ARIZONA’S CREATIVE APPROACHES TO REDUCING LOSS TO FOLLOW-UP

Impacting Loss to Follow-up: Utilizing Parent Support Organization to Enhance EHDI Collaborative

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OBJECTIVES

1) Identify strategies used by Arizona Department of Health Services (ADHS) to reduce loss to follow up

2) Identify benefit of utilizing parent support organization for parent outreach

3) Identify impact of concentrated approach of higher risk infants
## Arizona’s Data*

<table>
<thead>
<tr>
<th></th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
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</thead>
<tbody>
<tr>
<td>Births</td>
<td>104,516</td>
<td>100,088</td>
<td>93,331</td>
</tr>
<tr>
<td>Babies Screened</td>
<td>98,853</td>
<td>97,886</td>
<td>91,881</td>
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<tr>
<td>Referred IP Screen</td>
<td>3,456 (3.5%)</td>
<td>3,613 (3.7%)</td>
<td>2,805 (3.0%)</td>
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<tr>
<td>Confirmed Hearing Loss</td>
<td>142</td>
<td>155</td>
<td>115</td>
</tr>
<tr>
<td>Loss to Follow Up</td>
<td>1104 (31.9%)</td>
<td>810 (22.4%)</td>
<td>618 (22%)</td>
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</table>
ADHS & EHDI

Follow-up

Education

Consultants

Community Partners

Parent support
ADHS Newborn Screening

Hospital screening – Failed/Missed/Incomplete screening

ADHS Newborn Screening Follow-up

- **Well-Baby**
  - Refer IP
  - No risk factors

- **High Priority**
  - Refer IP & OP
  - No risk factors

- **High-Risk**
  - Refer IP
  - NICU stay > 5 days
  - Other risk factors*

**Evaluation** (screening/testing)

- **Confirmed Normal Hearing**
- **Confirmed Hearing Loss**

- **Early Intervention** (Referral/Enrollment)
  - **Ongoing support** (ex: resources)
ADHS Newborn Screening program was awarded a supplemental grant to reduce loss to follow-up.

**Goals of the MCHB grant:**

For infants who fail the newborn hearing screen, to reduce loss to follow-up rates between:

- Inpatient and Outpatient screens
- Outpatient screen and Diagnostic evaluation
**Newborn Screening: MCHB Grant 2009**

Three primary approaches:

1) High-Risk Follow-up – High-Risk Coordinator

2) Guide By Your Side (GBYS) parent support – Parent Guides

3) “Loss & Found” video (national Hands & Voices)

*ADHS MCHB Supplemental Grant 2009*
Newborn Hearing Screening High-Risk Follow-Up
Arizona Early Hearing Detection and Intervention

**Infants at a higher risk for hearing loss**
- Infants who refer with NICU stay >5 days
- Infants who refer with other risk factors

**Goal:**
- Improve the loss to follow up rate between inpatient and outpatient screenings
- Improve the loss to follow up rate between outpatient screening and diagnostic evaluation

**HIGH-RISK COORDINATOR**

**Partner with Hospital Case Managers, Discharge Coordinators, Screening Coordinators**
**Goal:**
To ensure that infants staying >5 days in the NICU receive a hearing screen and appropriate testing upon discharge

**Partner with Parents and Primary care providers (PCP)**
**Goal:**
To ensure referral to Pediatric Audiologist upon discharge for infants who fail hearing screen. Provide parents and PCPs with resources regarding infants at higher risk for hearing loss

**Partner with Specialists (Audiologist, ENT) and Early Intervention**
**Goal:**
To ensure infants diagnosed with a hearing loss are directed to the appropriate services
RISK FACTORS FOR HEARING LOSS: JCIH 2007

- NICU care of >5 days (or any of following regardless of length of stay)
  - Assisted ventilation,
  - **ototoxic medications** (gentamycin, tobramycin, loop diuretics)
  - **hyperbili/exchange transfusion**
  - ECMO*

- Caregiver concern* regarding hearing, speech, language
- Family history* of permanent childhood HL
- Intra-uterine TORCH infections, particularly CMV*
- Craniofacial anomalies, especially those involving the pinna, ear canal, ear tags, ear pits, and temporal bone anomalies, physical findings associated with a syndrome known to include permanent HL
- Syndromes associated with progressive HL such as NF, osteopetrosis, Usher’s syndrome
- Neurodegenerative disorders*, such as Hunter syndrome
- Postnatal infections associated with SNHL especially bacterial meningitis*
- Head trauma requiring hospitalization
- Chemotherapy*

ww.JCIH.org

(*Risk factor with a potential late onset/progressive component)
**ADHS Newborn Screening Follow-up**

