

# ACDHH & EHDI Advisory Committee Meeting Minutes

**Date:** December 12, 2024

**Time:** 10:07 AM

**Location:** Virtual Meeting via Zoom

**Meeting Called to Order:** 10:07 AM

**Chairperson:** Chairperson Harris-Lewis

## I. Roll Call

- **Present:**
  - Chairperson Harris-Lewis
  - Fran Altmaier
  - Bibi Ashley
  - Annie Converse
  - Dani Merrill
  - Kelly Randall
  - Dr. Wendy Steuerwald
  - Germaine Graham
  - Rob (Supervisor)
  - Interpreters and CART provider
- **Absent:**
  - Dr. Marla Broetz (recused, moving to Rochester, New York)
  - Amber (schedule conflict)
  - Melissa Klamon (unable to join for the third time-Harris-Lewis will follow up)
  - Katie Fizz (emergency absence)
- **Additional Attendees:**
  - Carmen Green Smith (may join later)

## II. Introduction of Kelly Randall

- Chairperson Harris-Lewis apologized for not introducing Kelly Randall in the previous meeting and invited Kelly to introduce herself.
- **Kelly Randall** shared her background, including:
  - Her son, 25 years old, with autism and epilepsy.
  - She joined Raising Special Kids as a volunteer and staff member ten years ago.
  - Her current roles: Parent Leader Program Coordinator and Project Director for the Family-to-Family Information Grant.
  - She is involved in the newborn screening work with Fran and the Mountain States Regional Genetics Network.

## III. Approval of Previous Minutes

The previous meeting minutes were reviewed and no other corrections were suggested.

## Motion to Approve:

- **Motion:** Fran Altmaier
- **Seconded:** Dr. Wendy Steuerwald
- **Minutes Approved** without additional corrections.

## IV. Work Sessions

### 1. List of Agencies for Newborn Screenings: Both Free and Paid Options

- Chairperson Harris-Lewis shared a document to review the payment schedule for newborn screenings and invited feedback or additions.
  - **Fran Altmaier** mentioned adding a link for midwife locations and clarified that ADHS screenings are free of charge.
  - **Dr. Wendy Steuerwald** added that newborn hearing screenings at Phoenix Children's are part of audiology and not the Nest Clinic, to avoid confusion. She also clarified the two locations: Thomas and Mercy Gilbert.
  - **Action Items:**
    - **Fran Altmaier** to add the midwife location link to the document.
    - **Dr. Wendy Steuerwald** to provide the addresses for the Phoenix Children's locations in the chat.
    - **Dani Merrill** asked who performs newborn screenings at other hospitals, noting that Honor Health was not listed.
      - **Fran Altmaier** explained that the major hospitals contract with companies such as **Pediatrics and Envision** for newborn screenings, with **Phoenix Children** handling the screenings for its **associated locations**.

### 2. Family Survey Development

#### Survey Structure:

- One general survey for all families, with initial demographic questions.
- After hearing screening results (pass or referral), the survey will branch into more specific questions for families with referrals or special needs (e.g., NICU stays).

#### Language Access:

- The survey will be available in ASL (via video) and Spanish.
- Consider hiring a Deaf person/CDI to sign the survey for accessibility.
- Ensure accessibility for families with different language needs.

#### Living Document:

- The survey is a working draft and will be reviewed before being sent to parents.

#### Survey Adjustments:

- Question 8 ("feeling supported by the screener") was moved for better flow.
- Ethnicity questions may be included, but could be removed if already on file to avoid repetition.
- Delivery questions might be made optional due to sensitivity.
- The survey will use a 1-4 scale instead of yes/no for better differentiation.
- Question 6 will assess if families were informed about follow-up actions.
- "Sometimes" and "Other" options will be added to Questions 10 and 11 for more accurate responses.
- A comment option will be provided for further details.

#### Decision Tree for Locations:

- If screening was at the hospital, the survey will skip to the next question.
- If elsewhere, the survey will ask about scheduling and convenience.

## Multiple Choice for Location:

- Use a dropdown menu (hospital vs. other) for simplicity.

## Final Adjustments:

- Continue refining the survey before finalizing it.
- The group decided not to split into smaller groups to maintain consistency across languages.

## 3. Resource Compilation

### Toolkit for Parents:

- **Goal:** Create a toolkit for parents after their child's hearing screening.
- **Focus:** Provide clear, balanced, and helpful information without overwhelming parents.

### Discussion Points:

- **Clarity is key**, as parents often receive conflicting information.
- The toolkit may include brochures and other helpful materials.

### Next Steps:

- Continue adding to the toolkit and ensure it remains a comprehensive, accessible resource.
- Add information on Chicanos Por La Causa, which provides free newborn screenings.

## 4. Review and Discussion of Germaine Graham's Experience

### Olivia (2 years old)

- **Premature birth:** Born 6 weeks early, weighing 3 pounds, 7 ounces.
- **NICU Stay:** Stayed in the NICU for 12 days.
- **Hearing Screening:** Conducted on day 11 in the NICU before going home. Olivia passed the screening, so no further screenings were needed.
- **Early Intervention:**
  - Olivia had developmental delays and received early intervention services starting at 5-6 months old, focusing on physical development.
  - Focused on **physical development**, as she wasn't hitting motor milestones.
  - Germaine later raised concerns about **communication delays** (lack of vocalization and response to stimuli).
- **Second Hearing Screening:** Germaine requested an **in-home screening**, which Olivia passed.
- **Outcome:** No follow-up was needed after the second screening.

