

Lessons Learned: From a Decade of Implementing EHDI Programs



Partnering For Progress
EHDI Southeastern Regional Conference
Jackson, Mississippi

by

Karl R. White

National Center for Hearing Assessment and Management

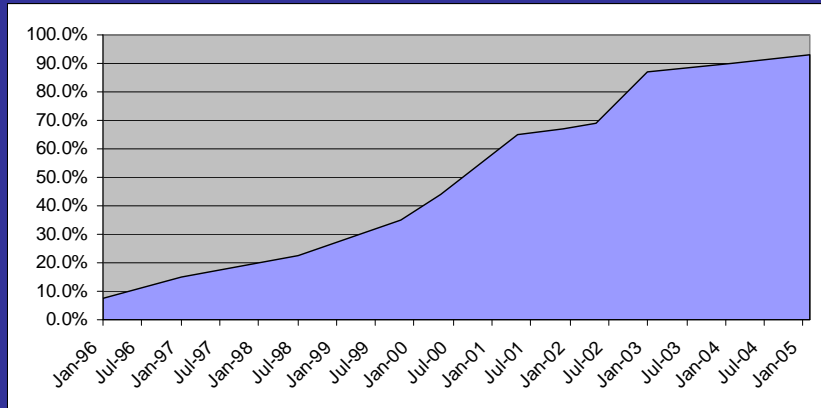
www.infanthearing.org

October 5-7, 2006

The Status of Early Hearing Detection and Intervention Programs

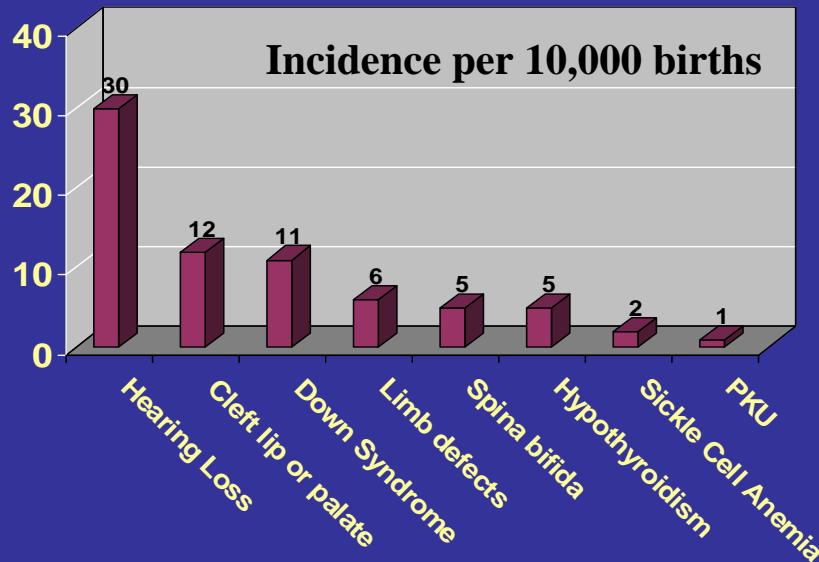
Newborn hearing screening has become the “standard of care”

- ✓ **38 states with legislative mandates**
- ✓ **93%+ of all newborns now screened for hearing before discharge**



Why is Early Identification of Hearing Loss so Important?

- Hearing loss occurs more frequently than any other newborn condition that may cause significant developmental delays.



- Undetected hearing loss has serious negative consequences.
- Early identification has dramatic benefits for affected children and families.
- Medical-legal issues



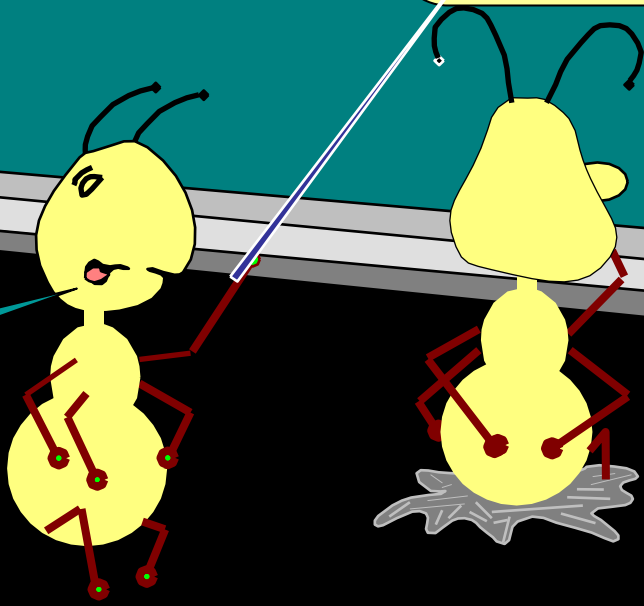
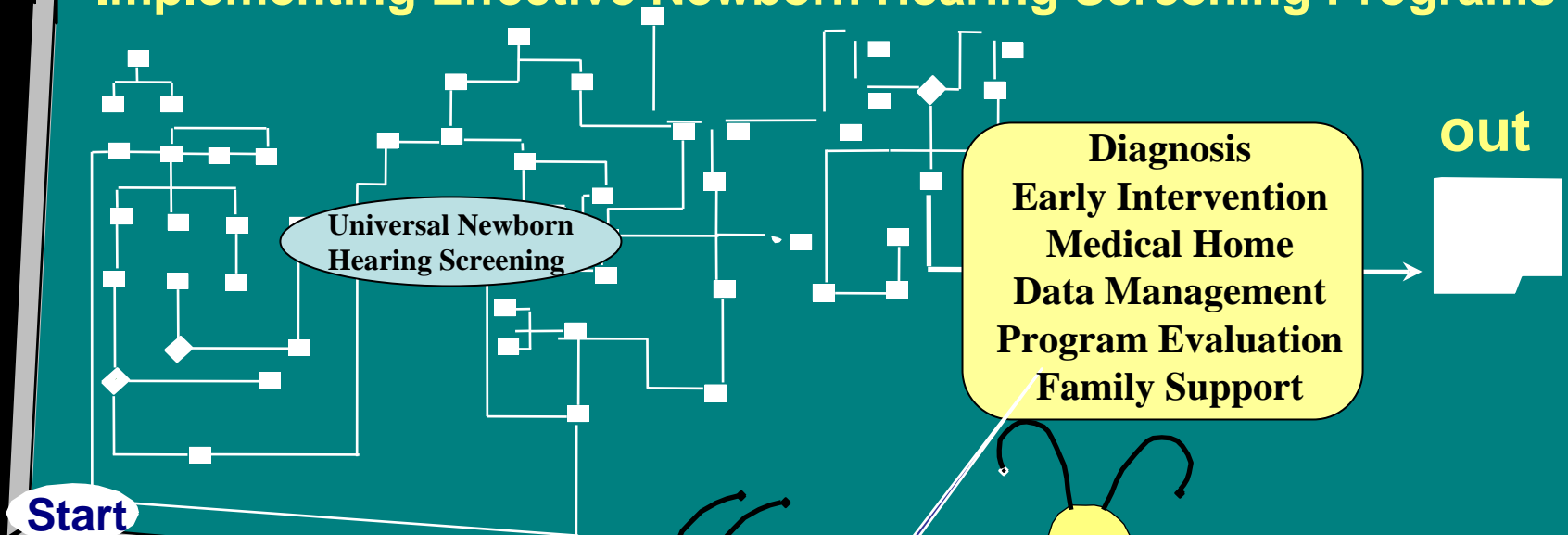
NIH Consensus Panel

