

# The Journey to Universal Parent Support

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## Heidi Klomhaus

- Parent of 3-youngest born and identified with a hearing difference
- Arizona Hands & Voices (AZHV)
  - Executive Director
  - Guide By Your Side (GBYS) Coordinator

## Cynthia Millard

- 20 years as Social Worker for State Agencies
  - Family Assistance
  - Division of Developmental disabilities
- Arizona Department of Health Services
  - Office of Newborn Screening (ONBS)
  - Follow Up Program Coordinator

- **Arizona Hands & Voices**
  - Established in 2007
  - Guide By Your Side (GBYS) program established in 2010
  - AzEHDI Coordinator ensured HRSA grants included parent to parent support component since 2005
- **History**
  - Prior to 2017
    - ADHS sent GBYS letters offering parent support enrollment with low responses
    - Audiologists and Early Intervention providers were encouraged to make referrals at time of diagnosis
  - EFAz & ADHS contract for Newborn Hearing Follow up case management 7/2017-8/2019
  - 1-3-6+ embedded parent to parent support to the family/guardian of any child identified as Deaf or Hard of Hearing (Bilateral and Unilateral)
    - Follow Up staff mostly parents of DHH children themselves
    - Ongoing relationship from the follow up process leading into diagnosis and enrollment to GBYS support
    - 85% enrollment to GBYS parent support program

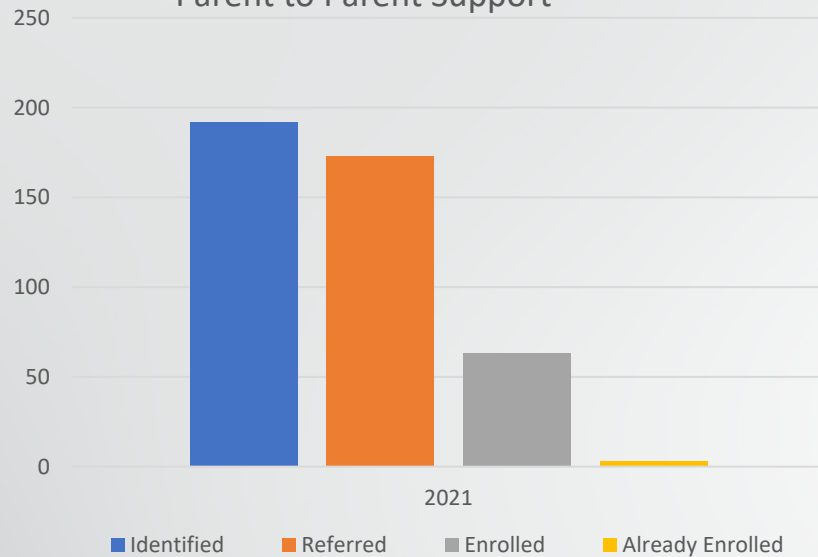
# Arizona Department of Health Services Office of Newborn Screening

- Hearing Follow up returned in house with ADHS
- DHS reverted to original follow up protocols
  - GBYS letter sent
  - Verbal recommendation of GBYS
  - Written Consent required parents to download, sign and return a consent form
  - 85% enrolled
- Quality improvement efforts led to AZHV and ADHS working together to improve the system

# Established Contract

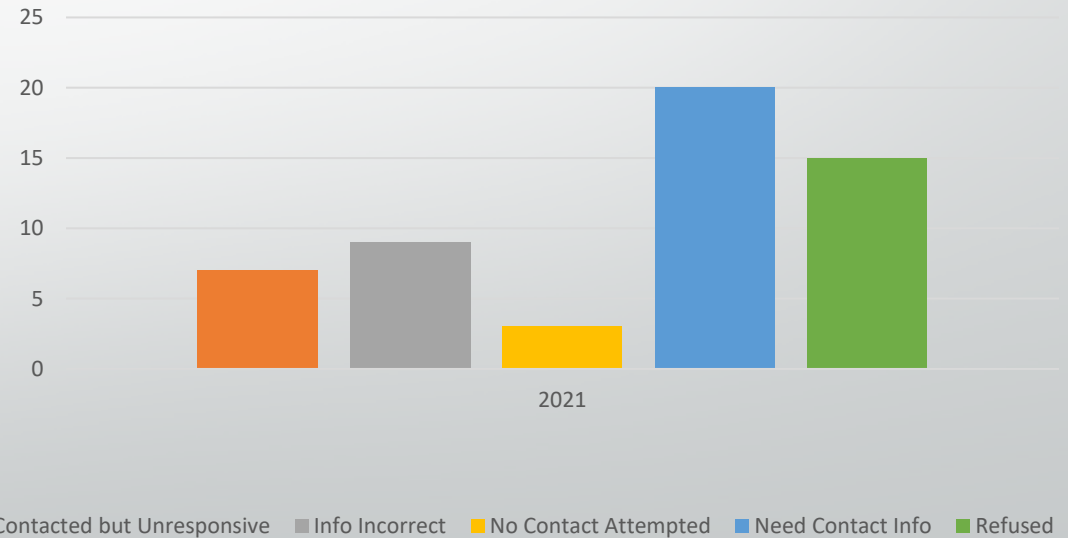
- Data Sharing Agreement-AZHV & ADHS
  - No Cost agreement
  - Allows AZHV access to ADHS database
  - ADHS Follow Up Coordinator assigns infants with diagnosed hearing loss to GBYS
  - GBYS calls to offer parent to parent support
    - Must receive written consent before official referral to GBYS

### AZHV Guide By Your Side Parent to Parent Support



- 192 infants identified with 173 assigned to GBYS for offer of GBYS enrollment
- 88 families successfully contacted and offered GBYS (50.9% 2021 success rate)
- 66 (75%) provided verbal and written consent including 3 already enrolled

- 3 families provided verbal consent but not written consent
- 15 families not interested or believed their child to have no hearing loss
- 4 Contacted but Unresponsive
- 20 families with incorrect or no contact information
- 3 families not contacted as data shows normal hearing for 2 and one is a recent referral



# Continuous Quality Improvement-AZHV

## “Small Tests of Change”

### Challenges

- Written consent is required as part of the workflow
- Unable to reach parents-ongoing
  - Lack of information
  - Incorrect information
- Matching running list of babies-ongoing

### Improvements

- Made changes to process
  - Implemented the use of Google Voice
  - Text families while on the phone with them
- Attempt calls at various times of days including weekends
- Consistent communication for timely updated lists

# Continuous Quality Improvement-ADHS

## “Small Tests of Change”

### Challenges

- Reassigning babies to GBYS
- Ensuring timely assignment to GBYS
- Staffing Challenges
- ADHS staff understanding

### Improvements

- Stay in communication with GBYS coordinator
- Ongoing monitoring of diagnosed infants to ensure timely assignment to GBYS
- Attending AZHV-GBYS Family Event



# Where We Are Now

- Working on Deliberate communication
  - Sharing Data with Cynthia-DHS
  - Providing Data for the HSFS-CDC Report
- Ongoing regular meetings with AzEHDI HRSA team
- Establishing a new Data Sharing Agreement
  - Current DSA ends in May 2023
  - Reviewing and expanding DSA



**Questions?**



# THANK YOU

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