

ACDHH & AHDI Advisory Committee Meeting Minutes

Date: October 17, 2024

Location: ACDHH-Board Room

Attendees: Fran Altmaier, Bibi Ashley, Dr. Marla Broetz, Annie Converse, Katie Fizz, Germaine Graham, Amber Hansen, Latrina Harris-Lewis, Dani Merrill, and Dr. Wendy Steuerwald

Absent: Melissa Klamann - Parent and Kelly Randall - RSK (Family Support Specialist)

Assistant Attorney General (assigned)/Intern: Elise Phalen & Pranav (last name?)

Call to Order

The meeting was called to order by Latrina Harris-Lewis at 10:05 AM.

Introduction of each members/guests in our committee:

Fran Altmaier

- 12 years with the Newborn Screening Program at the Department of Health Services
- Oversees follow-up programs, including:
- Hearing screening
- Dry blood spot screening
- Manages both short-term and long-term follow-up programs
- 18 years in early intervention with the Division of Developmental Disabilities (DDD) at Arizona Early Intervention Program (AZEIP)
- Served as early intervention and support coordinator
- Total of 30 years of experience with the state
- Strong background in pediatric social work

Annie Converse

- Position: Arizona Early Intervention Program Data Manager
- Supports the development of the program's data system
- Collaborated with Fran on linking EHDI data
- Participated in various conferences to showcase innovative data linking practices
- Experience in early intervention since her daughter was in early intervention at age 16
- Daughter started college courses this summer; both are learning ASL together
- Light-heartedly notes her ASL skills are at a toddler level
- Expresses appreciation for the opportunity to be here today

Katie Fizz

- Position: Parent of four children, including a two-and-a-half-year-old born hard of hearing
- High school teacher with 15 years of experience
- Inspired by her daughter to pursue a master's degree at the University of Arizona
- Aims to improve understanding of early intervention terminology
- Transitioning from teaching English to becoming a teacher of the Deaf
- Enrolled in a bilingual, bimodal program at the University of Arizona
- Daughter attends Desert Voices
- Grateful for the opportunity to share her experiences

Dr. Wendy Steuerwald

- Position: Pediatric Audiologist and Director of Audiology at Phoenix Children's Hospital
- Emphasizes the importance of audiology in meeting the 1-3-6 guidelines for hearing screening
- Provides newborn hearing screenings at three area birth hospitals
- Offers outpatient screenings for children who do not pass initial screenings
- Conducts diagnostic services for children who fail outpatient screenings
- Clarifies terminology: BAER (Brainstem Auditory Evoked Response) is also known as ABR elsewhere
- Performs BAER tests to assess infants' hearing
- Facilitates hearing aid fitting for children diagnosed with hearing loss, ensuring services are completed before six months of age
- Highlights the expertise of her team in both audiology testing and collaboration with parents and professionals
- Expresses gratitude for the opportunity to participate in the discussion

Dani Merrill

- Position: Parent of a 6-year-old Deaf child
- Experienced the early intervention system and appreciates its support
- Acknowledges the challenges parents face in understanding the information provided
- Recognizes the prevalence of acronyms in the field and the need for clarity
- Committed to bridging the gap between information and understanding for parents
- Works in early intervention for children who are Deaf or hard of hearing through Desert Voices
- Aims to enhance data collection and sharing to support children and families

Elise Phalen-guest

- Position: Assistant Attorney General assigned to the Arizona Commission for the Deaf and the Hard of Hearing (ACDHH)
- Responsible for attending open meetings to assist with legal issues and questions
- Provides legal support during executive sessions as per open meeting regulations
- Familiar with the interests of the Commission and its overlap with the Department of Health Services
- Represents the Commission in addressing any legal matters that arise
- Available for all meetings classified as open meetings to support the advisory commission's needs

Pranav-guest

- Current Status: Law student at Arizona State University (ASU)
- Internship: Interning at the Attorney General's Office
- Collaboration: Working alongside Elise Phalen during the internship

