

# **The National Early Hearing Detection and Intervention (EHDI) Landscape:**



May 8, 2013

**CT EHDI Roadmap Conference**

**GPS: Navigating the Deaf and Hard of Hearing Experience**

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**National Center for Hearing Assessment and Management**

**[www.infanthearing.org](http://www.infanthearing.org)**

# Disclosure Information

- I do not have a significant financial interest or other relationship with the manufacturers of products or providers of services that will be discussed in my presentation.
- This presentation will not include discussion of pharmaceuticals or devices that have not been approved by the FDA nor will I be discussing unapproved or “off-label” uses of pharmaceuticals or devices.

# Which of the following "birth defects" has the highest incidence?



- a. Down Syndrome
- b. Permanent hearing loss
- c. Spina bifida
- d. Cleft lip or palate
- e. Sickle cell anemia

## Frequency of Congenital Hearing Loss?

- 1 per 1,000
- 2 per 1,000
- 3 per 1,000
- 6 per 1000

1



# Rate Per 1,000 of Permanent Childhood Hearing Loss in EHDI Programs

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Site	Sample Size	Prevalence Per 1000
Texas (Finitzo et al 1998) (1/94 to 6/97)	54,228	2.15
Colorado (Mehl & Thomson, 1998) (1/92 - 12/96)	41,976	2.56
New Jersey (Barsky-Firsker & Sun) 1/93-12/95)	15,749	3.30
Hawaii (Johnson et al 1997) 1/96 - 12/96)	9,605	4.15
Massachussets (2004) (1/06 – 12/06)	78,515	2.87

# Population-based Ascertainment of Hearing Loss

	NHANES II		NHANES III	
	Point	Cumulative	Point	Cumulative
<b>Profound Bilateral</b> ( $PTA_4 > 75$ dB HL)	0.75	<b>0.75</b>	0.57	<b>0.57</b>
<b>Severe Bilateral</b> ( $45$ dB HL $< PTA_4 \leq 75$ dB HL)	0.51	<b>1.26</b>	0.28	<b>0.85</b>
<b>Moderate Bilateral</b> ( $30$ dB HL $< PTA_4 \leq 45$ dB HL)	2.37	<b>3.63</b>	1.66	<b>2.51</b>
<b>Mild Bilateral</b> ( $15$ dB HL $< PTA_4 \leq 30$ dB HL)	13.7	<b>17.33</b>	13.8	<b>16.31</b>
<b>Unilateral</b> (mild, moderate, severe)	49.0	<b>66.33</b>	57.0	<b>73.31</b>

National Health & Nutrition Examination (NHANES II: 1976–1980 NHANES III 1988–1994 )

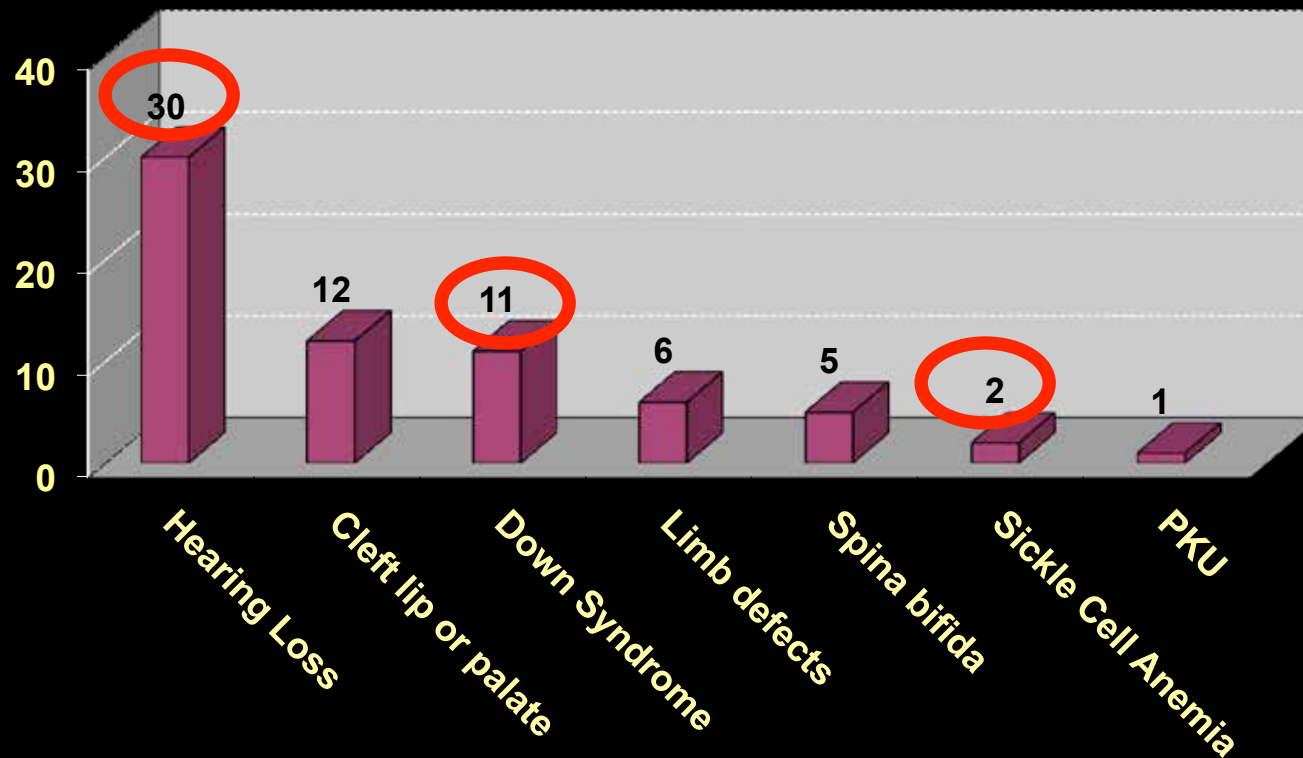
Target population is the civilian, non-institutionalized U.S. population.

Sample size for audiometry in children, 6 to 19 years old, was 7,119 in NHANES II and 6,166 in NHANES III.