Early Identification of Hearing Impairment in Infants and Young Children

March, 1993

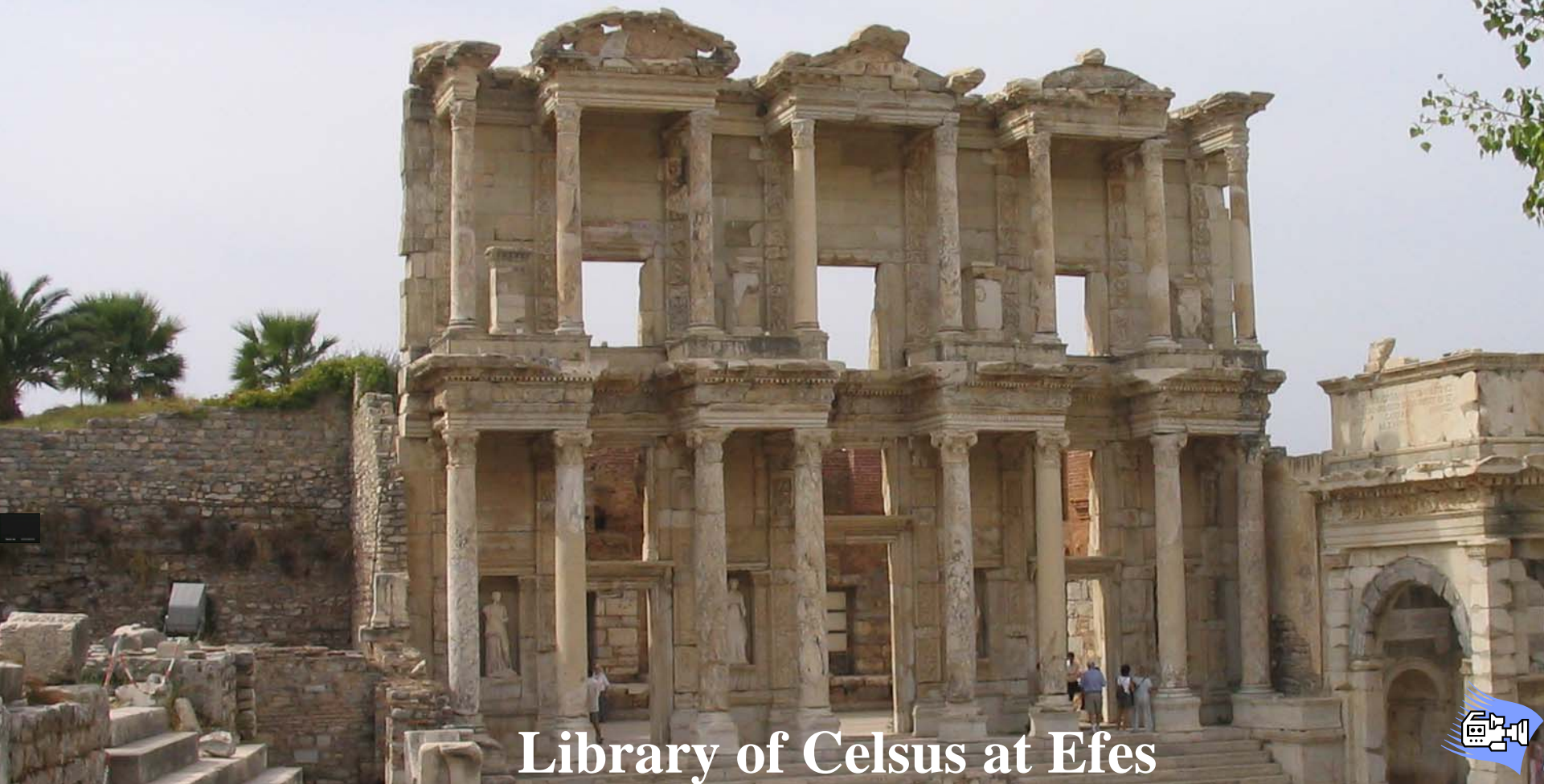
The consensus panel concluded that **all infants should be screened for hearing impairment**...this will be accomplished most efficiently by screening prior to discharge from the well-baby nursery. Infants who fail ... should have a comprehensive hearing evaluation no later than 6 months of age.

Implementing Effective Newborn Hearing Screening Programs



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

Universal newborn hearing screening is not a new idea



Library of Celsus at Efes



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



**Montreal School
For the Deaf**
Group 4 1977-78



A young girl with blonde hair, wearing a pink shirt, is looking towards the camera. In the background, a younger child with dark hair, wearing a white shirt and dark overalls, is looking towards the camera. The background shows a classroom setting with a wooden cabinet and various items on it.

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





What enabled us to move from



There



Here?

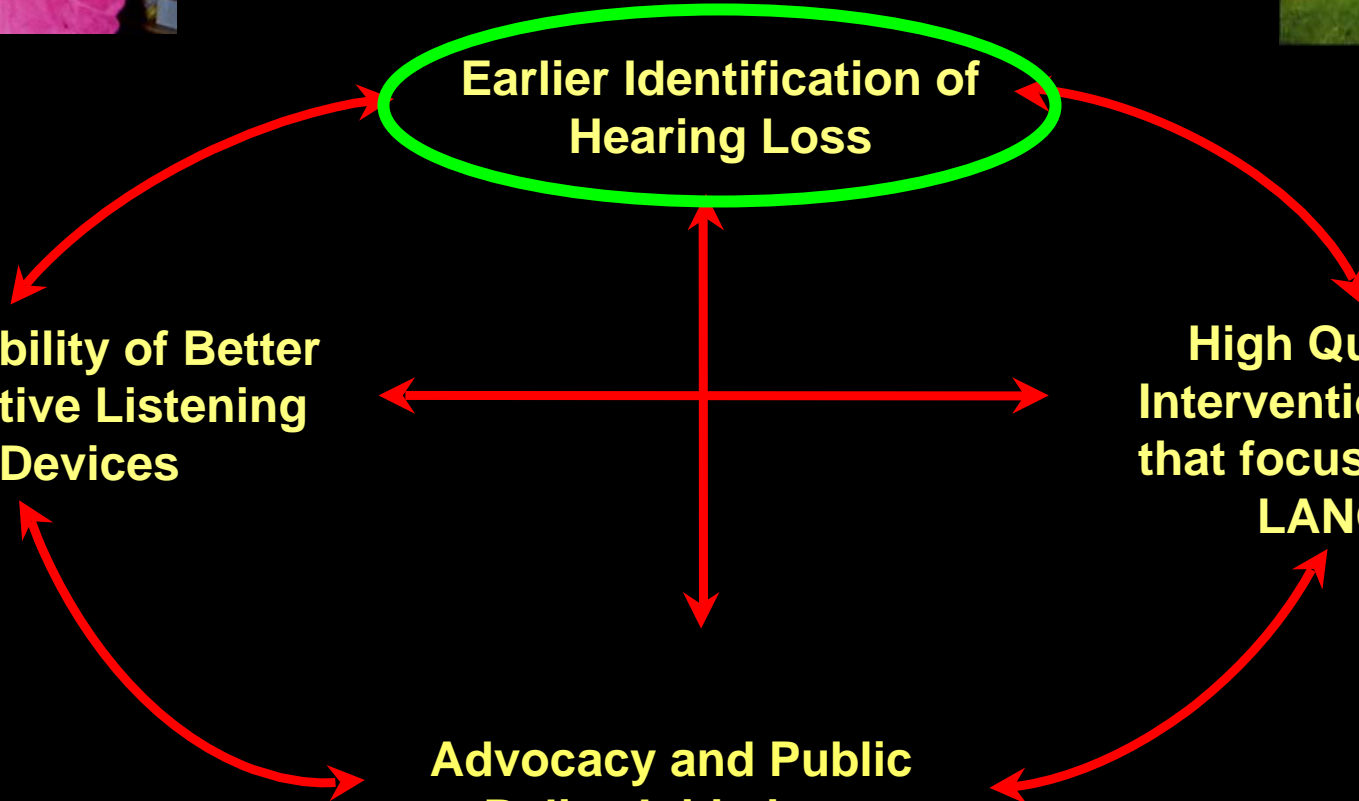


**Earlier Identification of
Hearing Loss**

**Availability of Better
Assistive Listening
Devices**

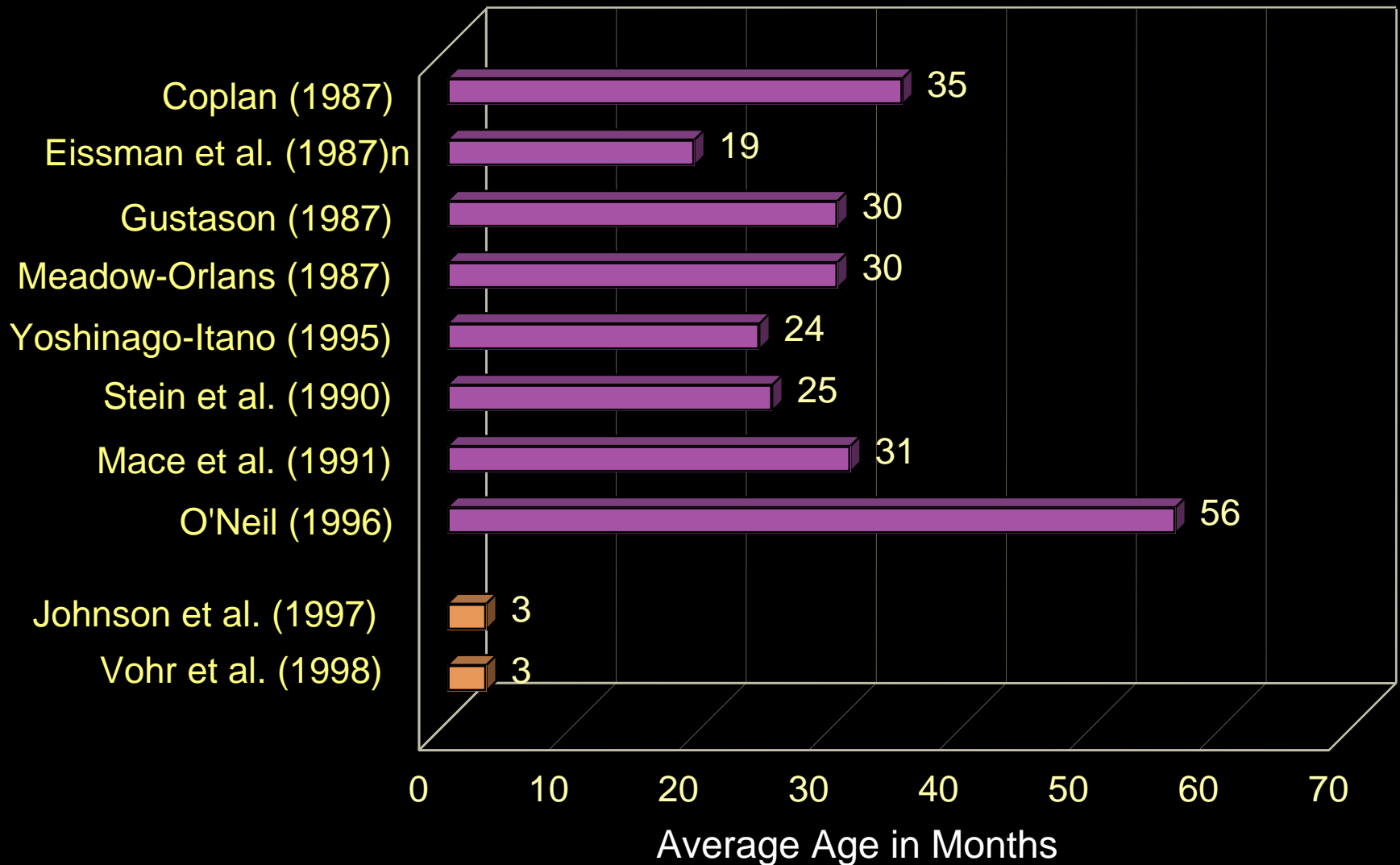
**High Quality Early
Intervention Programs
that focus on teaching
LANGUAGE**

