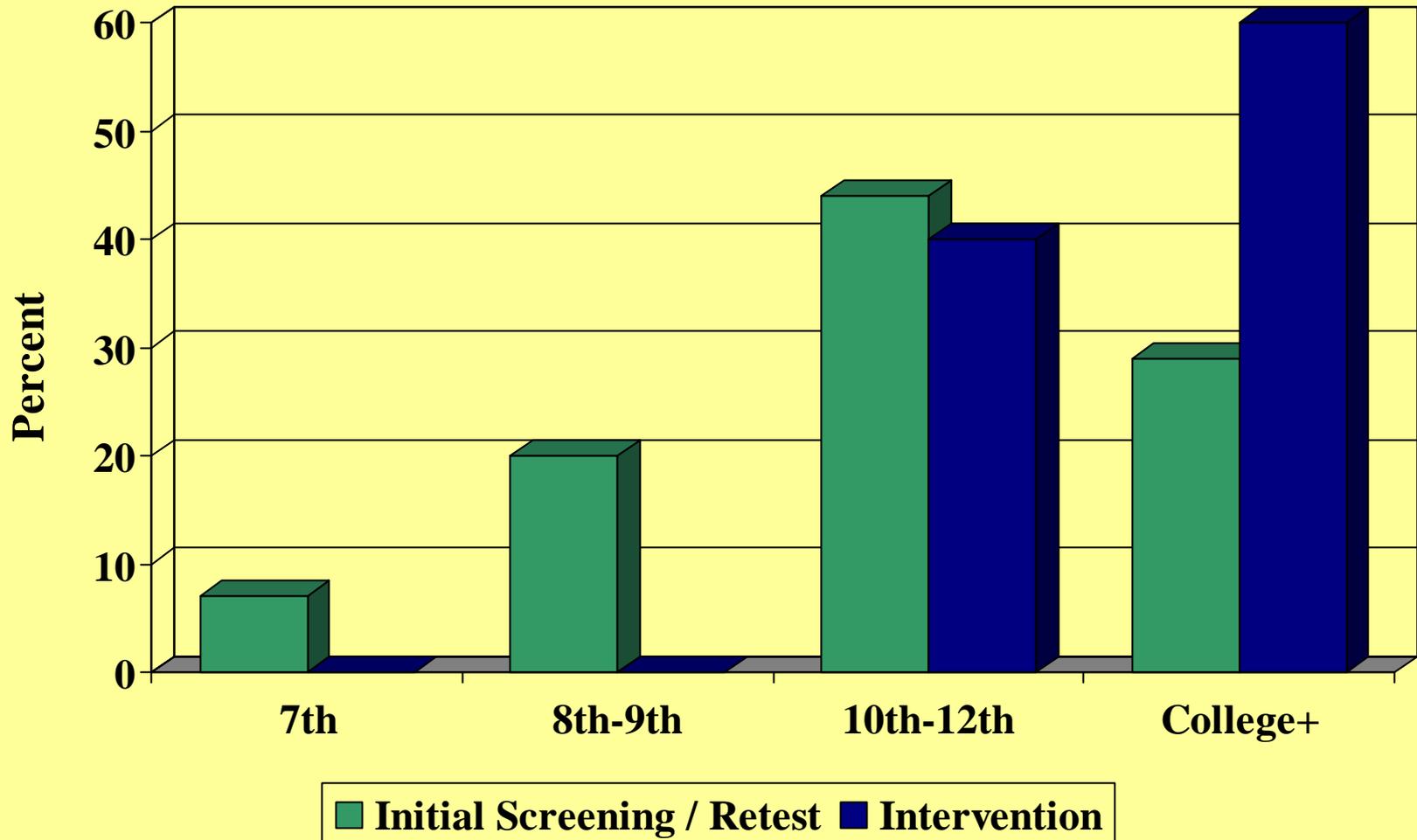
- Universal Newborn Hearing Screening
- Effective Tracking and Follow-up as a part of the Public Health System
- Appropriate and Timely Diagnosis of the Hearing Loss
- Prompt Enrollment in Appropriate Early Intervention
- A Medical Home for all Newborns
- Culturally Competent Family Support

Do current EHDI materials work?



Brochure Readability

Gold Standard Readability: ≤ 6 th Grade



Newborn Hearing Screening Tool Kit

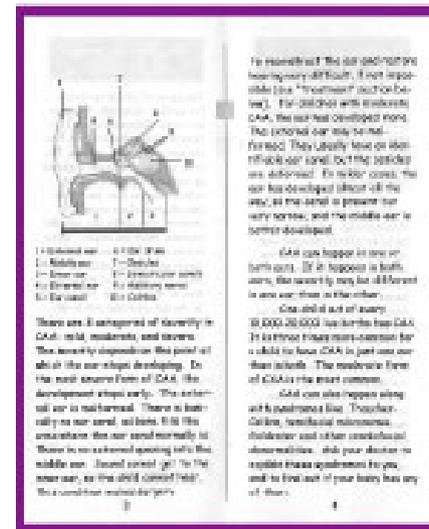
1. Is the layout user-friendly?

First impressions are important!

Does the pamphlet:

- Have ample white space?
- Limit paragraphs to 4 to 5 lines?
- Use bullets, boxes, indentation, bolding, vertical lists?
- Use bifold rather than trifold format?
- Use font that is 12 point or larger?
- Avoid use of ALL CAPS, italics and *specialty* fonts in large blocks of text?

Examples that illustrate key points:



This layout lacks white space, headings, and attractive graphics that would help make the text easier and more inviting to read.

Why does my baby need another hearing test?

- Some babies may need another test because:
 - Child is in the ear
 - Baby was missing a test
 - Baby has hearing loss
- Most babies who need another test have normal hearing. Some will have hearing loss.

Why is it important to have another hearing test as soon as possible?

- Testing is the only way to know if a baby has a hearing loss.
- The earlier a hearing loss is found, the better it is for a baby.
- If your baby has a hearing loss, there are many ways we can help your baby.

Finding hearing loss early can make a big difference in your baby's life.



This layout has ample "white space", a bold heading, a clear illustration, and bullets that make the text easier to navigate.

Hearing needs are going unheard for kids in Utah

By Amy Joi Bryson

Deseret Morning News

PLEASANT GROVE — Two years ago, Norm and Taunya Paxton discovered silence had crept into their home — a silence that would forever change their life: They learned their middle child, Chance, was profoundly deaf.

"It's like being thrown into the deep end of the pool and not knowing how to swim," Norm Paxton said.

The discovery left the couple flailing in their efforts to confront the mixed messages they received from doctors, the lack of coordinated support from hearing advocacy groups and, they say, the surprising indifference of the insurance industry.

"There's absolutely no guidance," said Taunya Paxton. "It was worse than shooting in the dark."

Beyond coping with a new-found disability, the hearing aids are not by most private health largely viewed as the best learning parents

, and while insurance or riders for dental, vision or even erectile aids don't make

That can be problematic when the device can cost a few hundred dollars to as much as \$7,200.

"Part of the industry's denial process is a sensory issue," says Rich Harward, the state and vision services.

"Most plans pay for eyeglasses; very few there are some out there who have helped.

The Paxtons, covered under Intermountain appeals, having been told by IHC officials early this year it would be "irresponsible" for them to modify their plan to include coverage.



Chance Paxton, left, who turns 5 today, hugs his friend, 5-year-old Payton McPhie.

Keith Johnson, Deseret Morning News

"It's like being thrown into the deep end of the pool and not knowing how to swim,"

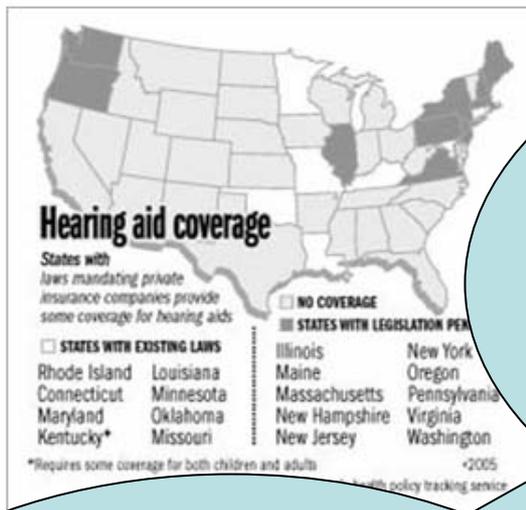
"There's absolutely no guidance. It was worse than shooting in the dark."

