

**Universal Newborn Hearing Screening:
Where We Have Come From and What We Have Learned**



Presented at the
Intermountain Special Study Institute

Idaho State University --- Pocatello, Idaho

by
Karl R. White

National Center for Hearing Assessment and Management
www.infanthearing.org

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Universal Newborn Hearing Screening is not a new idea ... in 1944 Ewing and Ewing wrote:

“[There is] an urgent need to study further and more critically methods of testing hearing in young children . . . during this first year the existence of deafness needs to be ascertained . . . training needs to be begun at the earliest age that the diagnosis of deafness can be established.”

Ewing IR, Ewing AWG. 1944. The ascertainment of deafness in infancy and early childhood. *The Journal of Laryngology and Otology* 59:309-333.

1973 compared to 2005

- What Remains the Same?
 - Babies may not talk much for a year, but they are learning
 - For babies to have a good start on learning language, they must be found at birth
 - Whatever the cause of hearing loss, each day counts
 - Expense of doing it keeps us from finding babies early
 - Technological advances accelerated the progress
 - Individual initiative and creativity is the key
- What Has Changed?
 - Keenan's hearing loss was discovered early --- 18 months
 - For the most part, it is up to the mother
 - Very few babies are identified at birth
 - No laws requiring states to screen babies
 - Technology for screening, diagnosis and amplification



Our first little girl, she was adopted and when we adopted her we were so thrilled to bring her home ...

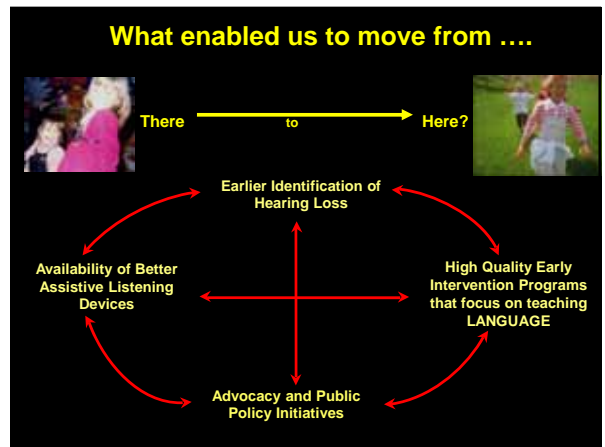
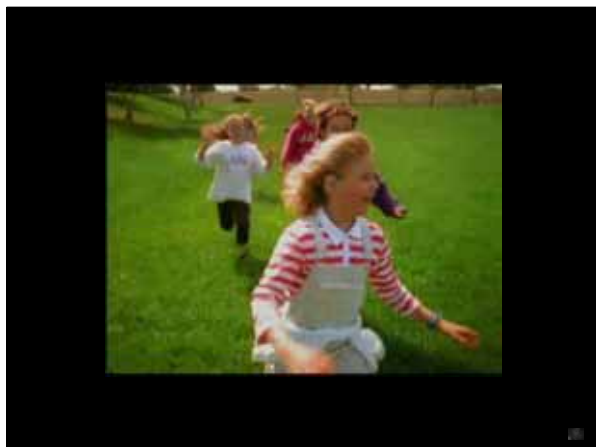




Spring is my favorite season. The sun shines bright. The flowers begin to grow. I like spring.



It is cold today. Where are your blue shoes? You need them to go outside. It might snow.



Unfortunately, this is not the outcome for with many deaf children born today



Why is Early Identification of Hearing Loss so Important?

- Hearing loss occurs more frequently than any other condition for which population-based screening is done

Frequency of Congenital Hearing Loss?

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

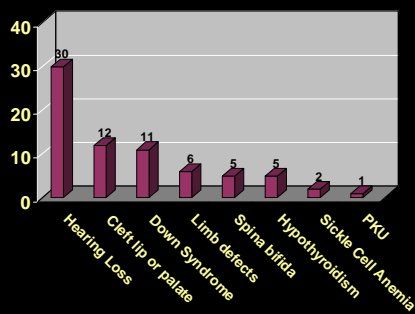


Rate Per 1000 of Permanent Childhood Hearing Loss in EHDI Programs

Site	Sample Size	Prevalence Per 1000
Rhode Island (3/93 - 6/94)	16,395	1.71
Colorado (1/92 - 12/96)	41,976	2.56
New York (1/96 - 12/96)	27,938	1.65
Utah (7/93 - 12/94)	4,012	2.99
Hawaii (1/96 - 12/96)	9,605	4.15
Massachusetts (1/04 - 12/04)	78,515	2.87

Adapted from White KR (2003). The current status of EHDI programs in the United States. *Mental Retardation and Developmental Disabilities Research Reviews*, 9(2), 79-88.

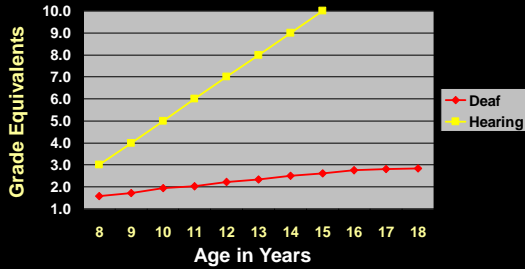
Incidence per 10,000 of Congenital Conditions



Why is Early Identification of Hearing Loss so Important?