**Advocacy and Public
Policy Initiatives**





Confirmation of Permanent Hearing Loss



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



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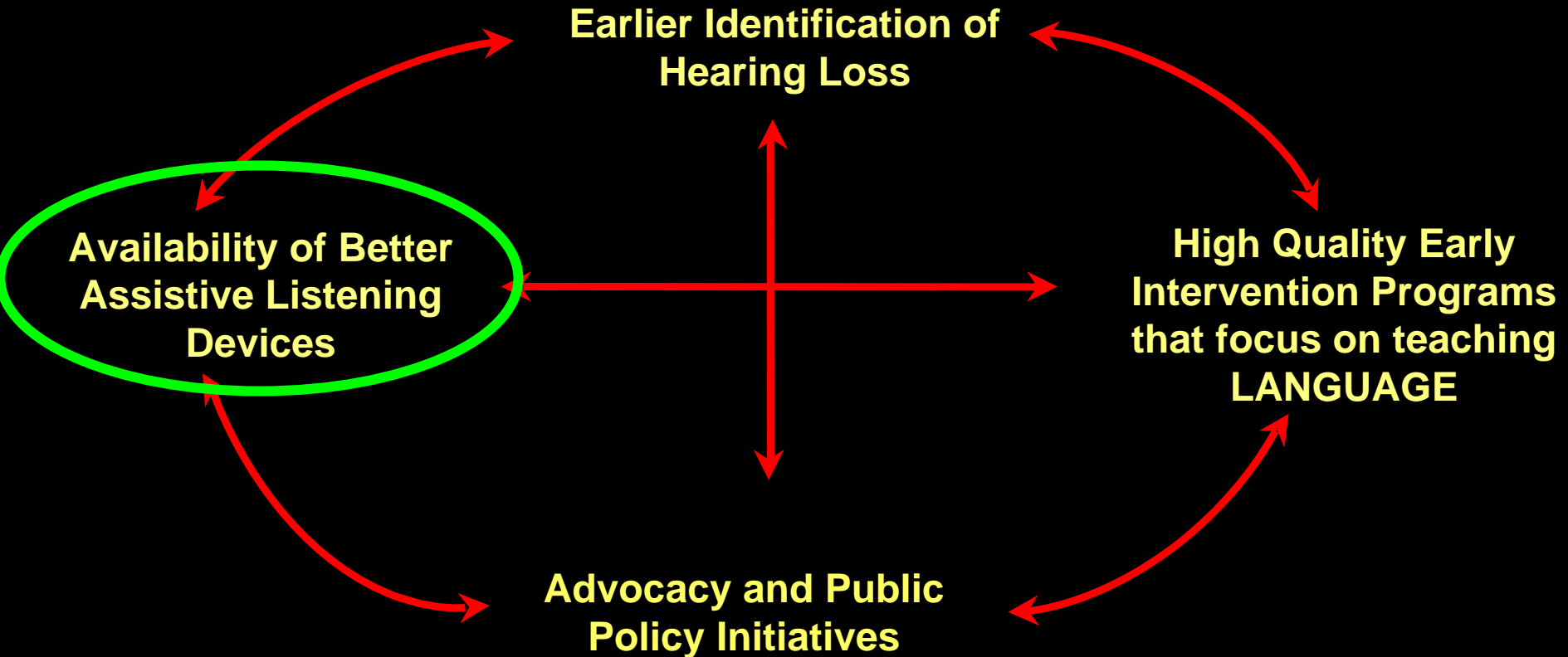


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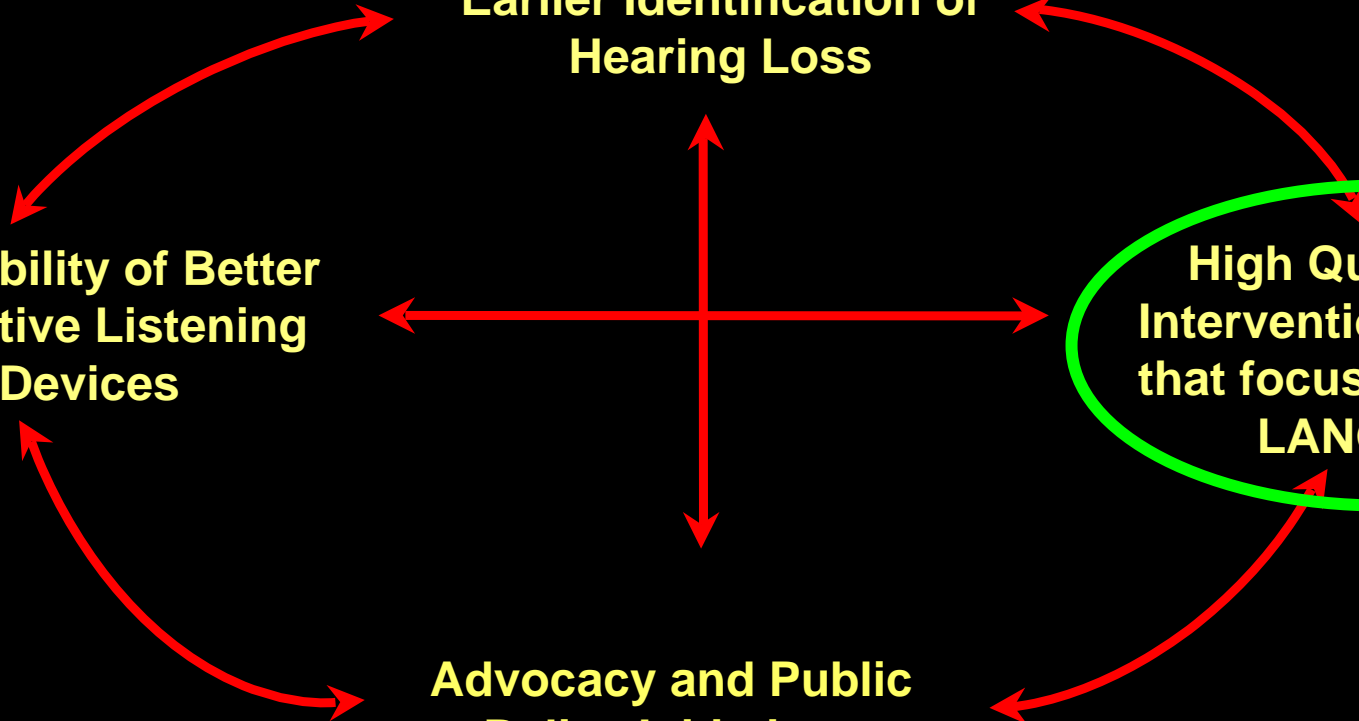