$PTA_4$  is the pure-tone average of air-conduction thresholds at 0.5, 1, 2, & 4 kHz; Normal hearing —  $PTA_4 \leq 15$  dB HL, both ears

- ✓ Permanent hearing loss occurs more frequently than any other condition for which we can screen at birth

Incidence per 10,000 of Congenital Defects/Diseases



**Blindness separates people from things.  
Deafness separates people from people.**

--- Helen Keller







Thomas Edison  
Inventor



Jonathan Swift  
Author & Clergyman

What do these people have in common?



Ludwig Van Beethoven  
Composer




Vinton Cerf  
Father of the Internet



Marlee Matlin  
Academy Award Winning Actress

# What percentage of children who are DHH are born to hearing parents?

- 
- a. <25%
  - b. 50%
  - c. 70%
  - d. 85%
  - e. >90%



# Key Points

1. Most parents with a newly identified deaf child are completely surprised
2. Many of the professionals from whom parents seek help are not up-to-date
3. The most important thing to parents is to be able to COMMUNICATE with their child

Total  
Communication

Cued  
Speech

Sign  
Language

Listening  
& Spoken  
Language

Visual  
Language

Spoken  
Language








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



Audio and picture courtesy of Susan Nittrouer, Ohio State University





A young girl with blonde hair, wearing a pink shirt, is holding a microphone and looking towards the camera. In the background, another child is visible, and there are some items on a table, including a yellow hat and a book. The scene appears to be indoors, possibly in a classroom or a library.

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





# What enabled us to move from ....



There



to

Here?



Earlier Identification of  
Hearing Loss

Availability of Better  
Hearing Technology

High quality, comprehensive  
Early Intervention programs  
that focus on teaching  
LANGUAGE

# From 1988-1993, the Rhode Island Hearing Assessment Project conducted a large-scale clinical trial of universal newborn hearing screening

SEMINARS IN HEARING—VOLUME 14, NUMBER 1 February 1993

## UNIVERSAL NEWBORN HEARING SCREENING USING TRANSIENT EVOKED OTOACOUSTIC EMISSIONS: RESULTS OF THE RHODE ISLAND HEARING ASSESSMENT PROJECT

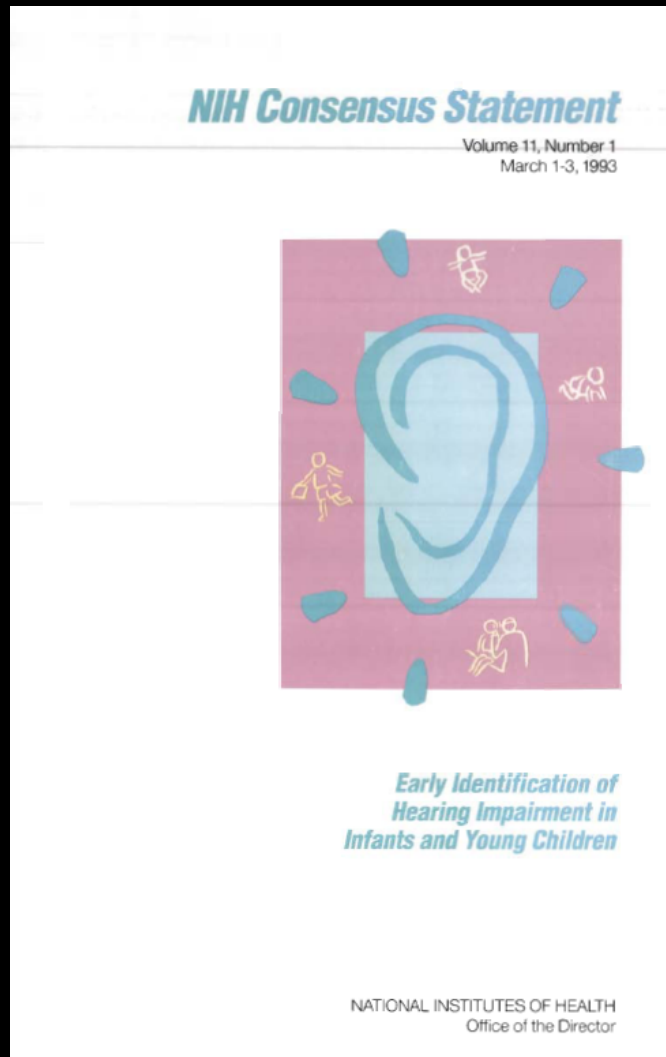
*Karl R. White, Ph.D., Betty R. Vohr, M.D., and Thomas R. Behrens, Ph.D.*

The earlier that hearing loss can be identified and intervention begun, the better the prognosis for the child in areas ranging from language development to academic success, social interactions, and successful participation in society.<sup>1</sup> Indeed, early identification of significant hearing loss is so important that the U.S. Department of Health and Human Services (HHS) recently set a goal to reduce to 12 months the average age at which significant hearing loss is identified.<sup>2</sup>

In spite of the acknowledged importance of identifying hearing loss as soon after birth as possible, the average age of identification in the United States is 24 to 30 months

of using auditory brainstem response (ABR) to identify hearing loss among infants and toddlers.<sup>4,5</sup> Such research certainly contributed substantially to the American Speech-Hearing Language Association's (ASHA) recommendation of ABR as the preferred method for screening the hearing of newborns.<sup>6</sup> However, the expense of doing ABR testing of newborns was very likely what led to ASHA's recommendation that it be done only with infants who exhibit one of the ten risk factors identified by the Joint Committee on Infant Hearing.<sup>7</sup> Unfortunately, recent research has demonstrated that as many as half of all children with bilateral severe-to-