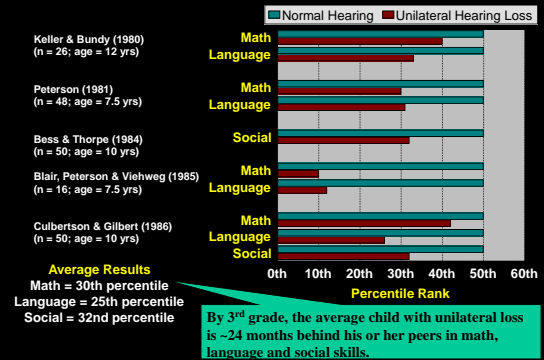
- Hearing occurs more frequently than any other birth defect.
- Undetected hearing loss has serious negative consequences.

Reading Comprehension Scores of Hearing and Deaf Students



Schildroth, A. N., & Karchmer, M. A. (1986). *Deaf children in America*. San Diego: College Hill Press.

Effects of Unilateral Hearing Loss

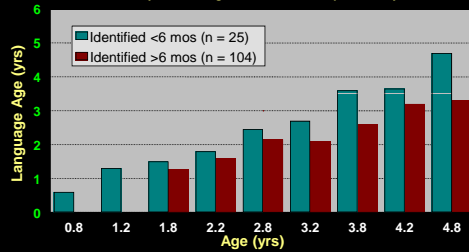


Why is Early Identification of Hearing Loss so Important?

- 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.

Boys Town National Research Hospital Study of Earlier vs. Later

129 deaf and hard-of-hearing children assessed 2x each year. Assessments done by trained diagnostician as normal part of early intervention program.

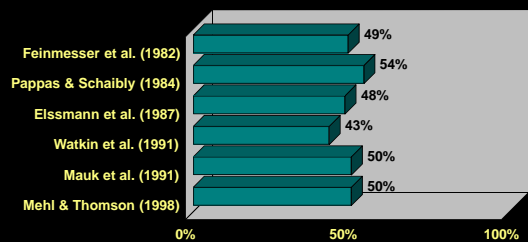


Moeller, M.P. (1997). *Personal communication*. moeller@boystown.org

Newborn Hearing Screening Prior to 1990

- **Conventional Auditory Brainstem Response**
 - Accurate, but too expensive
- **High Risk indicators**
 - Only about 50% of children with congenital hearing loss exhibit one or more of these high risk indicators

What Percentage of Hearing Impaired Children were High Risk as Infants?



Accuracy of High Risk Based UNHS Programs Mahoney and Eichwald (1987)

Program operational from 1978-1995.

JCIH indicators incorporated into legally required birth certificate.

Computerized mailing and follow-up, and free diagnostic assessments at regional offices and/or mobile van.

Program now discontinued because:

parents only made appointments for about 1/2 the children who had a risk indicator.

only about 1/2 of the children with an appointment showed up.

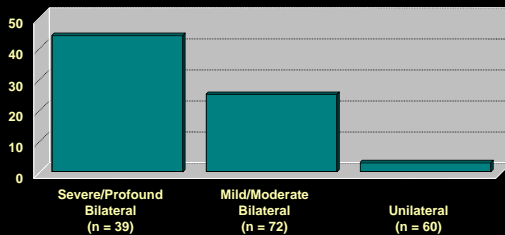
difficulty obtaining accurate information from hospitals for some risk indicators.

Mahoney, T.M., & Eichwald, J.G. (1987). The ups and "downs" of high-risk hearing screening: The Utah statewide program. *Seminars in Hearing*, 8(2), 155-163.

Newborn Hearing Screening Prior to 1990

- **Auditory Brainstem Response**
 - Accurate, but too expensive
- **High Risk indicators**
 - Only about 50% of children with congenital hearing loss exhibit high risk indicators
 - Only about 1/2 of those with high risk indicators make an appointment for further testing and only about 1/2 of those are ever tested
- **Behaviorally-based hearing screening**
 - Expensive
 - Inaccurate

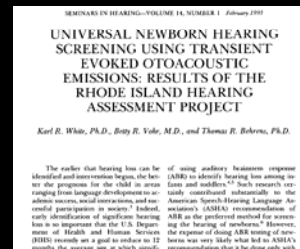
Percentage of Children with Permanent Hearing Loss Identified by the Infant Distraction Test Performed at 8 Months of Age



Watkin, P. M., Baldwin, M., & Loefer, S. (1990). Parental suspicion and identification of hearing impairment. *Archives of Disease in Childhood*, 65, 848-850.