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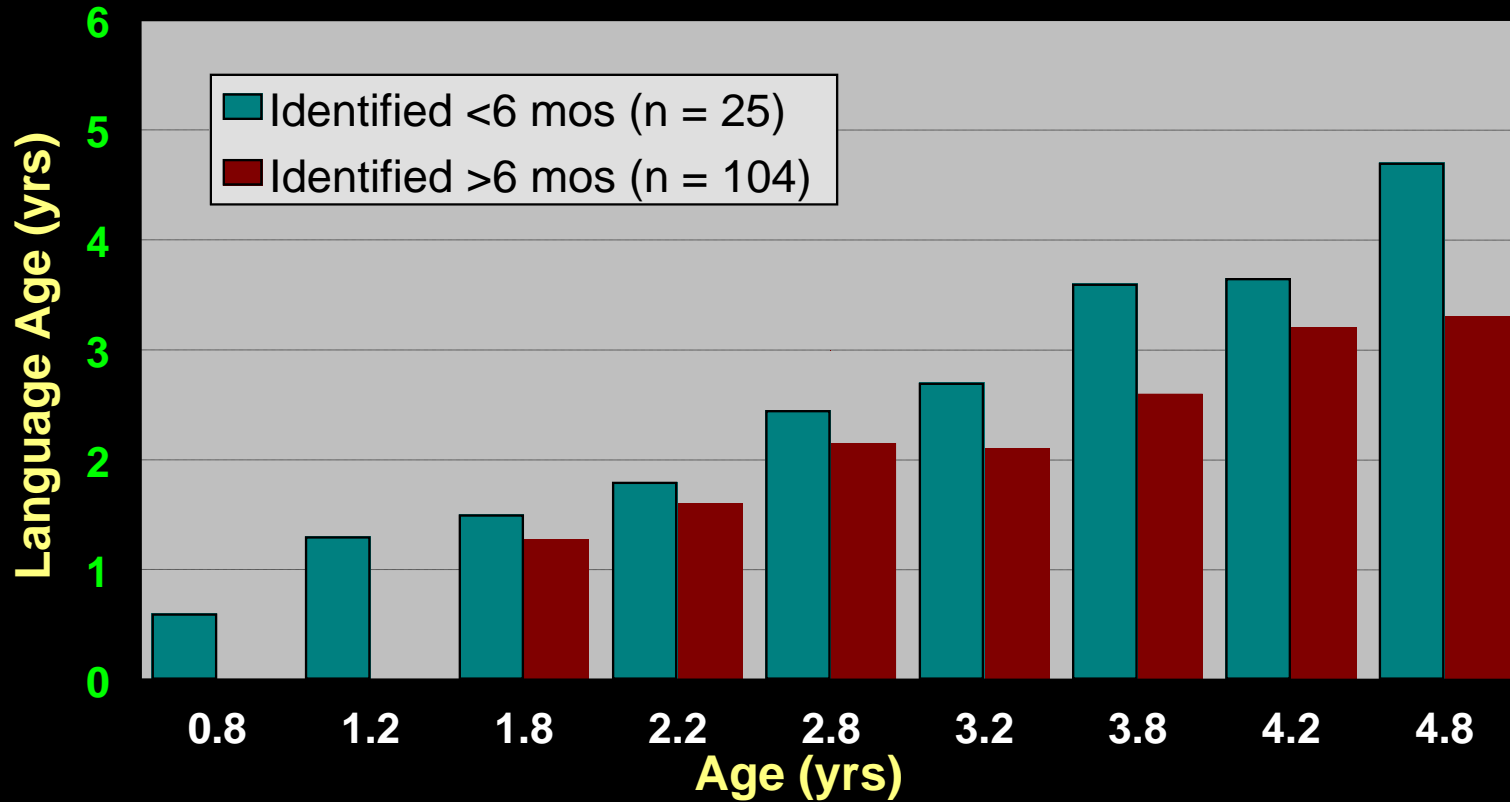
Advocacy and Public
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Boys Town National Research Hospital Study of Earlier vs. Later

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

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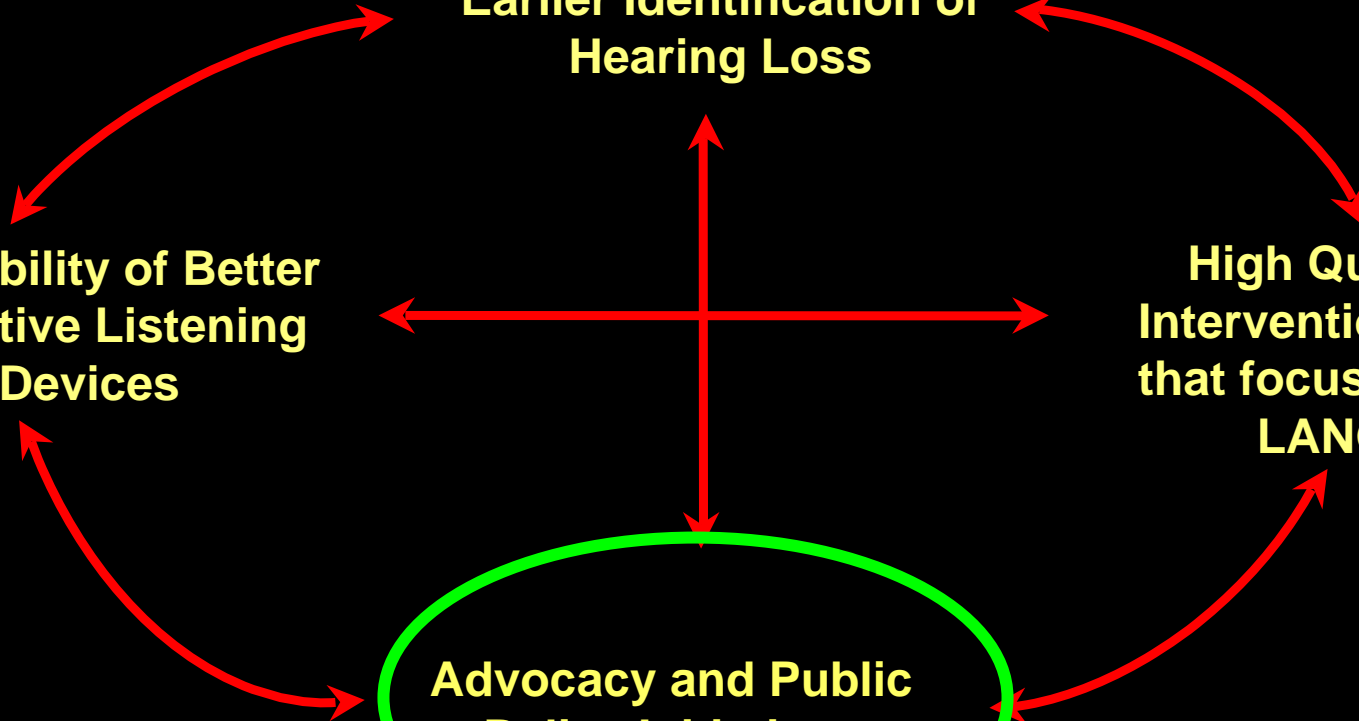


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hear and
now .ORG

can you hear me?

i can't hear you.



Help your child hear. And now.

