Strategies for Reducing Loss to Follow-up in EHDI Programs

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Why All This Concern About "Follow-up"?

- **Concrete**
- **Easily defined**
- **"bottom line" summary of whether we are achieving our goals**

- **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)

Rate Per 1,000 of Permanent Childhood Hearing Loss in UNHS 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 (1/2004 – 12/2004)	78,515	2.87

Rate Per 1000 of Permanent Childhood Hearing Loss in UNHS Programs

Site	Sample Size	Prevalence Per 1000	% of Refers with Diagnosis
Rhode Island (3/93 - 6/94)	16,395	1.71	42%
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 (1/2004 – 12/2004)	78,515	2.87	89%

Tracking "Refers" is a Major Challenge

	Births	Screened	Initial Refer	Rescreen	Rescreen Refer
Rhode Island (1/93 - 12/96)	53,121	52,659 (99%)	5,397 (10%)	4,575 (85%)	677 (1.3%)
Hawaii (1/96 - 12/96)	10,584	9,605 (91%)	1,204 (12%)	991 (82%)	121 (1.3%)
New York (1/96-12/96)	28,951	27,938 (96.5%)	1,953 (7%)	1,040 (53%)	245 (0.8%)

Data Required for MCHB Project Annual Reports

- # of infants screened
- # of infants referred for audiologic diagnosis
- # and age of infants receiving audiologic diagnosis (before 3 months)
- # of infants
  - in a medical home
  - connected with family-to-family support
- # and age at which identified infants are enrolled in early intervention services (before 6 months)

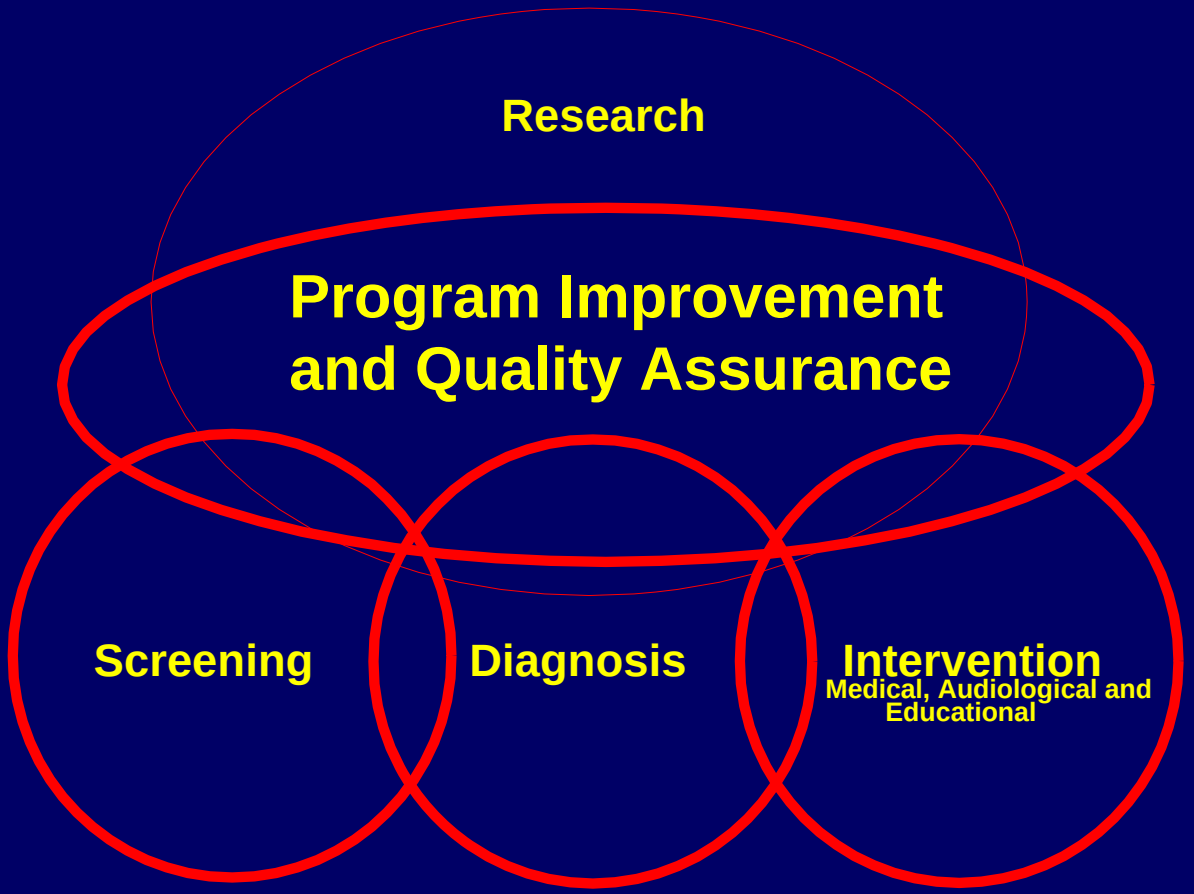
Examples of JCIH Benchmarks and Quality Indicators