# In March, 1993 an NIH Consensus Panel concluded that:



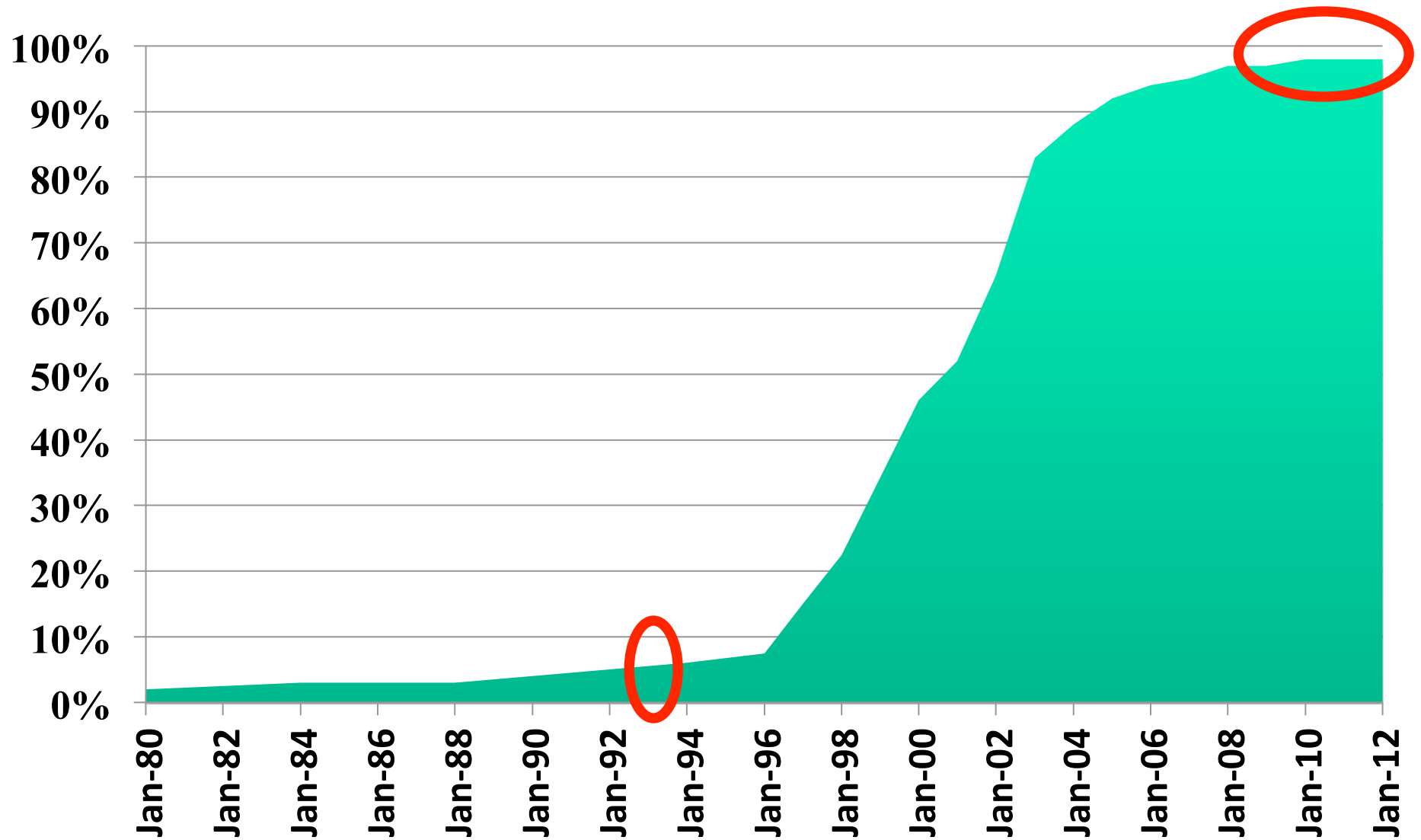
- The average age of diagnosis of hearing loss remains constant at about 2 ½ years of age.
- All infants should be screened for hearing loss...this will be accomplished most efficiently by screening prior to discharge from the well-baby nursery.
- Identification of hearing loss must be seen as imperative for all infants