Parents

Health Care Providers

Resources

About Us

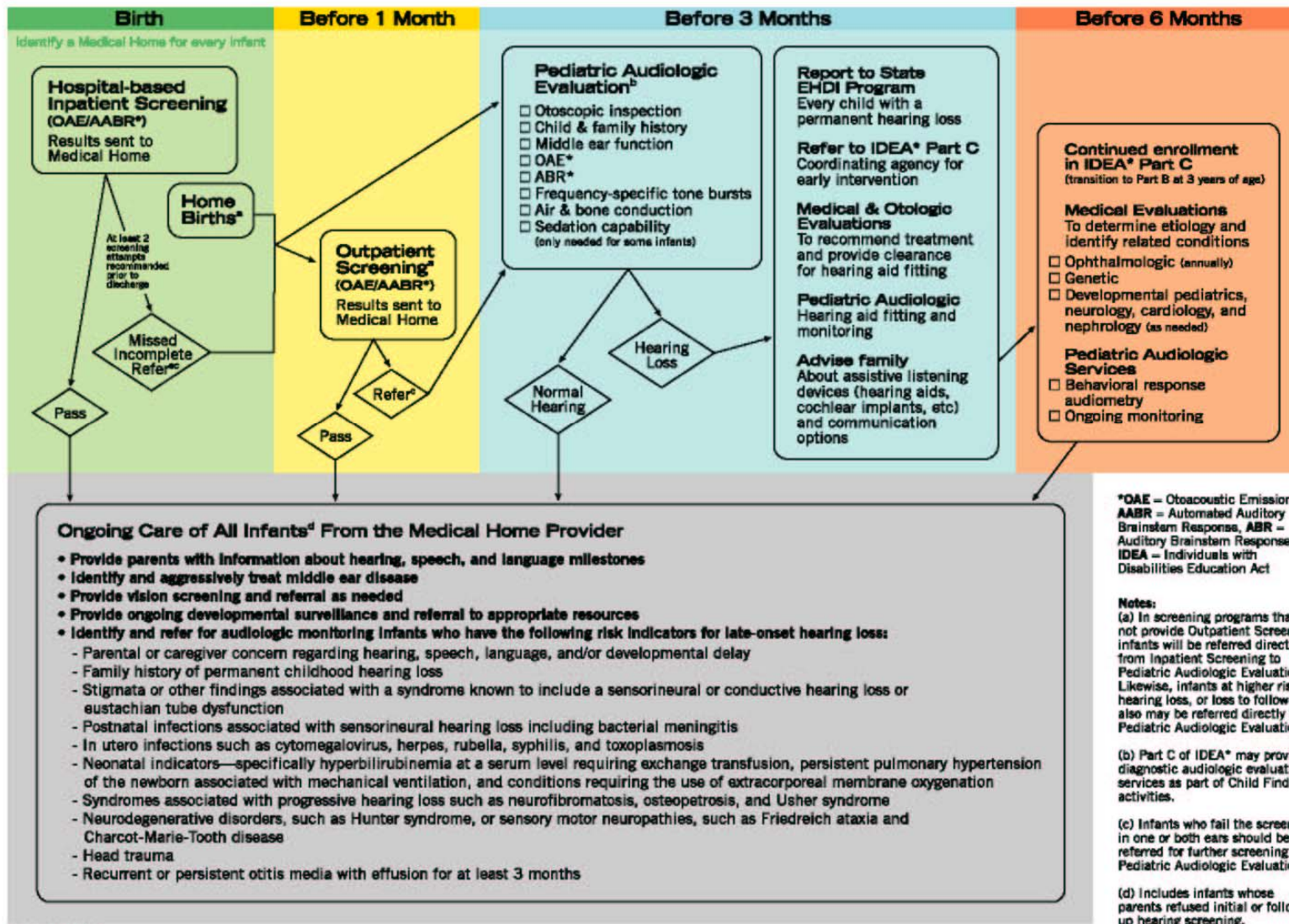
Parents

Many people are surprised to learn that 12,000 babies a year in the U.S. are born with a permanent hearing loss. That makes hearing loss the most common birth defect. It also means that about 1 out of every 300 babies will need special help to hear and speak. This is why hospitals now screen (test) the hearing of most newborns. When a hearing loss is found early, parents and professionals can work together to help a child develop normally. If you have questions or concerns about your child's hearing, don't wait and see--help your child.

- ◆ What do I do if my baby failed a hearing screening test?
- ◆ Was my baby's hearing screened?
- ◆ I am worried my child doesn't hear well.
- ◆ Why is hearing so important for children?

American Academy of Pediatrics

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



Policy and Legislative Initiatives with Local, State and Federal Partners



Examples of Current Challenges

- **Only 21 states are attempting to screen home births**
- **Only 56 % of babies who fail screening are known to receive follow-up**
- **Only 36 states collect data about the age at which diagnostic evaluation was completed for referred babies**
 - **Only 55% of those diagnosed babies completed evaluation before 3 months of age**
- **Only 34 states collect data about age at which early intervention began for babies with hearing loss**
 - **Only 49% of those babies with hearing loss began early intervention before 6 months of age**
- **62% of physicians think babies must be 4+ months of age before they can be fit with hearing aids**
- **Only 18 states report that children enrolled in Part C programs are screened for hearing loss**
- **Only 7 states have a written report of a systematic evaluation of their EHDI program done in the last 4 years.**
- **Only 17% of resources for the state EHDI program administration come from state appropriations**

Lessons Learned

---- *H. L. Mencken*

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

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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**

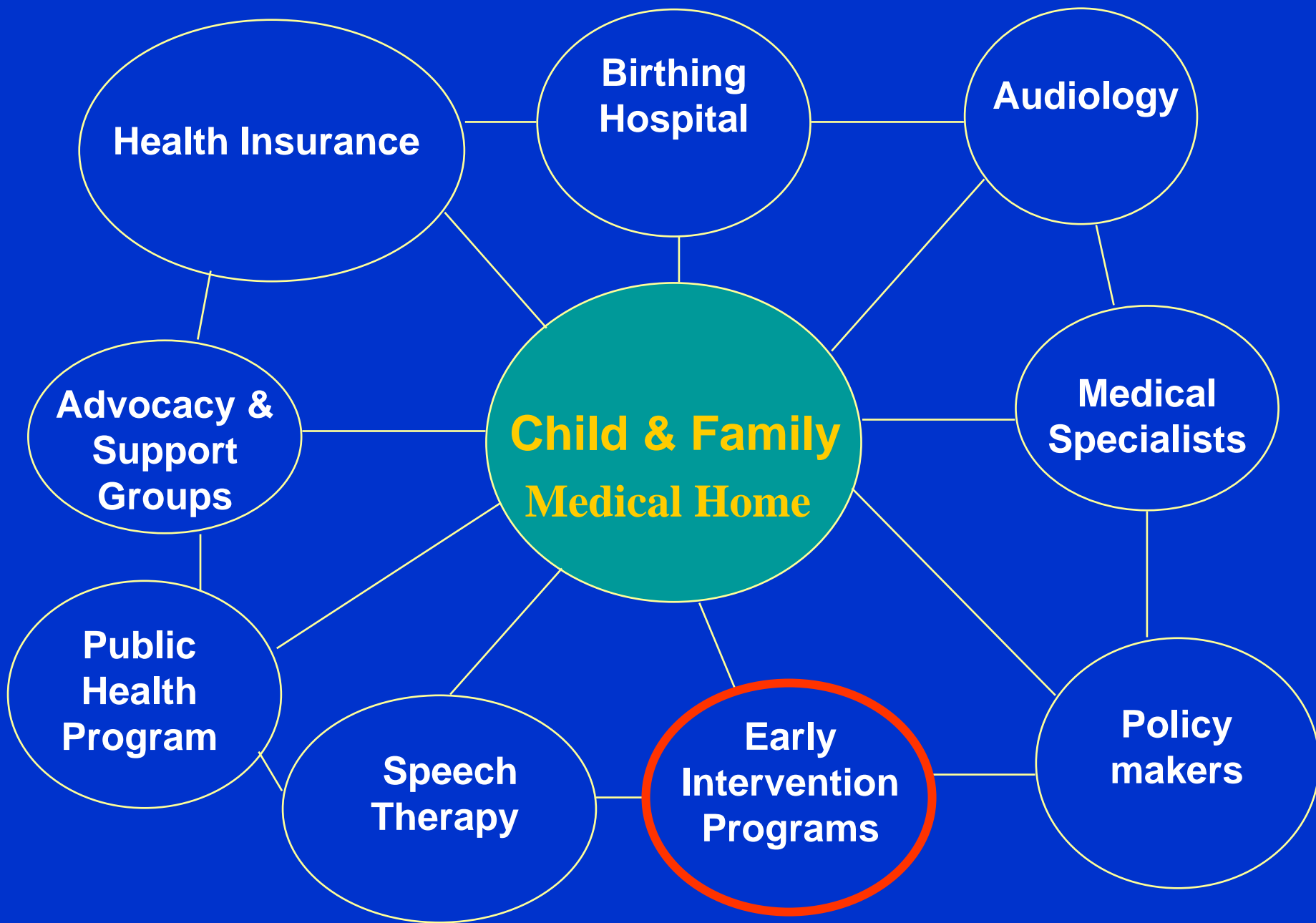
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4. **Partnership is the key to success**

Partnership is the Key to Successful EDHI Programs



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**

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.

www.infanthearing.org/earlyintervention/eligibility.pdf

Part C Early Intervention Eligibility for Infants and Toddlers with Hearing Loss

DRAFT: NOT FOR DISTRIBUTION

Part C State Coordinator as of November 13, 2002 as posted at www.nectac.org/contact/ptccoord.asp	As Defined by the State Plan, are infants and toddlers with established risk conditions eligible for Part C-funded services? ^{1a}	Are Specific Conditions Listed? ^{1b}	Is Hearing Loss Noted as a Specific Condition? ^{1c}	Is Hearing Loss Operationally Defined in the State Plan or in other official documents? If yes, what is the definition?
Alabama Elizabeth Prince, Part C Coordinator Early Intervention Program 2129 East South Boulevard PO Box 11586 Montgomery, AL 36111-0586 (334) 613-3543 Fax: (334) 613-3541 E-mail: bdprince@rehab.state.al.us http://www.rehab.state.al.us/intervention.html	Yes ... criteria applies to conditions with known etiologies... includes but is not limited to: <ul style="list-style-type: none"> • Chromosomal abnormalities • Genetic or congenital disorders • Severe sensory impairments (including hearing and vision) • Inborn error of metabolism • Disorders reflecting disturbances of the nervous system • Congenital infections • Disorders secondary to exposure to toxic substances (incl. fetal Alcohol Syndrome) • Severe attachment disorders 	Yes	Severe sensory impairments (including hearing and vision)	State Plan: No
Alaska Jane Atuk, Part C Coordinator Maternal and Child Health State Department of Health and Social Services 3601 C Street, Suite 934, PO Box 240249 Anchorage, AK 99524-0249 (907) 269-3419 Fax: (907) 269-3465 E-mail: jane_atuk@health.state.ak.us http://health.hss.state.ak.us/dph/mch/srs/default.htm	Yes Disabling condition means physical, mental, sensory or physical conditions which have a high probability of resulting in a 50% developmental delay... even though [it] may not be exhibited at the time. The team's decision shall be supported by a physician's report documenting the condition.	No	No	State Plan: No

¹ Notes:

- a) "Are infants and toddlers with established risk conditions eligible for Part C-funded services?" Based on State Plan, answered Yes or No as well as summarizing the relevant criteria and conditions under which child

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

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9. A lead agency
10. Procedural safeguards
11. State interagency coordinating council

Demographic Considerations Regarding Provision of Early Intervention Programs for Children with Hearing Loss

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

Mitchell RE and Karchmer MA. Chasing the mythical ten percent: Parental hearing status of Deaf and Hard of Hearing students in the United States. *Sign Language Studies*. 2004; 4(2), 138-163.



