

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

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

Jeanne Hollabaugh
Arizona H & V Guide By Your Side
Program Coordinator

Valerie Odeh
Arizona Department of Health Services
Office of Newborn Screening
High-Risk Coordinator

Brigitte Dufour (co-author)
Arizona Department of Health Services
Office of Newborn Screening
Case Management Coordinator



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



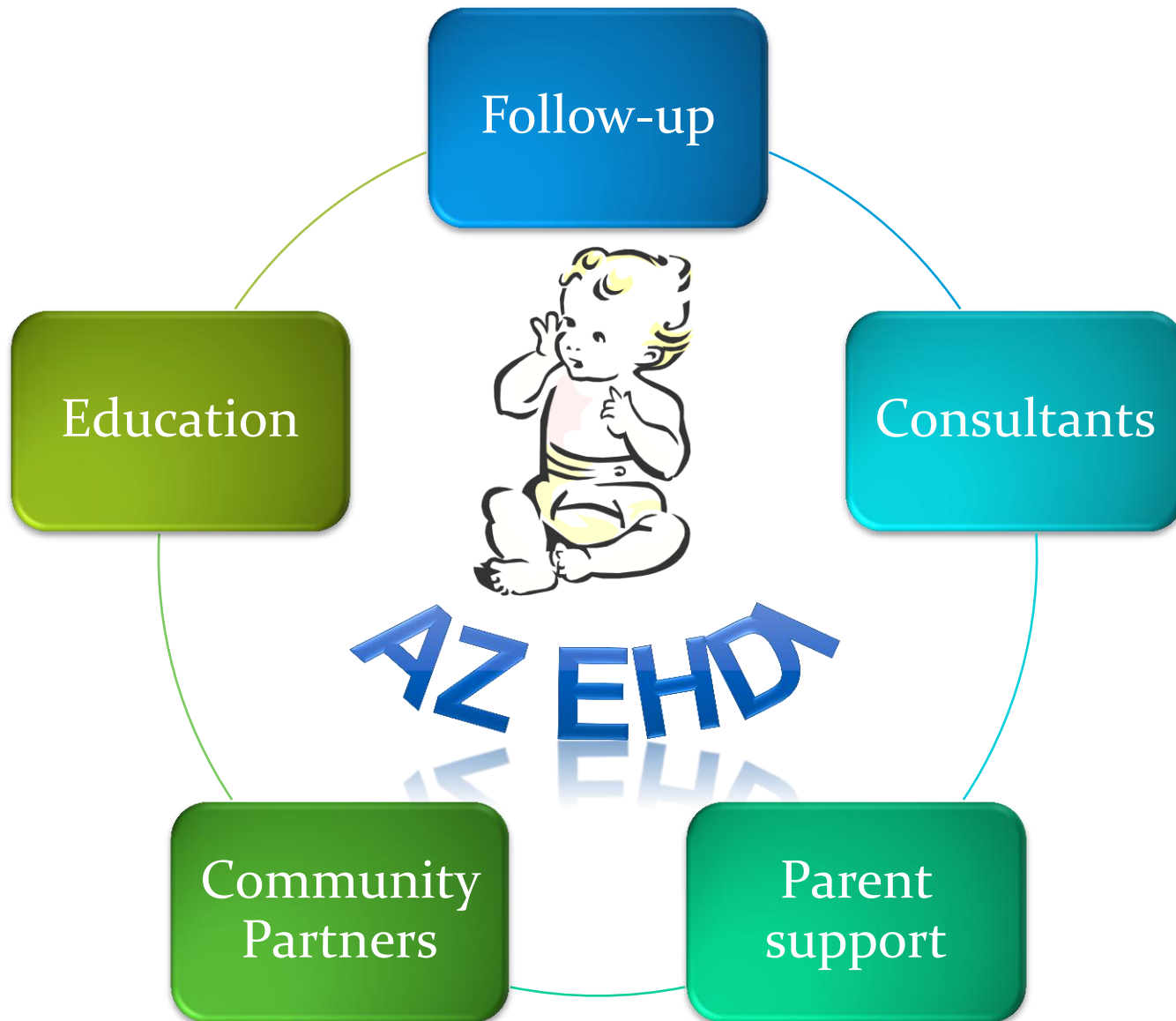
ARIZONA'S DATA*

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

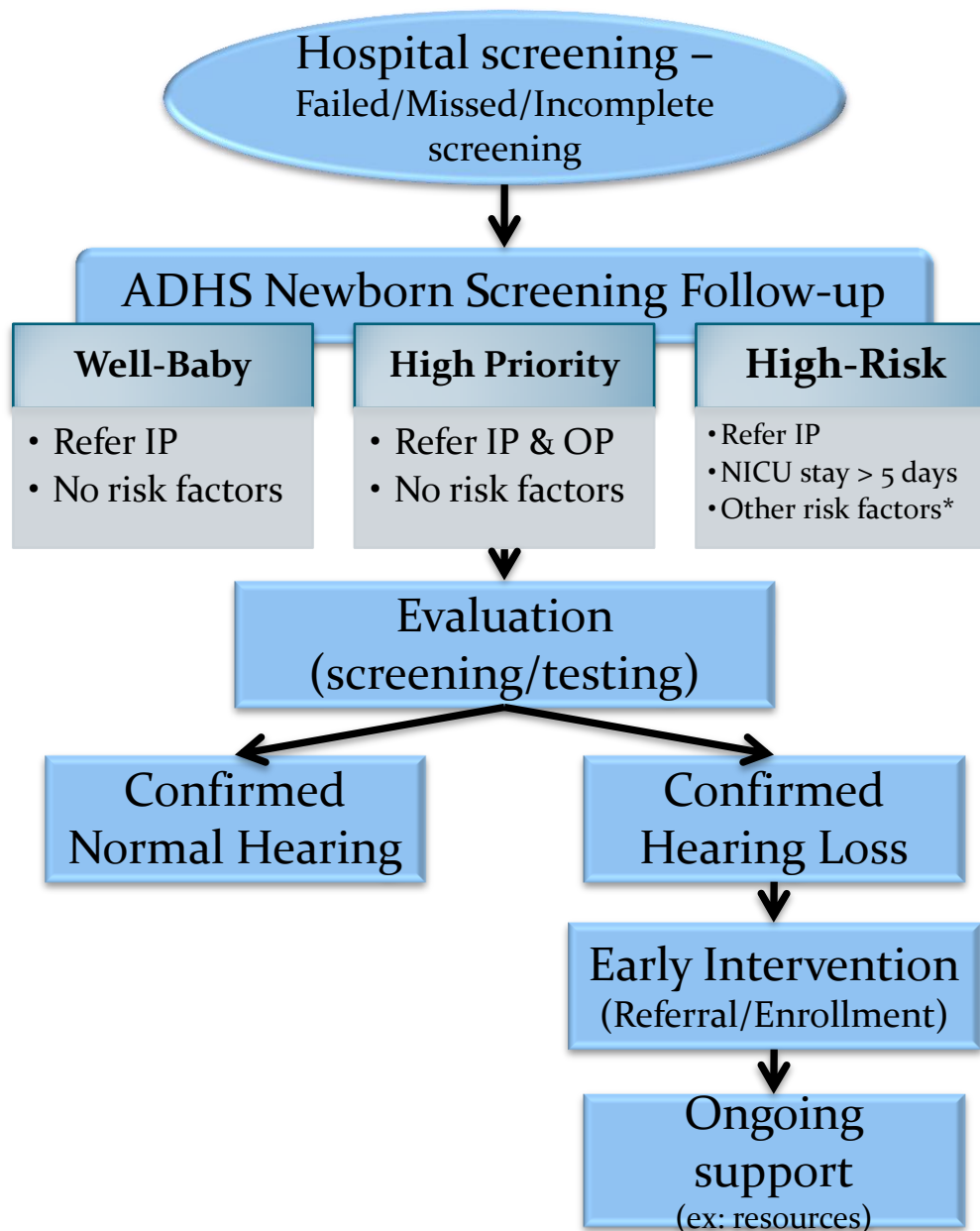
**Preliminary data*



ADHS & EHDI



ADHS NEWBORN SCREENING



NEWBORN SCREENING: MATERNAL AND CHILD HEALTH (MCHB) GRANT 2009

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*

www.JCIH.org

(*Risk factor with a potential late onset/progressive component)

PEDIATRICS
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs
First Committee on Early Hearing Detection
Pediatrics 2007;120:189-211
DOI: 10.1542/peds.2007-2348

The online version of this article, along with updated information and services, is located on the World Wide Web at
<http://www.pediatrics.org/cgi/content/full/120/4/e18>

PEDIATRICS is the official journal of the American Academy of Pediatrics. A monthly publication, it contains the most authoritative and up-to-date information available on child health, care, education and development. The journal is published by the American Academy of Pediatrics, 505 Duane Street, Elk Grove Village, Illinois 60007. Copyright © 2007 by the American Academy of Pediatrics. All rights reserved. Reproduction in whole or in part without permission is prohibited.