Rob Voreck-guest

- Position: Community Services Manager
- Role: Facilitated the advisory committee meeting
- Personal Connection: Parent of Deaf and hard of hearing children who are now adults
- Expressed excitement about meeting a fellow Gallaudet University alum (class of '93)
- Thankful for the attendees' presence and support
- Looks forward to learning from others to improve the EHDI and early intervention programs in Arizona

Carmen Green Smith-guest

- Position: Deputy Director at the Commission
- Welcomes attendees to the meeting
- Looks forward to hosting upcoming meetings
- Fostering a collaborative environment

Germaine Graham

- Position: Speech Language Pathologist
- Private Practitioner
- Specialization: Works primarily with Deaf and hard-of-hearing patients

Bibi Ashley

Background: Deaf individual originally from California, residing in Arizona for five years

Position: Deaf Mentor Program Administrator

Experience: Two years in the current role

Education: Master's degree in Human Services and Counseling

Oversees a statewide program with six Deaf specialist staff

Focus: Supports children aged 0 to 5 who are Deaf or hard of hearing

Responsibilities:

- Facilitates home visits for families with Deaf infants
- Teaches sign language and exposes families to Deaf culture
- Invites families to community events to foster interaction and support

Eager to participate in the committee and collaborate with others

Amber Hansen

Identity: Deaf individual with hearing parents; part of the 8% of families using sign language

Personal Experience: Recognizes the gaps in support services for the Deaf community

Professional Roles: Deaf mentor and ASL instructor, passionate about family influence on Deaf children

Education: Master's degree in social work from Arizona State University

Position: My Deaf Therapy, serving Deaf clients and CODAs

Committed to improving services for Deaf children and families in Arizona

Dr. Marla Broetz

Background: Grew up in a family that learned sign language; unique experience for the 1960s

Professional Experience:

- 30 years teaching interpreter programs at the college and university level
- Currently working at Arizona State Schools for the Deaf and Blind

Focus: Supports families wanting to learn ASL and helps staff improve their ASL skills

Dedicated to meeting the diverse needs of families

Committed to providing tailored services in the best interest of children

Latrina Harris-Lewis

Background

- Raised in Dallas, Texas, in a hearing family
- Family includes a Deaf sister and Deaf cousin, highlighting a possibility of genetic factors in Deafness
- Immediate family members learned basic American Sign Language alongside Deaf sister, while her older Deaf/HH cousin pursued spoken language and then learned ASL after HS

Personal Experience

- Observed the impact of different communication choices within families
- Recognized the critical nature of family support and interaction in a child's development
- Passionate about fostering an environment where children can become independent learners with a strong sense of identity

Professional Experience

- Taught Deaf children and CODAs in public schools for 20 years in Tucson
- Transitioned to the Arizona State Schools for the Deaf and Blind, focusing on first second and third graders
- Served as a role model for students, showcasing success in various communication modes

Focus

- Noticed many students struggled due to families needing more support and understanding of laws, rights, and milestones
- Transitioned to advocacy work to better assist families and still educate as a “teacher”
- Currently in my third week as a Family Service Specialist with ACDHH, eager to uplift children and help them succeed
- Committed to addressing language acquisition from birth through graduation and ensuring that no child is lost in the system

Overview of Grant Cycle

- **Background:**
 - Early Hearing Detection and Intervention (EHDI) has been established for many years, with newborn hearing screenings mandated in Arizona for 26 years.
 - This initiative began to ensure that every baby born in hospitals is offered a hearing screening, although parents can opt out.
- **Vision:**
 - The focus is on creating a system-dependent infrastructure that supports families and individuals with lived experiences.
 - Aiming to build a solid foundation for EHDI to continue successfully over time.
- **Recent Developments:**
 - Transitioned from a previous grant cycle awarded to a nonprofit to the Department of Health.
 - Continued focus on enhancing the foundational elements of newborn screenings and ensuring effective communication with families.