# What percentage of newborns in the United States are screened for hearing loss?

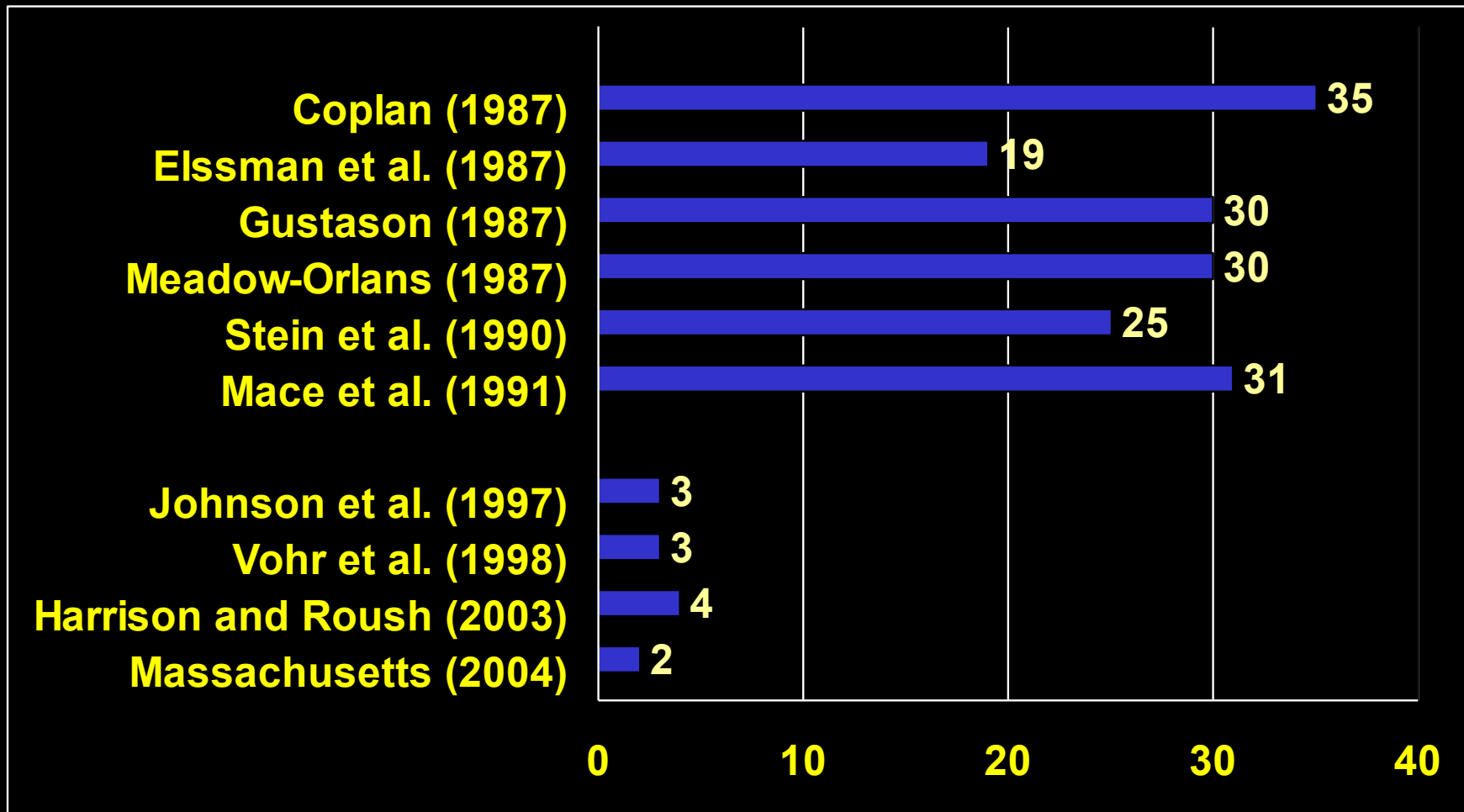


- a. 50%
- b. 70%
- c. 80%
- d. 90%
- e. 98%

# Percentage of Newborns Screened for Hearing in the United States



## Age in Months at Which Permanent Hearing Loss Was Diagnosed



White KR, Forsman I, Eichwald J, Munoz K (2010). The evolution of early hearing detection and intervention programs in the United States. *Semin Perinatol.* 34(2):170-9.



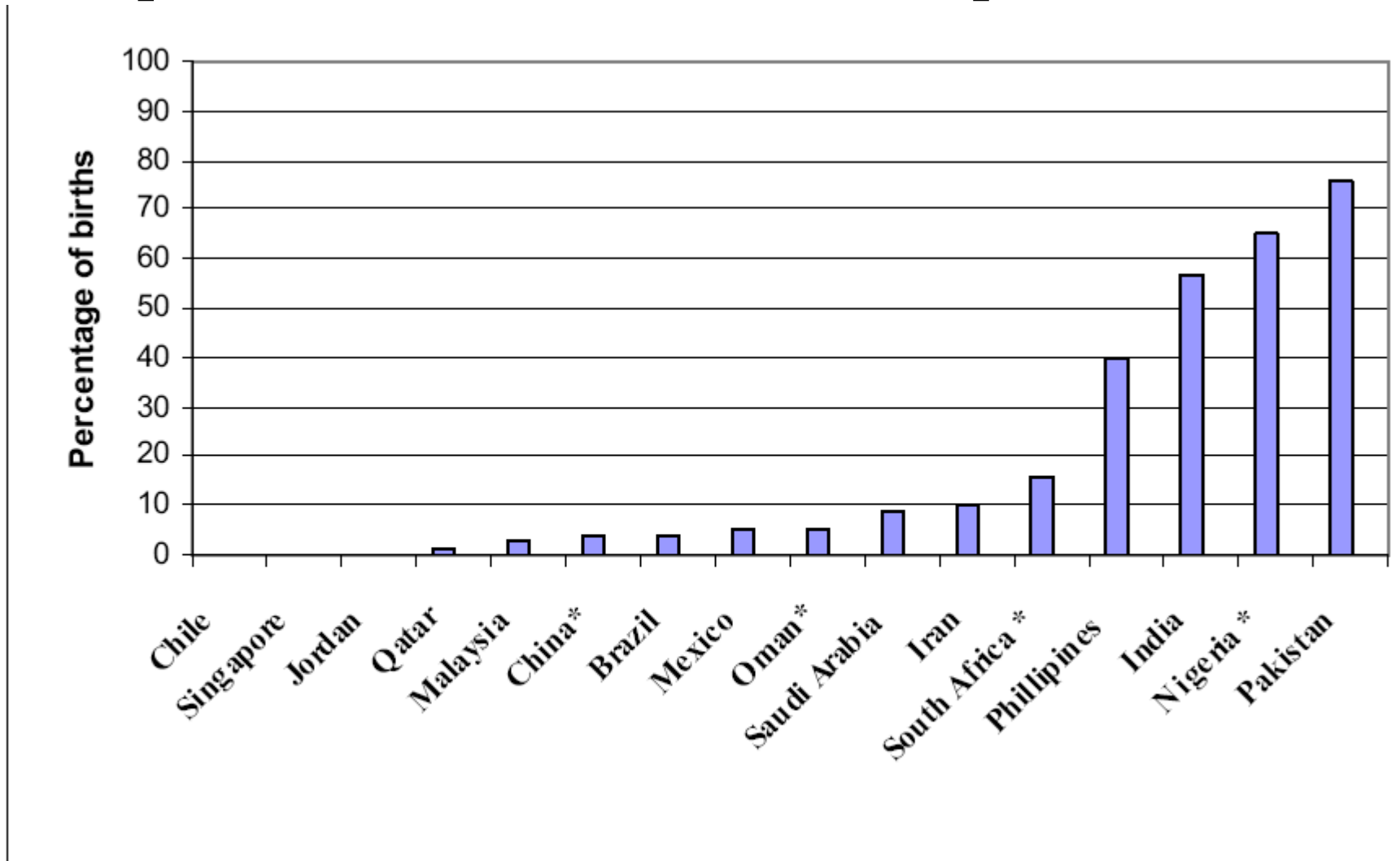
# Newborn Hearing Screening Around the World



