Ten Percent Loss to Follow-Up Rate...You Can Get There Too!!

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

2006 Program Data

- Total births: 563,522
- Total screened: 425,638
  - 76% of California births
  - 98% of participating hospitals
California Program Statistics

- Refer rate: 2.1%
- Miss rate: 0.3%
- Waive rate: 0.3%
California Program Statistics

- Identified with hearing loss: 919
- Incidence 2/1000
- Identified by 3 months of age: 515 (56%)
- Enrolled in Early Start: 669 (73%)
- By 6 months of age: 463 (69%)
Hearing Coordination Centers

- Contractors who serve one or more geographic service areas
- Total Births by region (2006)
  - Region A: 111,641
  - Region B: 97,082
  - Region C: 110,073
  - Region D: 240,602
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:**
  - Schedule an appointment for outpatient screening
  - Provide the family with appointment info at discharge
  - Report the appointment to the HCC with inpatient screening results

- **For Infants who are missed, the Hospital must:**
  - Contact the family and schedule the follow up appointment
  - Report the appointment to the HCC
# Newborn Hearing Screening

**Infant Reporting Form**

**Inpatient Screen Completed**

<table>
<thead>
<tr>
<th>IP Screening</th>
<th>Right Ear</th>
<th>Left Ear</th>
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<tbody>
<tr>
<td>DATE of Screening</td>
<td>ABR</td>
<td>ABR</td>
</tr>
<tr>
<td>TYPE of Screening (circle one)</td>
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<td>DPOAE</td>
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<tr>
<td>RESULT (circle one)</td>
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<td>PASS</td>
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</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 required)
- [ ] Baby has atresia- [ ] Bilateral [ ] Unilateral: right left *(circle one)* *(complete Follow-Up section below)*

**Follow-Up for Refers/Missed** *(fax completed form to HCC)*

- [ ] Parent/Legal Guardian information on face sheet verified/updated
  - Primary Language (Circle One): English Spanish Other:______________
  - Second contact information (relative or friend) is 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 FOR NICU PATIENTS OR INFANTS WITH ATRESIA
    - DATE: ________________ TIME: ____________ [ ] CCS Referral Made
    - PROVIDER: ____________________________ Phone: ____________________________
    - PCP who will see the Infant after discharge – Name: ____________________________
    - Phone: ____________________________

- [ ] Completed form faxed *with hospital face sheet* to your Hearing Coordination Center at (XXX) XXX-XXXX.
The HCC Role In a Perfect World
HCC Role Following Inpatient Refer
Result

- If follow up results are not received within 14 days of the scheduled appointment the HCC contacts the provider.
- If necessary, the HCC contacts family to ensure the appointment was kept and to determine the outcome.
- Lost to follow up is most likely to occur at the outpatient screening phase.
HCC Role Following Outpatient Refer Result

- Refer the baby to the Title V Children with Special Health Care Needs Program (CCS Program in CA) if not done by OP screening provider
- Available as a resource for medical justification for medical necessity
HCC Role Following Outpatient Refer

- Notify the diagnostic provider when an authorization has been issued.
- Notify Family
- Obtain appointment information from diagnostic provider
- If diagnostic results are not received within 14 days of scheduled appointment the HCC contacts the provider
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 to answer questions and make any necessary medical or community referrals
HCC Role After Hearing Loss is Identified

- Contact family 2 months after diagnosis
  - Assure Early Start Services are being provided
  - Provide parent support
  - Assess the need for community referrals
- Contact family 6 months after diagnosis
  - Confirm services
  - Offer support
  - Make necessary community referrals
  - Close the case
Reality Check

The HCC Role in a Not so Perfect World
Barriers to the Perfect World

Scenario

- Diagnostic providers not scheduling appointments; waiting for families to call
- Parents not scheduling or no showing appointments
- Providers not submitting results
- The CCS Program delaying or not issuing diagnostic authorizations
- Not enough qualified pediatric
HCC Role in Navigating the Barriers

- Encourage providers to contact families for appointments
- Assist the family in getting the appointment
- Send letters to the PCP and the family stating the child’s screening status and enlist the PCPs help if necessary.
HCC Role in Navigating the Barriers

- Make a referral to the local EPSDT program (CHDP in CA) if a family no shows more than two appointments or a provider is unable to contact a family after three attempts
- Contact providers for missing results
  - Elevate the problem to the State if there is no resolution
- Establish relationships with the CCS programs to encourage on-going communication regarding authorization of services
  - Elevate any problems to the State
Tracking and Monitoring Manual

- Outlines the minimum expectations for the HCC
- Five Tracking Categories
  - Outpatient Screen Required
  - Diagnostic Evaluation Required
  - Hearing Loss Identified
  - Infant Transferred between hospitals
  - Infant Resides outside of CA
- Provides HCC a framework to follow cases to their conclusion
Tracking and Monitoring Manual

- Includes guidance on contacts with providers and families
- Letter content
- When to close a case
Loss to Follow-Up: National

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<th>Region C</th>
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## Loss to Follow-up by Region

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Tracking a Baby with the CA Process
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 place.
Questions?