From 1988-1993, the first large-scale clinical trial of universal newborn hearing screening was conducted

-- the Rhode Island Hearing Assessment Project ---

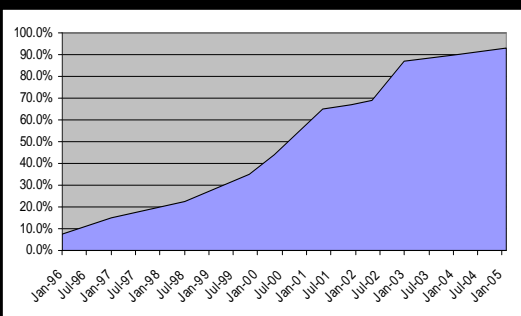


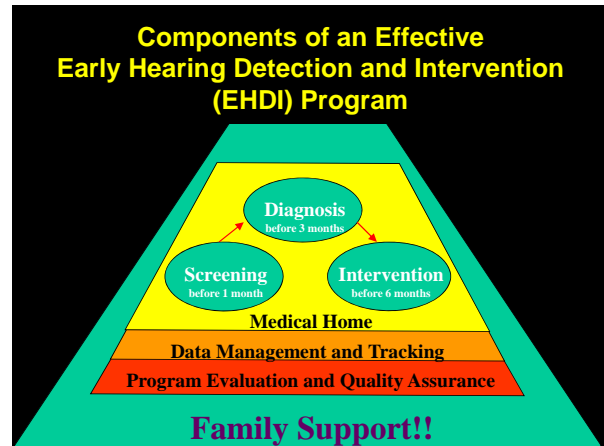
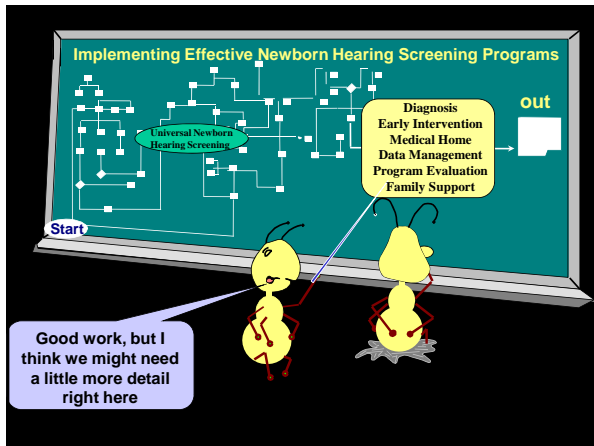
In March, 1993 an NIH Consensus Panel concluded that:



- The average age of diagnosis of hearing loss remains constant at about 2 1/2 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

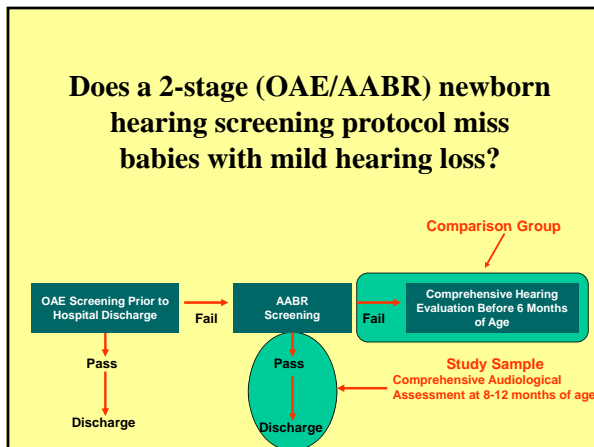
Percentage of Newborns Screened for Hearing in the United States





Status of EHDI Programs in the US: Universal Newborn Hearing Screening

- With ~95% of infants screened, newborn hearing screening has become the “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



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	158	21	179
Prevalence per 1,000	1.82	.55*	2.37

*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, Witzrather Y, & Holstrom J (2005). A multi-center evaluation of how many infants with permanent hearing loss pass a two-stage OAE/AABR newborn hearing screening protocol. *Pediatrics*, 116(3), 663-672.

The Hearing Head Start Project

- 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
- Programs now being replicated in 12 additional states



Eiserman WD, Shisler L, Foust T, Buhman J, Winston RL, White KR (2007). Screening for hearing loss in early childhood programs. *Early Childhood Research Quarterly*, 22, 105-117.

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

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Colorado (1/92 - 12/96)	41,976	2.56	48%
New York (1/96 - 12/96)	27,938	1.65	67%
Utah (7/93 - 12/94)	4,012	2.99	73%
Hawaii (1/96 - 12/96)	9,605	4.15	98%
Massachusetts (1/04 - 12/04)	78,515	2.87	89%

Tracking and Data Management



- 89% of states have created a statewide tracking system
 - information submitted for 80% of the births in 2003
 - 72% have individual identifying data --- up from 32% in 2001
- 57% track babies until at least 3 years of age
- Linkages with other Public Health Information systems are expanding (eg, Vital Statistics, heelstick, EI, Immunizations)

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)

0-3 year old children with Permanent Hearing Loss (PHL) Identified by Part C Program and State EHDI Program (January 1, 2003 through December 31, 2004)

		Part C Program		N=135
		Identified	Not Identified	
EHDI Program	Identified	81	54	
	Not Identified	62*	??	
				N=143

