

EMBEDDING PARENT SUPPORT IN EHDI

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1-3-6+

Added a “plus” component to the current 1-3-6 EHDI model based on the collective belief that all parents should have the opportunity to receive support from another parent with experience and a working knowledge of Early Hearing Detection and Intervention.

- ▶ The EAR Foundation of Arizona has had the unique opportunity to help institutionalize parent to parent support into the Arizona EHDI process over many years
- ▶ Not all efforts over the years were successful
- ▶ Sharing the current method of adding the “plus” to 1-3-6
 - ▶ What works
 - ▶ How it is embedded into follow up
- ▶ Case study in benefits of the “plus”



WHO ARE WE?

- ▶ The EAR Foundation of Arizona (EFAz)
 - ▶ EFAz was instrumental in establishing the Arizona chapter of Hands & Voices
 - ▶ HRSA grant recipient
 - ▶ Contracts with Arizona Hands & Voices GBYS program
 - ▶ Holds contract with AZ Department of Health for Newborn Hearing Follow up
 - ▶ Five (4+FTE) staff positions doing follow up
 - ▶ Embedded in contract is offering parent to parent support to the family/guardian of any child identified as Deaf or Hard of Hearing (Bilateral and Unilateral)
- ▶ Arizona Hands & Voices
 - ▶ Active chapter since 2007
 - ▶ Active Guide By Your Side program since 2010
 - ▶ Parent driven group that provides unbiased support
 - ▶ Standardized training for Parent Guides who provide support
 - ▶ Co-executive directors for AZHV are also follow up coordinators



Parent Perspective



Program Perspective

- ▶ What parents want most, according to research, is to speak to another parent
- ▶ The medical system is difficult and fragmented
- ▶ We need to develop parent leadership
- ▶ We need to building parent engagement
- ▶ We need to share personal stories of parent to parent support
- ▶ There is a need for ongoing support, especially through transitions

- ▶ Improve enrollment in Early Intervention
- ▶ Gap for families of child with a unilateral loss
- ▶ HRSA grant objectives
 - ▶ Parent to Parent support
 - ▶ Deaf and Hard of Hearing role models
 - ▶ Building Parent leadership/Engagement
- ▶ Included in AzDHS – EFAz follow up contract
- ▶ JCIH 2007 position statement
 - ▶ ***“EHDl systems should be family centered”***
 - ▶ ***“The success of EHDl programs depends on families working in partnership with professionals as a well-coordinated team”***

1-3-6+

MY STORY – WHY I AM HERE

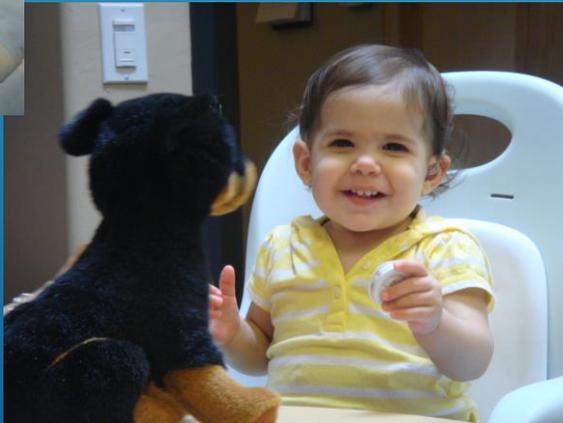
- ▶ 3 Children
- ▶ 2 born Profoundly Deaf
- ▶ Very different journeys from screening, diagnosis, and support.



DIFFERENT JOURNEYS

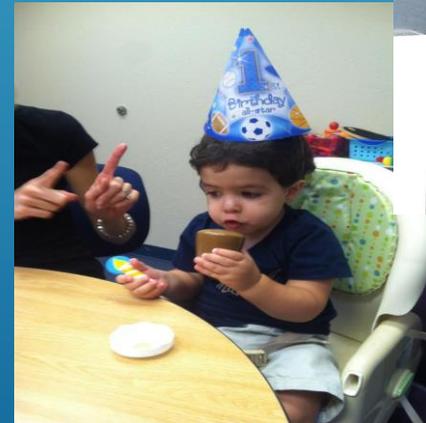
SAMANTHA'S JOURNEY

- ▶ Did not pass NBHS, told it was fluid
- ▶ Diagnosed with a Profound SNHL
- ▶ EI only, no parent support



MATTHEW'S JOURNEY

- ▶ Passed one ear in the hospital
- ▶ Passed follow up ABR with audiologist
- ▶ Recognized signs at 2 months of age of HL
- ▶ Sedated ABR showed a Profound SNHL
- ▶ Got involved with AZHV and received parent support



WHAT DIDN'T WORK

- ▶ Hospital Screening Program Post Cards/Brochures
 - ▶ Handed out to parents of children who did not pass
 - ▶ Offered parent guide information along with contact information
 - ▶ Responses were minimal to none each month
- ▶ Audiologist referrals
 - ▶ Brochures provided to pediatric audiologists for referrals
 - ▶ Very limited response
- ▶ Assigning to Parent Guides directly from follow-up
 - ▶ Parent Guide access to State database
 - ▶ No standards for timing or content of parent contact
 - ▶ No informed consent procedures
 - ▶ Some success but limited



