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)
<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>41,976</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 (1/2004 – 12/2004)</td>
<td>78,515</td>
<td>2.87</td>
</tr>
</tbody>
</table>
### Rate Per 1000 of Permanent Childhood Hearing Loss in UNHS Programs

<table>
<thead>
<tr>
<th>Site</th>
<th>Sample Size</th>
<th>Prevalence Per 1000</th>
<th>% of Refers with Diagnosis</th>
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<tr>
<td>Rhode Island (3/93 - 6/94)</td>
<td>16,395</td>
<td>1.71</td>
<td>42%</td>
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<tr>
<td>Colorado (1/92 - 12/96)</td>
<td>41,976</td>
<td>2.56</td>
<td>48%</td>
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<tr>
<td>New York (1/96 - 12/96)</td>
<td>27,938</td>
<td>1.65</td>
<td>67%</td>
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<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 (1/2004 – 12/2004)</td>
<td>78,515</td>
<td>2.87</td>
<td>89%</td>
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## Tracking "Refers" is a Major Challenge

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

- Screening
- Diagnosis
- Intervention (Medical, Audiological, and Educational)

Program Improvement and Quality Assurance

Research
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

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

<table>
<thead>
<tr>
<th></th>
<th>NON-STUDY</th>
<th>STUDY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Births</td>
<td>11,751</td>
<td>4,540</td>
</tr>
</tbody>
</table>

### INPATIENT RESULTS

<table>
<thead>
<tr>
<th></th>
<th>NON-STUDY</th>
<th>STUDY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Screened</td>
<td>98.7%</td>
<td>99.0%</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>1.1%</td>
<td>0.6%</td>
</tr>
<tr>
<td>Deceased</td>
<td>0.2%</td>
<td>0.4%</td>
</tr>
</tbody>
</table>

### OUTPATIENT RESULTS

<table>
<thead>
<tr>
<th></th>
<th>NON-STUDY</th>
<th>STUDY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>1,026</td>
<td>345</td>
</tr>
<tr>
<td>Passed</td>
<td>59.0%</td>
<td>84.6%</td>
</tr>
<tr>
<td>Not Screened</td>
<td>32.9%</td>
<td>11.0%</td>
</tr>
<tr>
<td>Referred</td>
<td>8.1%</td>
<td>4.3%</td>
</tr>
</tbody>
</table>

### STATUS Dx EVALUATION

<table>
<thead>
<tr>
<th></th>
<th>NON-STUDY</th>
<th>STUDY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>134</td>
<td>23</td>
</tr>
<tr>
<td>Normal Hearing</td>
<td>21.6%</td>
<td>39.1%</td>
</tr>
<tr>
<td>Lost/Refused</td>
<td>1.5%</td>
<td>8.7%</td>
</tr>
<tr>
<td>In Process</td>
<td>67.9%</td>
<td>26.1%</td>
</tr>
<tr>
<td>Confirmed Loss</td>
<td>9.0%</td>
<td>26.1%</td>
</tr>
</tbody>
</table>
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
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

Percent

7th 8th-9th 10th-12th College+

Initial Screening / Retest Intervention

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:

*Why does my baby need another hearing test?*

- Some babies may need another test because:
  - Poorly in the ear
  - Noise in the testing room
  - Baby was moving a lot
  - Baby has hearing loss
  - Infant breech, over- or under-developed head
  - Should be followed up with specialists

*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 the 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.*
Delta Zeta Sorority
Sound Beginnings

Together we can make a
difference in the lives of babies!
Partnerships are the Key to Success

- Parent Groups
- Birthing Hospital
- Audiology
- ENT
- Genetics
- Community Services
- 3rd Party Payers
- Services for Hearing Loss
- Early Intervention Programs

Primary Health Care Provider
Child/Family