8 states require hearing aid assistance for kids

Utah group hopes to get insurance firms to help

By Amy Joi Bryson

Deseret Morning News



"The char
are allo

"There is not an awareness out there. Another parent is going to find out their child is deaf and say, 'Thank goodness I have insurance' and they will find it isn't so. They will go through the same battle we have."

"The market is so incredibly price sensitive, we are being told to take away benefits rather than add them," said Kevin Bischoff, vice president of public and corporate affairs of Regence BlueCross BlueShield.

...should be some help for children.
...when it is so critical for a child who is
...developing in socialization, isn't there any
...ence in that child's life."
...ence related to deafness and hard-of-hearing
...parent is going to find out their child is deaf
...y will find it isn't so. They will go through

Special Report

U.S. Preventive Services
Task Force Report on
Newborn Hearing Screening

Site Guide

[Our Background](#)

[National EHDI Technical Assistance System](#)

[Research Projects](#)

[Sound Ideas Newsletter](#)

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The Basics

[EHDI Resource Center](#)

[Newborn Hearing Screening](#)

[Diagnostic Audiology](#)

[Early Intervention](#)

[Data Management](#)

[Family Support](#)

[Medical Home](#)



[Newsletter](#)
(Winter '01-'02)



[Bulletin Board](#)



[2002 EHDI Meeting](#)



[Audiology Workshop](#)



[For Families](#)

[Early Hearing Detection & Intervention Information & Resource Center](#)

In the [information & resource center](#) one will find a wealth of information and resources concerning the many dimensions of early hearing detection and intervention. Information and resources include some of the following:

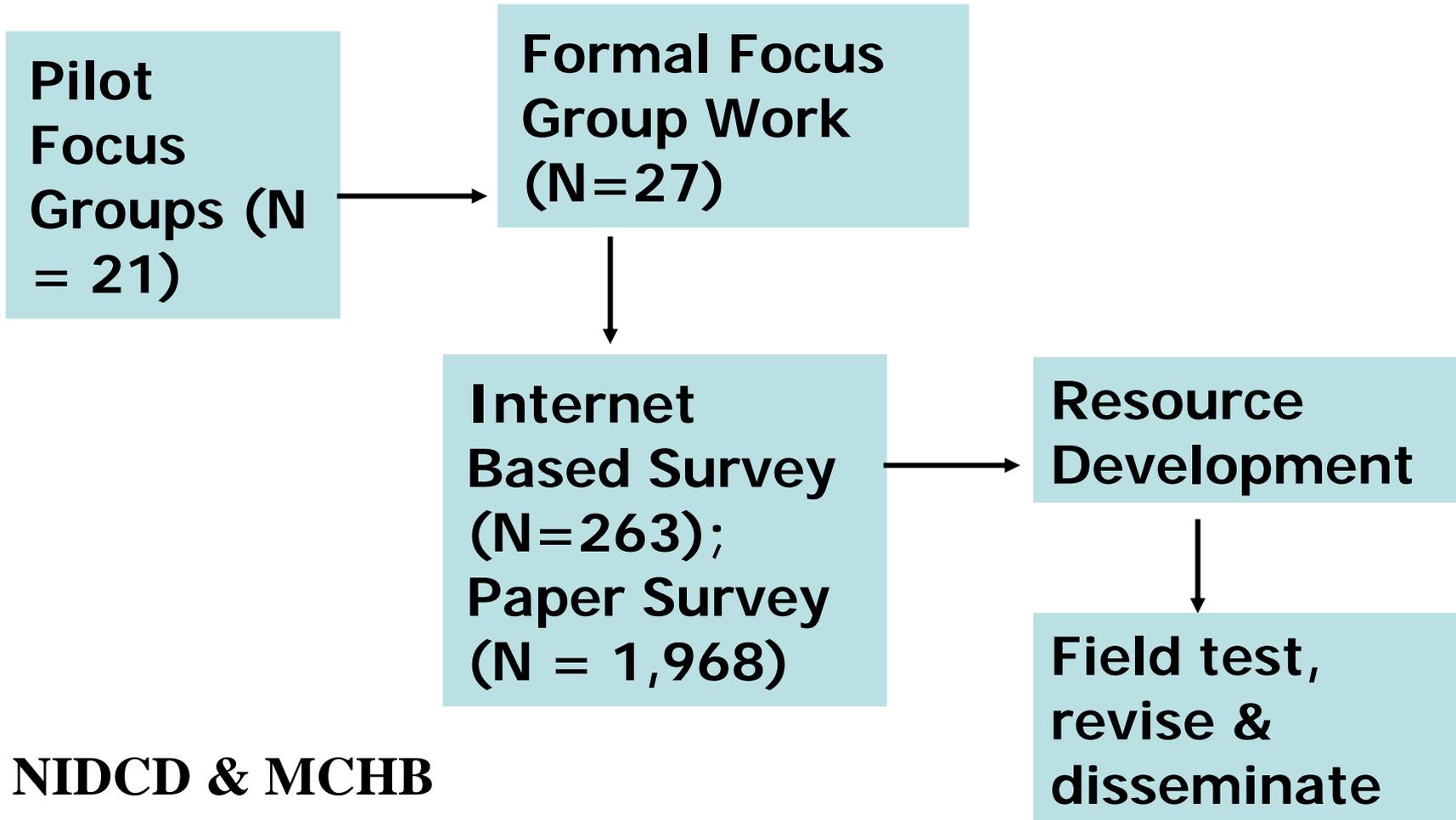
- [Newborn Hearing Screening](#)
 - [Calculating The Cost](#)
 - [Implementation Guide](#)
 - [Selecting Equipment](#)
- [Diagnostic Audiology](#)
- [Early Intervention](#)
- [Legislative Activities](#)
- [Data Management](#)
- [Family Support](#)
- [National Technical Assistance System](#)
- [Status of EHDI in the U.S.](#)
- [State EHDI Grants](#)
- [Issues & Evidence](#)
- [Slideshows & Videos](#)
- [Abstracts & Citations](#)
- [EHDI Bulletin Board](#)
- [Equipment Loan Program](#)
- [Links](#)

Physician Attitudes, Knowledge and Practices Related to NHS



Collaborative Effort of
BTNRH and NCHAM
Supported by NIDCD and MCHB

Project with Pediatricians



**NIDCD & MCHB
supported**

Survey Question Examples

- Attitudes:
 - Do you think NHS causes parents undue anxiety or concern?
 - Do you believe UNHS is worth what it costs?
 - Please list any concerns you have about NHS, diagnosis and intervention.



