**Colorado EHDI**

**Screening Task Force**

**Meeting Notes**

January 12, 2021

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| **Attendees** | |
| **Name** | **Role** |
| **Arlene Stredler Brown** | Facilitator |
| **Heather Abraham** | Notetaker |
| **Maureen Cunningham** | Pediatric Hospitalist CHCO; CO AAP Chapter Champion |
| **Dee Schuler Woodard** | Western Slope Regional CO-Hear Coordinator |
| **Sarah Wedekin** | Educational audiologist; Western Slope |
| **Christy Taylor** | Pediatrix/Mednax |
| **Kelly Miller** | Pediatrician; Durango, CO |
| **Lisa Shigio** | CSDB Audiologist |
| **Jilliann Gerstenberger** | Pediatrix; Pediatric Audiologist & Chief Operations |
| **Sara Kennedy** | CO Hands & Voices |
| **Becky Awad** | Audiologist, Children’s Hospital |
| **Lisa Cannon** | CDE Consultant for Educational Audiologists |
| **Hannah Glick** | Audiologist & Faculty, CU Boulder |
| **Ramona Pearce** | Pediatrix; site coordinator |
| **Annette Landes** | CO-Hear Coordinator |
| **Angela Harder** | Audiology Assistant, Children’s Hospital |
| **Andrea Gatlin** | Intern; Children’s Hospital |
| **Kristin Sommerfeldt** | Audiologist and Faculty, University of Colorado |
| **Jennifer Schryer** | Educational Audiologist; Western Slope |

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| **Agenda Overview** |
| 1. Hands & Voices *Roadmaps* and EHDI PALS – Updates 2. Update on HIDS’ Users 3. Update - 2019 Data Collection 4. Educational Audiologists Role in Screening/Rescreening – An Update 5. Support for Screening and Rescreening to Decrease LTF – A Discussion 6. Support for Babies Born at Home |

