**Colorado EHDI Alliance**

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

**Meeting Notes**

Date: 12/3/20

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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 |
| **Jamie Fries** | Parent of a 5-year-old who is deaf; works with CO Hands & Voices |
| **Annette Landes** | CO-Hear Coordinator: Weld, Larimer and NE counties |
| **Emily Chamberlain** | Audiologist at Denver Health (focus on pediatrics) |
| **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 |
| **Lynn Wismann** | CO-Hear Coordinator; Arapahoe & Douglas Cty |
| **Jill Jacobs** | Parent of a 14-year-old child who is deaf/hard of hearing |
| **Mah-rya Proper** | Parent of a child who is late identified as deaf/hard of hearing |

**2 minutes**

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| **Meeting Outcomes** |
| **Outcomes:**   * Recommendation to COEHDI Alliance for CO-Hear Coordinator Role in our system * Identification of priority topics for task force   **Agenda:**   * Introductions * Scope of this task force * Data Collection Update * Referral Process   1. Background and overview of legal referral requirements   2. Rationale for the current “interim” procedure   3. Discussion   4. Recommendation(s) for the CO EHDI Alliance * Future Topics * Wrap Up |

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| **Agenda/Actions/Decisions** | | | | |
| **Agenda Items** | **Discussion** | **Action/Decision** | **Champion** | **By When** |
| **Scope of Task Force** | There is an initiative to change the EHDI goal from 1-3-6 (screening by 1 month - identification by 3 months - intervention by 6 months) to 1-2-3. With the state of our state, a more realistic aspiration is 1-3-6 at this time. | n/a | n/a | n/a |
| **Data Collection Update** | Emily Chamberlain is the Alliance representative from this task force; the data collection issue was brought to the Alliance at the November 2020 meeting. There was unanimous support for the collection of 2019/20 data. CDPHE imported data that existed from the old database (IDS) into the HIDS system, and users are able to manually enter missing data. The Alliance supports users to enter 2019/20 data, to the best of their ability, into HIDS. At the Alliance meeting, Margaret Ruttenber, from CDPHE, stated that Leanne Glenn, the Newborn Hearing Screening Coordinator, would send letters to all previous users to ask them to backfill 2019/20 data. CDPHE has not done this, to date. Arlene will encourage CDPHE to do this, while EHDI also contacts diagnostic audiologists and screeners to encourage them to enter this data.  It is critical to have baserate data upon which to create realistic goals in the COEHDI Work Plan. | We will proceed with encouraging HIDS users to manually enter 2019/20 data  We will work with CDPHE to encourage letters from CDPHE to users to accomplish the same | Arlene  Arlene | January 2021  December, 2020 |
| **Referral Process from Diagnosing Audiologist to Early Intervention** | There is a current interim referral process that refers families of newly-identified children to CO-Hear Coordinators. This interim process was created on April 1st when the current EHDI grant was awarded.  Today’s discussion included a review of the CO-Hear Coordinator roles and responsibilities in the context of sustainability. For example, what is the role of the Part C Service Coordinator and what is the role of the CO-Hear Coordinator? How do they interface? Currently, the CO-Hear Coordinators are funded, exclusively, by CSDB; funding is a line item in the CSDB budget.  Arlene shared information about: (a) the prevalence of DHH in early childhood (1.7/1000) (CDC, 2017); (b) the distribution of children who are DHH in the 7 CO-Hear Coordinator regions; and (c) a comparison of the numbers in CO to the national average. The prevalence of DHH children in CO diagnosed with any kind of hearing loss (by type and degree) is higher than the national average of 1.7/1000. Heather gave task force members a link to this data during the meeting, and it is available on request.  Annette Landes & Lynn Wismann, 2 CO-Hear Coordinators at the task force meeting, reported that their role includes the following: (a) receiving referrals; (b) acting as the first contact for families; (c) sharing information and resources with families; (d) helping families navigate into early intervention; (e) supporting and mentoring EI providers (that are funded by the CCBs); (f) interfacing with personnel in the CCBs in their regions; (g) referring families to CO Hands & Voices; (h) connecting the family with appropriate community program options; (i) supporting the development of the IFSP; (j) supporting completion of the FAMILY Assessment; and (k) providing professional development to EI providers in collaboration with CCBs.  Questions were raised and these issues were discussed by members of the task force.   * There has been a gradual decrease in the number of CO-Hear Coordinators over the years while caseloads are increasing. A notable increase (~30%) happened with UHL referrals becoming part of the CO-Hear Coordinators’ caseload on April 1, 2020. Currently, no CO-Hear Coordinators are 1.0 FTE. The current framework at CSDB is reportedly to maintain a static FTE allocation (i.e., if you increase FTE in one area, then it needs to be decreased in other areas). * For some, there is a perceived bias toward sign language because CSDB houses and funds the CO-Hear Coordinators. * The interface with CO-Hear Coordinators regarding cCMV, and children who are deaf plus.   Some task force members were unable to attend the meeting and provided this input for topics for future meetings:   * frequency of CO-Hear Coordinators’ visits * collaboration between CO-Hear Coordinators and Part C * Support for family choice (e.g., language, communication modality) * distinguish programs and personnel from one another (e.g., Part C Service Coordinator, EI provider, CO-Hear Coordinator, CHIP Facilitator, CSDB, CCB) * CO-Hear Coordinators’ knowledge and skills about general development (beyond their expertise about hearing loss) * the number of people contacting a family shortly after identification of hearing loss, and the timing of these interactions * sharing information through printed materials v. electronic access   Our HRSA-funded EHDI grant gives COEHDI an opportunity to refresh and renew the referral/transition system. We have an opportunity to analyze families’ needs in relation to the capacity of the system. The question of sustainability is a benchmark of our four-year EHDI grant; HRSA has required each state EHDI program to work toward creating a sustainable system. | The decision was made to postpone a recommendation to the  Alliance to allow more discussion about the issues reported here.  Annette Landes suggested bringing topics to the CO-Hear Coordinator group for discussion. | All  CO-Hear Coordinators | Ongoing  Ongoing |
| **Ways to mitigate LTF** | Similar to other task force meetings, the potential role of CO-Hear Coordinators to reduce LTF was mentioned. Is this a viable issue to pursue? | Discuss with COEHDI Core Team, other task forces | Arlene | Ongoing |

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| **Next Meeting(s)** | | |
| **DATE** | **TIME** | **FUTURE AGENDA ITEMS** |
| January 7, 2021 | 4:00-5:00 PM | Address items shared in the section of the minutes titled, “Referral Process from Diagnosing Audiologist to Early Intervention” |