- % of infants screeened during birth admission
- % of infants who do not pass birth admission screen
- % of families who refuse hearing screeening
- % of infants and families whose care is coordinated between the medical home and related professionals
- % of infants with completed audilogic and medical evaluations by 3 months of age
- % of infants with confirmed hearing loss :
  - referred for otologic evaluation
  - that have a signed IFSP by 6 months of age
- % of infants with hearing aids receiving audiologic monitoring at least every 3 months

CDC EHDI Reporting System

- # of live births
- # screened prior to discharge
- # screened before 1 month of age
- # referred from screening for audiologic evaluation
- # with audiological diagnosis by 3 months of age
- # with permanent congenital hearing loss (0-7 years)
- Hearing loss classified by type, degree and laterality
- Average/median age at which hearing loss diagnosised
- # of infants receiving intervention by 6 months of age

Purposes of an EHDI Data System



Nature and Use of Information is Different For:

Hospitals

State Departments of Health

National Agencies

What Will Be Done With the Data?

- Tracking/scheduling related to screening, follow-up, diagnosis, and intervention
- Communication with stakeholders (e.g., parents, physicians, audiologists)
- Reporting to funding and administrative agencies
- Program management, quality control, and risk management

Statewide EHDI Data System

Monitoring program status to identify in-service and technical support needs.

Safety net for babies who "fall through the cracks"

Assisting with follow-up / enrollment for diagnostic and intervention programs

Access to data for public health policy and administrative decisions.

Linking to other Public Health Information databases (e.g., Immunization, WIC, Vital Statistics, Early Intervention, Birth Defects)

Examples of Benefits from Linking EHDI Database with Other Public Health Information Systems

- An infant referred from the hospital-based UNHS program, but lost to follow-up, could be identified and provided with EHDI services when he or she comes in for the DPT Immunization at eight weeks of age.
- By linking the Birth Defects Registry and EHDI data, children with birth defects that make them substantially more likely to develop late onset losses could be monitored and provided with assistance at a much earlier time.
- Many of the children who become “lost” for immunizations or birth defects tracking are the same children who are lost for EHDI. By sharing information, fewer resources are needed to more successfully find and provide services to “lost” children.
- Linking the EHDI and vital statistics allows a population-based system to be created so that every live birth in the state is included in the EHDI system.
- Linking EHDI to vital statistics substantially expands the types of epidemiological studies that can be done.

Hospitals Most Likely to Participate in a State EHDI Database If:

it provides locally useful data

gathering data is quick

transfer to the state is trouble-free

it reduces other reporting requirements

It reduces risk

Reducing Loss to Follow-up Is More Than a Good Tracking and Data Management System

- **Inadequate, slow, or incorrect transmission of information among stakeholders** (e.g., hospitals, physicians, state EHDI program).
- **Family demographics** (e.g., income, education, single working parent, etc.)
- **Lack of resources to manage follow-up activities**
- **Shortage of qualified professionals to do diagnostic evaluations** (exacerbated by low reimbursement, access from remote areas, etc)
- **Lack of knowledge among health care providers**
- **Inadequate public awareness**