# Newborn Hearing Screening Around the World

<b>Screening &gt; 90%</b>  <b>(n=9)</b>	<b>Screening 30-80%</b>  <b>(n=8)</b>	<b>Published Reports of Pilot programs</b>  <b>(n=41)</b>		
<b>Austria</b> <b>Croatia</b> <b>Luxembourg</b> <b>Germany</b> <b>Poland</b> <b>Netherlands</b> <b>Singapore</b> <b>United Kingdom</b> <b>USA</b>	<b>Australia</b> <b>Belgium</b> <b>Canada</b> <b>Chile</b> <b>Denmark</b> <b>Oman</b> <b>Russia</b> <b>Taiwan</b>	<b>Argentina</b> <b>Brazil</b> <b>China</b> <b>Columbia</b> <b>Costa Rica</b> <b>Czech Republic</b> <b>Finland</b> <b>France</b> <b>Greece</b> <b>Hong Kong</b> <b>Hungary</b> <b>India</b> <b>Iran</b> <b>Israel</b>	<b>Italy</b> <b>Japan</b> <b>Jordan</b> <b>Lithuania</b> <b>Luxembourg</b> <b>Malaysia</b> <b>Malta</b> <b>Mexico</b> <b>New Zealand</b> <b>Nigeria</b> <b>Norway</b> <b>Oman</b> <b>Pakistan</b> <b>Philippines</b>	<b>Portugal</b> <b>Qatar</b> <b>Romania</b> <b>Saudi Arabia</b> <b>Serbia</b> <b>Slovak Republic</b> <b>Slovenia</b> <b>South Africa</b> <b>South Korea</b> <b>Spain</b> <b>Sweden</b> <b>Switzerland</b> <b>Turkey</b>

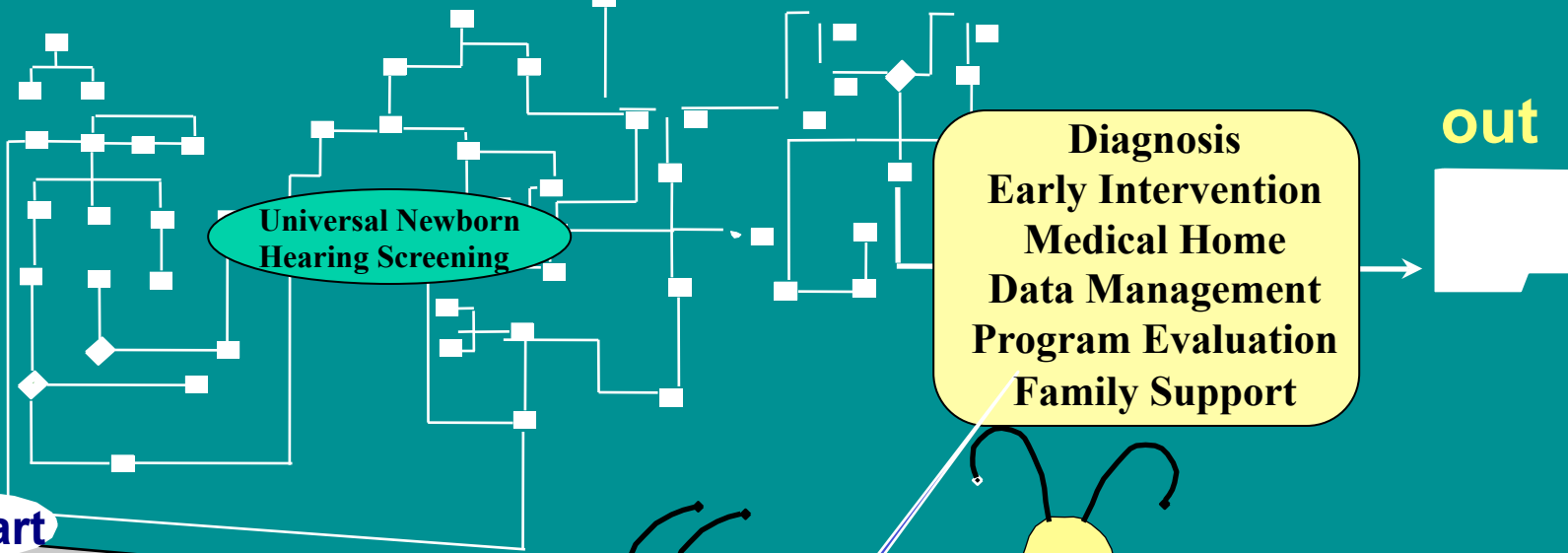
# Proportion of Births Outside of Hospital Facilities



Data Source: UNICEF 2005 [50]

See also WHO, World Health Statistics 2009, available at:  
<http://www.who.int/whosis/whostat/2009/en/index.html>.

# Implementing Effective Newborn Hearing Screening Programs



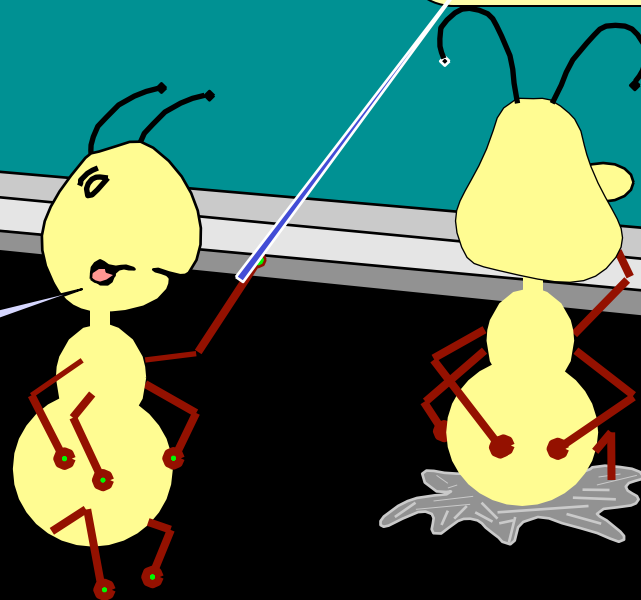
Start

Universal Newborn Hearing Screening

Diagnosis  
Early Intervention  
Medical Home  
Data Management  
Program Evaluation  
Family Support

out

Good work, but I think we might need a little more detail right here



# 2

## Rate Per 1,000 of Permanent Childhood Hearing Loss in EHDI Programs

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Site	Sample Size	Prevalence Per 1000
Texas (Finitzo et al 1998) (1/94 to 6/97)	54,228	2.15
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Massachussets (2004) (1/04 – 12/04)	78,515	2.87

