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.”


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, early identification is key
- 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
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.

What enabled us to move from ....

- Earlier Identification of Hearing Loss
- High Quality Early Intervention Programs that focus on teaching LANGUAGE
- Availability of Better Assistive Listening Devices
- Advocacy and Public Policy Initiatives
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 1,000

Rate Per 1000 of Permanent Childhood Hearing Loss in EHDI Programs

<table>
<thead>
<tr>
<th>Site</th>
<th>Sample Size</th>
<th>Prevalence Per 1000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rhode Island (3/93 - 6/94)</td>
<td>16,395</td>
<td>1.71</td>
</tr>
<tr>
<td>Colorado (1/92 - 12/96)</td>
<td>41,076</td>
<td>2.56</td>
</tr>
<tr>
<td>New York (1/96 - 12/96)</td>
<td>27,938</td>
<td>1.65</td>
</tr>
<tr>
<td>Utah (7/93 - 12/94)</td>
<td>4,012</td>
<td>2.99</td>
</tr>
<tr>
<td>Hawaii (1/96 - 12/96)</td>
<td>9,605</td>
<td>4.15</td>
</tr>
<tr>
<td>Massachusetts (1/04 – 12/04)</td>
<td>78,515</td>
<td>2.87</td>
</tr>
</tbody>
</table>


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.

Incidence per 10,000 of Congenital Conditions
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.

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?

- Feinmesser et al. (1982) 49%
- Pappas & Schaibly (1984) 54%
- Elssmann et al. (1987) 48%
- Watkin et al. (1991) 43%
- Mauk et al. (1991) 50%
- Mehl & Thomson (1998) 50%

Feinmesser et al. (1982) 49%
Pappas & Schaibly (1984) 54%
Elssmann et al. (1987) 48%
Watkin et al. (1991) 43%
Mauk et al. (1991) 50%
Mehl & Thomson (1998) 50%
Accuracy of High Risk Based UNHS Programs
Mahoney and Eichwald (1987)

JCIH indicators incorporated into legally required birth certificate.
Computerized mailing and follow-up, and free diagnostic assessments at regional offices and 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.


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.


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

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

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

Jan 96 Jul 96 Jan 97 Jul 97 Jan 98 Jul 98 Jan 99 Jul 99 Jan 00 Jul 00 Jan 01 Jul 01 Jan 02 Jul 02 Jan 03 Jul 03 Jan 04 Jul 04

Percentage of Newborns Screened for Hearing in the United States
Implementing Effective Newborn Hearing Screening Programs

Then a miracle occurs

Start

Diagnosis

Early Intervention

Medical Home

Data Management

Program Evaluation

Family Support

Start

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

Components of an Effective Early Hearing Detection and Intervention (EHDI) Program

Diagnosis

Screening

Intervention

Medical Home

Data Management and Tracking

Program Evaluation and Quality Assurance

Family Support!!

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?

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

*Adjusted for proportion of OAE fails that enrolled

Represents 23% of all babies with PHL in birth cohort

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


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

Rate Per 1000 of Permanent Childhood Hearing Loss in EHDI Programs

<table>
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<th>Site</th>
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<td>27,938</td>
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<td>2.87</td>
</tr>
</tbody>
</table>

Rate Per 1000 of Permanent Childhood Hearing Loss with Diagnosis in EHDI Programs

<table>
<thead>
<tr>
<th>Site</th>
<th>Sample Size</th>
<th>Prevalence Per 1000</th>
<th>% of Refers with Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rhode Island (3/93 - 6/94)</td>
<td>16,395</td>
<td>1.71</td>
<td>42%</td>
</tr>
<tr>
<td>Colorado (1/92 - 12/96)</td>
<td>41,976</td>
<td>2.56</td>
<td>48%</td>
</tr>
<tr>
<td>New York (1/96 - 12/96)</td>
<td>27,938</td>
<td>1.65</td>
<td>67%</td>
</tr>
<tr>
<td>Utah (7/93 - 12/94)</td>
<td>4,012</td>
<td>2.99</td>
<td>73%</td>
</tr>
<tr>
<td>Hawaii (1/96 - 12/96)</td>
<td>9,605</td>
<td>4.15</td>
<td>98%</td>
</tr>
<tr>
<td>Massachusetts (1/04 – 12/04)</td>
<td>78,515</td>
<td>2.87</td>
<td>89%</td>
</tr>
</tbody>
</table>

Tracking and Data Management

- 80% 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).

