**Colorado EHDI**

**Screening Task Force**

**Meeting Notes**

Date: October 29, 2020

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| **Task Force Membership Mindset** | |
| Collaborate with others regarding planning, execution and delivery of services to serve every family | Respect and honor the perspectives of others to provide support without bias |
| Share experiences, perspectives and expertise with respect to differing values | See beyond our own experiences to support improvement for the entire system |

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| **Attendees** | |
| **Name** | **Role** |
| Arlene Stredler Brown | Facilitator |
| Heather Abraham | Notetaker |
| Maureen Cunningham | Pediatric Hospitalist CHCO; CO AAP Chapter Champion |
| Lisa Cannon | Educational Audiologist (DPS) and CDE Consultant |
| Becky Awad | Audiologist, Children’s Hospital |
| Sandra Gabbard | Audiologist and Director, Marion Downs Center |
| Kristin Sommerfeldt | Audiologist and Faculty, University of Colorado |
| Jennifer Schryer | Educational Audiologist, Colorado River BOCES |
| Sara Kennedy | Director, CO Hands & Voices |
| Stacey Snow | Screening Coordinator; Hearing Screening Associates |
| Dee Schuler Woodard | W. Slope Regional CO-Hear Coordinator |
| Hannah Glick | Audiologist & Faculty, CU Boulder |
| Angela Harder | Audiologist, Children’s Hospital |
| Mah-rya Proper | Parent |
| Stacy Claycomb | Audiologist - UCHealth |
| Kalie Buchman | Audiology Extern/Children’s Hospital - LEND Program |

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| **Agenda Overview** |
| 1. Brief introductions 2. EHDI PALS and county-specific Hands & Voices Roadmaps 3. CO EHDI website development 4. Update on utilization of HIDS 5. Discuss topical issues in context of other states with similar structure (NBHS database in State Health Department and EHDI in a different agency) 6. Prioritized topics and rationale for moving forward    1. Professional Development    2. Role of PCPs    3. Role of Educational Audiologists 7. Open agenda |