Efficiency of Early Hearing Detection and Intervention in Utah

Year	**2000**	**2002**
Hospital Births	**47,631**	**49,134**
Inpatient Screened	**97%**	**99%**
Inpatient Passed	**87%**	**91%**
10 most effective hospitals	93%	96%
10 least effective hospitals	63%	75%
Outpatient Completed (ie, passed or referred)	**74%**	**77%**
10 most effective hospitals	96%	95%
10 least effective hospitals	53%	58%
% Referred for Dx still in-process or not evaluated	**27%**	**41%**

Utah Loss to Follow-up Study
(January – April 2003)

- Hospitals submitted data weekly instead of monthly
- Hired .25 FTE “follow-up specialist” to:
  - Contacted each hospital screening coordinator weekly
  - Called parents and schedule appointments
  - Tracked down missing phone #’s and addresses
- Spanish speaking assistant available whenever needed
- Home visits made in some cases

Summary Report

Comparison of results between Study and Non-Study hospitals

	NON-STUDY		STUDY
Births	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%**

Lessons from the Head Start Hearing Screening Program

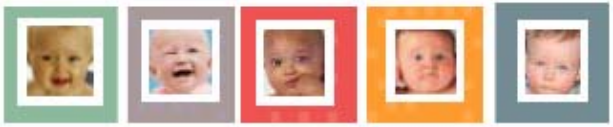
3,486 children in 69 programs screened during 2001-2004

80 children identified with treatable hearing loss…6 with permanent hearing loss

Where else should early childhood hearing screening be happening?

- Part C Programs
- Medical Homes
- WIC Programs
- Day Care Programs

hear and now .org



Help your child hear. And now.

- Parents
- Health Care Providers
- Resources
- Take Action
- About Us

versión en Español

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?

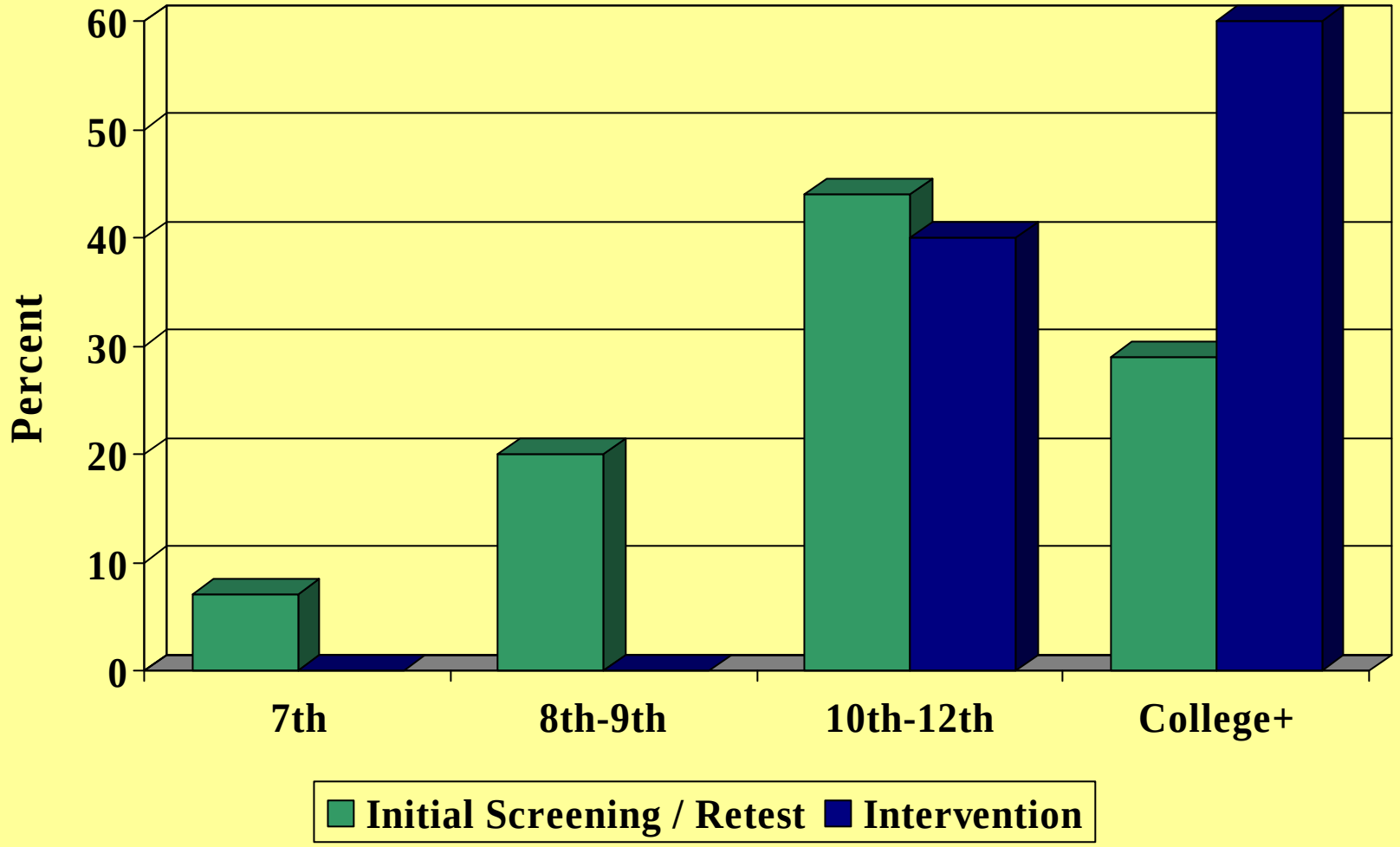
If you don't see your question click here.

