

Colorado EHDI Alliance Meeting

Date: June 17, 2022

Meeting Called By: Colorado EHDI

Type of Meeting: Colorado EHDI Alliance

Facilitator: Heather Abraham

Notetaker: Arlene Stredler Brown

Zoom Facilitator: Heather Abraham

Alliance & Core Team Members: Sandy Bowen, Stephanie Carson, Jami Fries, Leanne Glenn, Hannah Glick, Pat Greenway, Brian Herrmann, Sarah Honigfeld, Beth Little, Shauna Moden, Cliff Moers, Amy Novotny, Ashley Renslow, Sara Robinson, and Kristin Sommerfeldt

Absent Members: Emily Augsburger, Marti Bleidt, Allison Cunningham, Maureen Cunningham and Christy Scott

COEHDI Staff Participants: Heather Abraham and Arlene Stredler Brown

Accommodations: ASL/ English Interpreters: Leslie Blankis and Kirk Neuroth; and Zoom Live Captioning

Agenda Item 1: May Meeting Minutes		Presenter: All
Summary of Discussion: May meeting minutes were unanimously approved without discussion.		
Conclusion: n/a		
Action Items: n/a	Persons Responsible: n/a	Deadline: n/a

Agenda Item 2: Announcements		Presenter: All
Summary of Discussion:		
1. Heather Abraham: The UHL Infographic, developed by the Diagnostic/Identification Task Force, is being reviewed by additional groups. The infographic will be shared with Alliance members for their input in the not-too-distant future.		

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2. Heather Abraham: There will be no Alliance meeting (and no task force meetings) in July. Enjoy your summer.
3. Sarah Honigfeld: The public comment period for the national EHDI legislation is available. This document will be available for one month. It can be located at this URL: <https://www.federalregister.gov/documents/2022/06/17/2022-13037/request-for-information-early-hearing-detection-and-intervention-program>
4. Ashley Renslow: Wednesdays in the Park, an opportunity for families to gather, will take place in 4 locations.
5. Ashley Renslow: Two new CO-Hear Coordinators were hired effective June 6, 2022. Jill Cimino will cover the Pikes Peak area. She is an SLP who graduated from Gallaudet University. She has worked with the CCB in Colorado Springs as an early interventionist. Emily Motsinger is now covering the Southwest Region. A CO-Hear Coordinator position remains open for the Grand Junction area.

Conclusion: n/a

Action Items: n/a

Persons Responsible: n/a

Deadline: n/a

Agenda Item 3: Screening Updates

Presenter: Arlene Stredler Brown & Heather Abraham

At the start of the discussion, members were asked to consider the priorities for COEHDI activities specific to our screening system. Themes collected from the Virtual Site Visits (VSVs) to date were shared at the May Alliance meeting. (A VSV includes a one-hour interview with the in-house NBHS Coordinator and/or the Nurse Manager. Recommendations from the VSV are individualized for each hospital screening program.)

A recap of the discussion, and associated materials, follows:

- I. There are some problems with our screening system. Issues have been exacerbated by: (a) not having a data management system for approximately three years (~2018-2020); (b) impacts from the COVID pandemic and (c) multiple interpretations of the 2018 legislation by different stakeholder groups and agencies.
- II. CDPHE has initiated a strategic planning process that will be carried out over the next few months. All Alliance members are invited to join and should have received communication directly from CDPHE and/or the facilitator (Kim Boyd) to complete a survey and to participate in upcoming subgroup meetings.

Kristin Sommerfeldt shared that she has received limited information about this strategic planning process. Leanne stated that Chris Wells sent out a survey that was created by the facilitator, Kim Boyd, which could be forwarded to any stakeholder. The survey is now closed.; there were 97 respondents. In addition to the survey results, there will be facilitated subgroups that plan to include ~12-15 people in each subgroup.