## Rate Per 1,000 of Permanent Childhood Hearing Loss in EHDI Programs

Site	Sample Size	Prevalence Per 1000	% of Refers with Diagnosis
Texas (Finitzo et al 1998) (1/94 to 6/97)	54,228	2.15	31%
Colorado (Mehl & Thomson, 1998) (1/92 - 12/96)	41,976	2.56	48%
New Jersey (Barsky-Firsker & Sun) 1/93-12/95)	15,749	3.30	41%
Hawaii (Johnson et al 1997) 1/96 - 12/96)	9,605	4.15	98%
Massachussets (2004) (1/04 – 12/04)	78,515	2.87	89%

**I always wondered why somebody  
didn't do something about that.**

**Then I realized I was somebody.**

--Lily Tomlin



# What Contributes to “Loss to Follow-up”?

- **Referral rates in the hospital are too high** (because of poorly trained screeners, poorly maintained equipment, lack of commitment, etc)
- **Ineffective information for parents** (about initial results, need for follow-up, what to do next, etc)
- **Accurate data isn’t shared quickly with the right stakeholders** (hospitals, state EHDI program, medical home, audiologists, early interventionists, etc)
- **Shortage of pediatric audiologists** (because of not enough training programs, poor reimbursement rates, rural/remote residences, etc)
- **Lack of knowledge about current “effective practices”** (among program managers, health care providers, early interventionists, etc).
- **Not enough public awareness about importance of issue** (taxpayers, administrators, extended family, etc)
- **Lack of resources** (for screening, follow-up diagnosis, early intervention, case management, etc)



# 3

## The Hearing Head Start Project

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- Feasibility study from 2001-2004
- 69 programs in 3 states with 3,000+ children screened
- Identified 2 per 1,000 with permanent hearing loss and 20 per 1,000 with unidentified transient losses
- Currently in 42 of 50 states—expanding to others by 2015



Eiserman WD, Hartel DM, Shisler L, Buhrmann J, White KR, and Foust T. (2008). Using otoacoustic emissions to screen for hearing loss in early childhood care settings. *International Journal of Pediatric Otorhinolaryngology*, 72, 475-482.



# How Many Additional Babies with Permanent Hearing Loss were Identified?

	Comparison Group (Fail OAE/ Fail AABR)	Study Group (Fail OAE/ Pass AABR)	Total
Number of Babies	<b>158</b>	<b>21</b>	<b>179</b>
Prevalence per 1,000	<b>1.82</b>	<b>.55*</b>	<b>2.37</b>

\*Adjusted for proportion of OAE fails that enrolled

**Represents 23%  
of all babies with  
PHL in birth  
cohort**

Johnson J, White KR, Widen JE, Gravel JS, James-Trychel M, Kennalley T, Maxon AB, Spivak L, Sullivan-Mahoney M, Vohr BR, Weirather Y, & Holstrum J (2005). A multi-center evaluation of how many infants with permanent hearing loss pass a two-stage OAE/A-ABR newborn hearing screening protocol. *Pediatrics*, 116(3), 663-672.

**To which of the following specialists should a newborn with permanent hearing loss be referred?**

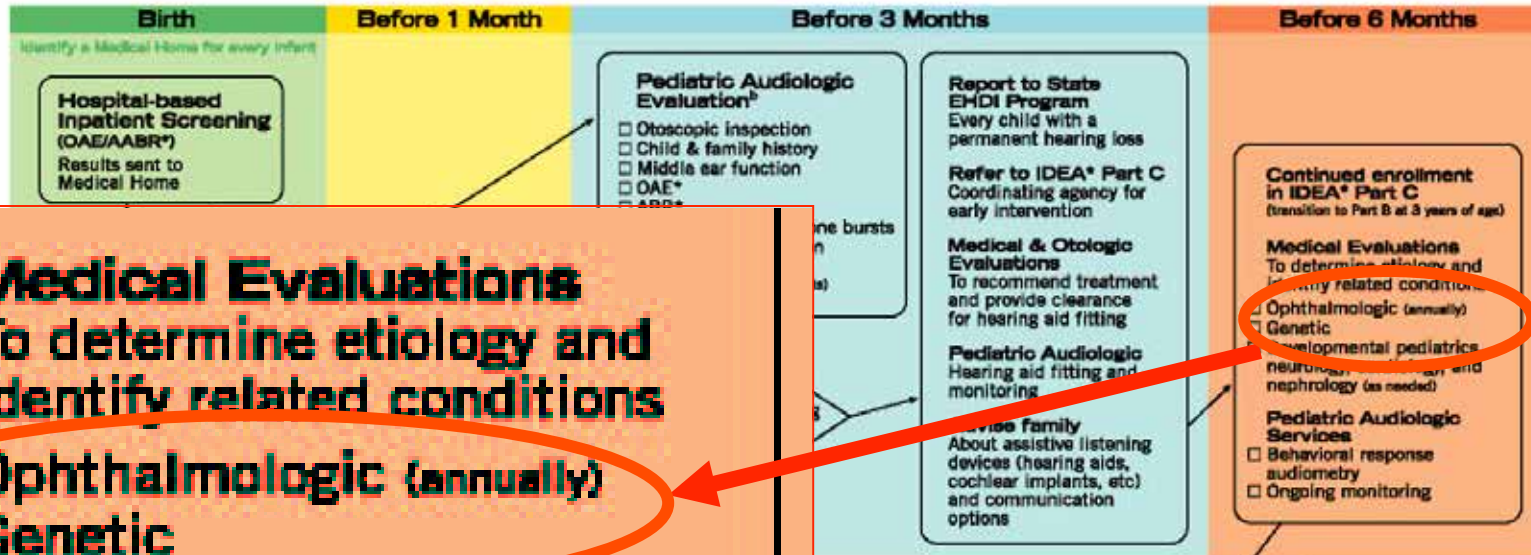


- a. Ophthalmologist
- b. Otolaryngologist
- c. Geneticist
- d. All of the above

# 5

## American Academy of Pediatrics

### Universal Newborn Hearing Screening, Diagnosis, and Intervention Guidelines for Pediatric Medical Home Providers



**Medical Evaluations**  
To determine etiology and identify related conditions

- Ophthalmologic (annually)
- Genetic
- Developmental pediatrics, neurology, cardiology, and nephrology (as needed)