Parent Educational Materials Developed by State EHDI Programs

(How Effective Are They?)

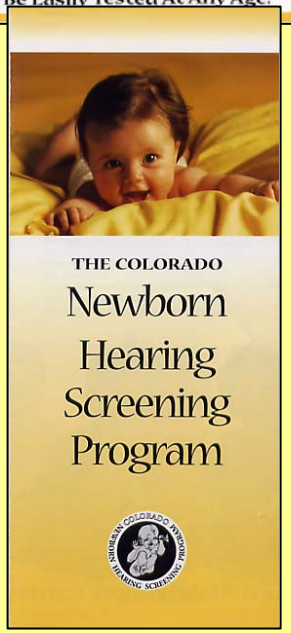
Brochure Readability

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.”



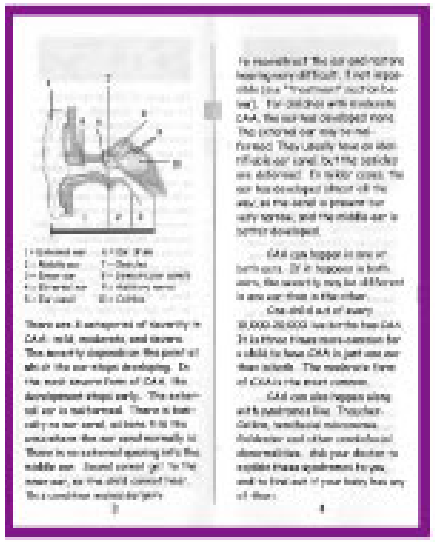
1. Is the layout user-friendly?

First impressions are important!

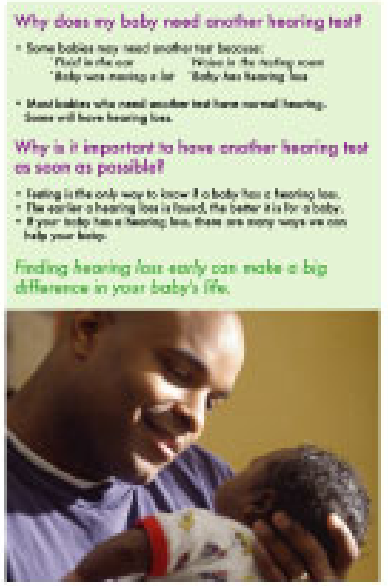
Does the pamphlet:

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

Examples that illustrate key points:



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



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

Delta Zeta Sorority
Sound Beginnings

Together we can make a difference in the lives of babies!

Partnerships are the Key to Success