American Academy of Pediatrics

Downloaded from www.pediatrics.org by on November 11, 2008

APPROACH 1: HIGH-RISK COORDINATOR

Hospital screening –
Failed/Missed/Incomplete
screening

ADHS Newborn Screening Follow-up

Evaluation
(screening/testing)

Confirmed
Normal Hearing

Confirmed
Hearing Loss

Early Intervention
(Referral/Enrollment)

Ongoing
support
(ex: resources)

- ✦ 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



GUIDE BY
YOUR SIDE™

APPROACH 2: GUIDE BY YOUR SIDE (GBYS)

PARENT SUPPORT

Hospital screening –
Failed/Missed/Incomplete
screening

ADHS Newborn Screening Follow-up




Evaluation
(screening/testing)


Confirmed
Normal Hearing


Confirmed
Hearing Loss


Early Intervention
(Referral/Enrollment)

Ongoing
support
(ex: resources)

 Work with hospital screening program
 Help with scheduling/following up for outpatient appointments
 Following up with parent after OP appointment.

 Work with ADHS Newborn Screening on difficult cases


 Support families through screening/diagnostic process

 Support families through screening/diagnostic process and, if needed, EI and beyond.


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.



Arizona Department of Health Services is partnering with Guide By Your Side to assist families through the screening process. A Parent Guide will be contacting you. If you prefer not to be contacted, please call the Program Coordinator at 866-685-1050.

GBYS brochure (English & Spanish)


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



GUIDE BY YOUR SIDE™

Follow Through Guides for Families

Providing unbiased, emotional support and resources by trained Parent Guides to families with children who have not passed hearing screening.




Why is parent support important?

- 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.




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.

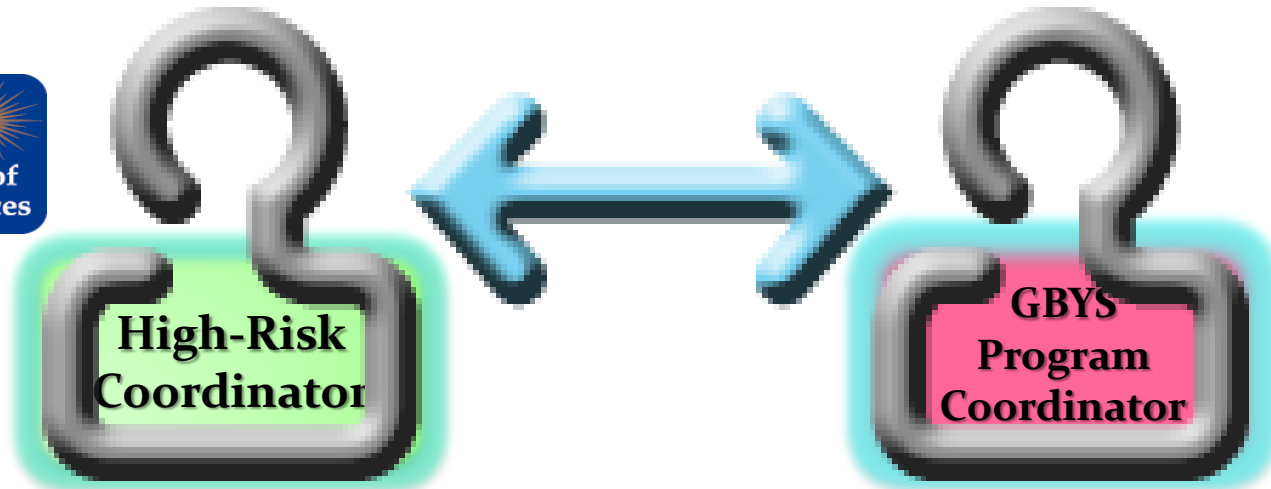
CALL Guide by Your Side **TODAY**
toll free: 866-685-1050
or
520-331-3125
EMAIL Guide By Your Side
gbys@azhv.org
WRITE TO Guide By Your Side
P.O. Box 64091
Tucson, AZ 85705



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.



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



Valerie Odeh
Arizona Department of Health Services
Valerie.odeh@azdhs.gov

Jeanne Hollabaugh
Guide By Your Side
jhollabaugh@azhv.org

Brigitte Dufour
Arizona Department of Health Services
Brigitte.Dufour@azdhs.gov