**Pediatric Audiologic Services**

- Behavioral response audiometry
- Ongoing monitoring

\*OAE – Otoacoustic Emissions, AABR – Automated Auditory Brainstem Response, ABR – Auditory Brainstem Response, IDEA – Individuals with Disabilities Education Act

**Notes:**

(a) In screening programs that do not provide Outpatient Screening, infants will be referred directly from inpatient Screening to Pediatric Audiologic Evaluation. Likewise, infants at higher risk for hearing loss, or loss to follow-up, also may be referred directly to Pediatric Audiologic Evaluation.

(b) Part C of IDEA\* may provide diagnostic audiologic evaluation services as part of Child Find activities.

(c) Infants who fail the screening in one or both ears should be referred for further screening or Pediatric Audiologic Evaluation.

(d) Includes infants whose parents refused initial or follow-up hearing screening.

# Educating Primary Health Care Providers About Early Identification of Hearing Loss

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Assume a newborn for whom you are caring is diagnosed with a moderate to profound bilateral hearing loss. If no other indications are present, to which specialists would you refer the baby?:

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	Always or Often
Ophthalmological evaluation	0.6%
Genetic evaluation	8.9%
Otolaryngological evaluation	75.6%

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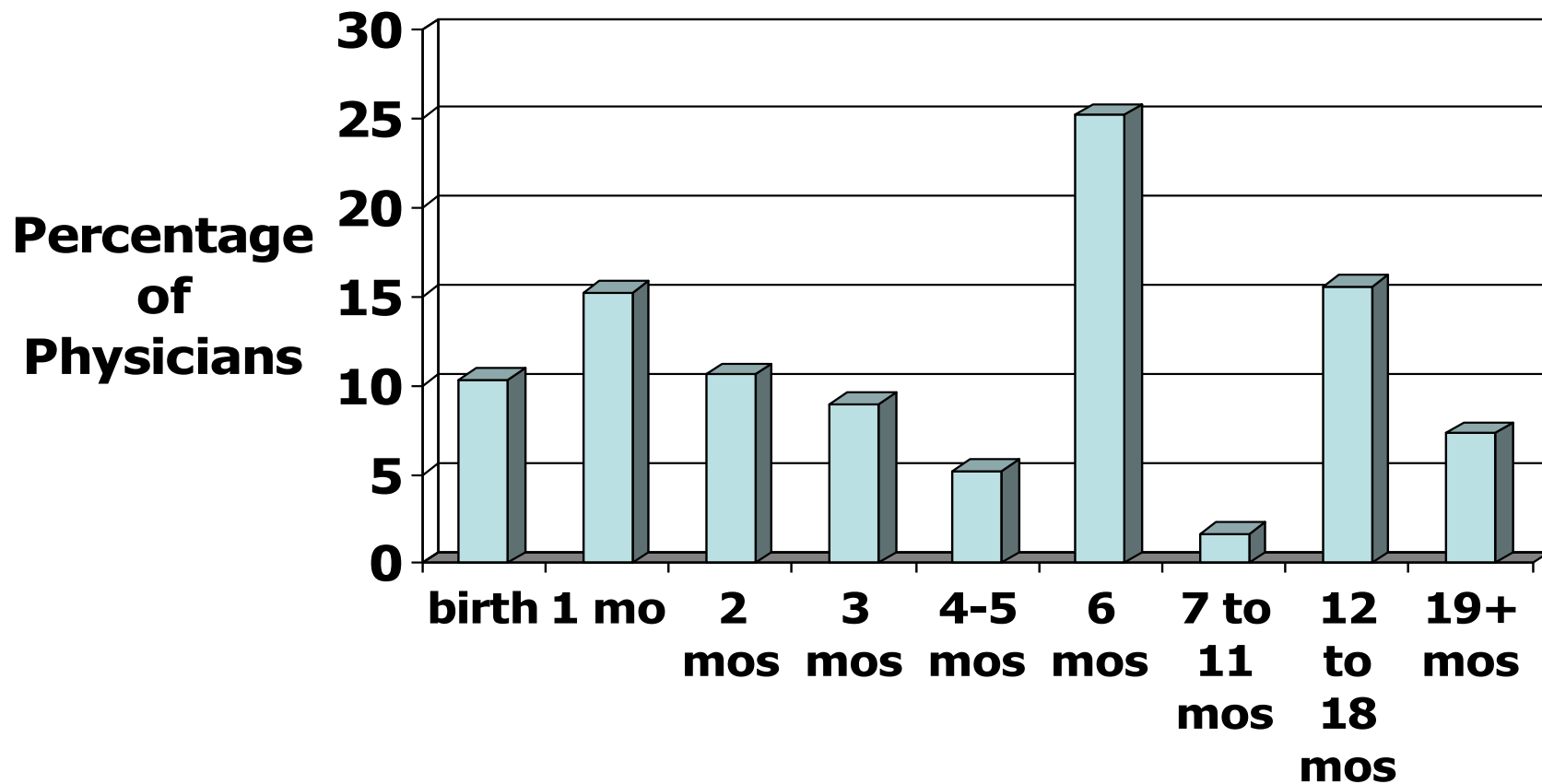
Responses of 1975 physicians in 21 states

