

# 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

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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

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# Rate Per 1000 of Permanent Childhood Hearing Loss in UNHS Programs

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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%

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# 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

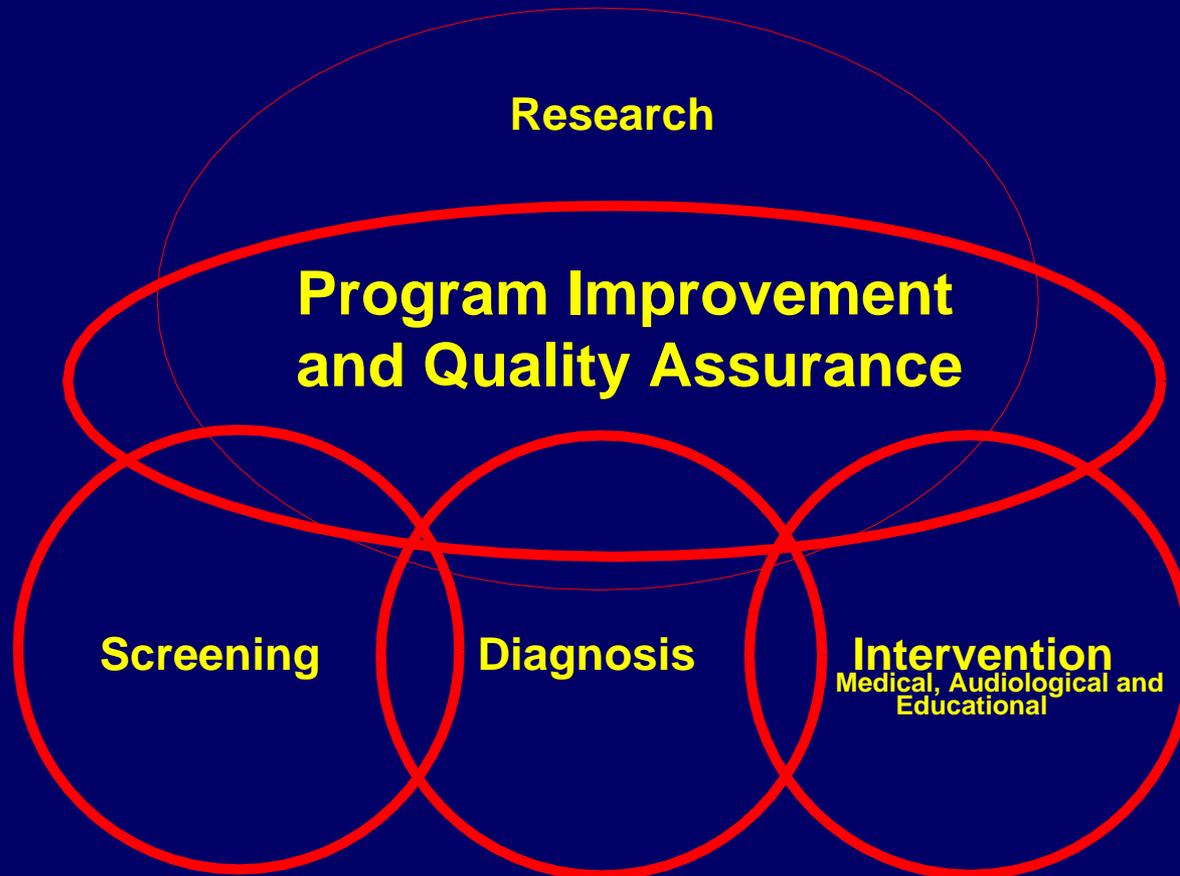
- **% of infants screened during birth admission**
- **% of infants who do not pass birth admission screen**
- **% of families who refuse hearing screening**
- **% of infants and families whose care is coordinated between the medical home and related professionals**
- **% of infants with completed audilogic 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 audilogic 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 diagnosed
- # of infants receiving intervention by 6 months of age

