

EHDI Family Connect: New Protocol Improves Knowing Early Intervention Status of Newly Identified Deaf or Hard of Hearing Babies Lisa Condes, MS and Alyssa Rex, AuD Indiana Hands & Voices Guide By Your Side & Indiana Early Hearing Detection and Intervention

The Story: EHDI Family Connect

The importance of Early Intervention is the reason for identifying babies at birth through UNHS, yet, it has been challenging to obtain data on the babies' status of early intervention by 6 months of age.



Our challenges:

- A decreasing # of families responded with a telephone call and a follow-up letter from Guide By Your Side (GBYS) Outreach
- Families not ready for support immediately after identification
- Some families connected emotionally to the first person who called, the GBYS Outreach Coordinator. Then, they did not follow-through with the assigned Parent Guide

New Protocol Goals:

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- Enhance early family support across the state
- Decrease loss to follow-up
- Assist families in accessing early intervention services

EHDI Family Connect Protocol

Initial Contact:

The diagnosing audiologist gives the family the *EHDI Family Connect* post card informs the family that a Parent Guide will call them soon



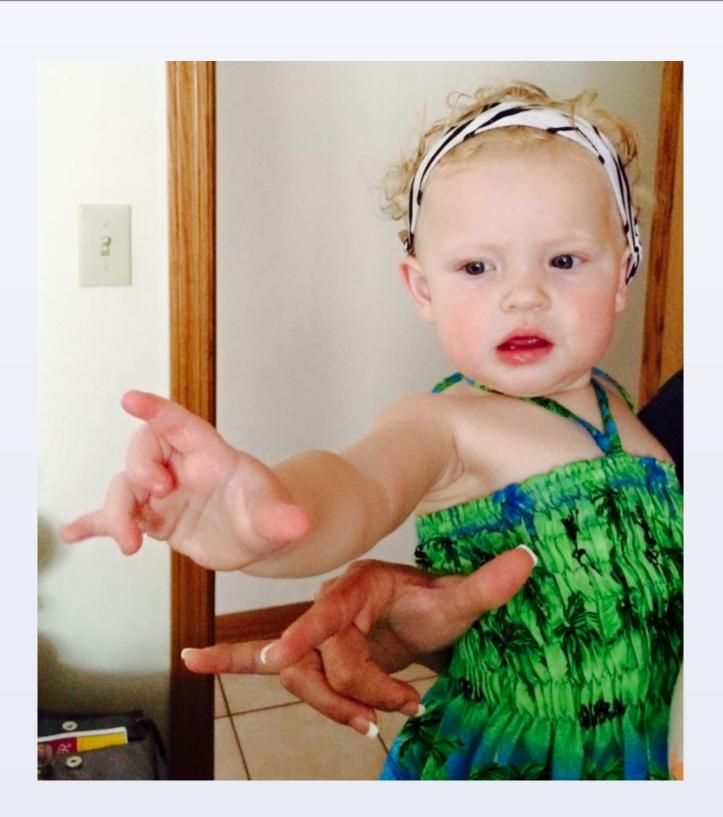
• Parent Guide reaches out to the family within 48 hours

Three Month Contact:

- Check in to make sure family is getting support and early intervention
- Parent Guide to obtain EI "Outcomes" Data for EHDI
- If unable to reach by telephone, email or text, sends "EHDI Family Connect – Trying to Reach You" follow-up letter

Twelve Month Contact:

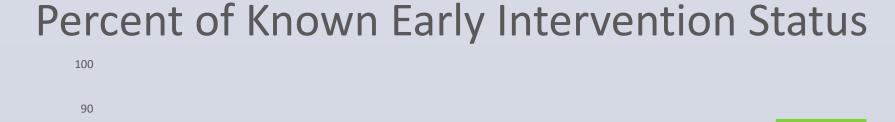
- Provide ongoing support, identify any challenges to enrollment in early intervention, language and communication focus
- One year membership to Indiana Hands and Voices
- Parent Guide to obtain EI "Outcomes" Data for EHDI
- If unable to reach by telephone, email or text, sends "EHDI Family Connect – Complete" follow-up letter to family



Support, Empower & Encourage Parents on Behalf of EHDI

- Improved family engagement
- Increased level of comfort and willingness to share information during follow up process with another parent
 - Not passing UNHS
 - Diagnosed hearing loss
- Training regarding decision making
- Self advocacy and improved communication with professionals
- Improved understanding of the importance of early intervention
- Referral for additional services, agencies, and support organizations

Charting the Progress





Involvement



Conclusions

• Keep Trying: Many families are very happy to be contacted by another family for support a year after their baby is identified deaf or hard of hearing

• Using multiple forms of communication is important, i.e. text, IPAD (Zoom visits)

• Periodic contact with families helps confirm entrance into early intervention services



References

American Academy of Pediatrics Supplement to the JCIH 2007 Position Statement: principles and Guidelines for Early Intervention After Confirmation that a Child is Deaf or Hard of Hearing, 2013.

The Center for Deaf and Hard of Hearing Education Transition Plan 2014

Center for Disease Control and Prevention Decision Guide to Communication Choices For Parent of Children who are Deaf or Hard of Hearing

Hands and Voices Ready Guide and Guided Family Notebook

Visual Language & Visual Learning Research Brief: Family Involvement in ASL Acquisition Gallaudet University VL2 Parent Information Package

AG Bell Association for the Deaf and Hard of Hearing Family Needs Assessment 2013 **BEGINNINGS** for Parents of Children Who are Deaf or Hard of Hearing, Inc

Family Voices Qualitative Study on Family Engagement

Harvard Family Research Project Data Collection Instruments for Evaluating Family