Demographics Considerations regarding Provision of Early Intervention Programs for Children with Hearing Loss

- 95% of all newborns with hearing loss have parents with normal hearing.
- When parents in North Carolina were given a choice
 - In 1995:** 60% chose sign-language options; 40% chose auditory-oral
 - In 2005:** 15% chose sign-language options; 85% chose auditory-oral

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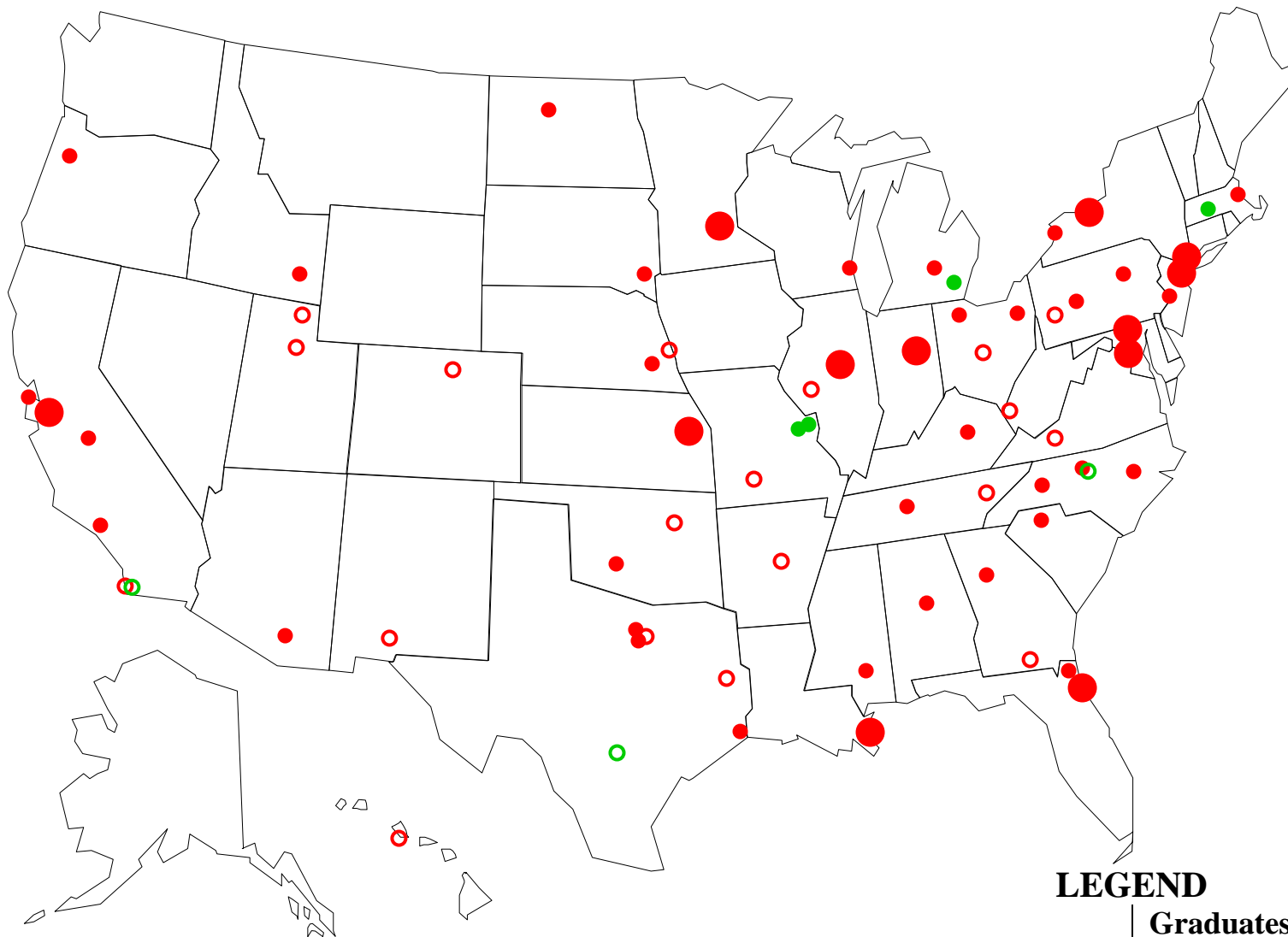
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 - In 1995:** 60% chose sign-language options; 40% chose auditory-oral
 - In 2005:** 15% chose sign-language options; 85% chose auditory-oral
- The number of cochlear implants for children under age 5 has quadrupled in the last 4 years (to 2000+ implants per year)

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Primary Emphasis of University-based Personnel Preparation Programs for Teachers of Deaf and Hard of Hearing

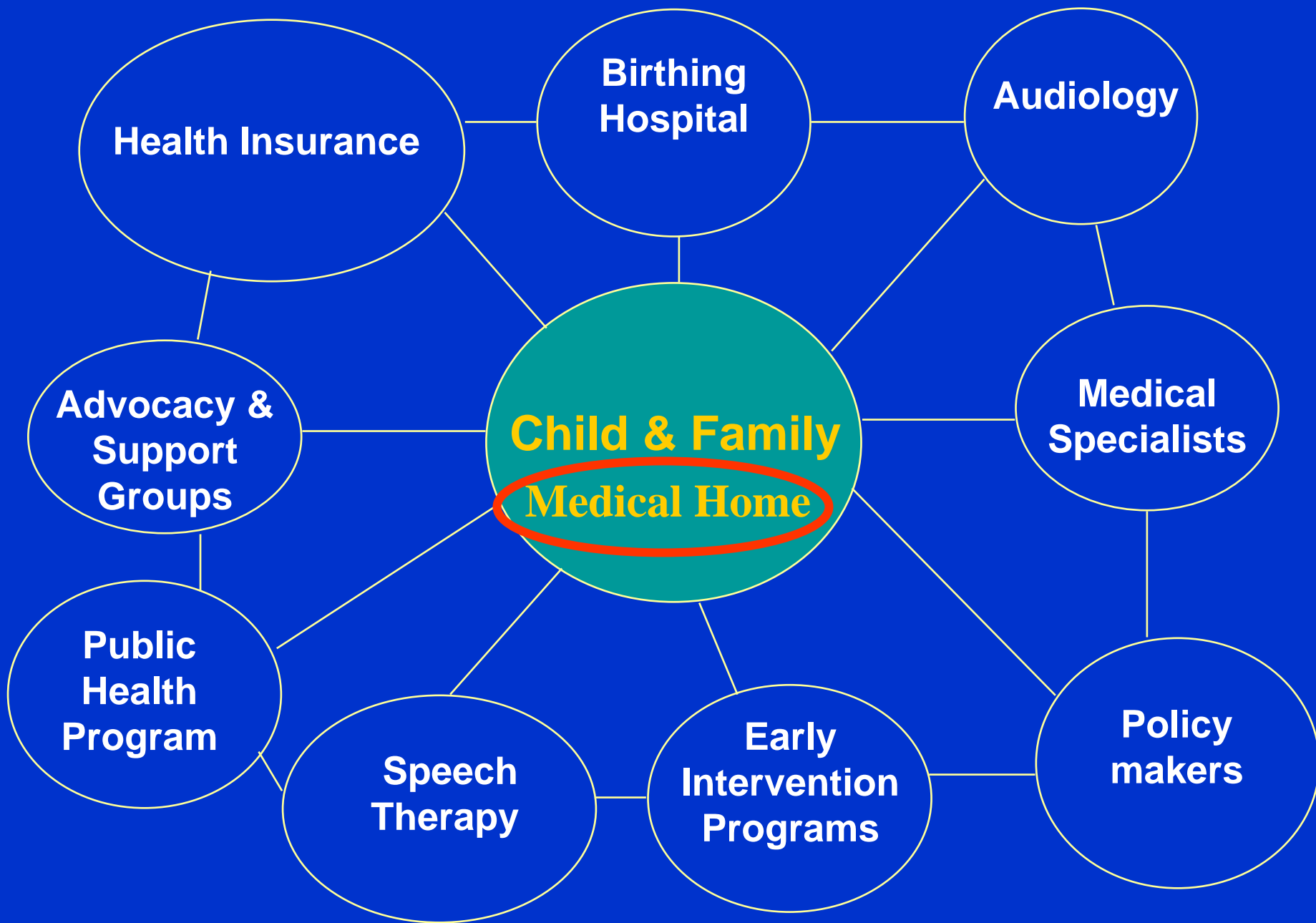


LEGEND

Primary Emphasis	Graduates per Year:		
	1-5	6-15	16+
Sign Language-based	○	●	●
Spoken Language-based	○	●	●