# Purposes of an EHDI Data System

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# **Nature and Use of Information is Different For:**

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**Hospitals**

**State Departments of Health**

**National Agencies**

# What Will Be Done With the Data?

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- **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

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**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

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- **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:

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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

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

# Utah Loss to Follow-up Study

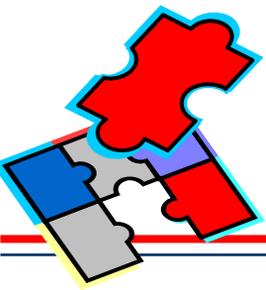
(January – April 2003)

- 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

	<u>NON-STUDY</u>	<u>STUDY</u>
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



Parents

**What do I do if my baby failed a hearing screening test?**

Health Care Providers

**Was my baby's hearing screened?**

Resources

**I am worried my child doesn't hear well.**

Take Action

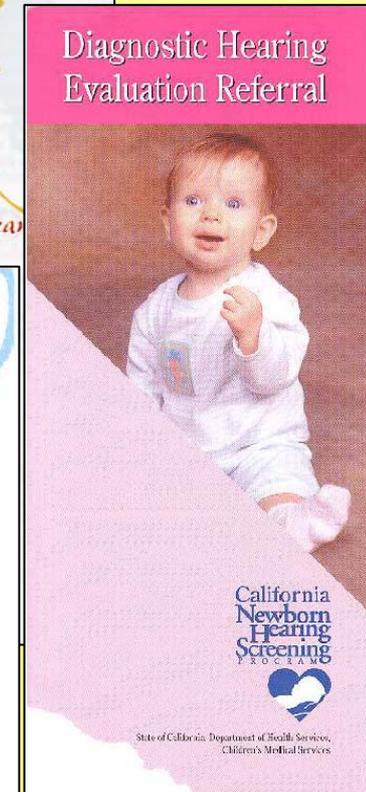
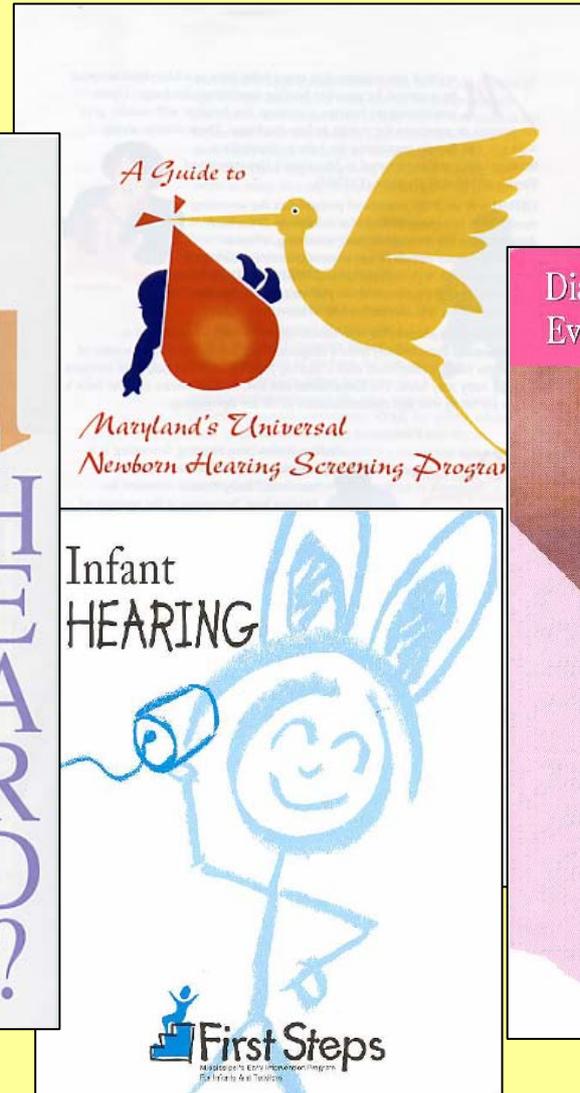
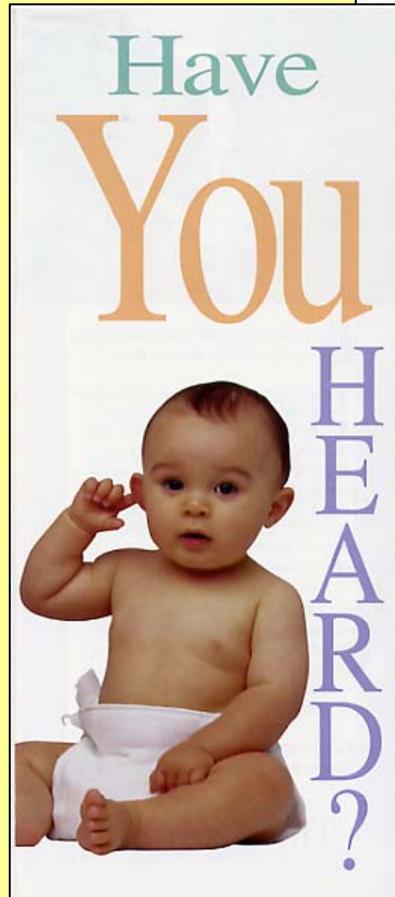
**Why is hearing so important for children?**

