

**Colorado EHDI Alliance
Dx/Id and Entry into Intervention Task Force**

**Meeting Notes
June 3, 2021**

Attendees	
Name	Role/Agency
Heather Abraham	Facilitator/Notetaker
Arlene Stredler Brown	Facilitator/Notetaker
Emily Wojahn	CO-Hear Coordinator
Allison Sedey	University of Colorado, ODDACE Project; Assessment Coordinator CSDB
Jami Fries	CO Hands & Voices; Guide By Your Side Coordinator; Mom
Annette Landes	CO-Hear Coordinator; Northern Colorado Counties
Richard Jeffries	Director of Outreach, CSDB
Brittany Goodside	Mom and EI Manager for Imagine! CCB
Laura Merrill	Early Intervention Colorado; Evaluation Manager EI Colorado @ CDHS
Kristin Sommerfeldt	Audiologist; University of Colorado Hospital and Faculty @ CU Boulder
Lynn Wismann	CO-Hear Coordinator; Douglas & Arapahoe Counties (not Aurora)
Dawn O'Brian Taylor	Pediatric Audiologist
Brian Herrmann	Pediatric Otolaryngologist; Children's Hospital
Jessi Cooney	Colorado AG Bell
Leanne Glenn	CDPHE; Newborn Hearing Screening Coordinator

ASL Interpreter: Julia Ostberg

Meeting Agenda

Outcomes:

- Continue to gain an understanding of the state of the state based on 2019 data
- Develop a common understanding of issues specific to children identified with unilateral hearing loss (UHL)

Agenda:

- 2019 Data Report
- System support for children identified with UHL

Agenda Item	Discussion	Action/Decision																																				
2019 Data Report	<p>Arlene shared information from the 2019 data reported to CDC regarding hearing loss characteristics. The following was shared:</p> <p>Summary by Type & Degree</p> <table style="margin-left: 20px; border-collapse: collapse;"> <tr> <td style="padding-left: 20px;">Slight (<i>n</i>=11)</td> <td style="text-align: right; padding-left: 20px;">5%</td> </tr> <tr> <td style="padding-left: 40px;">Bilateral (<i>n</i>=7)</td> <td></td> </tr> <tr> <td style="padding-left: 40px;">Unilateral (<i>n</i>=4)</td> <td></td> </tr> <tr> <td style="padding-left: 20px;">Mild (<i>n</i>=69)</td> <td style="text-align: right; padding-left: 20px;">35%</td> </tr> <tr> <td style="padding-left: 40px;">Bilateral (<i>n</i>=51)</td> <td></td> </tr> <tr> <td style="padding-left: 40px;">Unilateral (<i>n</i>=18)</td> <td></td> </tr> <tr> <td style="padding-left: 20px;">Moderate (<i>n</i>=28)</td> <td style="text-align: right; padding-left: 20px;">14%</td> </tr> <tr> <td style="padding-left: 40px;">Bilateral (<i>n</i>=16)</td> <td></td> </tr> <tr> <td style="padding-left: 40px;">Unilateral (<i>n</i>=12)</td> <td></td> </tr> <tr> <td style="padding-left: 20px;">Moderately Severe (<i>n</i>=31)</td> <td style="text-align: right; padding-left: 20px;">16%</td> </tr> <tr> <td style="padding-left: 40px;">Bilateral (<i>n</i>=17)</td> <td></td> </tr> <tr> <td style="padding-left: 40px;">Unilateral (<i>n</i>=14)</td> <td></td> </tr> <tr> <td style="padding-left: 20px;">Severe (<i>n</i>=19)</td> <td style="text-align: right; padding-left: 20px;">10%</td> </tr> <tr> <td style="padding-left: 40px;">Bilateral (<i>n</i>=8)</td> <td></td> </tr> <tr> <td style="padding-left: 40px;">Unilateral (<i>n</i>=11)</td> <td></td> </tr> <tr> <td style="padding-left: 20px;">Profound (<i>n</i>=12)</td> <td style="text-align: right; padding-left: 20px;">6%</td> </tr> <tr> <td style="padding-left: 40px;">Bilateral (<i>n</i>=9)</td> <td></td> </tr> <tr> <td style="padding-left: 40px;">Unilateral (<i>n</i>=3)</td> <td></td> </tr> </table>	Slight (<i>n</i> =11)	5%	Bilateral (<i>n</i> =7)		Unilateral (<i>n</i> =4)		Mild (<i>n</i> =69)	35%	Bilateral (<i>n</i> =51)		Unilateral (<i>n</i> =18)		Moderate (<i>n</i> =28)	14%	Bilateral (<i>n</i> =16)		Unilateral (<i>n</i> =12)		Moderately Severe (<i>n</i> =31)	16%	Bilateral (<i>n</i> =17)		Unilateral (<i>n</i> =14)		Severe (<i>n</i> =19)	10%	Bilateral (<i>n</i> =8)		Unilateral (<i>n</i> =11)		Profound (<i>n</i> =12)	6%	Bilateral (<i>n</i> =9)		Unilateral (<i>n</i> =3)		<p>Arlene will meet with Leanne to discuss ways to obtain a more complete list of pediatric audiologists.</p> <p>Leanne invited people to participate in the Data Committee that is being convened by the CIHAC. The first meeting is Monday, June 7th at 11:00. There will be future meetings too. Contact Sara Kennedy to attend.</p>
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Unknown (*n*=28) 14%
Bilateral (*n*=10)
Unilateral (*n*=18)