* 29 of these children are not in the EHDI data base — probably because they are out-of-state births or were among the 1.7% who were “missed” for screening in the hospital

Summary Report

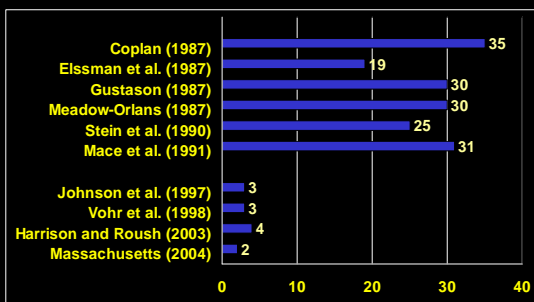
Comparison of results between Study and Non-Study hospitals
Timeframe: 1/03-4/03

Births	NON-STUDY	STUDY
	11,751	4,540
INPATIENT RESULTS		
Screened	98.7%	99.0%
Passed	92.3%	92.9%
Referred	7.7%	7.1%
Not Screened	1.1%	0.6%
Deceased	0.2%	0.4%
OUTPATIENT RESULTS		
Total	1,026	345
Passed	59.0%	84.6%
Not Screened	32.9%	11.0%
Referred	8.1%	4.3%
STATUS Dx EVALUATION		
Total	134	23
Normal Hearing	21.6%	39.1%
Lost/Refused	1.5%	8.7%
In Process	67.9%	26.1%
Confirmed Loss	9.0%	26.1%

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

Age in Months at Which Permanent Hearing Loss Was Diagnosed

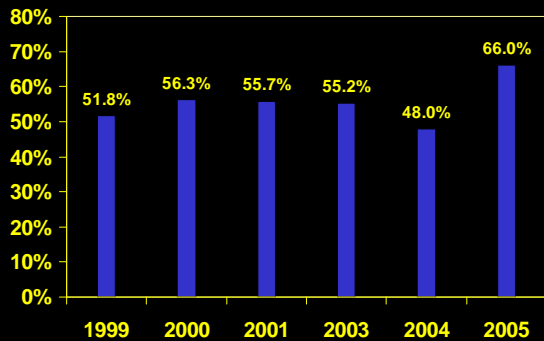


Status of EHDI Programs in the US: Audiological Diagnosis



- 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 66% *receive diagnostic evaluations before 3 months of age

Percent of "Failed" Screens Diagnosed Before 3 Months of Age



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

Status of EHDI Programs in the US: Early Intervention



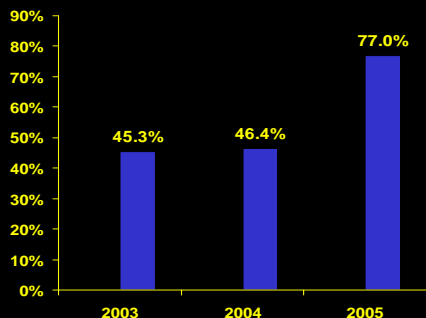
- Current EI system designed at a time when:
 - Most children were not identified until 2 1/2 years of age
 - Assistive Listening devices were not as advanced
 - Almost all university training programs for teachers of the deaf focused primarily on sign language.
- In 2004 State EHDI Coordinators estimated that
 - only ~ 50% of infants with hearing loss were enrolled in EI programs before 6 months of age
 - Only 31% of states had adequate range of choices for EI programs

We are certain that you are aware of the **growing national crisis** in the provision of essential early intervention and health care services for infants and toddlers with hearing loss... Studies have demonstrated that when hearing loss of any degree, including mild bilateral or unilateral hearing, is not adequately diagnosed and addressed, the hearing loss can adversely affect the speech, language, academic, emotional, and psychosocial development of young children.

Although efforts to identify and evaluate hearing loss in young children have improved... **many young children with hearing loss may not be receiving the early intervention or other services** they need in a timely manner that will enable them to enter preschool and school ready to succeed.

Letter sent by Departments of Education and Health and Human Services, July 2006

Percent of Children Diagnosed with Hearing Loss Enrolled in Early Intervention Before 6 Months of Age



Many Early Intervention Programs for Children with Hearing Loss are "Out-of-Sync"

- Most programs for young deaf children were developed 30+ years ago when:
 - The majority of deaf children were identified at 2-3 years of age
 - Sign language was the communication option chosen by most parents
- 95% of all newborns with hearing loss have parents with normal hearing.
- In one research study when parents were given a choice
 - In 1995:** 60% chose sign-language options; 40% chose spoken-language options
 - In 2005:** 15% chose sign-language options; 85% chose spoken-language options

Early Intervention: Finishing the EHDI Revolution



Deafness in infants is a serious concern because it interferes with the development of language -- that which sets humans apart from all other living things . . . early intervention with hearing impaired children results in improved language development, increased academic success, and increased lifetime earnings . . . [and] actually saves money since hearing impaired children who receive early help require less costly special education services later . . . I am optimistic. I foresee a time in this country . . . when no child reaches his or her first birthday with an undetected hearing impairment.

