**Colorado EHDI Alliance**

**Dx/Id and Entry into Intervention Task Force**

**Meeting Notes**

September 2, 2021

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| **Attendees** |
| **Name** | **Role/Agency** |
| Arlene Stredler Brown | Facilitator/Notetaker |
| Jessi Cooney | Colorado AG Bell |
| Jami Fries | CO Hands & Voices; Guide By Your Side Coordinator; Mom |
| Leanne Glenn | CDPHE; Newborn Hearing Screening Coordinator |
| Laura Greaver | Pediatric Audiologist; Children’s Hospital Colorado Springs |
| Brian Herrmann | Pediatric ENT @ CHCO |
| Annette Landes | CO-Hear Coordinator; Northern Colorado Region |
| Laura Merrill | Evaluation Manager EI Colorado @ CDHS |
| Dawn O’Brien Taylor | Pediatric Audiologist |
| Ashley Renslow | CSDB; Early Education Consultant |
| Allison Sedey | CU-Boulder; Director, ODDACE Project & CSDB; Assessment Coordinator |
| Kristin Sommerfeldt | Audiologist; University of Colorado Hospital; Faculty CU Boulder |
| Emily Wojahn | CO-Hear Coordinator; Colorado Springs and SE counties |

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| **Meeting Agenda** |
| **Outcomes:*** Identify current state of content delivered for children with UHL
* Identify avenues to increase effectiveness of messaging

 **Agenda:*** Announcements
* Update on Tele-Audiology Initiative
* Messaging for UHL
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| **Agenda Item** | **Discussion** | **Action/Decision** |
| **Announcement:** NBHS Brochure | The NBHS Brochure will be shared with the Screening Task Force this month; if approved, it will be presented to the COEHDI Alliance for their endorsement. Once approved, it will be distributed electronically with the intention of sharing printed copies with midwives.  | Arlene to investigate printing options. Arlene to update list of midwives who will receive brochures.  |
| **Announcement:** *Roadmaps* | COEHDI has offered funding to Hands & Voices to update the *Roadmaps*.  | Sara Kennedy providing an estimate of cost to COEHDI.  |
| **Announcement:** Changes in Pediatrix/Mednax | Pediatrix/Mednax announced this week that they will be limiting their scope of work effective September 1, 2021. In Colorado, they will continue to offer inpatient screens and outpatient rescreens. They will discontinue care coordination which had followed children until they were seen by a diagnostic audiologist. Fifteen hospitals that contract with Pediatrix/Mednax will be impacted by this change.  |  |
| **Update:** Tele-Audiology Initiative (report from the Tele-Audiology Subcommittee) | Colorado is adopting the NCHAM Learning Community’s terminology: the “hub” is the center where the clinical audiologist is housed, and the “spoke” is the remote site(s) where services take place. Arlene sent an email to many programs/organizations to inquire about their interest in being the hub site. Two sites reported interest. One site declined. There has been no response from the other sites. Should we move forward with a pilot site on the W. Slope, this information has been collected and reported by Dee Woodard (CO-Hear Coordinator) and Sarah Wedekin (Educational Audiologist): (a) there are 15 counties; (b) there are four CCBs; (c) there are 11 Administrative Units; (d) in 2020, there were 4095 births; and (e) from August 2020 - August 2021, there are 16 children who are DHH in these counties.  NCHAM has many materials related to tele-audiology. Anyone can access these at:* <http://www.infanthearing.org/flashplayer/hd_videos.htm?file=http://www.infanthearing.org/flashvideos/webinars/6-11-2021.mp4>
* Facebook page: NCHAM:Tele-Audiology.

