**Colorado EHDI Alliance**

**Dx/Id and Transition to Intervention Task Force**

**Meeting Notes**

Date: 11/10/20

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| **Norms of Collaboration** |
| Pausing | Paraphrasing |
| Posing Questions | Putting Ideas on the Table |
| Providing Data | Paying Attention to Self and Others |
| Presuming Positive Intent | Practice Economy of Language |

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| **Attendees** |
| **Name** | **Role** |
| Heather Abraham | Facilitator/Notetaker |
| Arlene Stredler Brown | Facilitator/Notetaker |
| Kristin Sommerfeldt | Audiologist; UC Health and CU-Boulder Faculty |
| Dani Nouguier | Parent of a son who is hard of hearing |
| Brittany Goodside | Parent of a son who has a hearing loss; Program manager for CCB (Imagine! in Boulder County) |
| Emily Wojahn | CO-Hear Coordinator; Colorado Springs and SE counties |
| Jamie Fries | Parent of a 5-year-old who is deaf; works with CO Hands and Voices |
| Marti Bleidt | Itinerant teacher for DHH; Representing CO AG Bell; has 2 daughters who are DHH |
| Annette Landes | CO-Hear Coordinator: Weld, Larimer and NE counties |
| Emily Chamberlain  | Audiologist at Denver Health (focus on pediatrics) |
| Laura Greaver | Audiologist; Children’s Hospital |
| Cathy Cortese | Parent of an 11-year-old girl who is deaf; also works with families of children who are DHH; Early interventionist; sign interpreter |
| Laura Merrill | Evaluation Manager with Early Intervention Colorado |
| Lisa Cannon | Educational Audiologist; DPS and Coordinator of Educational Audiologists for CDE |
| Lynn Wismann | CO-Hear Coordinator; Arapahoe & Douglas Cty  |
| Allison Sedey | University of Colorado, FAMILY Assessment |

**2 minutes**

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| **Meeting Outcomes** |
| * Collective understanding of the role of this task force
* Collaboration among group members
* Identification of priority topics for task force
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| **Agenda/Actions/Decisions** |
| **Agenda Items** | **Discussion** | **Action/Decision** | **Champion** | **By When** |
| **Background**  | Presentation of terminology: Shall we use the word “diagnosis” or “identification”? At this point in time, we are using both terms interchangeably. Please share your ideas, specific materials, and/or links to materials that we can include in our website which is currently under development. Contact Katie Cue: kcue@coehdi.org  | Contact Katie Cue if you have materials to recommend for our website: kcue@coehdi.org | n/a | Ongoing |
| **HIDS Update** | Arlene provided a description of the history of EHDI data collection during the past few years, and the new data system (HIDS) that launched on October 6th of this year. In order to be a HIDS user, the professional must work directly with children who are DHH. Emily Chamberlain (Denver Health) shared that she was able to login to HIDS and is entering data from 2019 to present. There is no generic “lost to follow up” button so even when you provide information, children stay in your pending group. Overall, Emily indicates that HIDS looks better than the previous IDS system. Without annual EHDI data for the past several years, we do not have a clear picture of how well we have been meeting the 1-3-6 EHDI guidelines. This makes it especially challenging to consider adopting a 1-2-3 guideline. A discussion about securing baserate data for 2019 and 2020 led to several recommendations that will be presented to The Alliance at the November 20th meeting. Some input from the discussion includes: * Arlene indicated that CDC is asking for data for 2019 and will ask for data for 2020. With the transition to HIDS, the first reliable reporting year from the HIDS database will be 2021. What can be done in the meantime?
* How will early intervention gain access to the information in HIDS: Annette Landes indicated that tracking of children from diagnostics to EI has been the responsibility of the CO-Hear Coordinators for many years. CO-Hear Coordinators have access to HIDS and will continue to input data about their caseloads. In addition, Part C has its own data system and it continues to be populated. We have 2 systems in place.
* Kristin Sommerfeldt suggested housing a second, temporary database in an encrypted database, such as Redcap. This approach could provide 2019 and 2020 data if CDPHE does not report data for these two years.
* Perhaps Pediatrix’s de-identified, aggregate data can be accessed. Pediatrix currently follows ~30% of the births in CO.
* Hannah Glick is working, on behalf of EHDI, with birthing facilities statewide. She may also be able to access aggregate, deidentified data.
* Emily Chamberlain asked if there is a way to encourage all users to add 2019 and 2020 data into HIDS. Allison Sedey indicated that it would likely be worth the effort to encourage people to enter as much information from 2019 and 2020 into the new HIDS system in order to get baserate data.

The group discussed the importance of having 2019 and 2020 data to ensure children are not lost to followup and that they receive the support needed. This information would also provide baserate data on which to design activities until the 2021 HIDS data can be reported. While the CO-Hear Coordinators have data regarding entry into intervention, we need screening data from the electronic birth certificate and diagnostic data from audiologists. Should this task force make a recommendation to the Alliance to pursue gathering of 2019 and 2020 data? The group unanimously agreed to bring their support to collect 2019 and 2020 data to The Alliance for discussion. This will be put on the Alliance agenda for November 20th.  | Contact CDPHE (Leanne Glenn) about improvements to HIDS (e.g., LTF button)Follow up with CDPHE about reporting 2019 and 2020 data from HIDS. Follow up regarding the potential to have AuD students support data collection for 2019 and 2020. Bring this issue to The Alliance at the November meeting.  | Arlene & Emily ChamberlainArlene and Alliance meetingKristin Sommerfeldt and ArleneArlene & Heather | OngoingASAPOngoing ASAP |
| **Meeting Schedule** | We will set a regular monthly meeting.  | Send out a poll to identify an optimal meeting day and time for monthly meetings | Arlene | ASAP |

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| **Next Meeting(s)**  |
| **DATE** | **TIME** | **FUTURE AGENDA ITEMS** |
| TBD | TBD | These topics have been compiled by Core Team and task force members: (a) Referral process from diagnosis/identification to early intervention; (b) referral process specifically for children diagnosed/identified with UHL; (c) printed resources shared with families upon entry into EI; (d) accommodations for families in rural areas; (e) accommodations for CLD families; (f) testing for cCMV; (g) EHDI PALS; (h) tele-audiology; (i) access to family-to-family supports during transition from diagnostics/identification to EI; (j) unique needs of families of children with additional disabilities (aka; Deaf Plus or DWD); and (k) CI eligibility for children with UHL.  |