Key Objectives and Strategies

1. **Improve Newborn Screening Process:**
 - Ensure every baby has access to screening and that screeners are adequately trained to prepare families for potential outcomes.
 - Address the gap in communication where families are often reassured with unclear information, emphasizing that not passing a hearing screening is just a different path rather than a negative outcome.
2. **Education for Screeners**
 - Develop scripts and training resources for hospital screeners to facilitate critical conversations with families.
 - Evaluate national recommendations to see if they align with Arizona's population needs and adjust accordingly.
3. **Timely Identification and Support**
 - Aim for children to be identified and diagnosed before three months of age and ensure they receive appropriate audiology testing.
 - Ensure timely reporting of results to the Newborn Screening program and appropriate referrals to early intervention services.
4. **Early Intervention Access**
 - Focus on providing families with comprehensive information to help them make informed decisions regarding early intervention services, ensuring these are presented in an unbiased manner.
 - Identify families who may not be ready for services and develop a strategy to reconnect with them when they are ready.
5. **Collaboration with Family Support Services**
 - Foster collaboration among organizations like the Commission and Raising Special Kids to enhance the support infrastructure for families.
 - Utilize existing resources and identify additional needs to improve family support services.

Work Plan Overview

- **Assessment and Analysis**
 - Assess the current state of the Early Hearing Detection and Intervention (EHDI) system using 2022 data as a baseline.
 - Identify gaps in infrastructure and develop a family survey to gather insights on support needs.
- **Data Sharing Agreements:**
 - Renew agreements with AzEIP and Guide By Your Side to ensure timely enrollment and service evaluation.
- **Advisory Committee Formation:**
 - The committee will help shape education plans for families and providers, identify infrastructure gaps, and conduct a family survey to gather essential feedback.
- **Educational Initiatives:**
 - Develop an education plan for parents, including a video series on Newborn Screening processes.
 - Create mechanisms for ongoing evaluation of EHDI outcomes and language acquisition.
- **Statewide Training:**
 - Plan and execute statewide training for providers about the EHDI system
 - Include: 1, 3, 6 benchmarks

Additional Discussion

- **Family Survey Development:** The advisory committee will contribute to creating a survey to gather insights from families about their experiences and needs.
- **Metrics for Language Acquisition:** Discussion on identifying appropriate tools for evaluating language acquisition outcomes in Arizona will be ongoing.

Open Forum

- **Questions from Committee Members:**
 - Dr. Marla Broetz raised a question regarding the survey's development and audience engagement.
 - Amber Hansen requested clarification on the responsibilities of various team members, as well as the process for inviting other Deaf and hard of hearing members to the advisory committee.
 - Germaine Graham inquired about integrating findings from the previous language acquisition task force.

Meeting Notes: Next Steps for November 14, 2024

1. **List of Agencies for Newborn Screenings: Both Free and Paid Options**
 - **Action Item:** Latrina Harris-Lewis will create a working/shared Google Document/Sheet.
2. **Family Survey Development**
 - **Action Item:** Latrina Harris-Lewis will draft survey questions and identify key information to gather, followed by sharing a working/shared Google Document.
3. **Resource Compilation**
 - **Action Item:** Latrina Harris-Lewis will compile and share a list of resources and packets already created or shared for families by newborn screeners, audiologists, early interventionists, Deaf mentors, family service specialists, and other related professionals. This will be shared via a working/shared Google Folder.
4. **Sharing Personal Experiences**
 - **Action Item:** Germaine Graham will prepare and share her recent experience with the newborn screening test, focusing on her newborn daughter and her two-year-old daughter.

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 type="checkbox"/>	Thurs. 6-12-25	ZOOM (Work Session)	<input type="checkbox"/>
Thurs. 12-12-24	ZOOM (Work Session)	<input 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"/>			

Meeting Adjourned: 11:39 AM
 Minutes Prepared By: Latrina Harris-Lewis
 Date of Preparation: October 21, 2024