The role of educational audiologists was discussed. This topic merits more discussion including the impact of the upcoming move of Child Find, for children birth – three years of age, from CDE to CDHS. The subcommittee agreed to conduct focus groups with stakeholders (e.g., ENTs, PCPs, audiologists, parents and educators) on the Western Slope to garner their opinions and support about the initiative.  |  |
| **UHL:** Messaging | At our last task force meeting, members recommended discussing the messaging related to UHL. We discussed what is *currently in place* from the perspective of six stakeholder groups: * Screeners: The members of the task force did not know what is currently shared by screeners.
* Audiologists: Messaging depends on the age of the child. For newborns, this involves ongoing conversations. The educational impact of UHL seems to be of most interest to families.
* PCPs: No information was shared.
* ENTs/Neurotologists: Dr. Herrmann shared that he discusses the evaluation process to identify the source of the hearing loss. He also discusses the risk of progression from UHL to bilateral hearing loss (~11%). He also noted that when a child is positive for cCMV, the chance of progression increases to ~75%. He emphasizes the importance of monitoring as children with UHL are ten times more likely to repeat a grade, and over one third of children with UHL have increased needs for educational assistance. He shared the challenges of localization; filtering background noise; and socialization. As a neurotologist, he works in conjunction with the clinical audiologist to discuss treatment. He recommends monitoring at 2-3 month intervals during the child’s first year of life. He reports there is a benefit to repeating the information until it is understood by parents.
* PCPs: Dr. Herrmann suggested what PCPs share depends on each PCP’s experience. Physicians have often said, “one ear is fine”, or referral on NBHS does not require follow up. Jami Fries from Hands & Voices reports that families do not experience concern about UHL from their PCPs.
* Part C Service Coordinators: Annette’s experience is that a child with UHL enrolled in Part C receives appropriate management from service coordinators.

*The goal* is for all six groups to present accurate and consistent messaging that is individualized for each child and their family. These goals were shared by the task force members:* Screeners: The NCHAM script can be shared with screeners (CEUs are offered if one takes the NCHAM course). Messaging needs to be more serious.
* Audiologists: No report
* ENT: TBD
* PCP: There is a need for messaging to ensure children with UHL receive follow-up. Dr. Herrmann pointed out that for children with other health issues UHL may be a less important concern. A parent perspective (Jami Fries from Hands & Voices) is that parents are more concerned about UHL as their child approaches preschool; the impact of UHL can be made a more prominent issue during the birth-3 years.
* Part C: Await information about services that may be offered by the Early Start Program.

The last part of this conversation identified *potential ways to improve messaging* by considering what is currently in place and moving toward a more desired state: * Screeners: NCHAM has a curriculum, which includes a script, for delivering information about UHL to families. This information can be shared at site visits (that are being piloted using the NCHAM Virtual Site Visit curriculum). NCHAM resources can be shared with screeners in our COEHDI *NBHS Monthly*. Could screeners schedule a rescreen and/or a diagnostic evaluation with the family?
* Audiologists: Review the potential impact on development (versus the impact on education).
* ENTs/Neurotologists: Emphasize a team approach and the value of monitoring. How do we share this information with the ENT community?
* PCP: Jami Fries stated that it is important for PCPs to “plant the seed” that issues due to UHL may become more prominent as a child gets older. Each child needs to be monitored so they don’t acquire a delay when entering preschool.
* Part C: Monitor the development of the Early Start Program.
 | Arlene will talk to Hannah Glick about dedicating an issue of the *NBHS Monthly* to UHL. Include NCHAM resources. The response of screeners at site visits will be shared with this task force. Arlene will discuss dissemination of messaging to ENTs/Neurotologists with Dr. Herrmann.  |
| **UHL:** Data Monitoring | Allison Sedey reported that a significant number of children do not participate in the developmental monitoring program that is offered through CU-Boulder in collaboration with the Regional CO-Hear Coordinators. Of those families (a significantly low number) that do connect with the CO-Hear Coordinators, at least 50% do not choose to participate in the developmental monitoring program.  |  |

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| **Next Meeting(s)**  |
| **DATE** | **TIME** | **FUTURE AGENDA ITEMS** |
| 10/7/21 | 4:00-5:00 PM | * How do we improve messaging about UHL?
 |
| 11/4/21 | 4:00 – 5:00 PM | TBD |

***A note about accommodations:*** *Beginning February 1, 2021, all Alliance meeting and task force meeting accommodations (e.g., American Sign Language interpreters, Cued Language Transliterators, and/or Spanish translators) must be requested at least 72 business hours or 3 business days in advance. Requests may be made by contacting the Alliance or your task force facilitator. We will also enable Zoom's Live Transcription feature for all meetings.*