- III. CDPHE sends quarterly data reports to individual hospitals. Reports have been distributed through December 2021. Individual hospital data are aggregated into four groups to reflect statewide trends. Each group includes hospitals that have a similar number of births/year. The four hospital groups reflect those with:
1. 50-350 births/year
 2. 350-750 births/year
 3. 750-1750 births/year
 4. >1750 births/year

A handout is attached to these meeting minutes with the data that were shared at today's meeting. The data have been updated to reflect inconsistencies identified during today's meeting. Notable findings include: (a) some hospital groups are close to the JCIH goal to screen more than 95% of babies, while others are as low as 89%; and (b) of the babies screened, 93%-98% were screened by 1 month of age.

Some discussion points include:

- The common metric for an initial screen is considered to be at the time of hospital discharge (and can include up to two IP screening attempts). Leanne indicated that the screening data is populated from the electronic birth certificate (EBC) and does not separate out in-patient and outpatient screens. Karen Brenhoffer (Pediatrix) shared that Pediatrix tracks refer rates based on the discharge status of the baby.
- Leanne offered to share CDPHE quarterly reports (aggregated by number of babies born in each hospital) with COEHDI Alliance members.

IV. There is confusion for some about the roles & responsibilities of the COEHDI Alliance and the CIHAC (which is established by statute). There are two Alliance members who are also CIHAC members: Ashley Renslow and Christy Scott. Leanne Glenn and Arlene Stredler Brown attend both Alliance and CIHAC meetings but may not be members, per se, of both groups. The following issues illustrate some of the confusion:

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- CDPHE does not provide technical assistance to birthing program staff. The only technical assistance that is provided is about HIDS.
- Unlike many states, CDPHE does not conduct any training to assist or assure birthing hospitals utilize best practices.
- Hannah Glick is contracted by the HRSA-funded COEHDI grant to provide technical assistance to hospitals. Notably, she does not have access to HIDS. Without access to hospital-specific data, there is no way to identify which birthing facilities are in need of technical assistance.
- Virtual Site Visits (VSVs) have been implemented by the HRSA-funded COEHDI staff. Hospitals volunteer to participate. There is no strategic prioritization based on a hospital's success with its screening program nor its need for improvement because HIDS data are not available to the VSV team.
- Karen Brennhofer stated the importance of care coordination. Pediatrix has been working with other State screening programs to address the gap that occurred when Pediatrix suspended care coordination as part of its scope of work.
- Leanne reiterated that CDPHE cannot provide guidance on best practices. They are, notably, in the CIHAC guidelines.

V. Group discussion points:

- A document was shared describing facilitators & barriers of EHDI systems nationwide including an emphasis on the screening phase of the system. This document can be opened at this link: [Click Here](#)
- Several links to pertinent documents were shared:
 - Leanne shared this link to the CIHAC bylaws. This may provide some insight about the role of the CIHAC as established by HB 18-1006 (our 2018 Newborn Screening legislation): <https://cdphe.colorado.gov/center-for-health-and-environmental-data/registries-and-vital-statistics/newborn-hearing-0>.
 - Kristin Sommerfeldt shared a link to the Newborn Screening legislation: <https://www.sos.state.co.us/CCR/GenerateRulePdf.do?ruleVersionId=8583&fileName=6%20CCR%201009-6>
 - Kristin noted Section 5.3 (C) that discusses utilization of the data identified in Rule 4.4(H) about implementation of quality improvement activities. The link is: <https://www.sos.state.co.us/CCR/GenerateRulePdf.do?ruleVersionId=8583&fileName=6%20CCR%201009-6> Nothing in this subsection should be read to limit the CIHAC's ability to recommend best practices and guidelines as delineated in § 25-4-1004.7(2)(a)(I), C.R.S. as those activities may also concern quality improvement.
 - Leanne shared a link to the CIHAC guidelines: <https://cdphe.colorado.gov/center-for-health-and-environmental-data/registries-and-vital-statistics/newborn-hearing-screening-provider-resources> The screening guidelines have been completed.