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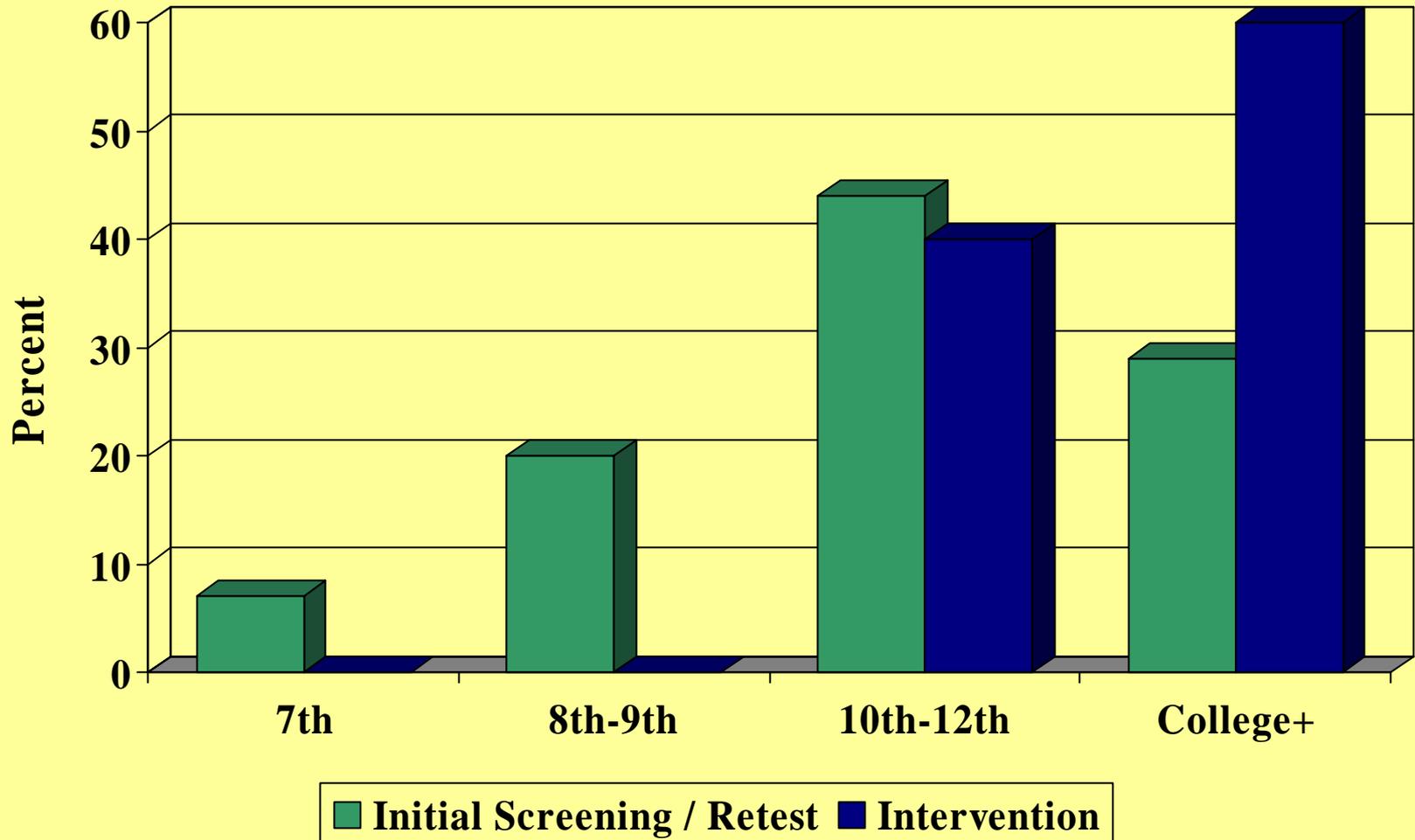
If you don't see your question click here.