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| **Agenda/Actions/Decisions** | | |
| **Agenda Items** | **Discussion** | **Action/Decision** |
| **HIDS Users** | Currently, there are 95 HIDS users:   * 42 screeners * 8 midwives * 33 clinical audiologists (4 are educational audiologists) * 12 early interventionists   Hannah indicated that there are about 100 diagnostic audiologists on our active list. | n/a |
| **2019 Data Collection** | The CO EHDI Alliance supported the recommendation of our task forces to report 2019 data to CDC. COEHDI has implemented several activities to encourage appropriate people to sign up to be HIDS users and to enter 2019 data into HIDS. These activities include: (a) announcements in our monthly COEHDI Newsletter; (b) discussions in task force meetings; (c) a survey sent by Hannah Glick to hospital screeners; and (d) a monthly communique (starting in January 2021) being sent to screeners, midwives, and clinical audiologists. Hannah Glick has received questions regarding how to proceed and suggestions for support that is needed. Many of these inquiries have been forwarded by Hannah to Leanne Glenn at CDPHE. Some people have responded that they are no longer involved in newborn screening and would like to be removed from the list.  It is notable that this role on the part of CO EHDI is not an ongoing, nor sustainable, activity. We were not funded to do this work, however, we see the importance of increasing the number of HIDS users and the value of collecting and reporting HIDS data. | Ongoing support from Hannah Glick to field queries and offer support to newborn hearing screeners and NBHS Coordinators.  Ongoing *Newborn Hearing Screening Monthly* will be published and sent, electronically, to screeners, midwives and clinical audiologists. |
| **Role of Educational Audiologists** | There are several ways that we have been looking at shoring up our screening and rescreening activities, and thereby reducing lost to follow up.  Context: Based on a birthing census of ~65,000 babies each year (~5400/month), at a 4% refer rate, ~217 babies will fail a NBHS each month. Based on Colorado’s prevalence of ~2.4/1000 babies who are DHH, ~12 babies each month will be diagnosed as DHH. This means than those who participate in rescreening and LTF issues can expect to be handling ~200 babies each month who fail a screen but are not expected to be DHH. With this in mind, we have several ways we can shore up our screening/rescreening activities which could include these agencies/programs: (a) roles and responsibilities of the CDPHE NBHS Coordinator; (b) educational audiologists; (c) PCPs; (d) H&V *Roadmaps*; (e) Hannah Glick’s currently-funded efforts; and (f) Regional CO-Hear Coordinators.  There was a lengthy discussion about system enhancements that could focus on a dedicated person versus a systematic approach. Currently, there is no one person at CDPHE in this role. Nor is there dedicated funding in the EHDI grant to sustain the support of personnel. Therefore, the discussion looked at multiple opportunities to impact the system. We are developing system recommendations.  Some factors influencing lost to follow up (LTF) are:   * Misdiagnosing hearing loss * Service providers who did not record children in the old database (IDS) * Families not returning for an outpatient rescreen after their child fails the inpatient screen; there is a lack of tracking for this * Lack of communication of failed screen/rescreen to the child’s PCP * Diagnostic audiologists may not connect a family whose child has been identified as DHH to early intervention * Families struggle to travel long distances for follow up   A role for Educational Audiologists (Ed Auds): Lisa Cannon reported that the survey sent out to educational audiologists had a good response rate. Most felt they could act as a resource and/or a screener using OAE equipment. The current need is significant on the western slope. The role of Ed Auds in EHDI are clearly included in their Child Find obligation. All administrative units (e.g., local school districts and BOCES) are responsible for identifying disabilities in children; the licence of the Ed Aud starts at birth. There are varying comfort levels among Ed Auds about working with newborns and some are concerned about their administrative unit support for them in this role.  A role for PCPs: There is frustration that the medical home does not receive information regarding the EHDI system which would be an effective way to prevent LTF. Maureen Cunningham doesn’t think PCPs will gain ready access to HIDS. In December, 2020, Margaret Ruttenber sent an email that she would not interfere with an effort to get newborn hearing screening results reported on the immunization registry (CIIS). This would give PCPs access to NBHS information, just as they get information about immunizations. CDPHE is neither supportive nor obstructive in this effort at this time.  Hannah is developing a monthly communique for screeners titled, *Newborn Hearing Screening Monthly.*  The first newsletter, in January 2021, will provide information on the HIDS system. Ensuing issues may include information related to COVID-19. Other topics are being solicited from task force members (and several have been made via email since this meeting). This newsletter will be sent, electronically, to newborn hearing screeners, newborn hearing screening coordinators, audiologists, and midwives. Hannah will coordinate with Maureen Cunningham about distribution to PCPs The information in the *Monthly* will be short and succinct. Maureen indicated that the AAP already sends out a newsletter and she’s not sure if another communication would be helpful. She will investigate the best avenues for communicating information.  The Role of the H&V *Roadmap:* The Roadmap has been around for more than a decade. It was an attempt to teach families about the EHDI process and to provide resources to families in their locale. *Roadmaps* are available in both English and Spanish. Any hospital may use them. There are currently 45 *Roadmaps* (among more than 70 birth hospitals). Arlene indicated that only diagnostic audiologists are currently listed on EHDI PALS. There will be some discussion about including Ed Auds who perform clinical evaluations on EHDI-PALS. | Lisa Cannon will indicate when the time is right to add educational audiologists to the *Roadmap*. First, Ed Auds will discuss their role in screening/rescreening at their March meeting. Arlene is invited, among others.  Hannah Glick will work with Maureen Cunningham to identify a collaborative way to get information in the *Newborn Hearing Screening Monthly* into the hands of PCPs as recommended by Maureen.  Maureen Cunningham is pursuing opportunities to integrate HIDS data into CIIS so that PCPs can be more actively involved in their patients’ hearing screening status.  Registering Ed Auds in EHDI PALS will be discussed with Randi Winston (NCHAM). Lisa Cannon and Arlene will be responsible.  Hannah will include EHDI-PALS to the *Newborn Hearing Screening Monthly.*  Arlene & Sara will discuss how EHDI can support the utilization of the *Roadmaps.*  Arlene is working with NCHAM to ensure that we have current information on the EHDI PALS site.  Future topics suggested for the *Newborn Hearing Screening Monthly* (supplied by task force members after our meeting): is our hearing screening equipment working; acceptable referral rates and red flags; scripts for screeners; what happens after a referral; what is EHDI; what to do in special situations (e.g., microtia), positive messaging when talking to parents, a word to Birth Certificate Clerks about recording hearing results; and where can I learn more about newborn hearing screening? |

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| **Next Meeting(s)**  **Meetings of the Screening Task Force are on the 2nd Tuesday of each month from 11:00 - noon.** | | |
| **DATE** | **TIME** | **AGENDA ITEMS** |
| February 9, 2020 | 11:00 - 12:00 | * Discuss the role CO-Hear Coordinators could play in screening/rescreening activities * Support for midwives to increase their participation in screening/rescreening |
| March 9, 2020 | 11:00 - 12:00 |  |

*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 your task force facilitator****. We will also enable Zoom's Live Transcription feature for all meetings.*