- Hospital screening – Failed/Missed/Incomplete screening

**Evaluation (screening/testing)**

- Confirmed Normal Hearing
- Confirmed Hearing Loss

**Early Intervention (Referral/Enrollment)**

- Ongoing support (ex: resources)

**Approach 1: High-Risk Coordinator**

- Establish liaison in hospital NICU (Discharge Coordinators/NICU Case Managers)
- Obtain list of infants staying in the NICU >5 days on a weekly basis
- Ensure inpatient screening
- Hospitals provided feedback on success of HR follow-up through newsletter

- Follow-up with parents and providers of infants who failed the hearing screen within 5 days of hospital discharge to ensure referral to Pediatric Audiologist

- Follow-up with Pediatric Audiologist, ENTs, other specialties to obtain reports

- Ensure EI referral/enrollment for those diagnosed with a hearing loss
**Approach 2: Guide By Your Side (GBYS)**

**Parent Support**

1. **Hospital screening – Failed/Missed/Incomplete screening**
   - Work with hospital screening program
   - Help with scheduling/following up for outpatient appointments
   - Following up with parent after OP appointment.

2. **ADHS Newborn Screening Follow-up**
   - Work with ADHS Newborn Screening on difficult cases

3. **Evaluation (screening/testing)**
   - Support families through screening/diagnostic process

4. **Confirmed Normal Hearing**
   - Support families through screening/diagnostic process and, if needed, EI and beyond.

5. **Confirmed Hearing Loss**
   - Early Intervention (Referral/Enrollment)
   - Ongoing support (ex: resources)
**GUIDE BY YOUR SIDE – MATERIALS FOR PARENTS**

**Parent Postcard** (English & Spanish) *after inpatient screen*

To remind parents to return for rescreen & to inform them of a Parent Guide who will be contacting them.

- Mom, I just had my hearing screened and I need to have my ears re-checked in two weeks.
- It is very important to bring me back to the hospital or to an Audiologist. I might have a hearing loss. Someone may be calling you to answer questions and help get my ears checked. If you don’t want someone to call you, please call 1-866-685-1050.

**GBYS brochure** (English & Spanish)

Can be utilized by hospitals, Medical homes, audiologists, etc.

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Guide By Your Side follows up with families to take the next step for their baby.

- Parent Guides are trained to support families from newborn screening to confirmed diagnosis.
- Parent Guides call parents to see if they have been able to get the necessary referrals and make appointments for the next step.
- Parent Guides answer questions and concerns about what the next step is.

Guide By Your Side Parent Guides are themselves parents of children who did not pass screening. Parent Guides are knowledgeable about the screening process and resources in Arizona. Parent Guides are here to help families.

- It helps families take the next step in the screening process.
- It offers experience from Parent Guides who know what it is like to have a child not pass screening.
WORKING TOGETHER

- Work together on various aspects of follow-up
- HRC is the liaison between ADHS Follow-up team and GBYS
- Ensure GBYS has up-to-date information
- Provides GBYS with parent information
- GBYS provides correspondence with parent on secure website and hearing screening database
Why are all these approaches important?

High Risk follow-up:

- According to JCIH 2007 Position Statement –
  - Infants in the NICU are at an increased risk of neural hearing loss compared with healthy term infants.
  - About 1/100 infants in Special Care Units will have permanent childhood hearing loss.

- Hearing screening can be problematic due to their conditions and length of hospital stay

Parent support through screening process:

- Fractured Healthcare System can be a barrier.
- Parent Time-evening and weekends
- Been there, done that.
CURRENT STATUS

- High Risk follow-up: implemented in 4 high level NICU hospitals throughout 2010
  - Obtain NICU census through hospital liaison
  - NICU babies born at other hospitals are still followed

- GBYS: implemented in 7 hospitals
  - Hospital sends release from parent
  - Work with hospital screening program
  - ADHS provided babies
OUTCOME/CHALLENGES

- Parents’ positive response to GBYS
- HRFP & GBYS has been implemented successfully at various hospitals throughout 2010
- Ongoing effort, hospitals appreciate support/services
- Changes in hospital structures affects consistency of information
- Lack of services in rural areas
- Currently compiling data
THANK YOU FOR YOUR TIME

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