C. Everett Koop, US Surgeon General, 198

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

It is therefore the policy of the United States to provide financial assistance to States –

- 1) to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system that provides early intervention services for infants and toddlers with disabilities and their families

Public Law 105-17, further amended by Public Law 108-446 in 2004

Section 631 of PL 108-457 states the purpose of Part C is to:

- Enhance the development of infants and toddlers with disabilities to minimize the potential for developmental delay.
- Reduce the education costs to society by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age.
- Minimize the likelihood of institutionalization and maximize the potential for independent living in society.
- Enhance the capacity of families to meet the needs of their children.
- Enhance the capacity of states and local programs to meet the needs of underrepresented populations, particularly minority, low income, inner city, and rural populations.

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

In order to be eligible for a grant...a state shall demonstrate...

- 1) It has adopted a policy that appropriate early intervention services are available to all infants and toddlers with disabilities in the State and their families

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

Eligibility

(34 CFR Part 303.16)

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 Services?

- **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.

www.infanthearing.org/earlyintervention/eligibility.pdf

Part C Early Intervention Eligibility for Infants and Toddlers with Hearing Loss
READY TO USE FOR REFERRALS

Part C State Coordinator (state name, title, address, phone, fax, email, website)	Do children with congenital or acquired hearing loss who meet the criteria for Part C (Federal criteria)?	Are children with hearing loss eligible for Part C services?	Do children with hearing loss meet the criteria for Part C (Federal criteria)?	Do children with hearing loss meet the criteria for Part C (Federal criteria)?	Do children with hearing loss meet the criteria for Part C (Federal criteria)?
Alabama Elizabeth Wilson, Part C Coordinator Early Intervention Program 2228 East South Boulevard PO Box 12126 Montgomery, AL 36112-0126 (205) 251-1247 Fax: (205) 251-1184 Email: ewilson@hhs.al.gov http://www.al.gov/earlyintervention	Yes	Children eligible for intervention: children with hearing loss who meet the criteria for Part C (Federal criteria)	Yes	Children with hearing loss meet the criteria for Part C (Federal criteria)	State Plan: No
Arkansas New ARS, Part C Coordinator Medical and Child Health State Department of Health and Social Services 601 S. Main, Room 212, Little Rock, AR 72202 Montgomery, AR 72119-0001 (501) 281-1419 Fax: (501) 281-3443 Email: new_ars@hhs.ar.gov http://www.ar.gov/earlyintervention	Yes	Children eligible for intervention: children with hearing loss who meet the criteria for Part C (Federal criteria)	Yes	Children with hearing loss meet the criteria for Part C (Federal criteria)	State Plan: No

Comprehensive Child Find System 34 CFR Part 303.321

(b) Procedures. The child find system must include the policies and procedures that the state will follow to ensure that:

- 1) All infants and toddlers in the state who are eligible for services under this part are identified, located, and evaluated.... The procedures required in paragraph (b) (1) of this section must:
 - (i) Provide for an effective method of making referrals by primary referral sources.
 - (ii) Ensure that referrals are made **no more than 2 working days** after a child has been identified.
 - (iii) Include procedures for determining the extent to which primary referral sources, especially hospitals and physicians, disseminate the information....prepared by the lead agency on the availability of early intervention services to parents of infants and toddlers with disabilities....

Comprehensive Child Find System

(continued)

(e) Timelines for public agencies to act on referrals.

- (1) Once the public agency receives a referral, it shall appoint a service coordinator as soon as possible.
- (2) **Within 45 days** after it receives a referral, the public agency shall...
 - (i) Complete the evaluation and assessment activities in Sec. 303.322, and
 - (ii) Hold an IFSP meeting in accordance with Sec. 303.342

Figure 2. Percentage of Infants and Toddlers Served in Part C Programs

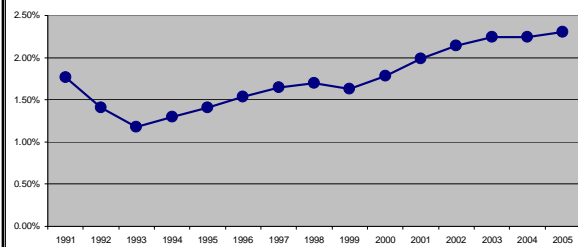
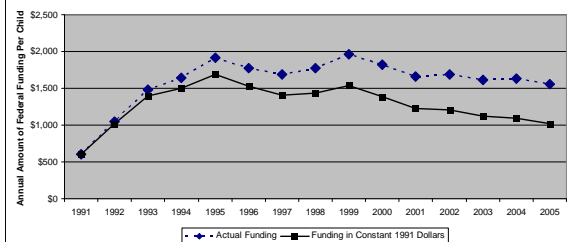


Figure 3. Per Child Funding from Part C of IDEA



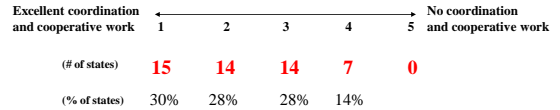
At what point in time does the state EHDI program typically report a child who is identified with a (potential) hearing loss to the state IDEA Part C (early intervention) program?

