



# Unapproved Minutes

## Newborn Hearing Screening Advisory Committee

May 12, 2026

9:00 am to 10:30 am

Join Zoom Meeting: <https://utah-gov.zoom.us/j/81874078388>

Meeting ID: 799 849 9427

Join instructions

<https://utah-gov.zoom.us/meetings/81874078388/invitations?signature=JxuQmbYKhb5MoQlMwMzACG0t76uyLXOs524W615Jp8>

### Committee Members Present:

Adrienne Johnson	Annette Stewart	Ashleigh Sorenson	Brittany Chandler
Charlene Frail-McGeever	Chris Furner	Eliza Hintze	Eric Christensen
Fara Bitter	Karl White	Kevin Baird	Lara Waite
Lauri Nelson	Nicole Pilling	Sally Ormsby	Stephanie Morgan
Taylor Enochson	Taunya Paxton		

### Excused/Absent:

Aubri Ogden	Erin Zinkan	Jeff Jackson	Jordan Schramm
Sarah Cordingly	Todd Huffman		

### Staff:

Holley Ezzell	Jacinda Merrill	Jenny Pedersen	Krysta Badger
Max Sidesinger	Shannon Wnek	Stephanie McVicar	

### Guests:

Libby Holley	Amber - ASL Interpreter	Hilary - ASL Interpreter
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Minutes: Alexis Weight, Secretary

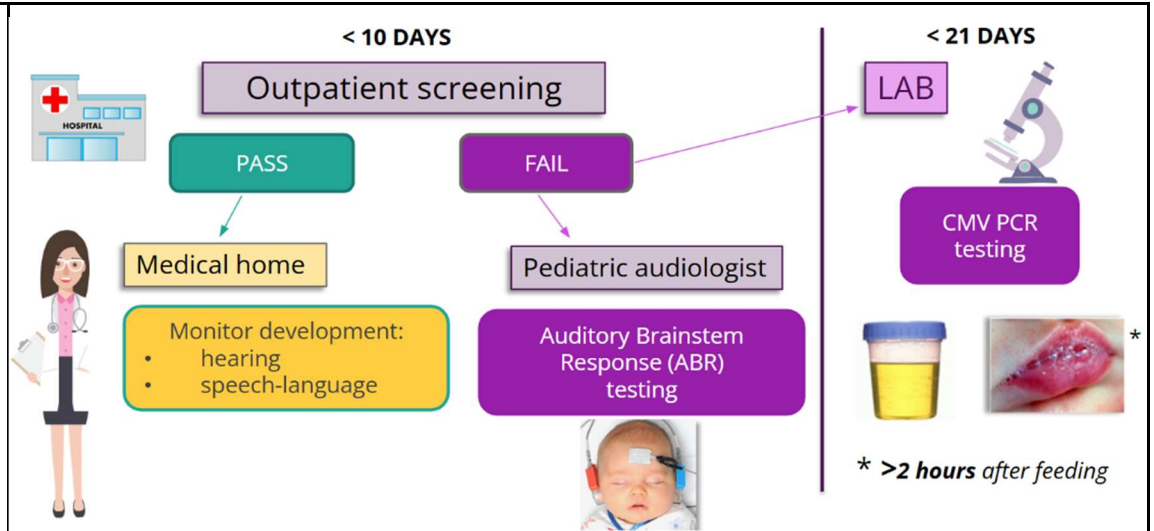
Topic	Discussion
Welcome	Fara Bitter opened the meeting at 9:03 am and welcomed the Committee.



	Krysta Badger assisted in attendance.
Approval of Minutes	The minutes from the February 10 <sup>th</sup> , 2026, meeting were reviewed. <i>Sally Ormsby made the motion to approve the minutes as written.</i> <i>Charlene Frail-McGeever seconded the motion. The motion passed unanimously.</i>
Public Comment	No public comments
Membership	Open Seats <ul style="list-style-type: none"><li>● Family Physician</li><li>● Public Health Nurse</li></ul>
Parent Experience, National EHDI Conference	Libby Holley, Parent Scholarship recipient, shared her experience as a parent at the National EHDI Conference: <ul style="list-style-type: none"><li>● Thanked Utah EHDI for the opportunity to attend the National EHDI Conference and said she appreciated the experience and learned a great deal during her time there.</li><li>● Two sessions and their key topics that really stuck out:<ul style="list-style-type: none"><li>○ Interactions &amp; Connections: Following a Child’s Lead in Conversation<ul style="list-style-type: none"><li>▪ Five steps for building quality interactions: Recognize, Contact, Serve &amp; Return, Goodbye Ritual, and End Contact</li><li>▪ Copresence &amp; Interaction: Caregivers must practice "co-presence" - being fully present to notice what the child notices (using context, tactile shapes, or movement) and acting as a "detective" to build a shared experience.</li><li>▪ Mitigating Sensory Imbalances: Ms. Holley highlighted the "still face experiment" to illustrate how deeply babies read social cues. Children with hearing loss are highly susceptible to overstimulation or sensory deprivation, making deliberate socialization crucial.</li><li>▪ Three Rs: <b>R</b>elate, <b>R</b>upture, <b>R</b>epair - Recognizing that daily life brings natural "ruptures" (like a parent saying goodbye), and the importance of intentional "repairs" (like returning home) to prioritize attunement and create moments of joy.</li></ul></li><li>○ Families as Leaders - A Collaborative Model for Student &amp; Community Success<ul style="list-style-type: none"><li>▪ Putting emphasis on families as leaders. Because early intervention programs often conclude at age three, families are the long-term navigators.</li></ul></li></ul></li></ul>



