Developing an Effective EHDI Tracking System in Alaska

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Alaska’s EHDI Program

- 2000 – Voluntary program – paper reporting
- 2005 – Database goes “live”
- 2006 – State law is passed mandating Newborn Hearing Screening, Tracking and Intervention Program
- January 2008 – law and regulations take effect
Provisions of Statute and Regulations

- Birth Screen Providers - Goal: all newborns screened by 1 month of age
  - Notify parents and primary care provider of the results of the birth screen
  - Weekly entry into the EHDI database of all hospital births and outcomes including screening results, missed screenings, refusals
  - Referral for rescreening and/or referral to audiology
Provisions of Statute and Regulations

- Audiology – Goal: Audiologic diagnostic assessment by 3 months of age

- **Monthly** reporting of assessment and diagnosis to the EHDI Program

- Early Intervention referral information reported to the EHDI Program
Provisions of Statute and Regulations

- Early Intervention – Goal: all infants with a confirmed hearing loss enrolled in intervention services by 6 months of age

  - MOA – signed between EHDI and Part C for reporting children enrolled in early intervention services to the EHDI Program

  - Goal – Obtain a signed release of information at the time of enrollment in early intervention services to report to EHDI
Current Status of Screening

- Screening equipment in all **21 birthing hospitals** in Alaska

- Screening equipment placed in 8 **Public Health Centers** where hospitals have few births per year or communities with a high rate of home or midwifery births.

- **2007– 92.5%** of all Alaskan newborns were screened – over 10,000 infants
  - approx. 5% of infants born out of hospital
Tracking Infants Needing Follow-Up

- All hospital facilities and public health centers report into database

- Data Provisions: demographics, infants screened, screening results, audiology results, children diagnosed with hearing loss, referrals for case management and early intervention

- EHDI Database linked with Newborn Metabolic Screening data January 2008.
Implementing Effective EHDI Programs

Then a miracle occurs

Start

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

More detail........

Tracking infants who missed or referred on screening
Beginning a Tracking System

- 2007 -- Birth screeners reported *initial* screens in database – follow-up screens not always documented

- Infants transferred to another facility often created duplicate records

- Need to ensure screening results are given to medical home and parents
FIRST ATTEMPTS

- Generated lists of names from database of infants “in process”
  - Contacted primary care providers by fax and telephone calls – calls and faxes not generally not returned – time consuming
  - Telephone calls to parents – unclear results
  - No system for documenting of progress
Follow-up for Infants with a Missed or Failed Screening

- Reports generated from EHDI data base of infants with a missed or failed hearing screening – name, birth date, screening result, parents name

- Developed monthly “fax back” system to communicate with birth screen providers
### Fax - Back Report

<table>
<thead>
<tr>
<th>Last Name</th>
<th>First Name</th>
<th>DOB</th>
<th>Birth Screen</th>
<th>Outpatient</th>
<th>Contact Last Name</th>
<th>City</th>
<th>State</th>
<th>Zip Code</th>
<th>COMMENTS</th>
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<tbody>
<tr>
<td>George</td>
<td>Boy</td>
<td>12/14/2008</td>
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<td>Required - Not Scheduled</td>
<td>George</td>
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<td>Pipi</td>
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<td>MTN VILLAGE</td>
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<tr>
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<td>Ron</td>
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<td>Required - Not Scheduled</td>
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<td>BARROW</td>
<td>AK</td>
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<tr>
<td>Potter</td>
<td>Harry</td>
<td>12/22/2008</td>
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<td>Required - Not Scheduled</td>
<td>Dumbledore</td>
<td>WASILLA</td>
<td>AK</td>
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<tr>
<td>Rabbit</td>
<td>Jessica</td>
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<td>Christmas</td>
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<td>Swan</td>
<td>Bella</td>
<td>12/4/2008</td>
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Report Completed by Facility Faxed Back to EHDI Program

- Status of follow-up screenings
- Parent Contacts
- Referrals to Audiology
Next Step

- Letter to Parent
  - Milestone Checklist
  - Hearing Screening Location Card
  - Alaska EHDI Brochure
- Certified Letter to Physician
  - Hearing Screening Location Card
What We Learned

- Duplicates
- Missed/undocumented data
- Facilities returning fax back report can account for the screening status of their patients
Adapt Process

- Private Hospitals
- Indian Health System
- Military
Challenge of A Site Visit...
### Hospital A Births in 2007 = 445

<table>
<thead>
<tr>
<th>Year</th>
<th>Before Clean Up</th>
<th>After Clean Up</th>
<th>Preliminary 2008</th>
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Hospital A Births in 2007 = 445
### Hospital B Births in 2007 = 360

<table>
<thead>
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<th>Year</th>
<th>Before Clean Up</th>
<th>After Clean Up</th>
<th>Preliminary 2008</th>
</tr>
</thead>
<tbody>
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<td></td>
<td>Refer</td>
<td>Missed</td>
<td>Refer</td>
</tr>
<tr>
<td>2007</td>
<td>24</td>
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<td>13</td>
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<tr>
<td>2008</td>
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</table>

**Hospital B Births in 2007 = 360**
Hospital C Births in 2007 = 722

Before Clean Up | After Clean Up | Preliminary 2008
---|---|---
2007
Refer | Missed | Refer | Missed | Refer | Missed
21 | 50 | 19 | 38 | | |
2008
Refer | Missed | Refer | Missed | Refer | Missed
8 | 2 | | | |
Challenges

- Follow-up on “refers”
- Staff changes and shortages throughout EHDI system
- Access to audiology for diagnostic follow-up
- Infants who return to remote communities
Infants Born Out of Hospital

- Statute addresses notification by Bureau of Vital Statistics (monthly) to EHDI Program of infants delivered outside of a hospital.

- EHDI Program to notify parents of the merits of newborn hearing screening.

- Names checked against database and letters generated.

- Match with Newborn Metabolic Screen.

- Certified Letter sent to Parents.
WHAT TO WATCH FOR...
A Check List | YOUR BABY’S HEARING

Post and use this Hearing Checklist. If you suspect your baby can’t hear, call your baby’s doctor or nurse as soon as possible. Your baby is counting on you.

BIRTH TO THREE MONTHS...
B-3

- Startles to sudden loud noises
- Shies, wakes up, or cries to loud sounds
- Soothes or calms to your voice
- Makes cooing sounds

THREE TO SIX MONTHS...
3-6

- Begins to turn eyes or head to sounds
- Stares intently at moving objects
- Awakens easily to sounds
- Begins making vowel sounds such as “ah” and “ou”

SIX TO NINE MONTHS...
6-9

- Looks for family members when named
- Turns head towards sounds
- Will respond to own name
- Responds to simple requests with gestures
- Begins babbling such as “baba” and “mamama”
- Uses voice to get your attention

NINE TO TWELVE MONTHS...
9-12

- Understands “No”, “Bye bye”
- Responds to soft sounds
- Looks at pictures when named
- Repeats simple sounds that you make
- Uses voice when playing alone
Contacts

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Please contacts us for information or materials.