- 7 (15%) When the baby is referred from the screening test
- 33 (69%) When the child is diagnosed with hearing loss
- 8 (17%) Never

Are children enrolled in your Part C Early Intervention programs for reasons other than permanent hearing loss regularly checked for hearing?

- 18 (33%) Yes
- 7 (15%) No
- 23 (48%) Don't Know

Circle the number that shows the degree to which you feel your state's Part C and EHDI programs are coordinated



Comprehensive System of Personnel Preparation (34 CFR 303.168)

IDEA requires the state early intervention system to operate “a comprehensive system of personnel development [that promotes] the preparation of early intervention providers who are fully and appropriately qualified to provide early intervention services.”

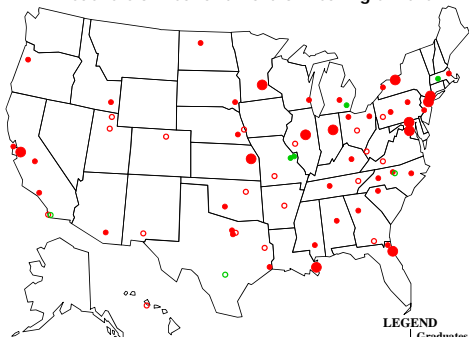
Recall that ...

95% of all newborns with hearing loss have parents with normal hearing.

In one research study when parents had clear choices:

- In 1995: 60% chose sign-language options; 40% chose spoken-language options
- In 2005: 15% chose sign-language options; 85% chose spoken-language options

Primary Emphasis of University Training Programs for Teachers of Deaf and Hard of Hearing Children



Note: Although some programs describe themselves as providing “bilingual/bimodal” services, most have a primary emphasis on a specific approach as indicated by the red/green colorings. The placement of graduate, the type of graduate available, etc. Classification of programs on the map considered these factors in conjunction with annual self-report survey data from the 2001 and 2005 issues of the American Annals of the Deaf.

Appropriate Early Intervention Services

(Section 635 of PL 108-446)

- Historically, deaf children have required more than triple the educational resources as their hearing peers (\$26,207 versus \$7,823)¹
- Private Health Insurance policies seldom pay for hearing aids²
- Medicaid usually covers hearing aids, but often only provides analog aids due to “medical necessity” clauses and reimbursement rates are 38% of what is paid by private insurers³

¹Schroeder L, Petrow S, Kennedy C, McCann D, Law C, Watkin PM, Worsfold S, & Yuen HM. (2006). The economic costs of congenital bilateral permanent childhood hearing impairment. *Pediatrics*, 117(4), 1101-1112.

²Fox HB, McManus MA, & Reichman MB. (2002). *The Strengths and Weaknesses of Private Health Insurance Coverage for Children with Special Health Care Needs*. Washington, DC: Maternal and Child Health Policy Research Center.

³McManus M, Levov R, White K, Forsman I, Foust T, & Thompson M. (2004). *The adequacy of Medicaid reimbursement of hearing services for children*. Washington, DC: Maternal and Child Health Policy Research Center.

Appropriate Early Intervention Services

(Section 635 of PL 108-446)

- Part C of IDEA seldom pays for hearing aids or FM systems
- In 1990, Congress specifically added the definitions of “assistive technology devices” contained in PL 101-476 to the Education of the Handicapped Act (what is now IDEA)

The term “assistive technology device” means any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.

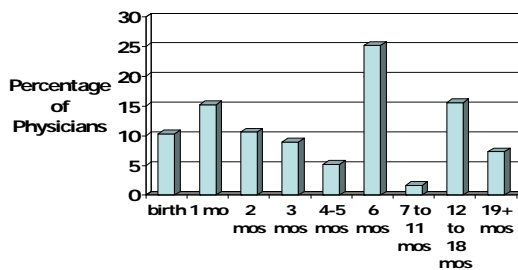
- Thus, hearing aids and FM systems should be covered under Part C of IDEA whenever a child requires hearing aids “to increase, maintain, or improve functional capabilities”

Public Awareness

(Section 635 of PL 108-446)

A public awareness program focusing on early identification of infants and toddlers with disabilities, including the preparation and dissemination ... to all primary referral sources, especially hospitals and physicians...

When can an infant be fit with hearing aids?



“Take Home” Messages

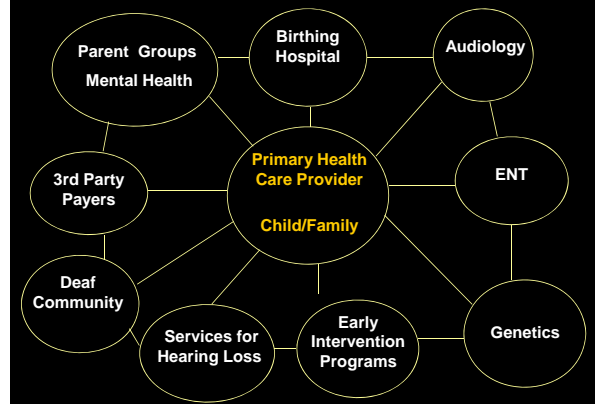
- Part C of IDEA is a untapped resource for improving early intervention services for children who are deaf or hard-of-hearing.
- Part C is not the “pot of gold” at the end of the rainbow
- Better education of and collaboration with Part C program managers and providers is needed
- Persistent advocacy and public policy work is essential



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

EHDI and the Medical Home



Educating Primary Health Care Providers About Early Identification of Hearing Loss

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

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

Responses of 1975 physicians in 21 states

Moeller MP, White KR, & Shisler L (in press). Primary care physicians' knowledge, attitudes and practices related to newborn hearing screening. *Pediatrics*.