	<ul style="list-style-type: none"><li>▪ Trust families lived experience as expertise</li><li>▪ Connecting with parents who are a step or two behind can provide a powerful shared experience that medical providers cannot duplicate. Reaching back to guide others gives meaning and purpose to the otherwise overwhelming and isolating challenges of raising a child with medical complexities.</li><li>▪ Investing in parents by teaching them their rights, system navigation, and advocacy language builds confidence that directly transfers to the child.</li><li>▪ Working at the School for the Deaf, Ms. Holley has observed a direct correlation between how supported a parent feels and how well their child succeeds. Providing parent coaching and a sense of belonging within a community directly impacts a child's language development and academic momentum.</li></ul>
Provider Education	<p>Holley Ezzell, Health Program Specialist with the Utah EHDI Program, presented and led a discussion on provider education. Presentation slides are available on the <a href="#">Utah Public Notice Website</a>. Topics included:</p> <ul style="list-style-type: none"><li>● Newborn Hearing Screening Process: 1-3-6<ul style="list-style-type: none"><li>▪ Hearing screening process complete before <b>1</b> month of age</li><li>▪ Diagnostic evaluation before <b>3</b> months of age</li><li>▪ Early intervention before <b>6</b> months</li></ul></li><li>○ Two stages of hearing screening<ul style="list-style-type: none"><li>▪ Stage 1: First screening, 24-48 hours after birth</li></ul>If baby fails first screening, then a second screening is done<ul style="list-style-type: none"><li>▪ Stage 2: Second screening, 7-10 days after birth</li></ul></li><li>○ Utah newborn hearing screening protocol</li></ul>



• Case studies:

- Case #1 Review - Infant born 01/2026 with **microtia**
  - **Screening Gap:** Not screened at birth. Although hospital staff intended to refer the patient to audiology upon discharge (2/01/26), the pediatrician only referred the family to an ENT (seen 3/05/26).
  - **Resolution:** EHDI contacted the family and referred them for an Auditory Brainstem Response (ABR) test. Following the ABR (completed 3/31/26 and 4/06/26), the infant was successfully fitted with a hearing aid.
- Case #2 Review – Infant born 09/2025 via a **home birth, no midwife**
  - **Screening Gap:** The pediatrician who performed the well-check informed the mother that their clinic does not offer newborn hearing screenings (NBHS) and advised waiting until school age to check the infant's hearing.
  - **Resolution Attempt:** EHDI contacted the mother and provided a screening resource at an audiology clinic located in the exact same building as the pediatrician's office. However, the mother never followed up to complete the screening.
- Case #3 Review – Infant born 02/2025 **CMV positive**. Hospital records note a 90-min. hearing screening with pediatrician. No additional info.
  - **Initial Evaluation:** The pediatrician referred the patient to a non-pediatric hearing clinic (2/25/25). Results suggested normal hearing in the right ear and a severe-to-profound sensorineural hearing loss in the left ear. The clinic recommended specialist



follow-up at the University of Utah/Primary Children's Hospital (PCH) and a 6-month re-evaluation to monitor for progressive hearing loss secondary to CMV.