# How old must a baby be to be appropriately fit with a hearing aid?

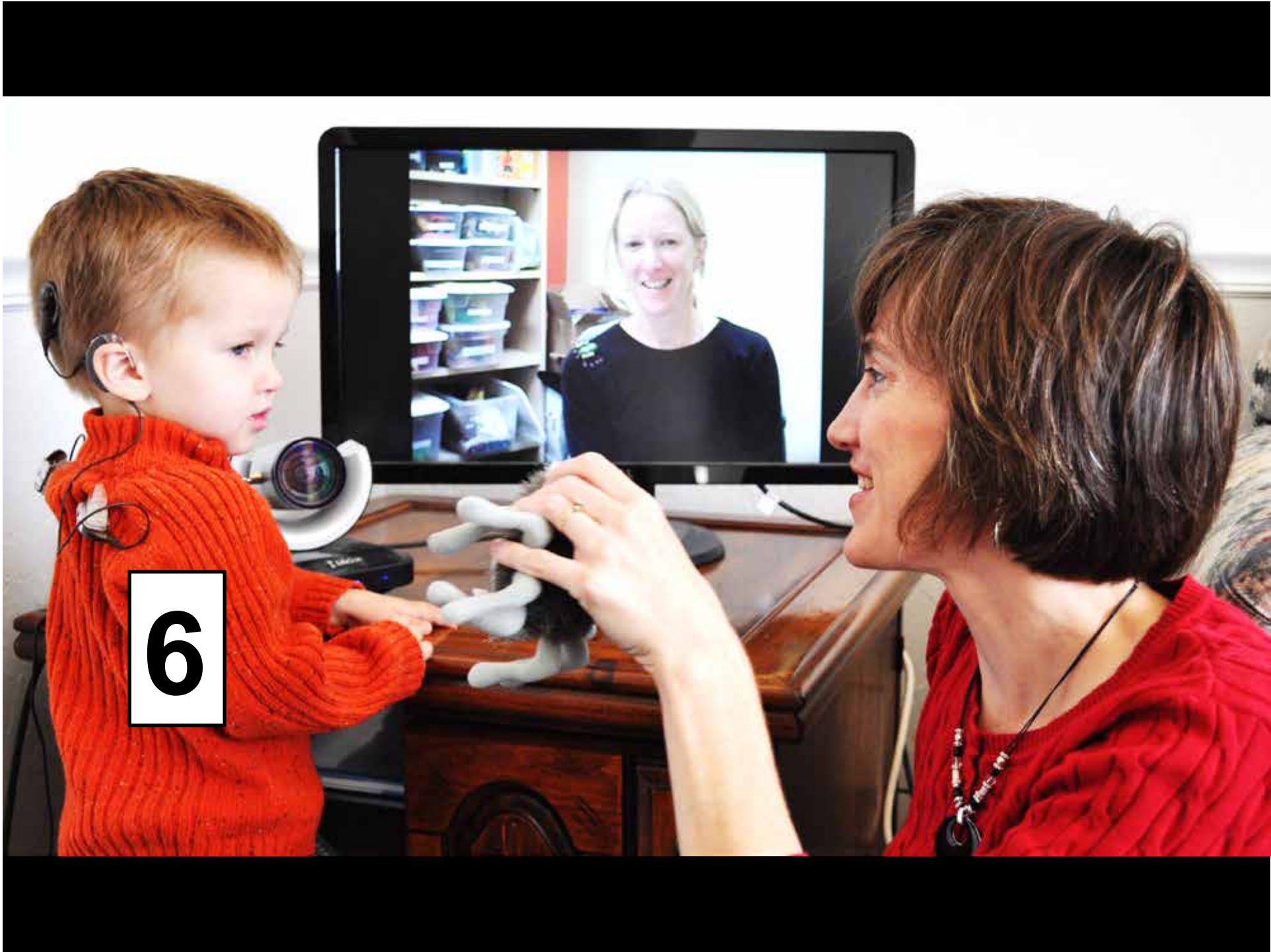


- a. 1 month
- b. 3 months
- c. 6 months
- d. 12 months

# When can an infant be fit with hearing aids?







6



7

lorrylorry

# Protests at 2012 National EHDI Meeting

It is time to raise our fists and demand solidarity!

Don't get mad! Get EVEN! Show them!  
STAND UP for your rights!

The same goes for all oral programs around the country. It is an act of terrorism. We are experiencing domestic terrorism from those audists.



# Take Home Messages



**Ah, but a man's reach should exceed his grasp. Or what's a heaven for?**

---- Robert Browning

- 1. Reducing Loss to Follow-up**
- 2. Hearing screening in early childhood programs**
- 3. More efficient screening**
- 4. More and better trained providers**
- 5. Better access to services**
- 6. Respectful collaboration**



*I am only one, but still I am one. I cannot do everything, but still I can do something; and because I cannot do everything, I will not refuse to do something that I can do ....The world is moved along, not only by the mighty shoves of its heroes, but also by the aggregate of tiny pushes of each honest worker.*

*-----Helen Keller*





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Home

Components

Resources

States

Legislation

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## News and Events

We have a new look! All of our information and resources are still available.



RSS



Events



Links



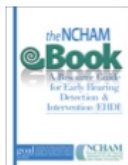
Meetings



Workshops

## EHDI E-Book

The EHDI E-Book is Now Available to Download.



## NHSTC DVD

Our Newborn Hearing Screening training curriculum DVD is now available.



((NCHAM serves as the **National Resource Center** for the implementation and improvement of comprehensive and effective Early Hearing Detection and Intervention (EHDI) systems. As a multidisciplinary Center, our goal is to ensure that all infants and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention.

## EHDI Components

- Newborn Hearing Screening
- Early Childhood Hearing Screening
- Diagnostic Audiology
- Early Intervention
- Family Support
- Medical Home
- Data Management
- Financing & Reimbursements
- Program Evaluation



## State EHDI Information

- Status of the United States
- State Profiles
- Web Sites & Guidelines
- EHDI Contacts
- 2004 State EHDI Survey
- State Coordinator Toolbox



## EHDI/UNHS Resources

- UNHS Implementation Guide
- Addressing Privacy Regulations
- Position Statements
- EHDI/UNHS FAQ
- Slideshow Presentations
- Educational and Training Videos
- Fact Sheet [PDF]
- NCHAM Materials
- EHDI Implementation in Latin America
- EHDI E-Book
- More EHDI/ UNHS Resources...



## EHDI Legislation

- State Legislation
- Rules & Regulations
- Legislative Summaries
  - By State: Table | Text
  - By Provisions