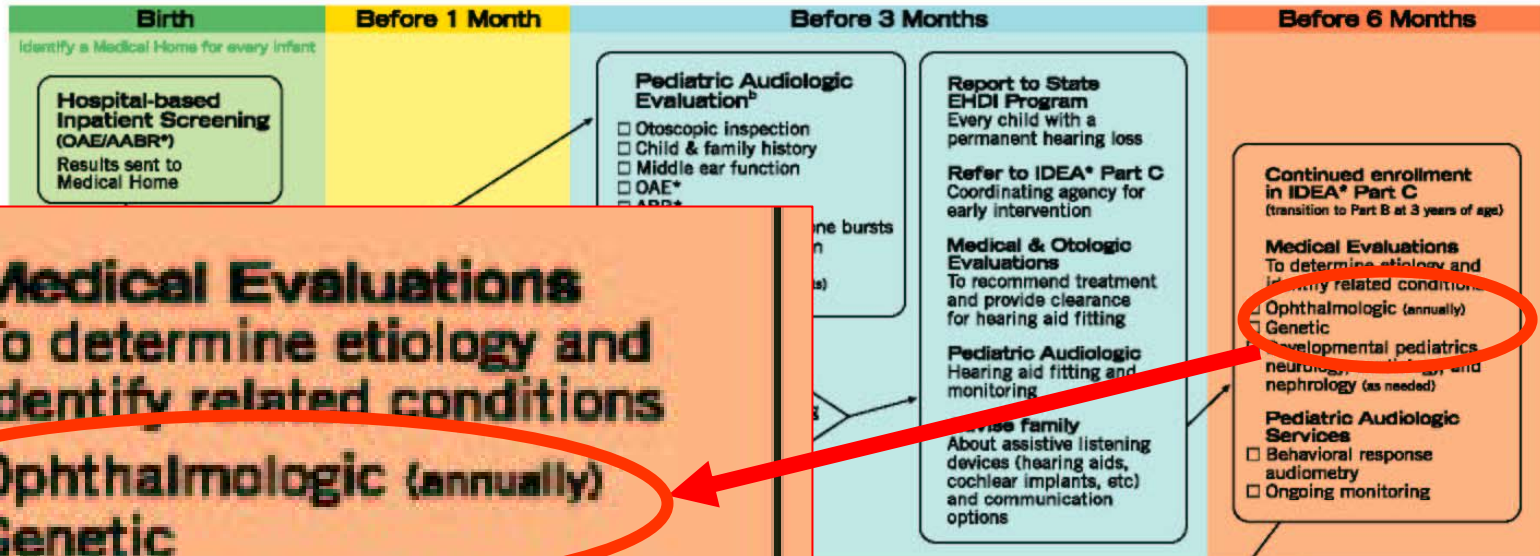
Note: Although many programs describe themselves as providing “comprehensive” services, most have a primary emphasis on a specific approach as indicated by the curriculum offerings, the placement of graduates, the type of practicum available, etc. Classification of programs on this map considered those factors in conjunction with annual self-report survey data from the 2004 and 2005 issues of the *American Annals of the Deaf*.

Partnership is the Key to Successful EDHI Programs



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 audiological 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.

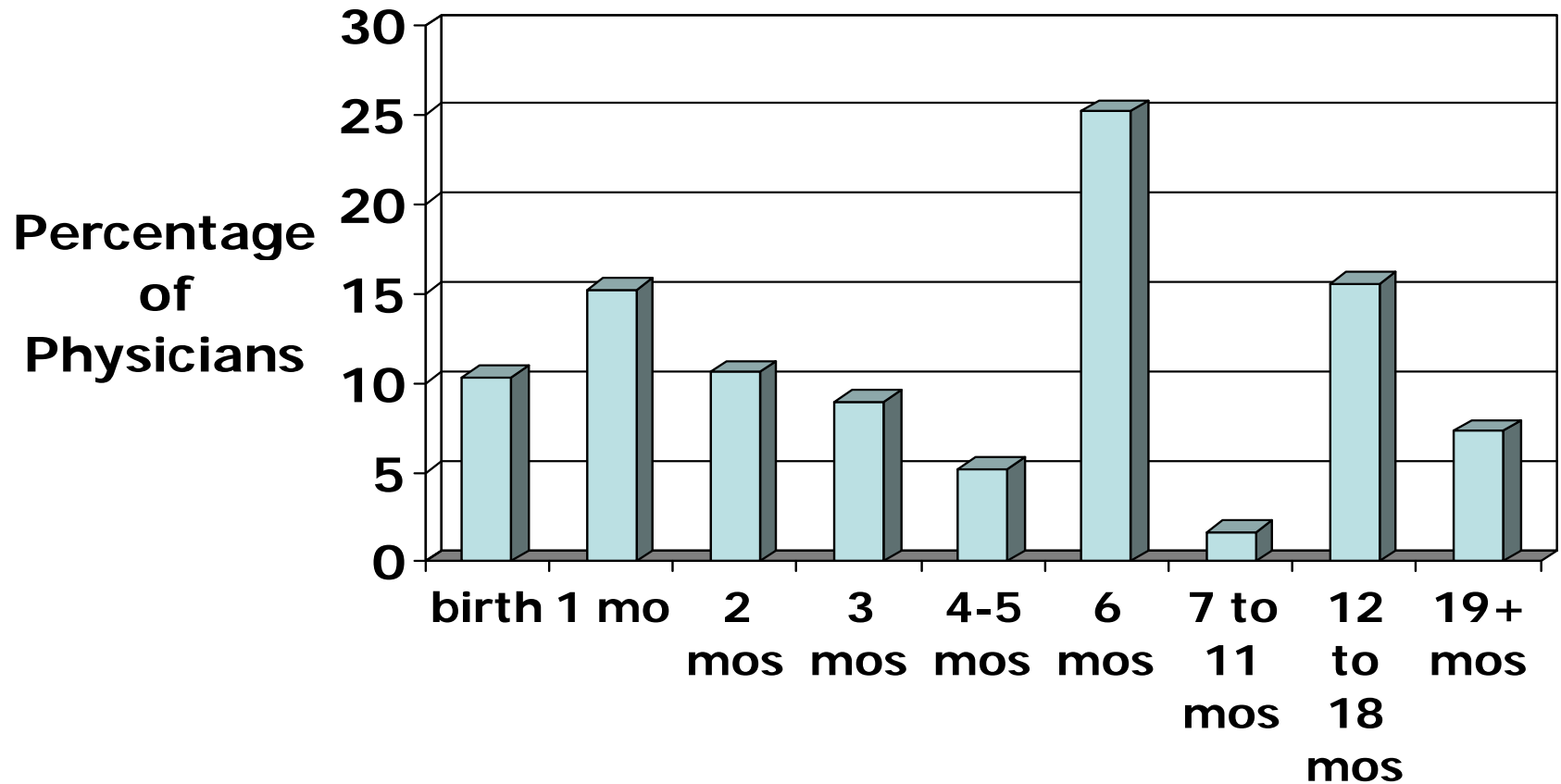
(d) Includes infants whose parents refused initial or follow-up hearing screening.

Educating Primary Health Care Providers About Progress in 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%

When can an infant be fit with hearing aids?



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%

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. 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

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



Hearing Screening During Well Child Visits to Health Care Providers

Early Identification of Hearing Loss



Conducting periodic Otoacoustic Emissions (OAE) hearing screening with infants and toddlers during well-child visits



Helping Children Hear... and Now

NCHAM
National Center for Hearing Assessment and Management
Utah State University


OTICON FONDEN

- 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 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."

issue

W

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should be some help for children.

"That's what blows my mind," Evelyn Paxton says, 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."

Paxton believes, in part, that pervasive ignorance related to deafness and hard-of-hearing issues is to blame.