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

JOINT COMMITTEE ON INFANT HEARING YEAR 2000 POSITION STATEMENT: Principles and Guidelines for Early Hearing Detection and Intervention Programs

The Year 2000 Position Statement and Guidelines were developed by the Joint Committee on Infant Hearing. Joint committee member organizations and their respective representatives who prepared this statement include (in alphabetical order) the American Academy of Audiology (Teresa Fentz, Ph.D., chair, and Vynone Springer, Ph.D.), the American Academy of Otolaryngology-Head and Neck Surgery (Patrick Brodthuis, M.D., vice-chair, and Stephen Epstein, M.D.); the American Academy of Pediatrics (Allen Ehrenberg, M.D., and Nancy Roizen, M.D.); the American Speech-Language-Hearing Association (Allan O. Denendorf, Ph.D., Judith S. Gravel, Ph.D., and Richard C. Folsom, Ph.D.); the Council on Education of the Deaf whose member organizations include Alexander Graham Bell Association for the Deaf and Hard of Hearing, American Society for Deaf Children, Conference of Educational Administrators of Schools and Programs for the Deaf, Convention of American Instructors of the Deaf, National Association of the Deaf, and Association of College Educators of the Deaf and Hard of Hearing (Patrick Stone, Ed.D.); Joseph J. Innes, Ph.D., and Donna M. Ockman, Ph.D. (1); and the Directors of Speech and Hearing Programs in State Health and Welfare Agencies (Lorraine Michel, Ph.D.; Linda Rose, M.D.; Thomas Mahoney, Ph.D.); six offices to the JCIH include: Evelyn Charlow, MA (American Speech-Language Hearing Association); Deborah Hayes, Ph.D., (Maine Down National Center for Infant Hearing); and Liz Osterhus, MA and Thomas Tonnesen, M.D. (American Academy of Audiology).

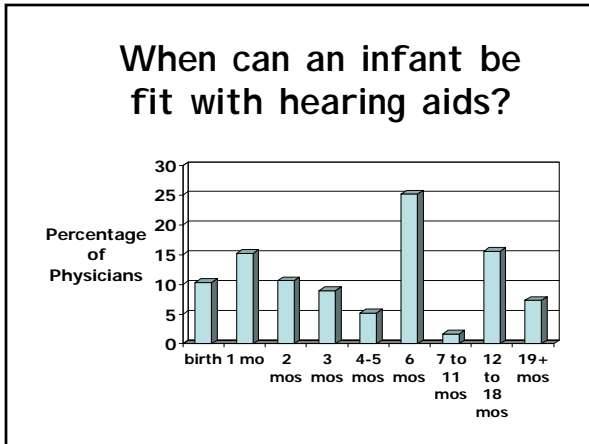
... every infant with hearing loss should receive an ophthalmologic evaluation at regular intervals

ACMG Position Statement

Genetics Evaluation Guidelines for the Etiologic Diagnosis of Congenital Hearing Loss

Genetic evaluation of congenital hearing loss is a key step in the identification of the etiology of hearing loss. The identification of the etiology of hearing loss is important because it allows for the identification of the etiology of hearing loss, which may be associated with other medical conditions. The identification of the etiology of hearing loss is also important because it allows for the identification of the etiology of hearing loss, which may be associated with other medical conditions.

Appropriate management of all persons identified with congenital hearing loss, as defined above, requires a comprehensive genetic evaluation.

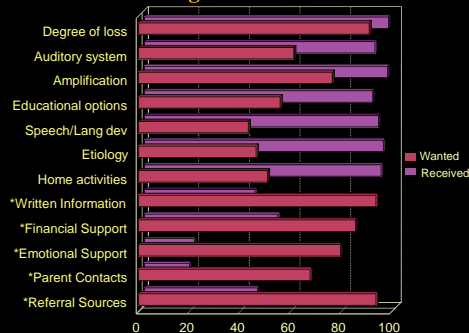


Type of Physician	Age at which hearing aids can be fit				
	<=1 mo	2-3 mos	4-6 mos	7-11 mos	12+ mos
Pediatrician (n=1145)	36.3%	16.9%	29.0%	2.1%	15.6%

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- Culturally Competent Family Support

Information Wanted vs. Received by Parents at Hearing Loss Confirmation



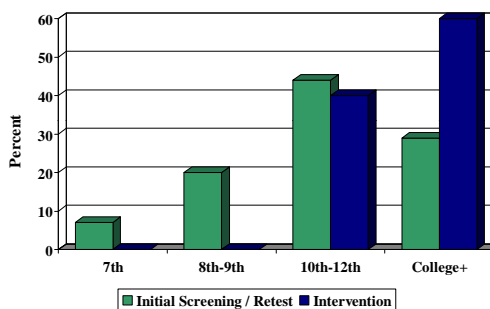
Martin, George, O'Neal, & Daly (1987); *Sweetow & Barrager (1980)

Are current EHDI materials effective?