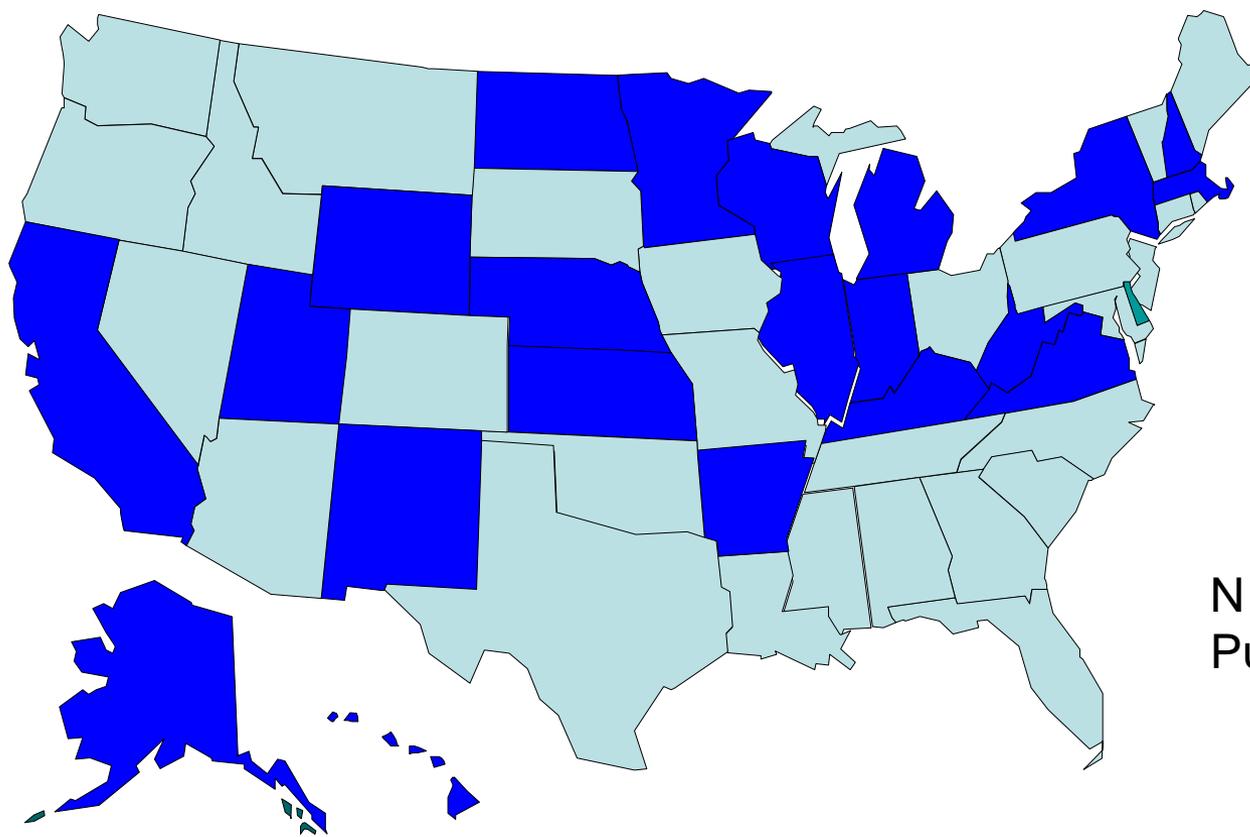
Survey Questions Examples

- Practices:
 - Approximately how many children with permanent hearing loss (EXCLUDING OTITIS MEDIA) have you had in your practice over the past 3 years?
 - List any specialists to whom you routinely refer the family of a child with permanent hearing loss (list the types of specialists).

Survey Question Examples

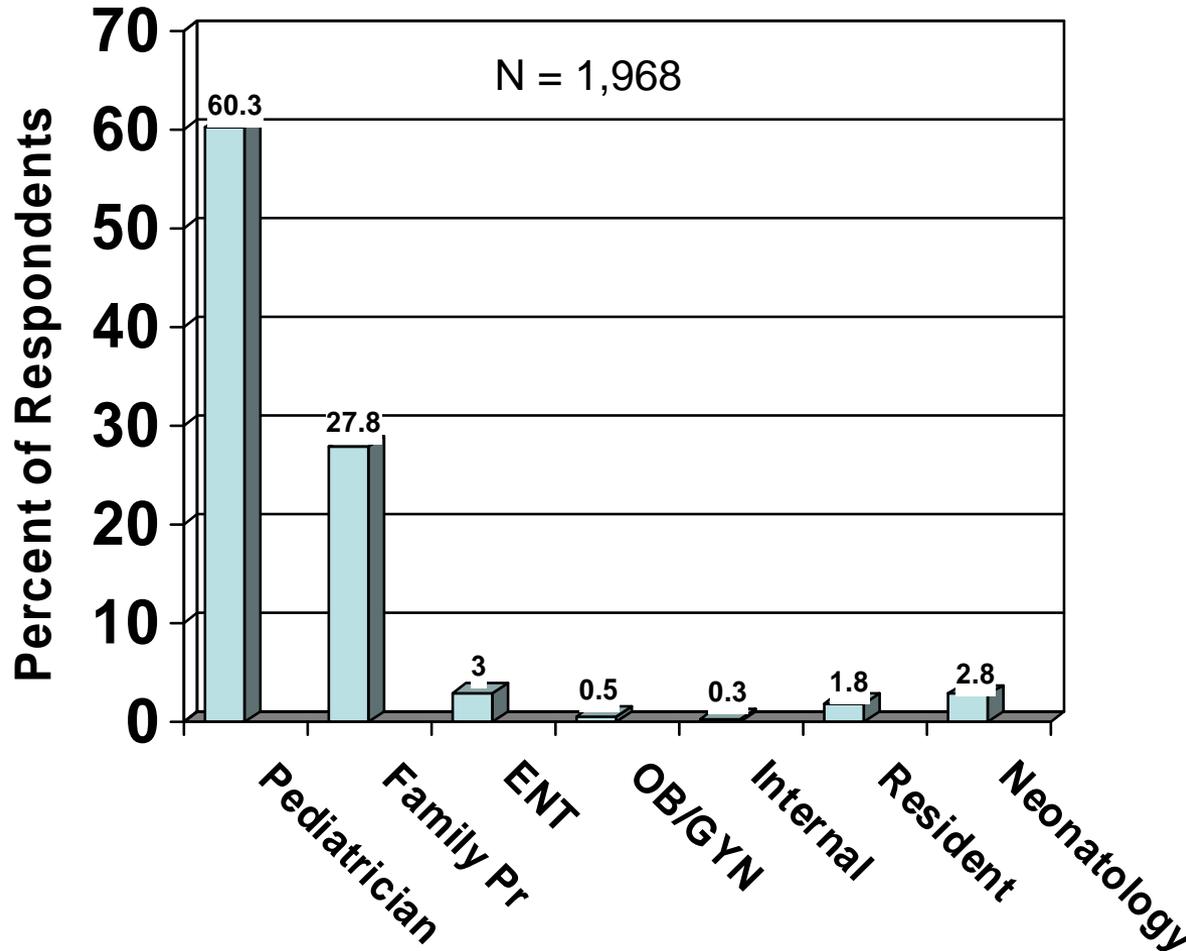
- Knowledge:
 - What is your best estimate of the earliest age at which:
 - A child not passing the screening should be seen for follow up testing
 - A child can be definitively diagnosed with permanent hearing loss
 - A child can begin wearing hearing aids
 - A child with permanent hearing loss should be referred to early intervention
 - Enter age estimates _____

States Involved in Survey of Physicians



N = 21 States +
Puerto Rico

Physician Survey: Demographics



Gender:

53.2% Male

46.8% Female

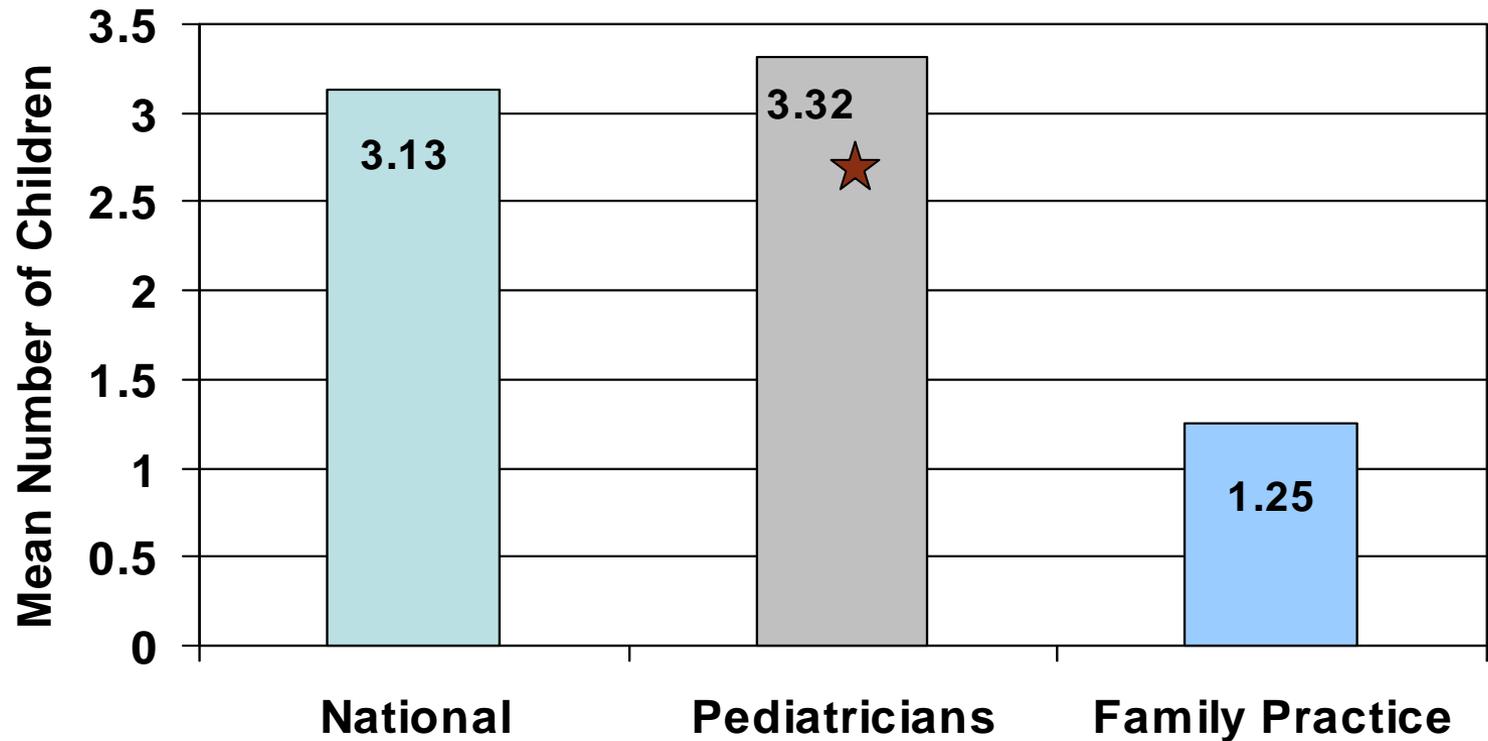
Location:

62.5% Metro

24.1% Small town

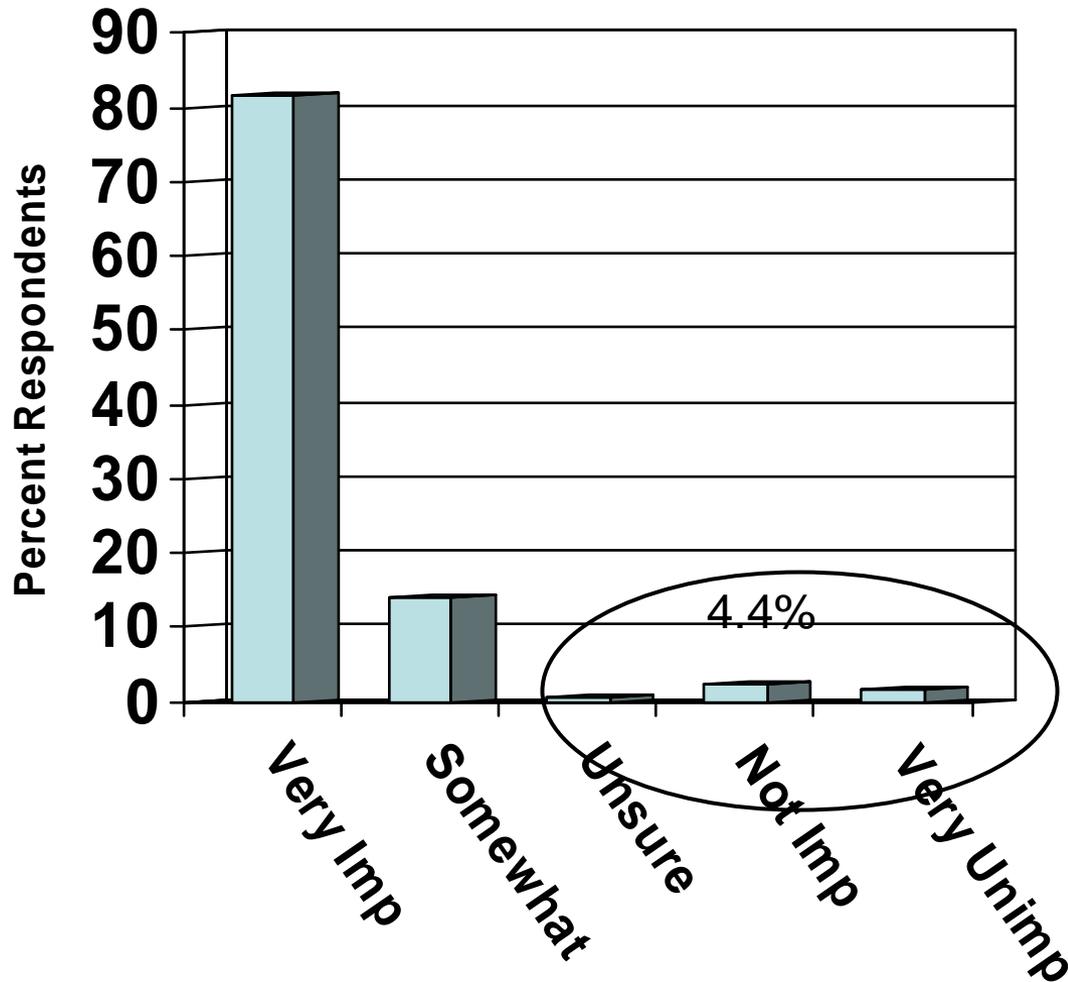
13.3% Rural

Children with SNHL in past three years of practice



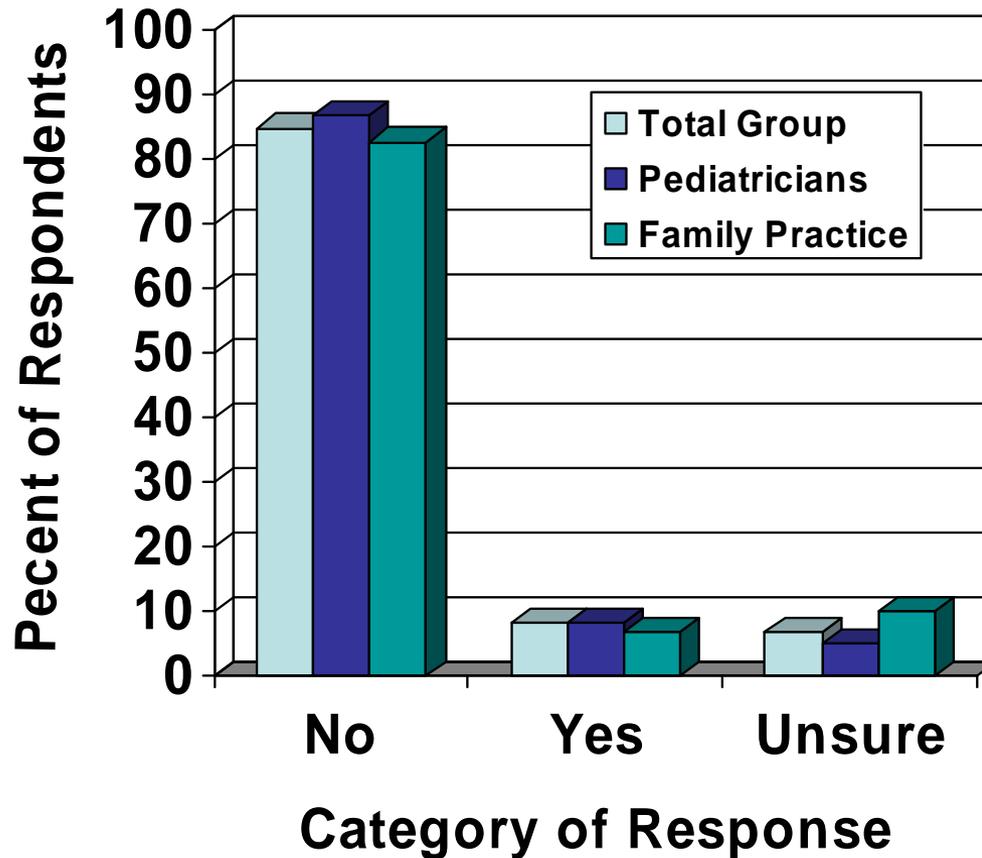
ENT $\bar{X} = 16.95$

Importance of testing all newborns



3% Pediatricians;
6% Family Practice
 $p < .001$

Does NHS cause undue parental anxiety?