- **Resolution:** Following an ENT visit on 3/17/25, an ABR was recommended and performed at PCH on 3/19/25. The infant was successfully fitted with a hearing aid.
- Case #4 Review – Infant born 06/2023 **referred on the inpatient (IP)** newborn hearing screening
  - **Screening Gap:** The family canceled the outpatient follow-up screening. When EHDI contacted them, the family stated their pediatrician had looked in the baby's ears and assured them there was nothing to worry about.
  - **Resolution:** Following the contact from EHDI, a midwife successfully screened the baby on 9/16/23.
- Case #5 Review – Infant born 06/2023 **referred on the inpatient (IP)** newborn hearing screening
  - **Screening Gap:** The family did not show up for their outpatient follow-up screening. Upon contact from EHDI, the family explained that their pediatrician had looked inside the baby's ears and assured them there was no cause for concern.
  - **Resolution:** Following intervention and contact from EHDI, the baby was screened at Utah Valley Audiology on 10/09/23.
- Summary of case reviews
  - Microtia/ Atresia Case (not screened at hospital)
  - Screening program relied on Neonatologist to refer to audiology
  - Referred to ENT only by pediatrician
  - Pediatrician not aware of audiology services
  - Referred to non-pediatric audiologist
  - Pediatrician looking in ears and telling parent there is nothing to worry about after a failed newborn hearing screening

Ms. Ezzell opened the time up for suggestions from the committee on what EHDI can do to help resolve some of these issues.

- Dr. Ormsby suggested doing short presentations at various hospitals, provider offices, or even annual provider gatherings.
- Ms. Frail-McGeever offered three suggestions:
  - Utah DHHS and Medicaid partner to implement mandatory educational



	<p>modules that hospital, clinics, and providers must attest to completing.</p> <ul style="list-style-type: none"><li>○ Utilizing Utah's network of medical staff services professionals to tie hearing education to initial provider appointments or the re-credentialing process.</li><li>○ Marketing directly to pediatric program managers through the Accreditation Council for Graduate Medical Education (ACGME) to ensure hearing screening education is embedded into resident and fellow curriculums.</li></ul> <ul style="list-style-type: none"><li>● Dr. McVicar requested that committee members email Krysta Badger with specific contact information, ideas, or leads.</li><li>● Ms. Johnson suggested creating a highly visible, one-page reference sheet (like one used for CMV testing) to place in hospital nurseries, resident break rooms, and pediatrician offices alongside informational family brochures.</li><li>● Dr. Ormsby suggested deploying small teams on “road trips” to conduct concentrated regional outreach.<ul style="list-style-type: none"><li>○ Ms. Ezell noted that the primary problem areas are currently in Davis County and the Logan area (Northern Utah), alongside a general lack of pediatric audiologists in the Southern part of the state.</li></ul></li><li>● Ms. Ezell said she intends to start a formal tracking sheet to monitor these recurring education gaps.</li></ul>
Hospital Compliance	<p>Dr. Shannon Wnek, Audiologist with the Utah EHDI Program, led a discussion on hospital newborn hearing screening compliance.</p> <ul style="list-style-type: none"><li>● Dr. Wnek highlighted a long-standing challenge with a specific rural hospital that shows no interest in program improvement despite years of intensive outreach. Efforts already taken include:<ul style="list-style-type: none"><li>○ Conducting hospital site visits and providing performance report cards.</li><li>○ Presenting individual case studies of missed opportunities.</li><li>○ Traveling down to the facility to provide diagnostic assessments for the babies the hospital failed to screen.</li><li>○ Escalating the issue through all administrative levels, from the hearing screening coordinators and screeners to the managing audiologist, and finally up to the Chief Nursing Officer (CNO)—all to no avail.</li></ul></li></ul> <p>If you have a hospital that is not willing to participate in hospital improvement,</p>



	<p>is there a way to get them on board? Ms. Frail-McGeever suggested:</p> <ul style="list-style-type: none"><li>○ Collaborating with Medicaid and Accountable Care Organizations (ACOs) to offer reimbursement or kickbacks for hospitals who are more compliant.</li><li>○ Establishing a state mandate for tracking and compliance, like how the state previously mandated CMV (Cytomegalovirus) testing.</li><li>○ Penalizing hospitals by withholding additional revenue or reducing standard reimbursements if they fail to meet performance thresholds.</li><li>○ Implementing shared performance scorecards to show where the facility stands among its peers.</li></ul>
<p>Parent Consultant Updates</p>	<p>Ms. Sorenson went over parent updates:</p> <ul style="list-style-type: none"><li>● Family contact calls (initial contacts &amp; birthday check-ins):<ul style="list-style-type: none"><li>○ March: 37 calls</li><li>○ April: 35 calls</li><li>○ May: 38 calls</li></ul></li><li>● National EHDI Conference March 15<sup>th</sup> – 17<sup>th</sup> in Jacksonville, Florida<ul style="list-style-type: none"><li>○ Parent Scholarship recipient, Libby Holley</li><li>○ Parent Consultants presented: “Making Connections Through Family Events in Utah”</li><li>○ Sat on a parent panel for a student session</li></ul></li><li>● Spring Family Event<ul style="list-style-type: none"><li>○ Co-hosted with the Parent Infant Program (PIP) on March 27, 2026, at Kidstopia in Bluffdale, UT</li><li>○ 210 individuals in attendance</li></ul></li><li>● EHDI/PIP Summer 2026 Events<ul style="list-style-type: none"><li>○ Family Summer Kick Off Activity<ul style="list-style-type: none"><li>▪ Tuesday, May 19, 2026, at Town Square Park – Splash Pad in Tooele, UT</li></ul></li><li>○ June Summer Activities – For kids who are deaf/hard of hearing and their families. Full list available on the Utah Parent Center EHDI social media pages (<a href="#">@utahEHDI</a>) and <a href="#">Utah Public Notice Website</a>.</li></ul></li><li>● Parent Volunteer Network:<ul style="list-style-type: none"><li>○ Always looking for parents to join</li><li>○ Help plan and attend events, connect with other families, help</li></ul></li></ul>