Brochure Readability

Gold Standard Readability: ≤6th Grade



Five User-friendly Criteria

- Layout makes reading easier.
- Illustrations help carry message.
- Messages are clear.
- Information is manageable.
- Parent feels "information meant for me."



Lessons Learned

---- H. L. Mencken

There is always an easy solution to every human problem — neat, plausible, and WRONG.

Lessons Learned

1. Be wary of simple answers to complex problems

Lessons Learned

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2. Technological Advances have been critical to past success....and will continue to be important
 - ✓ Faster and more effective screening equipment
 - ✓ Linking physiological screening to genetic analysis based on the dried blood spot
 - ✓ Screening for cytomegalovirus (CMV)
 - ✓ Regeneration of hair cells

Lessons Learned

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5. Coordination of screening with effective data systems will provide the data to dramatically improve programs
 - ✓ Late-onset hearing loss
 - ✓ Risk indicators
 - ✓ CMV
 - ✓ Auditory neuropathy

All Politics is Local



Lesson #6

Policy and Legislative Initiatives with Local, State and Federal Partners



Lessons Learned

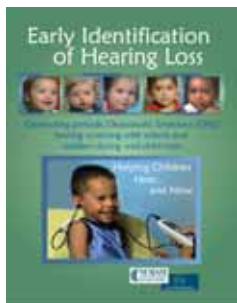
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7. **Good Begun ... Is half done**



Hearing Screening During Well Child Visits to Health Care Providers



- Pilot studies and materials development 2005-2006
- Worked with American Academy of Pediatrics to develop recommended policy changes
- Development of training and implementation materials funded by Oticon foundation

Materials available from www.HearAndNow.org

8 states require hearing aid assistance for kids

Utah group hopes to get insurance firms to help

By Anne J. Peterson
Special: Morning News

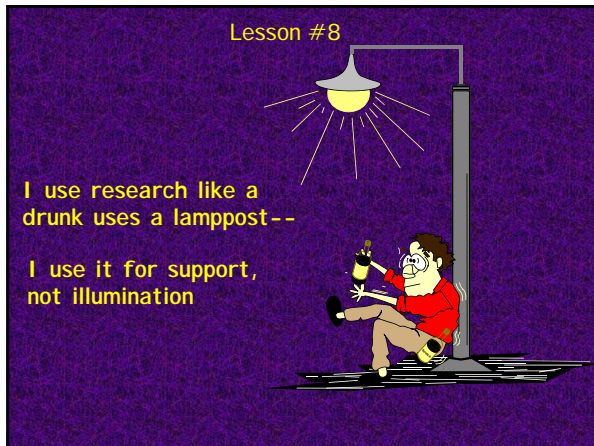


"There is not an awareness out there. Another parent is going to find out their child is deaf and say, 'Thank goodness I have insurance' and they will find it isn't so. They will go through the same battle we have."

"That's what blows my mind," says [Name] when it is so critical for a child who is developing in language, developing in socialization, isn't there any coverage? Hearing aids could make a difference in that child's life." Patton believes, in part, that the pervasive ignorance related to deafness and hard-of-hearing issues is to blame.

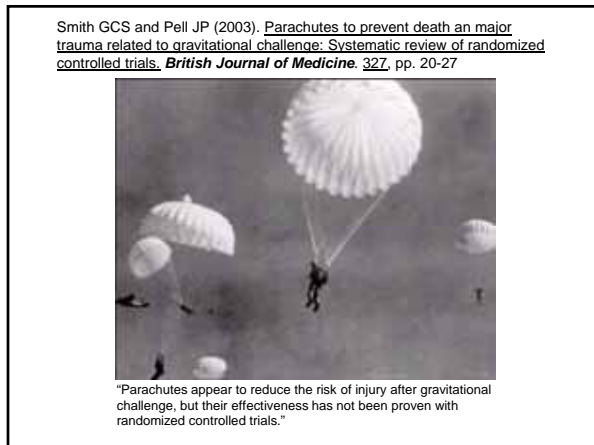
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E-mail: annej@deafnews.com



However beautiful the strategy, you should occasionally look at the results.

Sir Winston Churchill



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Never, never, never,
never give up!



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www.infanthearing.org



Take Home Messages

- The world has changed for infants and young children with permanent hearing loss
- Screening is only the first (and the easiest!) step
- Just as scientific and technological advances have made the revolutionary changes of the last 15 years possible --- more are coming
- Education and advocacy are the foundation on which future progress will be built