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- Karen Brennhofer hopes to see a system that includes targeted follow-up. She shared that screening practices in Colorado are the most cautious that she has seen. The legal interpretation she has received states that the sharing of NBHS results with pediatricians, and anyone relevant to follow-up, is authorized in order to ensure continuity of care.
- While data is solicited during VSVs from each birthing facility, only the most recent quarter’s data is obtained. This may not provide an accurate big picture of each facility’s data.
- Hannah Glick and Pat Greenway requested information about other States’ EHDI systems. Attached to these meeting minutes are descriptions of systems in several states. Some, like Colorado, store data in their State Health Departments and house their HRSA grants in a different agency.
- Cliff commented on the opportunity to utilize the results of the CDPHE strategic planning process to guide COEHDI priorities and associated activities. He mentioned that there may be a need for additional funding for these activities.
- Ashley Renslow prioritized screening as a COEHDI activity. She questioned the role of care coordination (aka; follow-up coordination) based on screening results. There seems to be a need to share more information among agencies.
- Sarah Honigfeld inquired about training materials to encourage birthing facilities to utilize best practices. To date, materials are distributed in these ways: (a) surveys of birthing facilities; (b) COEHDI’s *Newborn Hearing Screening Monthly* (includes highlights from the NCHAM Newborn Hearing Screening Training Curriculum); (c) COEHDI newsletter; and (d) COEHDI website. These are all *general* education materials. Arlene suggested there is a need for *targeted* education.
- One of our state’s challenges is that no agency is ensuring implementation of best practices. Arlene would like to encourage *targeted follow-up* and *targeted care coordination*. Currently, when communicating with parents about a missed screen or the need for a rescreen, CDPHE sends only one notification and this is a letter sent via the USPS. Other states are contacting families by text, hiring a Follow-Up Coordinator, and/or contracting with an organization (e.g., Hands & Voices) to provide *targeted* follow up with each family. Karen Brennhofer stated that recent research shows that text messages, phone calls and email are all more effective than postal mail when communicating with parents.
- Leanne shared that names of babies who missed a screen are on a “worklist” in HIDS. Providers can pull discrete worklists to identify specific groups of children. Could this be a way to identify children who missed a screen and/or did not receive a rescreen when they did not pass the initial screen?

Conclusion: Alliance members have received information about problems with the current screening system. After CDPHE completes its strategic planning process, Alliance members may be asked to identify priorities and activities associated with these priorities.

Action Items: n/a

Persons Responsible: n/a

Deadline: n/a

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<p>Agenda Item 4: Closing - Individual Recap of COEHDI Work</p>	<p>Presenter: All</p>	
<p>Challenge (for screening system); opportunity (to make growth); passion (promotes change); systemic change (it's essential and will take time); influencer (how to influence a complex system); start with the end-goal in mind to work toward making changes; big picture (find a way to fill the gaps); digesting (think about the big picture and what we can do to move forward); process; as we've been breaking down silos, start to build bridges (aka; collaborations, partnerships).</p>		
<p>Conclusion: n/a</p>		
<p>Action Items: n/a</p>	<p>Persons Responsible: n/a</p>	<p>Deadline: n/a</p>

COEHDI Alliance meetings are held on the third Friday of each month.

The next meeting will be August 19, 2022, 10:00 – 11:30 AM

*Note about accommodations: Beginning February 1, 2021, all Alliance meeting and task force meeting accommodations (e.g., American Sign Language (ASL) interpreters, Cued Language Transliteration, and/or Spanish translators) must be requested at least 72 business hours/3 business days in advance. **Requests may be made via your task force facilitator and/or at info@coehdi.org.** ASL interpreters will continue to be provided for all Alliance meetings. We will also enable Zoom's Live Transcription feature for all meetings. (Note, Live Transcription utilizes automatic voice-recognition and computer-generated captioning. As such, the accuracy cannot be guaranteed. It is not a substitute for the full functionality of Communication Access Realtime Translation (CART)).*