	<p>monitor GroupMe, spotlight for newsletter</p> <ul style="list-style-type: none"> <li>● Utah EHDl Parents Support GroupMe <ul style="list-style-type: none"> <li>○ Space for parents of Deaf and Hard of Hearing children in Utah to connect, share experiences, and support one another</li> <li>○ Flyer with joining info can be found on the Utah Parent Center EHDl social media pages (@utahEHDl) and the <a href="#">Utah Public Notice Website</a>.</li> </ul> </li> <li>● Youth/Young Adult Ambassador Program <ul style="list-style-type: none"> <li>○ D/HH Teens and Young adults (ages 14 - 25)</li> <li>○ A flyer is available on the Utah Parent Center EHDl social media pages (@utahEHDl) and the <a href="#">Utah Public Notice Website</a> to download and share in offices or with Youth/Young Adults that would be interested in volunteering</li> </ul> </li> <li>● EHDl Parent Newsletter <ul style="list-style-type: none"> <li>○ April Issue: <ul style="list-style-type: none"> <li>▪ English – sent to 927 email addresses</li> <li>▪ Spanish – sent to 56 email addresses</li> </ul> </li> <li>○ Newsletters go out at the beginning of every other month <ul style="list-style-type: none"> <li>▪ Next issue in June</li> </ul> </li> <li>○ If you would like to be added to the newsletter mailing list, email: <a href="mailto:ehdiparents@utah.gov">ehdiparents@utah.gov</a></li> </ul> </li> <li>● EHDl Parent Consultant <a href="#">Flyer</a> <ul style="list-style-type: none"> <li>○ Ashleigh Sorenson 385-275-4916, <a href="mailto:ashleigh@utahparentcenter.org">ashleigh@utahparentcenter.org</a></li> <li>○ Aubri Ogden 385-419-2156, <a href="mailto:aubri@utahparentcenter.org">aubri@utahparentcenter.org</a></li> <li>○ Social Media Pages: @utahEHDl</li> </ul> </li> </ul>
EHDl* Updates	<p>Dr. Stephanie McVicar reviewed Utah EHDl updates:</p> <ul style="list-style-type: none"> <li>● <b>CDC EHDl Grant:</b> The state Early Hearing Detection and Intervention (EHDl) program received an unexpected one-year extension offer. Despite a tight two-week turnaround, the team submitted the application and anticipates a formal notice of award by July 1.</li> <li>● <b>HRSA EHDl Grant:</b> The program entered Year 3 of its 5-year cycle on April 1. Funding has been delayed, with only 17% of the total amount received so far. Full funding is expected to arrive a few months later, which is critical as</li> </ul>



