

ACDHH & EHDI Advisory Committee Meeting Minutes

(Minutes are not considered final until approved at the next meeting.)

Date: April 11, 2025

Time: 10:00 AM – 12:00 PM

Location: Zoom Meeting

I. Call to Order

Time: 10:08 AM

Chairperson: Latrina Harris-Lewis

II. Roll Call

Present Members:

- Latrina Harris-Lewis
- Amber Hansen
- Rob Vorek (Notetaker)
- Fran Altmaier
- Annie Converse
- Dr. Wendy Steuerwald
- Bibi Ashley
- Katie Fizz
- Dani Merrill

Absent Members

- Germaine Graham
- Melissa Klamann
- Kelly Randall

Guests/Visitors:

None.

III. Approval of Previous Meeting Minutes

- Motion to approve: Katie Converse
- Seconded by: Dani Merrill

IV. Old Business

1. Katie Fizz's Experience with Newborn Hearing Screening

Summary: Katie Fizz shared her experiences with her children and how they inspired her to change careers—from teaching English to pursuing a Master's in Deaf Education. She expressed gratitude for early identification and early intervention.

Katie's story prompted discussion around referrals to Phoenix Children's Hospital (PCH). Dr. Steuerwald explained that at PCH, only doctors can sign referrals—not PAs, RNs, or NPs.

Fran shared that during the recent EHDI Conference, she learned another state allows their state newborn screening coordinator to issue a standing order for screenings, eliminating the need for a doctor's signature.

This led to a conversation about the screening video developed by AZDHS.

Initial Screening & Confusion at Birth (March 2022)

- Katie gave birth in March 2022 in Yavapai County.
- Techs did a newborn hearing screening and said her baby was referred due to fluid in the ears.
- She was told fluid was likely due to the baby not spending much time in the birth canal.
- Given a referral for a follow-up screening far away (Litchfield), without guidance or materials.
- The second screening happened in a storage room, not a clinical space.
- Again told it was “probably just fluid” — no clear info or next steps.

Challenges with Referrals & Access to Specialists

- No initial sense of urgency; was unfamiliar with the process despite having three older children.
- Tried to schedule with an audiologist in Prescott who didn’t specialize in pediatrics.
- Her friend (a lactation consultant) pointed out she should find a pediatric audiologist — Katie hadn’t realized the difference.
- Delays in scheduling with Phoenix Children’s due to:
 - Poor communication between pediatrician and facility.
 - Referrals not being received or processed correctly.
 - I needed to follow up 3–4 times and push hard to get appointments.

Navigating Without Clear Information or Support

- Felt unsupported; received mixed messages from professionals.
- Didn’t understand medical terminology (like “sensorineural hearing loss”).
- Described herself as “bulldozer” — had to be assertive and proactive constantly.
- Although she knew the importance of early intervention from her background, she found the system confusing and inaccessible.

Early Intervention & Support

- Despite obstacles, got her daughter into early intervention by 2 months old, aided by 3 months.
- Parent guide through Hands & Voices was a key support — offered emotional validation and concrete advice.
- The early interventionist focused on parent-centered goals (e.g., how to talk about hearing differences).
- Katie later learned about “language deprivation” during graduate school and wished this had been explained earlier

Systemic Gaps Identified

- Lack of information at hospital discharge — never received pamphlets or materials.
- Parents were not told the importance of follow-up screenings.
- Referral system breakdowns:
 - Providers unsure how to properly submit orders.
 - Orders not accepted unless signed by an MD (not NP or PA).
 - Parents left chasing paperwork.

Personal Strengths & Privileges That Helped

- Katie's background as a seasoned parent and educator, along with a supportive partner, helped her navigate the system
- She did not experience denial or sadness, which she acknowledged as a privilege
- Compared her experience to others who did not pursue early intervention and regretted it

Outcomes & Advocacy

- Once in the Phoenix Children's system, care was cohesive, efficient, and supportive.
- Ultimately, she left high school teaching to pursue a Master's in Deaf Education.
- She hopes to support other families by making the system more accessible and parent-friendly.

2. Committee Membership Discussion

- Continued discussion on adding a DeafBlind or Deaf Plus representative to the committee
- Annie Converse suggested someone from ASDB's Early Learning Program
- Germaine Graham proposed contacting the DeafBlind Project for adult/parent representation
- Danielle Merrill proposed adding a representative from an agency that provides training for hearing screenings
 - Sonia Samaniego was recommended as a candidate with relevant expertise
- Latrina shared background details on Ms. Samaniego's qualifications
- Amber suggested expanding Deaf representation on the committee
- Bibi recommended several ASDB teachers as potential members
- Fran recommended that if Delight from Hands & Voices is unavailable, another representative from the organization should be considered

3. Final Revisions to the Family Survey on Newborn Hearing Screenings

The group reviewed and finalized the structure and wording of the family survey.

Next Step: Add ASL videos and Spanish translations by hiring a Certified Deaf Interpreter (CDI) and a Spanish Translator.

- Latrina noted Google Forms is likely to be used.
- Fran expressed accessibility concerns.
- Amber and Bibi shared that Google Forms is generally more accessible than Survey Monkey.

3. Educational Video Review

Draft Video Viewing

- The committee watched a draft of the newborn hearing screening educational video, filmed at Phoenix Children’s Hospital.
- The video includes a demonstration of both OAE (Otoacoustic Emissions) and AABR (Automated Auditory Brainstem Response) screenings, along with interviews with families and providers.

Feedback & Reactions:

- Committee members appreciated the video’s clarity, warmth, and accessibility.
- Praised the inclusion of real families and hands-on demonstrations.

Discussion Included:

- Ensuring terminology in the video aligns with the survey and materials (e.g., using “referred” instead of “fail”)
- Incorporating visual aids such as ear models, screening pamphlets, and the 1-3-6 model for better understanding

Next Steps

- Goal to complete video by late spring or early summer.
- Potential to share it at the EHDI Conference and via public health channels.

V. New Business

Tabled for the next Work Session Meeting scheduled for May 8, 2025:

1. EHDI Conference Updates
 - a. Fran Altmaier
 - b. Annie Converse
 - c. Rob Voreck
 - d. Latrina Harris-Lewis
2. Family support resource development
3. Letter to newly diagnosed families
4. Hands & Voices GBYS collaboration



VI. Upcoming Meeting Plans - Next Work Group Meeting

Date: May 8, 2025

Time: 10:00 AM – 12:00 PM

Location: Zoom

Agenda Items:

- Revisit New Business items tabled from the April 11 meeting

Next Public Meeting

Date: July 10, 2025

Location: In-person (ACDHH in Phoenix, AZ)

Note: *Latrina may be traveling to Seattle, Washington during that time but will confirm availability closer to the date.*

VII. Adjournment

Motion to adjourn: Amber Hansen

Seconded by: Annie Converse

Time: 11:59 AM