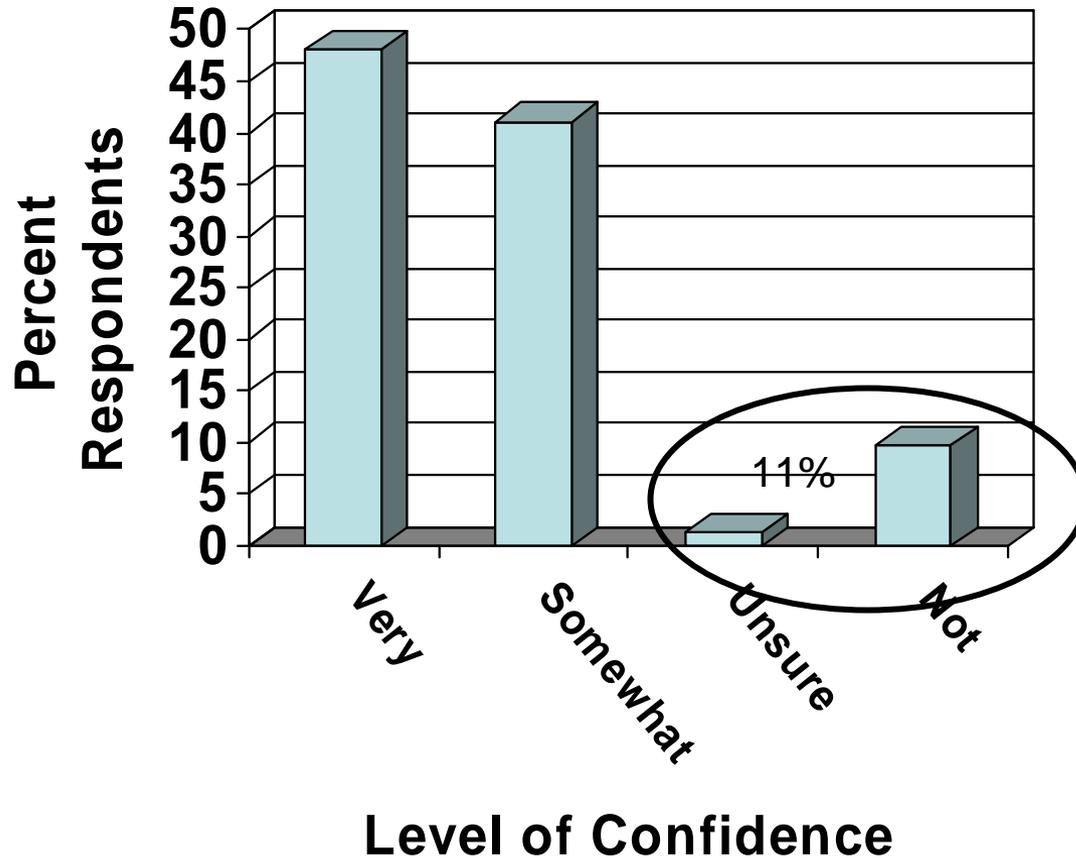
Things are changing...but

- 88.61% receive screening results
- But...12% - 17% receive < 50% of results!
- 89.2% refer < 3 mos
- But...24.3% unsure NHS is worth what it costs

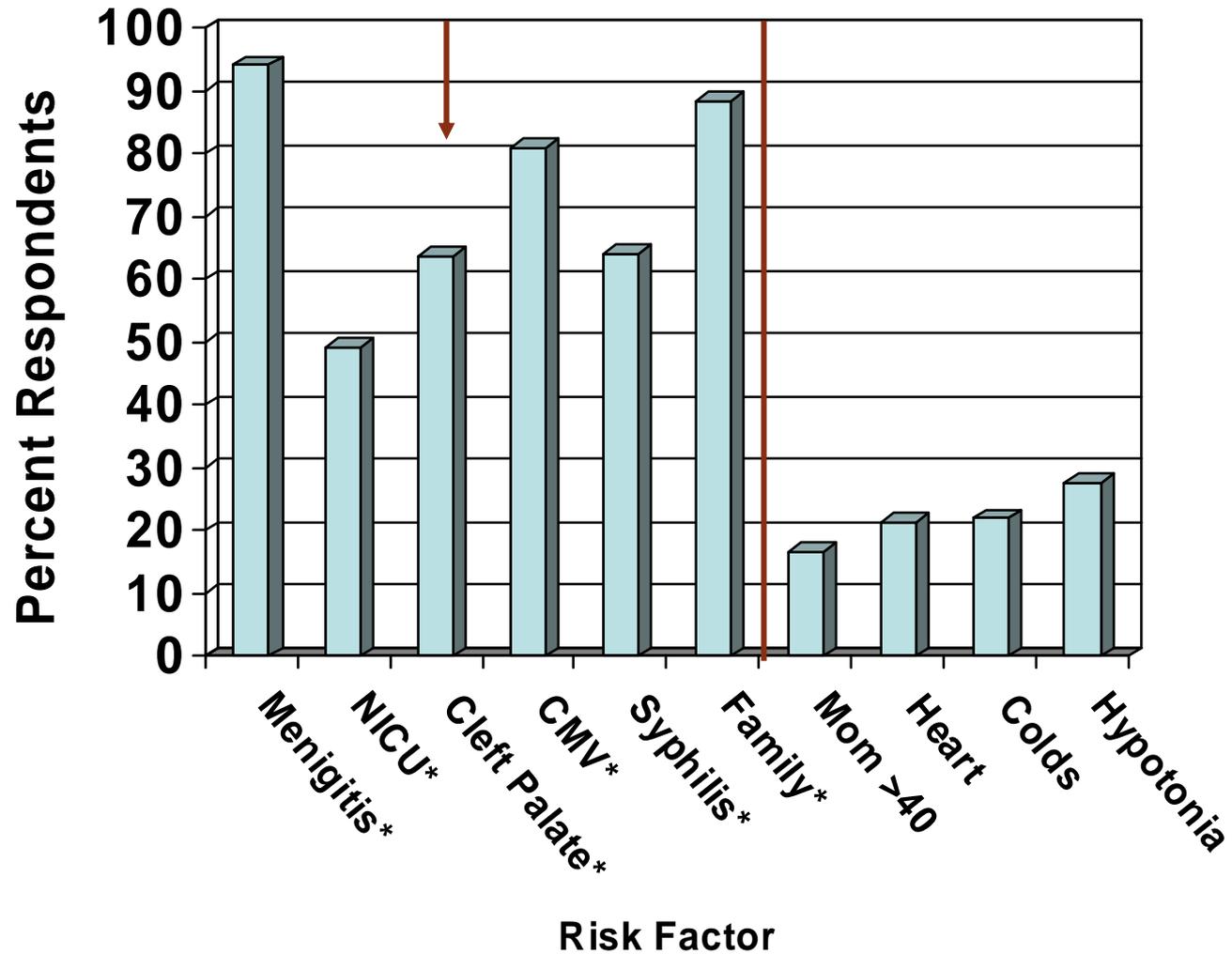
Concerns about NHS

- Too many false positives
- Costs outweigh benefits
- Loss to follow up
- Need for training
- Unclear about procedures; complex
- Inconclusive results
- Need for parent education
- Need for funding & better equipment