	<p>it covers personnel, the HITRAC database, and parent consultants.</p> <ul style="list-style-type: none"><li>● <b>Flyer Distribution:</b> Dr. McVicar requested that attendees working in audiology clinics (such as Primary Children’s) post flyers to help recruit youth ambassadors and promote parent-to-parent support.</li><li>● <b>Primary Performance Measure Progress:</b> The team is nearing completion on tracking language outcomes for deaf and hard-of-hearing children at age 3. They expect to begin receiving data within the next few months and hope to share a report in August.</li></ul> <p>Ms. Johnson said she’s heard there’s a termination of EHDI at the federal level, and asked Dr. McVicar if she knew anything about it.</p> <p>Dr. McVicar confirmed that the President's proposed FY27 federal budget outlines the elimination of the HRSA EHDI program at the federal level to consolidate agencies into an " Administration for Healthy America." This would dissolve state grants and national technical/parent support centers. It should be noted, however, that while the program has been zeroed out in previous budget proposals, Congress has historically restored the funding.</p> <p>Dr. Karl White advised against panicking and urged participants to write short, impactful personal letters to Utah's congressional representatives (Blake Moore, Celeste Maloy, Michael Kennedy, and Burgess Owens). Attendees Adrienne Johnson and Sarah Corningley agreed to coordinate and share advocacy templates from professional audiology organizations like AAA and ASHA.</p>
NCHAM Updates	<p>Dr. Karl White provided NCHAM updates:</p> <ul style="list-style-type: none"><li>● <b>EHDI 2027 Conference:</b> Following a successful recent meeting, planning is underway for the March 2027 conference in Bellevue, Washington. A 30-person planning committee will organize it, and suggestions are welcome.</li><li>● <b>Regeneron Gene Therapy:</b> Regeneron received FDA approval for a gene therapy procedure treating the otoferlin (OTOF) mutation, a rare genetic cause of congenital or late-onset profound hearing loss. Over 100 children have been treated in trials, with the vast majority showing dramatic improvements. Long-term side effects remain unknown since they have only been monitored for about two years. Eli Lilly and Regeneron are looking to</li></ul>



	<p>expand this technology to other mutations. Regeneron provides this specific medication to eligible families at no cost.</p> <ul style="list-style-type: none"><li>● <b>Oberkotter Foundation RFP:</b> A new call for proposals is aimed at improving hearing aid and cochlear implant wearing time.</li><li>● <b>JEHDI Journal:</b> A new issue of the <a href="#"><i>Journal of Early Hearing Detection and Intervention</i></a> is scheduled for release in June.</li><li>● <b>EHDI Program Reauthorization:</b> The EHDI program's legislative authorization expires at the end of the current congressional session in September 2027. Work on the reauthorization language will heavily ramp up after the November midterms.</li></ul> <p>Dr. McVicar asked about the future of the <b>CMV Public Health and Policy Conference</b> and whether there has been any forward movement to it. Dr. White responded, saying the CMV Conference (held every other year) has historically lost money. However, after a warning letter about its sustainability, \$20,000 in funding commitments has been secured about halfway toward covering the shortfall for the next potential conference in 2028.</p>
Future Agenda Items	<p>Krysta Badger summarized a previous poll outlining what members want to get out of future meetings. The top interests include:</p> <ul style="list-style-type: none"><li>• EHDI program and performance updates</li><li>• Medical and technical advancements</li><li>• Family support resources and advocacy</li><li>• Collaboration, professional insights, and community connection</li></ul> <p>Stephanie Morgan emphasized the importance of aligning future presentations and sharing data directly with the committee's core objectives.</p> <p>Committee members offered additional future topic ideas:</p> <ul style="list-style-type: none"><li>● <b>Genetics &amp; Genetic Testing:</b><ul style="list-style-type: none"><li>○ Sarah Cordingley offered to ask Dr. Schramm (an ENT she works with who handles frequent genetic testing) to present.</li><li>○ Adrienne Johnson suggested reaching out to geneticists within the local hearing assessment clinic.</li></ul></li><li>● <b>Cytomegalovirus (CMV):</b></li></ul>



	<ul style="list-style-type: none"><li>○ Ms. Johnson proposed inviting Shelly Lawrence to speak. She noted the timing is perfect because the University of Utah NICU plans to launch universal CMV testing, followed closely by Intermountain facility NICUs.</li><li>● <b>Deaf/Hard of Hearing "Life Hacks":</b><ul style="list-style-type: none"><li>○ Sarah Cordingly suggested Emily Segura, a highly public advocate with a large Instagram following dedicated to DHH life hacks who previously presented at the EHDI conference.</li><li>○ Taunya Paxton mentioned that her son, Chance, is always available to present on cochlear implant life hacks.</li><li>○ Dr. Karl White suggested structuring the life hacks segment as an interactive panel with broad, diverse representation rather than single presentations, citing a highly successful model he observed at a recent American Cochlear Implant Alliance meeting.</li></ul></li></ul>
Next Meeting	August 11, 2026
Adjourn	Charlene Frail-McGeever made a motion to adjourn the meeting. Adrienne Johnson seconded the motion. The meeting adjourned at 10:25 am.
Minutes Approved	

*Note: These minutes are not intended to be a verbatim transcript but are to record the significant features of the business*

*conducted in this meeting. Discussed items are not necessarily shown in the chronological order they occurred.*