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| **Agenda/Actions/Decisions** | | |
| **Agenda Items** | **Discussion** | **Action/Decision** |
| **EHDI PALS and Hands & Voices Roadmap** | Sara Kennedy shared information about **EHDI PALS**, a website that provides families with information about the pediatric audiology centers closest to each family. There have been some recent improvements that will make EHDI PALS more accessible to people in CO. Parents need to indicate the reason for an audiology appointment, which is a bit concerning because parents might not be sure why they need the appointment. However, once you enter information, the app pulls up the nearest audiology testing centers. In some rural areas, some parents are referred to Part C rather than to an audiologist. This may not be the most effective way for them to access the audiologic diagnostic system. The website for EHDI PALS is: <https://www.ehdi-pals.org/default.aspx>  Sara indicated that the state EHDI coordinators have the ability to see the names of audiology centers for their state, and they can reach out to individuals if there is a concern about a specific person or clinic.  The **Roadmap**, supported by CO Hands & Voices, outlines the 1-3-6 EHDI system. Parents can access information regarding: (a) birthing center screening coordinators; (b) closest audiologists; (c) regional CO-Hear Coordinator; (d) EI providers; and/or (e) a parent guide. This resource is available for each birthing center to distribute to families. Some birthing centers use it as documentation, and other facilities have developed their own handout. The goal is for families to know where they are in the 1-3-6 process and to know their next steps.  The Roadmaps are located on the Hands & Voices website. The website landing page is: <http://cohandsandvoices.org/rmap/roadmap/>. | Sara indicated that the link could be included in birthing center newsletters.  Arlene offered to include a link to this information on the COEHDI website. Let’s give consideration to additional ways in which our state can distribute this information to birthing centers.  Arlene will contact Sara about including information regarding EHDI PALS and the Roadmap in the December COEHDI newsletter.  Arlene is working with Randi Winston at NCHAM to keep our EHDI PALS listings up to date. |
| **CO EHDI website development** | CDPHE, in previous communications, endorses our decisions as to the information we post on our website. Our goal is to make our website as accessible as possible to parents, professionals (e.g., screeners, audiologists, early interventionists, PCPs) and DHH adults.  Hannah Glick provided an update indicating that the COVID-19 Task Force distributed a survey to birthing facilities regarding screening, rescreening, and loss to follow up. In addition, a survey was sent to midwives regarding the type of supports they would like due to the impact of COVID-19. Based on the surveys returned, we will develop resources for the CO EHDI website. We want Screening Coordinators, hospital screeners, and midwives to have access to the most up-to-date information. We will be posting links to NCHAM materials as well; they have resources regarding safe screening during COVID-19.  Arlene shared that Alyson Ward from NCHAM has released new information about screening and diagnostic services impacted by COVID. This information will be forwarded to our webmaster and posted on our website. The task force indicated that they would like this information forwarded to them as well. Arlene shared the contact information for Katie Cue, our webmaster, with the members. Please contact Katie if you have information you would like to post on our website: [kcue@coehdi.org](mailto:kcue@coehdi.org).  Task force members indicated that the 2019 JCIH statement would be a good resource for our website as well as a Hands & Voices resource defining the importance of follow up for screening. | Hannah will provide resources for our COEHDI website based on survey results.  Arlene will share NCHAM resources regarding screening during COVID with task force members.  Arlene will ask Katie to upload the 2019 JCIH Position Statement to our website.  Arlene will connect Katie & Sara K. to identify information to post on our website. |
| **Update on HIDS** | Dee Woodard (W. Slope CO-Hear Coordinator) shared that CO-Hear Coordinators met with the HIDS database developers for a Q&A session earlier this week. The developers are willing to make changes to HIDS based on end-user needs.  There is a concern regarding the low number of people, to date, who have signed on to input data into the HIDS database. How shall hospital screeners, and various groups that need access to HIDS, be encouraged to apply for access? Becky Awad suggested reaching out to individual Screening Coordinators at hospitals to help them understand the importance of becoming users. Becky indicated that the Screening Coordinator at CDPHE would, in most states, reach out to each hospital. Dee suggested talking with other Regional CO-Hear Coordinators about contacting birthing centers in their respective regions to encourage screeners to sign up and enter information.  Hannah indicated that the midwives are struggling to enter data as well.  Sandy Gabbard stated the importance of having CDPHE assume a lead role to ensure the implementation of the new data management system. | Arlene will put this issue on the agenda for her monthly check-in with Margaret R. and Hannah Glick next week.  The information will be included in the COEHDI newsletter.  An update on this issue will be provided to the Alliance by Kristin Sommerfeldt (our rep. from this task force) at the Alliance’s November meeting. The recommendation of the task force highlights the importance of having CDPHE’s participation in enrolling users of the database. |
| **Topical issues pertinent to having NBHS database our State Health Department and EHDI in a different agency** | Arlene shared information from three states that have infrastructures similar to CO. Comparisons were collected about: (a) home births; (b) collecting/sharing data; and (c) babies born out of state. Arlene solicited input from the task force members to apply what we have learned from other states to the issues we have in CO.  At past meetings, Margaret Ruttenber reported on EBC data as a way to monitor screenings and rescreenings. A limitation to the EBC is that this data only documents screening tests that were conducted in the birthing facility while the child was an inpatient; it does not include children who did not pass the screening and returned *after* discharge to the birthing or went to another facility for a rescreen. Therefore, numbers related to LTF may not be accurate.  Sandy Gabbard indicated that the screening data collected by CDC only asks the number of children screened prior to one month of age.  Arlene shared that Colorado statistics were last shared with CDC in 2015, and that data was not included in the national report. Colorado EHDI will be providing as much data as possible to CDC for 2019. We will not be able to complete all data fields that are requested.  Sandy Gabbard asked about CDPHE’s role in reporting. This item will be brought to the EHDI Alliance in November. | Kristin will include this issue when reporting to the Alliance as part of the Screening Task Force update. |
| **Prioritized topics and rationale** | ***Professional Development*:** COEHDI has received funding for COVID-related activities which will give us an opportunity to provide some one-on-one support to newborn hearing screeners. Hannah Glick is the contact person for hospital screeners and midwives. Our CO EHDI website will be a repository of resources.  ***Role of Educational Audiologists*:** Lisa Cannon shared that we are surveying all educational audiologists about their ability to participate in screening and/or rescreening activities. The survey asks educational audiologists to report on their comfort conducting screenings, the equipment they have, and if they have administrative support to screen.  Jennifer Schryer indicated that she was added to a list by Leanne Glenn, and she is periodically contacted to support rescreening. Her biggest concern is that she doesn’t know how to report the results that she obtains. Until now, she has been sending, via email, any testing results to Leanne Glenn. It is unclear if educational audiologists will have access to HIDS.  Arlene asked if educational audiologists can be added to the H&V Roadmap. Sara Kennedy stated that only some educational audiologists feel qualified &/or have the equipment to do the screening. Sandy indicated that there would need to be a disclaimer regarding the recommendation by JCIH that ABR be conducted for certain populations. (Most, if not all, educational audiologists would only have OAE equipment.)  ***Role of PCPs*:** PCPs act as a safety net for children to reduce LTF. PCPs, for several years, have not been in the “communication loop” about screening results. PCPs often do not have access to records at a birthing center. Yet, when a child needs a referral to audiology, the PCP plays a key role. At this point in time, PCPs do not have access to HIDS.  CDPHE has indicated that it is not practical to enroll hundreds of PCPs into HIDS at this point in time. Margaret has indicated that a pilot with specific practitioners may be a possibility in the future.  The task force members identify PCP’s lack of involvement in the EHDI system - for both screening/rescreening and referral to diagnostic audiology - as a problem that needs to be addressed. In rural areas, this becomes an even larger issue due to limited diagnostic resources in many communities.  Maureen Cunningham suggested CDPHE play a role in identifying resources for referral. The Alliance can play a role as well by identifying resources for pediatric follow up.  Most PCPs have access to the immunization system (CIIS); other states include newborn hearing screening data on the immunization record accessed by PCPs. Increasing communication with PCPs is the primary way to ensure that families return for follow up screening/rescreening after being discharged from the birthing facility.  Sara Kennedy shared that PCPs can access Patient Care 360. More discussion is warranted.  Arlene asked if there is a role for the CO EHDI Alliance to increase awareness and education via our website, newsletter, etc. Maureen indicated that information provided in a variety of ways is helpful. She also emphasized, and it was acknowledged, that EHDI’s role does not include sharing of specific patient information. Rather awareness about screening, rescreening, LTF, and audiologic diagnostics is helpful and can fall within the purview of EHDI. This will be brought up at the November Alliance meeting. | Maureen recommended including hearing screening data on the immunization database; PCPs have access to this system (CIIS). |

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| **Next Meeting(s)** | | |
| **DATE** | **TIME** | **AGENDA ITEMS** |
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