# Parent Educational Materials Developed by State EHDI Programs (How Effective Are They?)



# Brochure Readability

*Gold Standard Readability:  $\leq 6$ th 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.”



**Why Should My Baby's Hearing Be Screened?**  
One out of every 100 babies has a significant hearing loss at birth. More than half of babies born with hearing problems are otherwise healthy and have no family history of hearing loss. Therefore, to be sure we identify every baby with hearing loss, hospitals in Colorado are required to either screen babies for hearing loss or to provide information to parents on where to obtain an infant hearing screening.

Of course it is unlikely that your baby will have a hearing loss. However, it is important for you to be sure that your baby has normal hearing. The first year of life is critical to the development of normal language and speech.

**How Will My Baby's Screening Test Be Done?**  
There are two types of hearing screening tests that may be used with your baby. Auditory Brainstem

Response Testing (ABR) tests the infant's ability to hear soft sounds through miniature earphones. Sensors measure your baby's brainwaves to determine if the sounds are heard normally. Otoacoustic Emissions (OAE) are measured directly with a miniature microphone and sent to a special computer to determine your baby's hearing status. Both tests are very safe and take only minutes to do each ear. Most babies sleep through the hearing screening tests.

**What If My Baby Does Not Pass The Test?**  
There are many reasons your baby may not "pass" the first hearing test and require a second evaluation. Perhaps your baby was too tired, too wide-awake, or you were discharged before the procedure was completed.

**It is important that you follow through with any recommendations made by your hospital staff, audiologist and/or physician.**

**If My Baby Passes The Screening, Do I Need To Have The Hearing Checked Again?**  
The hearing screening test can usually confirm that your baby has normal hearing at the time of the procedure. However, hearing loss can develop later after you leave the hospital for a variety of reasons. If you have a family history of hearing loss, your baby should be tested every year. For infections that occur as you and/or your baby are also cause hearing loss.

**If you ever have concerns about your child's hearing, speech or language, be sure to discuss this with your audiologist and/or physician.**

**Your Baby's Hearing Can Be Easily Tested At Any Age!**



THE COLORADO  
Newborn  
Hearing  
Screening  
Program



# 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.

### Why does my baby need another hearing test?

- Some babies may need another test because:
  - Child is the one
  - Baby was missing a test
  - Baby has hearing loss
- Most babies who need another test have normal hearing. Some will have hearing loss.

### Why is it important to have another hearing test as soon as possible?

- Testing is the only way to know if a baby has a hearing loss.
- The earlier a hearing loss is found, the better it is for a baby.
- If your baby has a hearing loss, there are many ways we can help your baby.

Finding hearing loss early can make a big difference in your baby's life.



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