**GUIDE BY
YOUR SIDE™**

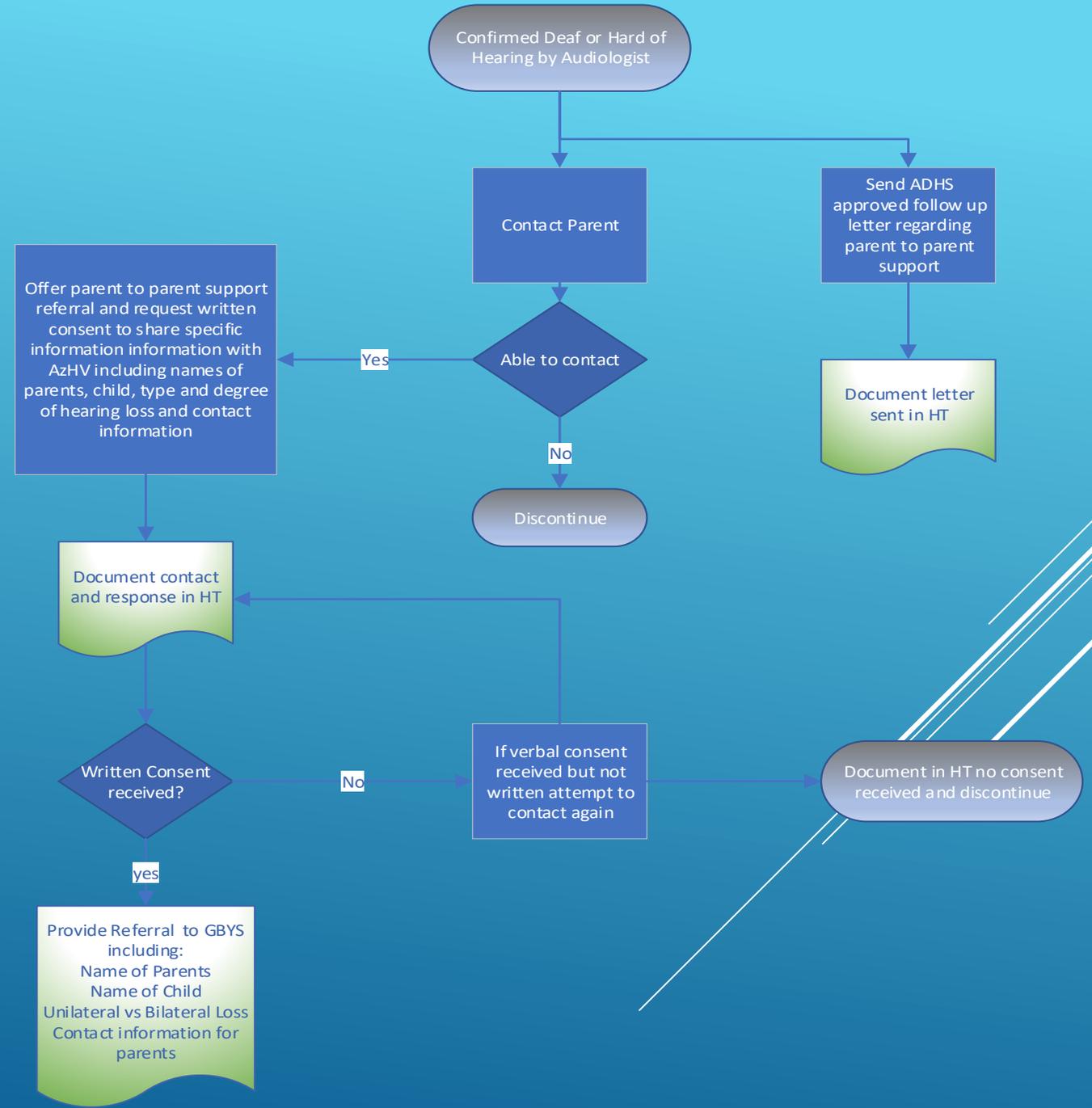
FOR HEARING
SCREENING PROGRAMS

Providing unbiased, emotional
support and resources by trained
Parent Guides for

-families with babies who have not
passed screening

-the professionals who serve them

The Newborn Hearing Screening Follow up program will assure that parent to parent support is offered to all families with an infant that known to the newborn hearing screening follow up program with a permanent hearing loss. Follow up staff will work with the consulting audiologist to identify those families with infants who are likely to have a permanent hearing loss. All parents with a child with a confirmed hearing loss will be provided with a letter (approved by ADHS-ONBS) through HiTrack that will inform them of the availability of parent to parent support. Follow up staff will attempt to contact a parent to obtain consent to refer for parent to parent support. If the parent indicates that they do desire information about parent to parent support and willingness to be contacted by a parent, confirmation must be received by follow up in writing that the parent consents to have information shared with GBYS.



ARIZONA SUCCESS STORY

“Having a parent guide offered to me has been a gift. Your life has been turned upside down and you have no idea what you should do or how. The parent guides and AZ Hands & Voices meet you at your need. Because they are also on the journey they have great advice and counsel. They not only offer the tools and resources, but the much needed emotional support required to adjust to your new normal. Additionally, seeing other children with hearing loss thrive is so comforting. These kiddos are no different than any other kiddo.

“I will forever be grateful for you both and this organization....I feel like it's time we started giving back to the organization that walks with us on this journey and provides so many great resources.”

