Strategies for Reducing Loss to Follow-Up in EHDI Programs

Hallie Morrow, M.D.
Jennifer Sherwood, M.A.

California Department of Health Care Services,
Newborn Hearing Screening Program
California Program Statistics

2008 Program Data

- Total births: 552,618

- Total screened prior to hospital discharge: 511,830
  - 93% of California births
California Program
Hospital Statistics

- Refer rate: 2.0%
- Miss rate: 0.2%
- Waive rate: 0.1%
California Program Statistics

• Identified with hearing loss: 832
  o Incidence 1.6/1000 screened
  o Identified by 3 months of age: 553 (66%)

• Enrolled in Early Start: 718 (86%)
  o By 6 months of age: 494 (69%)
CA Lost to Follow Up Rates

- Did not pass final screen=14.5%
- Left hospital needing outpatient follow-up=3.9%
Geographic Service Areas
HCC Responsibilities

- Hospital Certification
- Quality Assurance Monitoring
- Infant Tracking and Monitoring
Hearing Coordination Center Staff

- Director
- Audiologist
- Registered Nurse
- Clerical Support
- Parent
The Process of the CA NHSP

WBN

NICU*

Outpatient Re-screen*

Pass

Refer

Diagnostic Evaluation

*ABR required for NICU
Hospital Responsibilities

- Hospitals that have been certified by the HCC report individual results on babies that have:
  - Referred
  - Missed
  - Waived
  - Expired
  - Transferred
  - Been determined not medically indicated by a physician
Hospital Responsibilities

• For Infants who refer, the Hospital must:
  o Schedule an appointment for outpatient screening
  o Give family appointment info at discharge
  o Report the appointment to the HCC with inpatient screening results
  o Identify PCP
  o Get second contact
Hospital Responsibilities

- For Infants who are missed, the Hospital must:
  - Contact the family and schedule the follow up appointment
  - Report the appointment to the HCC
  - Identify PCP
  - Get second contact
# NEWBORN HEARING SCREENING

## Infant Reporting Form

### Inpatient Screen

<table>
<thead>
<tr>
<th>IP Screening</th>
<th>RIGHT Ear</th>
<th>LEFT Ear</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE of Screening</td>
<td>ABR, DPOAE</td>
<td>ABR, DPOAE</td>
</tr>
<tr>
<td>TYPE of Screening (Circle one)</td>
<td>TEOAE</td>
<td>TEOAE</td>
</tr>
<tr>
<td>RESULT (Circle one)</td>
<td>PASS</td>
<td>PASS</td>
</tr>
<tr>
<td></td>
<td>REFER</td>
<td>REFER</td>
</tr>
</tbody>
</table>

**Inpatient Screen**

- [ ] Not Done (Fax completed form to HCC)
  - Transferred out to: ____________________________ Hospital on (date): ____________
  - Missed; discharged without screen (Complete Follow-Up section below)
  - Waived (Face Sheet not required) [ ] NHSP Brochure given to parent
  - Expired or physician determined screening not medically indicated (Face Sheet not needed)
  - Baby has atresia [ ] Bilateral [ ] Unilateral: right [ ] left (Circle one) (Complete Follow-Up section below)

**Follow-Up for Refers/Missed**

- [ ] Parent/Legal Guardian information on face sheet verified/updated
  - Primary Language (Circle one): English [ ] Spanish [ ] Other: ____________
  - Second contact information/relative or friend verified/updated on face sheet or below
    - Contact Name: ____________________________ Phone: ____________________________
    - Address: ____________________________
    - City/Zip: ____________________________
    - Primary Language (Circle one): English [ ] Spanish [ ] Other: ____________

- [ ] Print Infant’s Full/Legal Name: ____________________________
- [ ] NHSP Brochure given to parent (Circle one): Refer [ ] Refer to DX
- [ ] Follow-Up Appointment made and written on Parent brochure:
  - APPOINTMENT [ ] OP SCREENING [ ] DX EVALUATION RECEIVED BY NICU PATIENTS OR INFANTS WITH ATRESIA
  - DATE: ____________________________ TIME: ____________________________
  - PROVIDER: ____________________________ Phone: ____________________________
  - PCP who will see the infant after discharge: ____________________________
    - Phone: ____________________________

- [ ] Completed form faxed with hospital face sheet
  - P.O. Box: ____________________________
  - Our Hearing Coordination Center at (XXX) XXX-XXXX

- [ ] Completed form faxed with hospital face sheet
HCC Role Following Outpatient Refer Result

- Refer baby to the Title V Children with Special Health Care Needs Program (CCS Program) if not done by OP screener
- Notify diagnostic provider, PCP, and family when an authorization has been issued.
- Obtain appointment information from diagnostic provider
- Contact diagnostic provider if results are not received within 14 days
HCC Role After Hearing Loss is Identified

- Assure referral to the Early Start Program (CA Early Intervention Birth to 3 Program)
- Contact the family 1 week after diagnosis
HCC Role After Hearing Loss is Identified

• Contact family 2 months after diagnosis
  o Assure Early Start Services are being provided
  o Provide parent support
  o Assess the need for community referrals
  o Assure linked with audiology and medical services

• Contact family 6 months after diagnosis
  o Confirm services
  o Offer support
  o Make necessary community referrals
  o Close the case
California Challenges

- Not enough qualified pediatric audiologists
- Diagnostic providers not scheduling appointments; waiting for families to call
- Parents not scheduling or no showing appointments
- Providers not submitting results
- CCS Program delaying or not issuing diagnostic authorizations
HCC Role in Addressing California's Challenges

- Encourage providers to contact families for appointments
- Assist the family in getting the appointment
- Contact family if appointment is cancelled or they no show
- Send letters to the PCP with child’s screening status and enlist the PCPs help if necessary
HCC Role in Addressing California's Challenges

• Referral to the local EPSDT program (CHDP in CA)
  o For families that no show two appointments or can’t be reached after three attempts
• Contact providers for missing results
  o Elevate the problem to the State if there is no resolution
• Establish relationships with the CCS programs for on-going communication regarding authorizations
  o Elevate any problems to the State
National Initiative for Children’s Healthcare Quality (NICHQ)

- Letter to families needing OP follow-up introducing HCC
- Schedule two diagnostic appointments two weeks apart
- 3-way calls to schedule appointments
National Initiative for Children’s Healthcare Quality (NICHQ)

- Liaison in diagnostic provider office for appointment scheduling
- Hospitals submit reporting forms on specific day of week
- Return incomplete Infant Reporting Forms
Tracking a Baby with the CA Process
Tracking and Monitoring Manual

- Five Tracking Categories
  - Outpatient Screen Required
  - Diagnostic Evaluation Required
  - Hearing Loss Identified
  - Infant Transferred between hospitals
  - Infant Resides outside of CA
Tracking and Monitoring Manual

- Provides HCC a framework to follow cases to their conclusion
- Guidance on number and frequency of contacts with providers and families
- Letter content
- When to elevate to the State and when to close a case
- Currently updating to include DMS activities
Tracking and Monitoring Manual

- The manual is available on our website:

http://www.dhcs.ca.gov/services/nhsp
Conclusions

• Procedures implemented regionally in CA can transfer to other state’s programs
• The CA Tracking and Monitoring Manual can be adapted to suit any size program
• Steps can be implemented within any program to put safety nets in to place.
Questions?