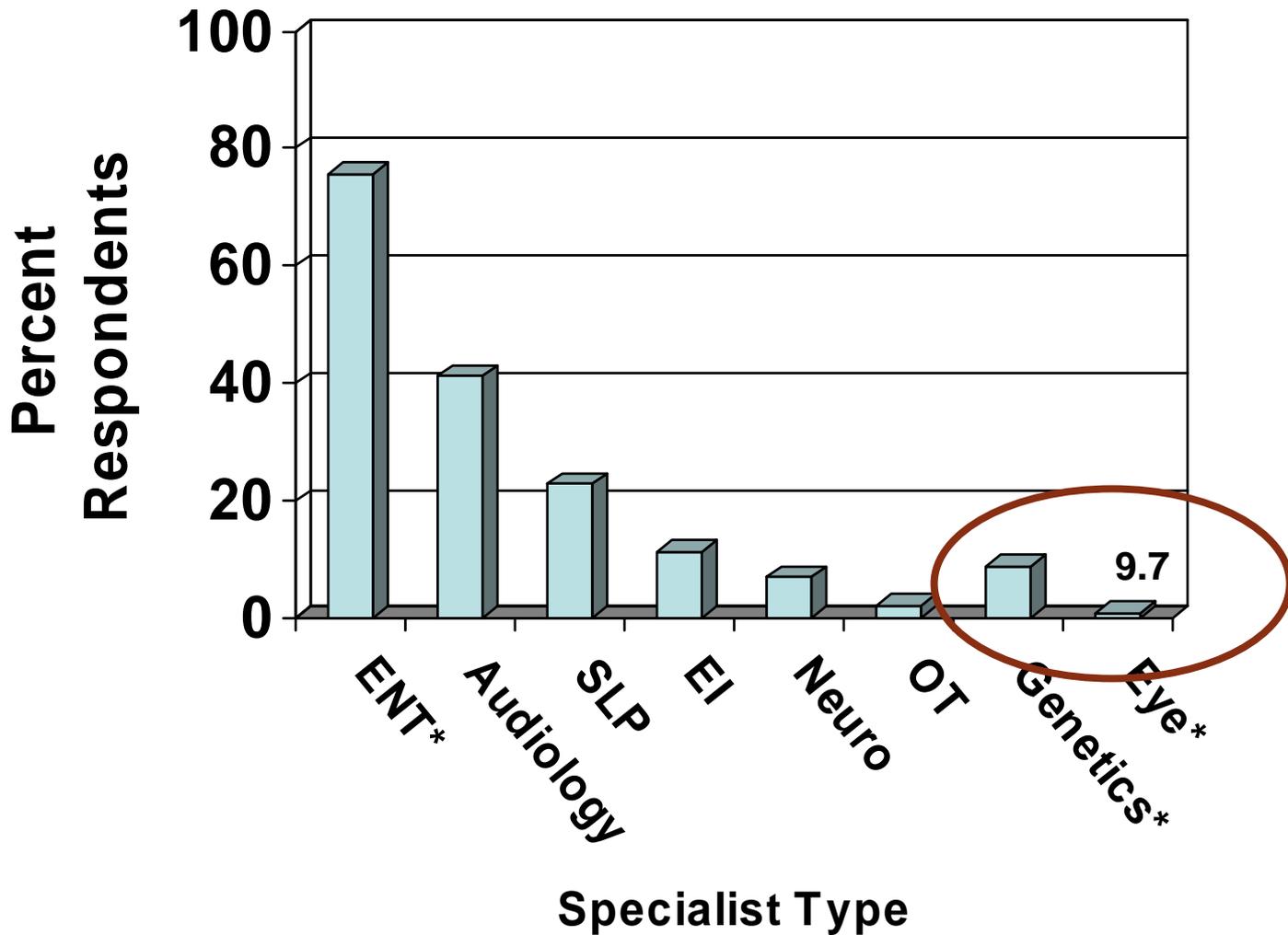
Confidence in Counseling Parents following Screening