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

<table>
<thead>
<tr>
<th>Births</th>
<th>NON-STUDY</th>
<th>STUDY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Screened</td>
<td>98.7%</td>
<td>99.5%</td>
</tr>
<tr>
<td>Passed</td>
<td>92.3%</td>
<td>92.9%</td>
</tr>
<tr>
<td>Referred</td>
<td>7.7%</td>
<td>7.1%</td>
</tr>
<tr>
<td>Not Screened</td>
<td>0.8%</td>
<td>0.4%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Status of EHDI Programs in the United States</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Universal Newborn Hearing Screening</td>
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<tr>
<td>- Effective Tracking and Follow-up as a part of the Public Health System</td>
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<tr>
<td>- Appropriate and Timely Diagnosis of the Hearing Loss</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age in Months at Which Permanent Hearing Loss Was Diagnosed</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Status of EHDI Programs in the US: Audiological Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Equipment and techniques for diagnosis of hearing loss in infants continues to improve</td>
</tr>
<tr>
<td>- Severe shortages in experienced pediatric audiologists delays confirmation of hearing loss</td>
</tr>
<tr>
<td>- State coordinators estimate only 66% “receive diagnostic evaluations before 3 months of age</td>
</tr>
</tbody>
</table>
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
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. It 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, 1988

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.

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.

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

Eligibility

(34 CFR Part 303.10)
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.

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:
2) (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....

(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
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

<table>
<thead>
<tr>
<th>Excellent coordination and cooperative work</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>No coordination and cooperative work</th>
</tr>
</thead>
<tbody>
<tr>
<td>(%) of states</td>
<td>15</td>
<td>14</td>
<td>14</td>
<td>7</td>
<td>0</td>
<td>(%) of states</td>
</tr>
<tr>
<td></td>
<td>30%</td>
<td>28%</td>
<td>28%</td>
<td>14%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

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 aids\(^2\)
- 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 insurers\(^3\)

---

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…

“Take Home” Messages

- Part C of IDEA is an 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
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 an:

- Ophthalmological evaluation
- Genetic evaluation
- Otolaryngological evaluation

Responses of 1975 physicians in 21 states


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

When can an infant be fit with hearing aids?

<table>
<thead>
<tr>
<th>Age at which hearing aids can be fit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of Physician</td>
</tr>
<tr>
<td>&lt;1 mo</td>
</tr>
<tr>
<td>Pediatrician (n=1145)</td>
</tr>
<tr>
<td>36.3%</td>
</tr>
<tr>
<td>Family Practice (n=531)</td>
</tr>
<tr>
<td>38.2%</td>
</tr>
<tr>
<td>Neonatologist (n=52)</td>
</tr>
<tr>
<td>28.8%</td>
</tr>
<tr>
<td>ENT (n=58)</td>
</tr>
<tr>
<td>27.6%</td>
</tr>
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**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

**Are current EHDI materials effective?**

**Brochure Readability**

**Gold Standard Readability: 5th 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
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
3. The greatest enemy of good is excellent
4. Partnership is the key to success
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
Lessons Learned

1. Be wary of simple answers to complex problems
2. Technological Advances have been critical to past success...and will continue to be important
3. Excellent is the greatest enemy of good
4. Partnership is the key to success
5. Coordination of screening with effective data systems will provide the data to dramatically improve programs
6. Standardization is a double-edged sword
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

“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.”
I use research like a drunk uses a lamppost --
I use it for support, not illumination

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

Sir Winston Churchill

Lessons Learned

1. Be wary of simple answers to complex problems
2. Technological Advances have been critical to past success and will continue to be important
3. Excellent is the greatest enemy of good
4. Partnership is the key to success
5. Coordination of screening with effective data systems will provide the data to dramatically improve programs
6. Standardization is a double-edged sword
7. Good begun is half done
8. Research/evaluation is important but not a silver bullet
9. Avoid sibling rivalries


"Parachutes appear to reduce the risk of injury after gravitational challenge, but their effectiveness has not been proven with randomized controlled trials."
Never, never, never, never give up!

Lessons Learned

1. Be wary of simple answers to complex problems
2. Technological Advances have been critical to past success... and will continue to be important
3. Excellent is the greatest enemy of good
4. Partnership is the key to success
5. Coordination of screening with effective data systems will provide the data to dramatically improve programs
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7. Good Begun ... Is half done
8. Research/evaluation is important ... but, not a silver bullet
9. Avoid sibling rivalries
10. Never, never, never, never give up!

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