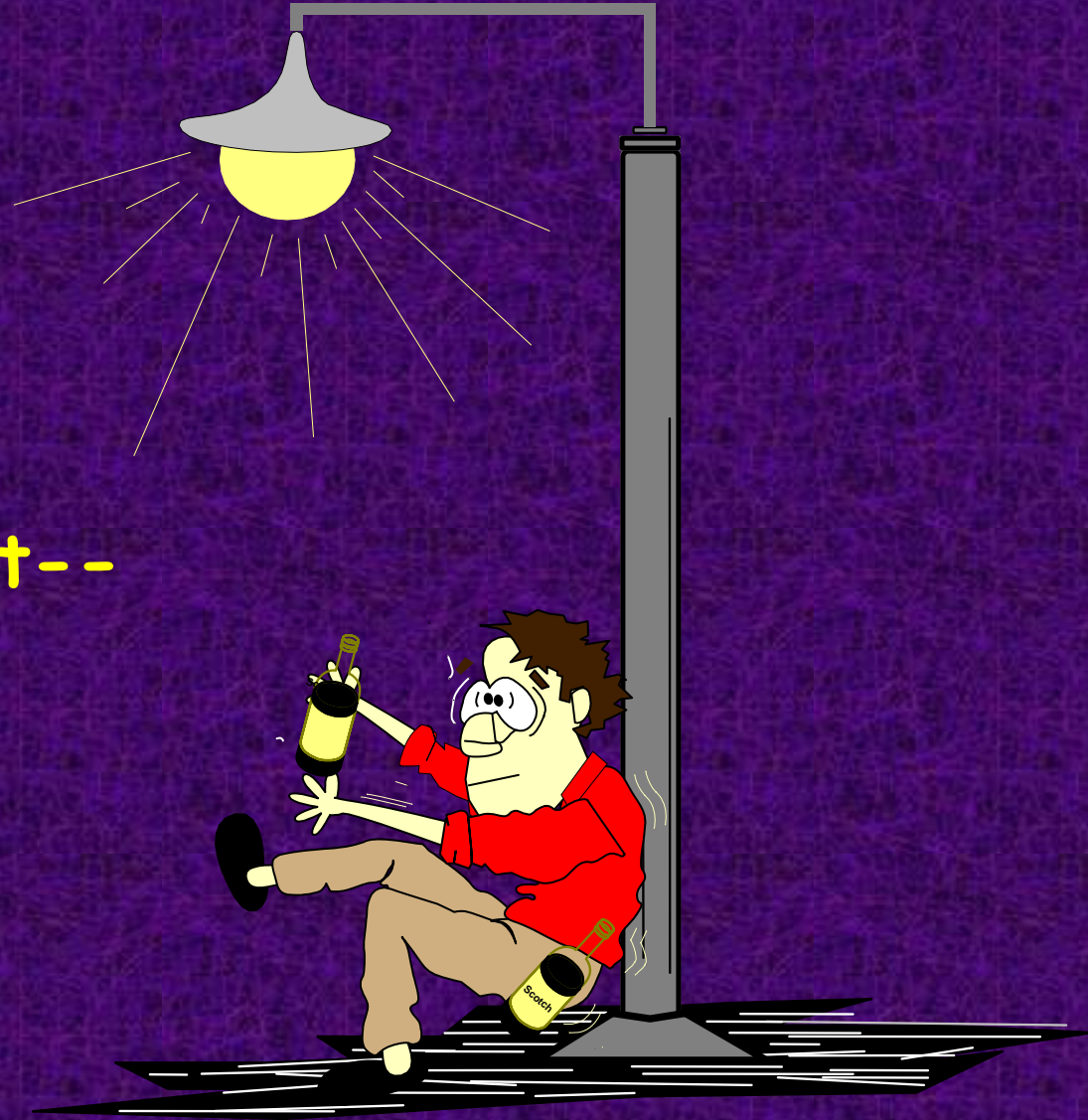
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E-mail: amyjoi@desnews.com

Lesson #8

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

Smith GCS and Pell JP (2003). Parachutes to prevent death an major trauma related to gravitational challenge: Systematic review of randomized controlled trials. *British Journal of Medicine.* 327, pp. 20-27



“Parachutes appear to reduce the risk of injury after gravitational challenge, but their effectiveness has not been proven with randomized controlled trials.”

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lorrylorry

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9. **Avoid sibling rivalries**

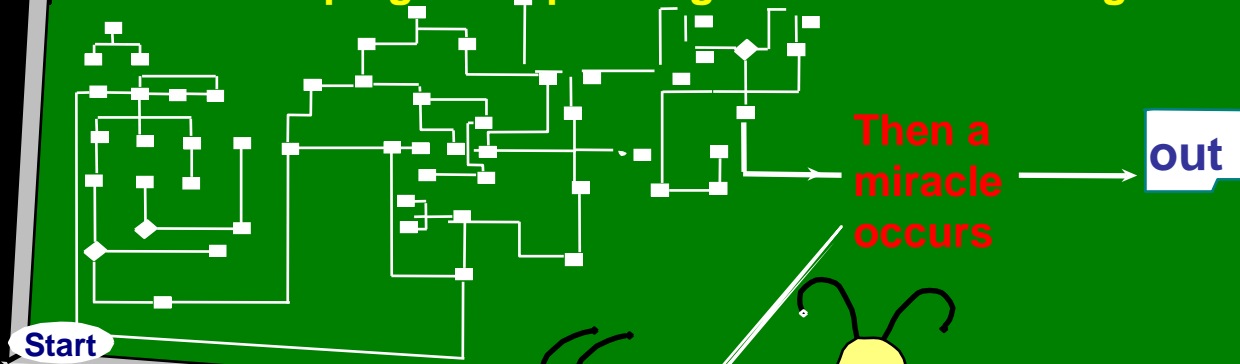
**Never, never, never,
never give up!**



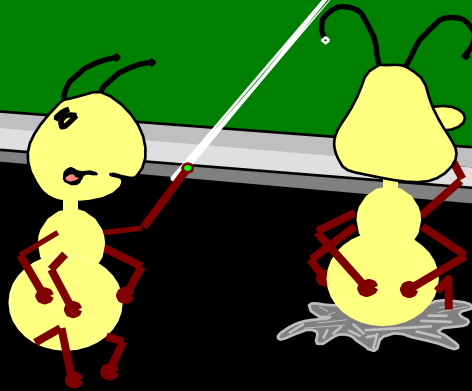
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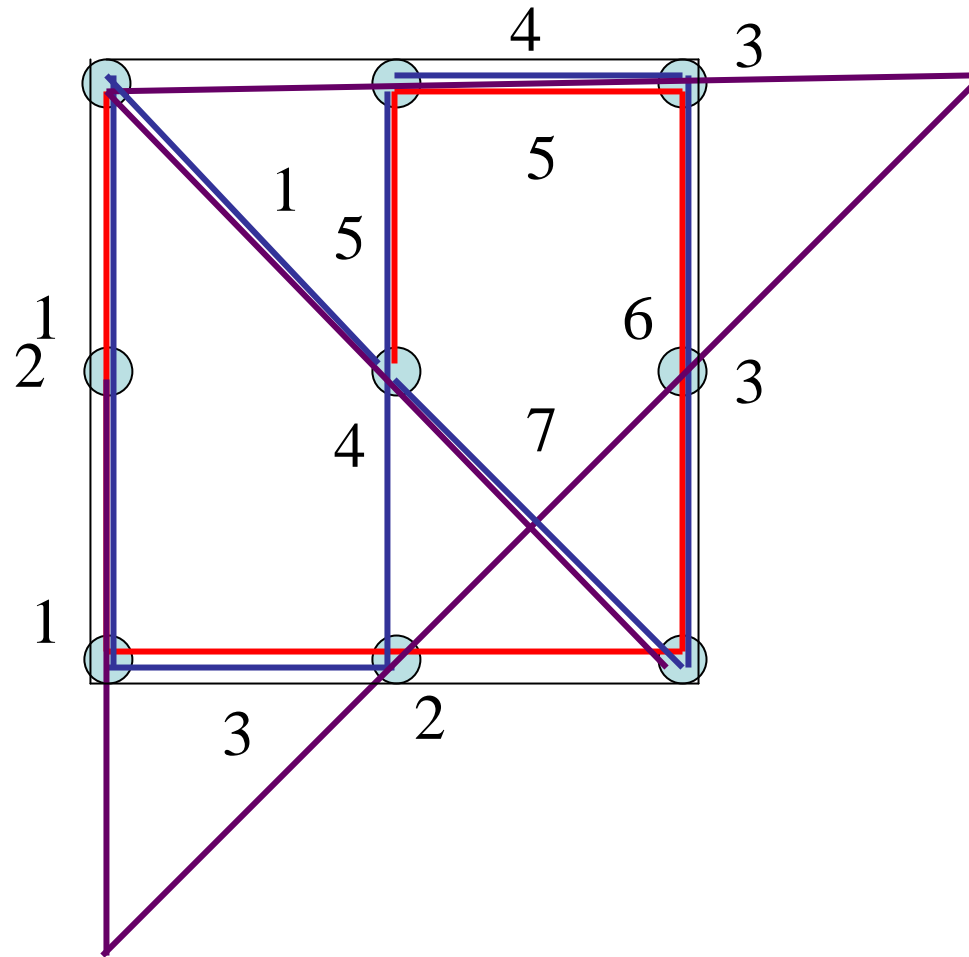
Developing and Operating Effective EHCI Programs



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



Without lifting your pencil off of the paper, draw 4 straight lines that connect all of the dots



Think Outside the Box!



**Stopping by the woods
on a snowy evening**

**Whose woods these are I think I know.
His house is in the village, though;
He will not see me stopping here
To watch his woods fill up with snow. . .**

**The woods are lovely, dark, and deep,
But I have promises to keep,
And miles to go before I sleep,
And miles to go before I sleep.**

---Robert Frost



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