Risk for late onset SNHL

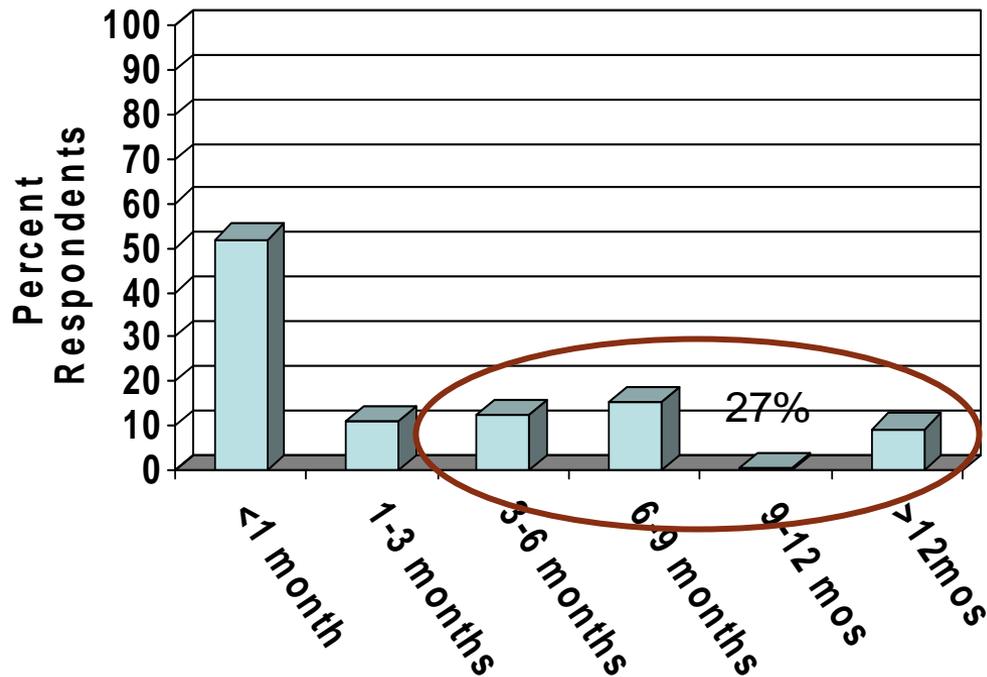


Referral to Specialists

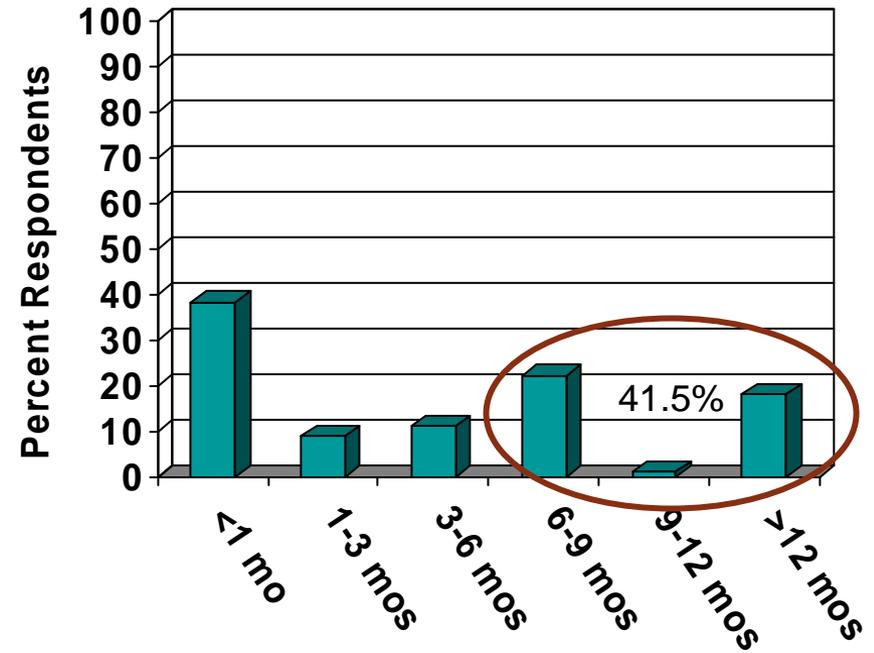


Follow Up & Intervention

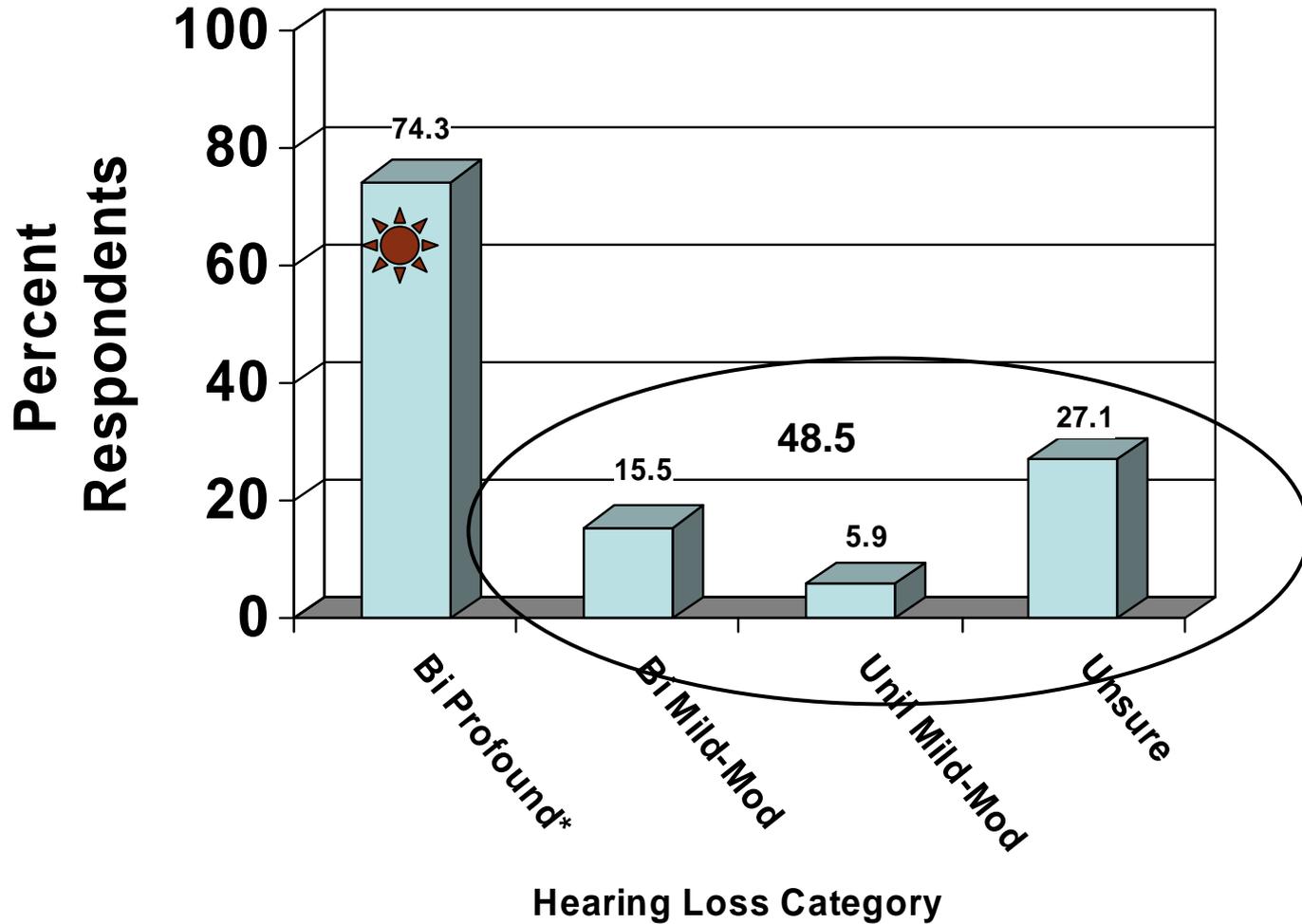
Age Diagnosis Possible



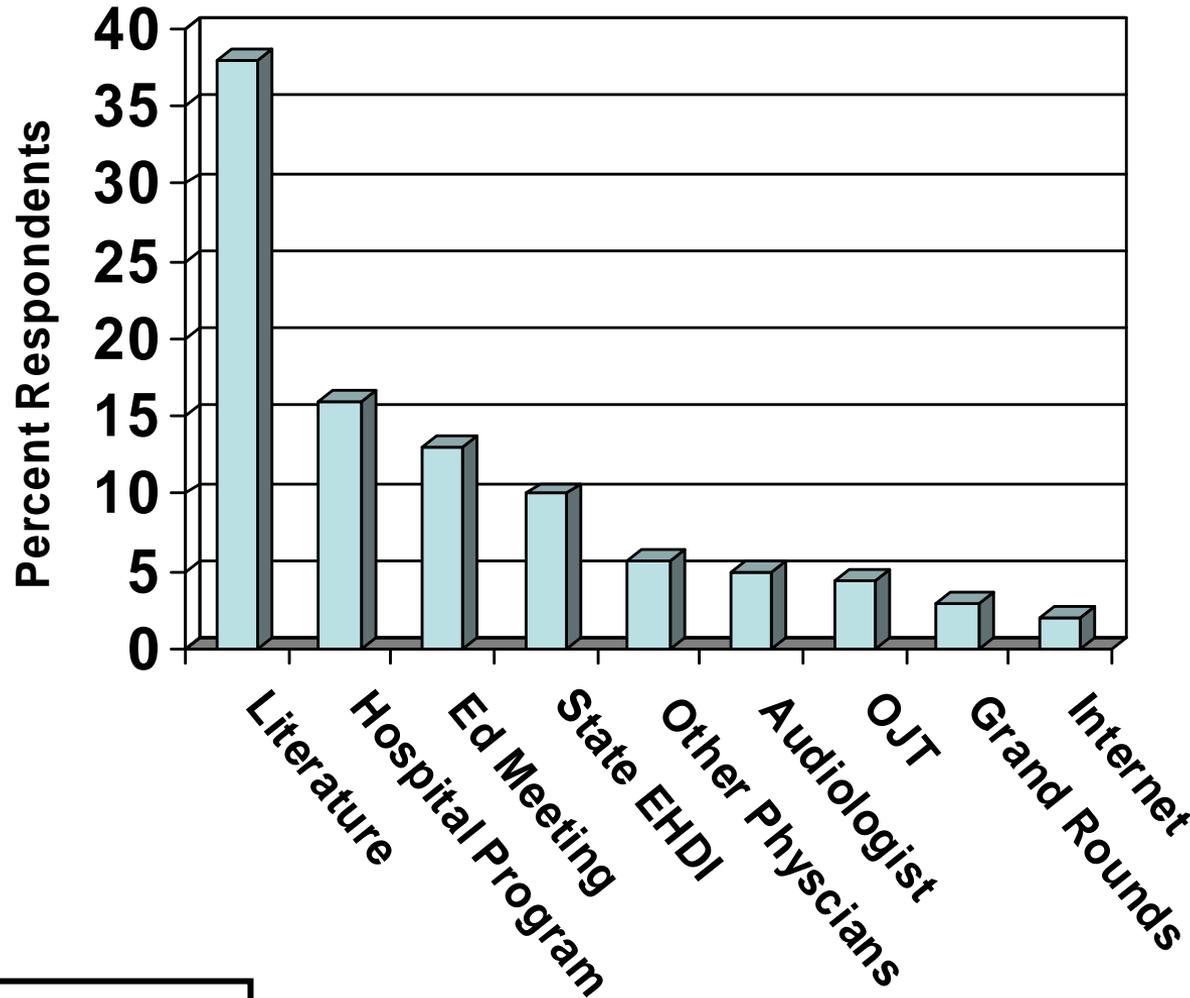
Wear Hearing Aids



Candidates for Cochlear Implants



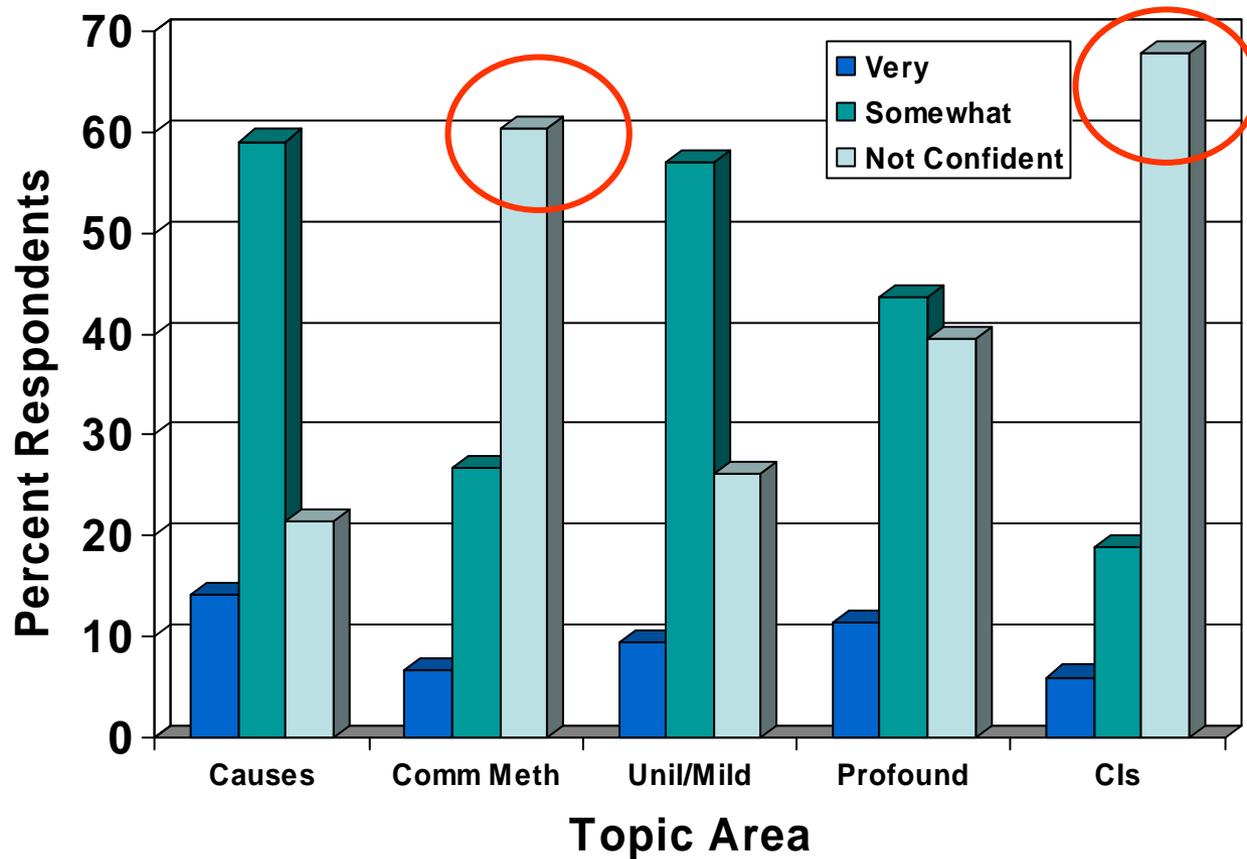
Primary Sources of Info on NHS



Frequent Internet
Use = 51.7%

Information Source

Confidence in Talking with Parents about...



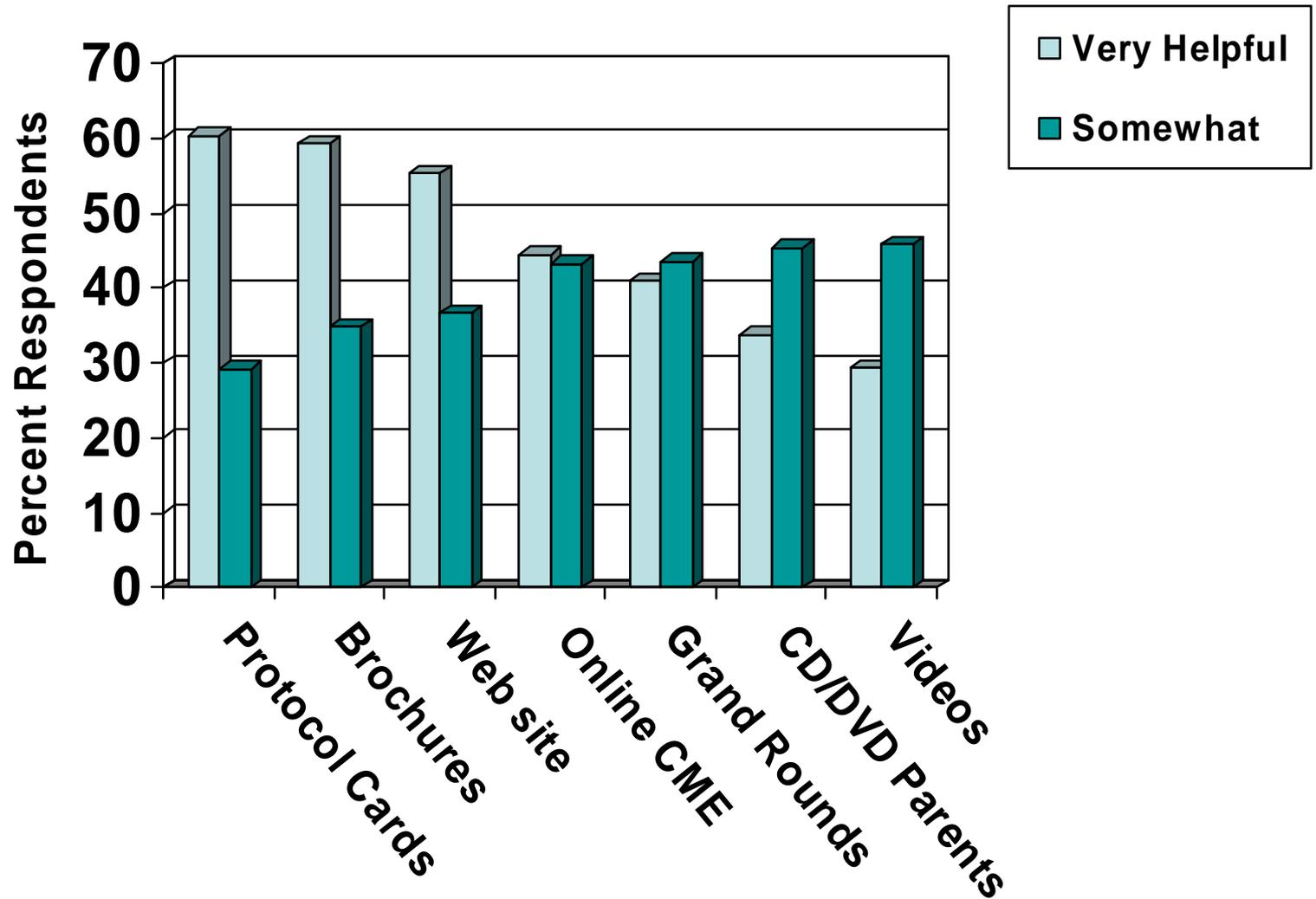
Policy Statement Awareness

Organization	
AAP	56.8%
AAO	1.9%
AAFP	6.6%
State	1.1%
AMA	.3%
CDC	.5%
USPSTF	.7%

Topics Judged as Needs (In prioritized order):

1. Protocol for f/u
2. Early intervention
3. Contacts for more information
4. Screening for late onset SNHL
5. Patient Education Resources
6. Impact of HL on language
7. Screening at well-child visits
8. Hearing Aids and cochlear implants
9. Genetics and hearing loss
10. Counseling families about screening results

Usefulness of Resources

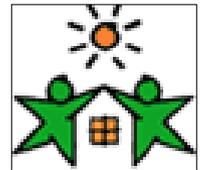


Most Recommended Resources

1. Protocol cards
2. Patient brochures