Type and degree of hearing loss is likely entered at the initial diagnostic evaluation, and it is likely that it is not revised after subsequent testing. The accuracy this data needs to be considered in light of this assumption.

Fourteen percent of the children have the degree of hearing loss in the “unknown” category. No information is available to identify any patterns that may exist among the different diagnostic centers.

A question was raised regarding the degree to which the 2019 data is complete. The data indicates that Colorado’s prevalence is a bit higher (at ~3/1000) than the national prevalence data (~1.7/1000). And, large diagnostic centers reported that they entered their 2019 data. Could this add confidence to the numbers reported?

Leanne Glenn shared some information about HIDS including: (a) there is no worklist in the system to connect a child with an audiologist unless a referring agency is attached to that child; (b) an audiologist can “break glass” in order to see a child when that audiologist’s agency has not been designated as the “responsible agency”; and (c) entries include both children with a confirmed hearing loss and no hearing loss.

There was a request to know the incidence, statewide, for these two topics: (a) the incidence of false positive screens; and (b) the percentage of children who “did not pass” an initial screen that did have a follow-up screen. Arlene and Heather have met with Bill Vertrees and shared a list of data requests that have emerged from our COEHDI task forces. He is identifying the type of data that can be gathered and reported in the future.

CDPHE indicated that they would like to expand their list of pediatric audiologists statewide and will work with Arlene toward this goal.

	<p>There has also been a request for clarification regarding the definitions of data fields specific to entry into early intervention. A group will be convened to discuss this before we start to analyze 2020 data.</p>	
<p>System support for children identified with unilateral hearing loss (UHL)</p>	<p>The 2019 data report indicate discrepancies between the number of children referred to early intervention (EI) and the number enrolled in EI. This can be due, at least in part, to children with UHL not being categorically eligible for Part C services. That said, children with UHL who have additional disabilities may be eligible for services.</p> <p>The group discussed goals and aspirations regarding supports for children with UHL:</p> <ul style="list-style-type: none"> ● Pursue categorical eligibility. ● Identify avenues to enhance families' participation in the monitoring of their children's developmental milestones (e.g., communication, language) so that children demonstrating delays can be offered Part C services. An assessment is currently available through the efforts of CSDB and CU-Boulder. But, the majority of families do not utilize it in spite of repeated efforts by CO-Hear Coordinators. ● Laura Merrill explained that momentum to review Part C eligibility for children with UHL was thwarted by COVID and ensuing budget cuts. ● The Early Start program, through EI Colorado, is currently in the "task force" stage of development. It will provide services to children who are not eligible for early intervention services but have "at risk" conditions. Children with UHL could be considered "at-risk". ● We could review messaging to families regarding the benefit of ongoing developmental monitoring. Families may not see the urgency for monitoring because there is no referral to Part C and they perceive things to be "fine" if their child can hear in one ear. ● It would be valuable to reach out to families as children approach 36 months of age to see if they have any developmental delays that make them eligible for Part B services. ● The only way a child can be eligible for Part C due to a parent's need is if a parent meets the criteria of having a developmental disability themselves. 	

	<ul style="list-style-type: none"> • Hands & Voices is an available resource for families who need support. There is a UHL Guide. Jami Fries is the contact for referrals for families of children who have UHL. Often, the Part C Service Coordinator refers to H&V. To access the link to the H&V referral form Click Here • A CO-Hear Coordinator stated that the current process, wherein all children with UHL are referred to the Regional CO-Hear Coordinator, has demonstrated an increase in the participation of families of children with UHL. 	
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Next Meeting(s)		
DATE	TIME	FUTURE AGENDA ITEMS
7/1/21	4:00 - 5:00 PM	<ul style="list-style-type: none"> • Supporting developmental monitoring of children with UHL • COEHDI Regional Meetings
8/5/21	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.