**Colorado EHDI**

**Screening Task Force**

**Meeting Notes**

August 13, 2020

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| **Attendees** | |
| **Name** | **Role** |
| Arlene Stredler Brown | Faclitator |
| Heather Abraham | Notetaker |
| Maureen Cunningham | Physician, CO AAP Chapter Champion |
| Margaret Ruttenber | State Birth Defects Registry, CDPHE |
| Lisa Cannon | Educational Audiologist (DPS) and CDE Consultant |
| Becky Awad | Audiologist, Children’s Hospital |
| Sandra Gabbard | Audiologist and Director, Marion Downs Center |
| Kristen Sommerfeldt | Audiologist and Faculty, University of Colorado |
| Jennifer Schryer | Educational Audiologist, Colorado River BOCES |
| Lisa Morales | Educational Audiologist, Pikes Peak BOCES |
| Sara Kennedy | Director, CO Hands & Voices |
| Sarah Wedekin | Educational Audiologist, Mesa 51 |
| Stacey Snow | Screening Coordinator; Hearing Screening Associates |
| Trudy Fredericks | Audiologist, Denver Health |
| Romona Pearce | Pediatrix |
| Kelly Miller | Pediatrician, Durango |
| Lisa Shigio | Audiologist, Colorado School for the Deaf and Blind |
| Dee Woodard | CO-Hear Coordinator; CSDB |
| Mathew Landman | Pediatrix |

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| **Meeting Outcomes** |
| * Welcome and Introductions * Topical Issues – Priorities, facilitated discussion, action steps * Representative to CO EHDI Alliance meeting |

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| **Agenda/Actions/Decisions** | | |
| **Agenda Items** | **Discussion** | **Action/Decision** |
| **Topical Issue: Integrating EHDI work with CDPHE after the launch of the Health Information Data System (HIDS)** | Margaret Ruttenber offered an update on the HIDS database. CDPHE has been creating training videos. Last week, the Office of Information Technology identified the need for an encrypted system. It is unknown how long the encryption will take. They are hoping that it will be complete by the end of September. Users will only be able to see patients on their caseloads. CDPHE will have a meeting to launch the database after it is encrypted.  Aggregate data will be shared on the CDPHE website and CDPHE will work with the CIHAC to determine what the needs are for users. Each site will be provided with their own data. For those who are not direct users, CDPHE reports data on an annual basis. Screening and diagnostic information will be available to users with access. (Users will apply for access and sign a confidentiality agreement.) The CO-Hear Coordinators will be able to see their caseloads. They will get an automatic notification when an audiologist makes a note that a child was diagnosed with a hearing loss. Margaret stated that facilities will be able to get their own data from the system.  Becky Awad asked about proactive steps that can be taken to address gaps in the system and who will be responsible for follow up. Margaret indicated that CDPHE does not have the authority to conduct follow up and that it will be up to the CIHAC to make recommendations/decisions. She indicated that they would provide guidance on their website.  Becky requested more active sharing of information, such as monthly updates. | Arlene, on behalf of CO EHDI, will work with CDPHE/CIHAC and the Screening Task Force members to identify action steps on who can follow up on children missing a hearing screen and/or rescreen. Any steps taken are intended to increase screening rates and decrease LTF. Any actions need to be implemented statewide.  More discussion will occur at future task force meetings. The EHDI Coordinator could send out some type of regular communication with birthing facilities. Need guidance from Screening Task Force. |
| **Topical Issue: Communication between diagnostic centers and birthing facilities and medical home** | Maureen Cunningham shared that, historically, the medical home has been left out of communication regarding screening and diagnostic results. Currently, screening results are expected to be communicated to the PCP by the screening facility and diagnostic results are expected to be communicated by the audiologist. But, each facility has its own process and this varies throughout the state. She believes that much of the LTF could be resolved through a more systematic way of facilitating communication with PCPs. There are so many PCPs that it is not realistic to give *all* of them access to the HIDS database.  Much of the LTF is occurring between discharge and families returning for rescreening. Families in rural areas are particularly vulnerable to LTF.  Kelly Miller reported that the NBH Screeners in the Durango area put the results of a failed screening in the discharge notes. The local audiologist is keeping track and following up with families as well. Maureen asked if this system could be replicated or if there could be a consistent statewide system to address LTF. | Arlene indicated that it is her intention to identify what is working (i.e., in Durango) and work with Screening Task Force members to make statewide recommendations.  Perhaps a survey of all medical homes?  More discussion will occur at future task force meetings to identify next steps. |
| **Topical Issue: Equitable Services in Rural Areas** | Kelly Miller reported that when there is an issue in Durango with the screening equipment, those children don’t get screened and it requires active follow up to find those families.  Sarah Wedekin stated that some educational audiologists function as a safety net. They see children through Child Find and can screen (and diagnose) children on the W. Slope. Sarah and Dee Woodard are working with a local birthing facility regarding their referral process. Some medical homes are contacting Child Find and CO-Hear Coordinators for children LTF, but the numbers aren’t good.  Jennifer Schryer indicated that one of the biggest issues is access to diagnostic follow up after a failed rescreen. Families have issues with timely follow up, financial challenges, and have to travel extensive distances for services.  Dee indicated that the team on the W. Slope is taking baby steps to improve the system, however, communication continues to be an issue.  Sandra Gabbard indicated that Early Headstart sites might be an additional safety net. | Check with PCPs statewide about current practices.  Work with Lisa Cannon (CDE lead with educational audiologists) about the role of educational audiologists statewide.  Arlene indicated that there will be another task force to address transition from screening to diagnostics and yet another task force related to diagnostics. Hold this item til then.  Investigate the work Dee is doing in her region to address screening/rescreening and LTF. Is what they are creating a model for other rural areas?  Pursue Early Headstart’s potential role to accomplish our goal.  More discussion on all potential action steps will occur at future task force meetings. |
| **Topical Issue: Audiology Regional Coordinators (ARC)** | Sara Kennedy reviewed the role of Audiology Regional Coordinators (ARC) in the state EHDI system. Each ARC connected with several birthing facilities to help them understand their statistics, provide updates, communicate about new initiatives, and to act as a liaison to the EHDI system. There is research indicating that facilities had a more accurate screening system when they had an audiologist assigned to them. The ARCs no longer have funding.  It is unclear who the staff at birthing facilities should contact when they have questions or concerns. Arlene is receiving queries.  Margaret stated that CDPHE could apply for a CDC grant which could include oversight of this activity. The next round for CDC grants is ~2024. | Need to identify who will communicate with birthing facilities and what needs to be included in this communication. It could come from EHDI. Need guidance from the Screening Task Force members.    Consider a survey of birthing facilities to determine supports they want.  More discussion on all potential action steps will occur at future task force meetings. |
| **Topical Issue: cCMV** | Screening for CMV must be done in the first three weeks of life. This can only be done when there is a way to notify the family of hearing screening results.  Kelly Miller described what is happening in Durango. They are doing cCMV testing on all children who fail a hearing screening. She tracks those results and communicates with PCPs. | There is an established group in Colorado pursuing cCMV screening. Arlene will be attending these meetings.  More discussion on all potential action steps will occur at future task force meetings. |
| **Representative to Alliance** | Volunteers to represent the Screening Task Force on the CO EHDI Alliance were solicited. | Kristin Sommerfeldt will represent our work to the Alliance this year. |

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| **Next Meeting(s)** | | |
| **DATE** | **TIME** | **AGENDA ITEMS** |
| ASAP – Expect a Doodle poll soon | TBD | * Discuss remaining Priority Topics * Identify priority issues and associated action steps |