3. Web sites
4. On-line CME*
5. Peer education
6. Grand rounds materials

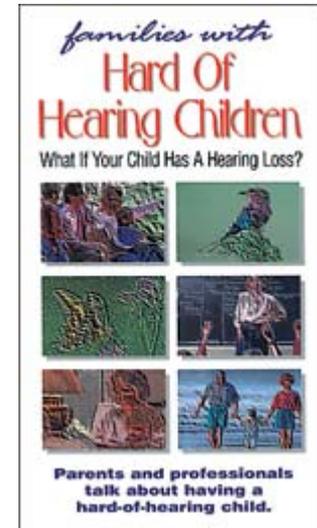


AAP Pedialink



Less Recommended Resources for Physicians

- CDs or DVDs to use in patient education
- Videotapes to use in parent education



...but some offices prefer this type of material

...reinforces need for multiple avenues



Big Picture: Physicians

- Positive changes seen...more education needed
- “One size” will not fit all
- “Just in time” resources; protocol steps
- Action-oriented
 - medical management
 - counseling families
- Clear, time efficient language
- Peer education and internet resources

Next Steps:

- Manuscript (in preparation)
- Working with National Organizations
 - Nurse practitioners & Pediatric nurses
 - Physician Assistants
 - Nurse Midwives
- Sound Health Connections Conference held in Oct, 2005
- Action plans developed & in progress

Acknowledgments

- Lenore Shisler, NCHAM
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- Diane Schmidt, BTNRH
- Roger Harpster, BTNRH
- Tom Behrens, NCHAM



Association of
**Maternal
& Child**
Health Programs

2006
AMCHP
Annual Conference

Questions?