### Sariah (2 months old)

- **Full-term birth:** Discharged from the hospital after one day.
- **Hospital Hearing Screening:**
  - Offered at the hospital, but Germaine was concerned about the **out-of-pocket cost** (approximately \$300 to \$500).
  - The screening wasn't covered by insurance, so Germaine declined it and signed a form acknowledging the potential risks.
- **Alternative Screening:**
  - Germaine found a **midwife** who could perform the screening at no cost.
  - The screening was done near Germaine's home, and the results were sent to the state department.
- **Outcome:** The screening was successful, and no follow-up was required.

## Key Takeaways from Germaine's Experience

- **Cost Concerns:**
  - Germaine emphasized the financial burden of hearing screenings, particularly for uninsured families.
  - Insurance coverage for newborn screenings varies, and families need to be aware of potential **out-of-pocket costs**.
- **Midwife Option:**
  - Germaine found a **free alternative** through a **midwife**, which may benefit **uninsured families**.
- **Development Monitoring:**
  - Germaine highlighted the importance of monitoring both **physical and communication development** in infants, as her first daughter Olivia needed extra support in these areas.

## V. Additional Discussion:

### 1. Insurance Coverage for Newborn Hearing Screenings:

- **Bibi Ashley's Question:** Are hearing screenings covered by insurance?
- **Germaine's Response:** Not all insurance plans cover hearing screenings. Some hospitals charge separately.
  - **Hospital Fees:** Some include it in the delivery package; others charge separately. If the hospital doesn't have a contract with the insurance provider, families may pay out-of-pocket
- **Medicaid Clarification:**
  - **Annie Converse:** Clarified that Medicaid does not typically cover hearing screenings when performed outside primary care settings under EPSDT (Early and Periodic Screening, Diagnostic, and Treatment), adding confusion for families.

### 2. Educational Video on Newborn Hearing Screenings:

- **Fran Altmaier:** The team is producing a video to explain newborn hearing screenings and ease concerns.
- **Bibi Ashley's Suggestion:** Include a Deaf mother with a Deaf child in the video for insight into the screening experience from Tucson.
- **Tucson Family:** Discussed involving a family from Tucson to record a video, with captions and a voiceover for broader accessibility.
- **Germaine Graham's Contribution:** Offered to share video footage of her second daughter's hearing screening for the educational video (after checking video quality).

### 3. Hospital Newborn Hearing Screening Costs:

- **Dr, Wendy Stueerwald's Point:** Raised a concern about the need for clear communication regarding whether hospitals include newborn hearing screenings as part of the birthing package or charge separately.
- **Group Agreement:** This should be addressed clearly in both the educational video and accompanying written materials to help families understand the potential costs.

### 4. Next Steps:

- Continue reviewing and improving the parent toolkit and resources.
- Aim to create a clear, comprehensive guide for parents to navigate newborn screenings, follow-up actions, and available resources.
- Focus on gathering more personal stories to help parents connect with others and understand the importance of early intervention and screenings.

## 5. Other Contributions:

- **Dani's Suggestion:** Add **Chicanos Por La Causa** to the resources list, as it offers free screenings, making the toolkit more diverse and accessible.
- The group was encouraged to keep adding new resources and personal experiences to the toolkit as relevant information becomes available.

## VI. Upcoming Meeting and Action Items

The next meeting will take place on **January 9, 2025 in-person**, and it will focus on:

- Finalizing the survey and refining the questions for the Google Form.
- Continuing to work on the educational video about newborn hearing screenings.
- Gathering more real-life stories, particularly from Deaf parents with Deaf children, to highlight the screening process.

### Action Items:

- **Bibi Ashley/Latrina Harris-Lewis** will contact the Tucson family to check if they are interested in participating in the video.
- **Fran Altmaier** will continue progressing on the video production, ensuring all key information, including cost considerations, is covered.
- **Germaine Graham** will check the quality of her video footage of Olivia's screening and share it for inclusion in the video.

## Future Meetings:

Date	Meeting Place	Meeting Status	Date	Meeting Place	Meeting Status
Thurs. 10-17-24	ACDHH	<input checked="" type="checkbox"/>	Thurs. 5-8-25	ZOOM (Work Session)	<input type="checkbox"/>
Thurs. 11-14-24	ZOOM (Work Session)	<input checked="" type="checkbox"/>	Thurs. 6-12-25	ZOOM (Work Session)	<input type="checkbox"/>
Thurs. 12-12-24	ZOOM (Work Session)	<input checked="" type="checkbox"/>	Thurs. 7-10-25	ACDHH	<input type="checkbox"/>
Thurs. 1-9-25	ACDHH	<input type="checkbox"/>	Thurs. 8-14-25	ZOOM (Work Session)	<input type="checkbox"/>
Thurs. 2-13-25	ZOOM (Work Session)	<input type="checkbox"/>	Thurs. 9-11-25	ZOOM (Work Session)	<input type="checkbox"/>
Thurs. 3-13-25	ZOOM (Work Session)	<input type="checkbox"/>	Thurs. 10-9-25	ACDHH	<input type="checkbox"/>
Thurs. 4-10-25	ACDHH	<input type="checkbox"/>			

## VII. Closing Remarks/Adjournment:

Chairperson Harris-Lewis thanked all attendees for their participation and contributions, and wished everyone happy holidays.

### Adjournment:

The meeting was adjourned at 11:49 AM.

**Minutes prepared by:** Latrina Harris-Lewis

**Date Submitted:** December 17, 2024