**Colorado EHDI**

**Screening Task Force**

**Meeting Notes**

August 8, 2023

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| **Attendees** |
| **Name** | **Role** |
| Heather Abraham | Notetaker & Facilitator |
| Arlene Stredler Brown | Facilitator & Notetaker |
| Becky Awad | Audiologist; Children’s Hospital of Colorado  |
| Maureen Cunningham | Physician; Children’s Hospital of Colorado, AAP Chapter Champion |
| Brenda Elliot | Parent; Colorado Hands & Voices |
| Jami Fries | Director; Colorado Hands & Voices |
| Kirsten Nelson | Pediatrician; Representative for CO-AAP about cCMV |
| Dawn O’Brien Taylor | Audiologist; North Star Audiology |
| Stacy Stiel | Audiologist; UC Health Anschutz |

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| **Agenda/Actions/Decisions** | **Next Steps** |
| **NICU NBHS Brochure** | * Becky approached Arlene several months ago to discuss the benefit of creating a NBHS brochure specific to children who are in a Neonatal Intensive Care Unit (NICU). Several colleagues drafted a first iteration of this brochure. Input has been solicited from several NICU audiologists around the state. COEHDI is now bringing a draft of this brochure to the task force for their input.
* Arlene shared a draft document with the group with the meeting agenda. Comments on the document were discussed today.
	+ **Statement regarding fluid being a potential reason for a refer:** Brenda Elliot recommended removing the sentence referring to possible reasons for referral, including the reference to fluid. The concern is that this statement will prevent a family from following up and possibly lead a family to ask a screener questions they may not be able to answer. Dr. Nelson noted that families continually refer to fluid during follow up appointments and that this has been misleading. Stacy Stiel stated that UC Health refers to this type of terminology as “comfort counseling” and they try to avoid using statements that could impede follow up.
	+ **These statements were reviewed: “There are many reasons why your child did not pass.” or “Your medical team will provide you with additional information.”** The group questioned whether to keep these statements in the brochure or delete them. Stacy Stiel suggested referring the family to the next step in the process (e.g., outpatient screen). Kirsten Nelson suggested this wording, “Without further testing, we cannot know why your baby didn’t pass the screen.” There was a recommendation to phrase this statement positively, for instance, “Further testing is the only way to learn more about why your baby did not pass their screening.”
* Readability level will need to be analyzed, and terminology and wording will likely be modified during that process. Becky has resources at CHCO to do this.
* Brenda Elliot suggested, for future consideration, to add a QR Code or URL for the Hands & Voices Virtual Waiting Room. https://handsandvoices.org/virtual-waiting-room/about-vwr.html
 | Upon the next printing of the NBHS *well baby* brochure, review the statement regarding fluid being a potential cause of a “did not pass”. Becky will proceed with recommendations from today’s meeting to create a second draft of the brochure.  |
| **NBHS Scripts** | * We have received additional comments and are working to reduce the reading level to ensure that the message spoken by the screener is clear.
* At the request of this task force, Arlene met with Drs. Ted Maynard, Kirsten Nelson and Maureen Cunningham to solicit language to be added to the scripts regarding cCMV testing for children who DNP the hearing screening.
* Jami shared that some families are being denied a test for cCMV; some doctors have said it’s a rare virus so no testing is needed. Jami is concerned that the responsibility for testing is being transferred to the parent and that cCMV resources are not always shared. Jami suggested having stronger language about the need for cCMV testing. Kirsten Nelson modulated this suggestion by sharing that this is a script for a screener who generally does not have medical training. It would be beyond the scope of a screener’s roles and responsibilities to be knowledgeable about cCMV.
	+ To address Jami’s concern, is it satisfactory if printed copies of the “Congenital CMV and Hearing Loss” brochure is shared with hospitals so they can give it to families?
	+ Jami suggested making a referral to another parent as well.
	+ Kirsten Nelson emphasized the importance of stating that parents should talk to their physician about cCMV testing results.
* The question was asked as to whether or not a screener knows what kind of cCMV testing capability their birthing facility has in place. Kirsten Nelson stated that most screeners know this. Arlene was asked to pose this question to management at Pediatrix.
* The group needs to be aware of and discuss the resources that are associated with each script (e.g., pass, DNP, etc).
	+ For “Pass” Result: The group endorsed the recommended resources to remain in place.
	+ For “Did Not Pass” This will be discussed at the September meeting of the task force.
 | Arlene will check with Pediatrix management to see if screeners are knowledgeable about the cCMV testing procedures at their contracted sites.  |

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| **Next Meeting** |
| **DATE** | **TIME** | **AGENDA ITEMS** |
| September 12, 2023 | 11:00-12:00 | * Continued review and discussion about NICU NBHS Brochure
* Continued review and discussion about NBHS Scripts
* Arlene will report on Pediatrix’s response to knowledge of screeners about cCMV practices in each facility
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*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 of the meeting.* ***Requests may be made by contacting your task force facilitator****. We will also enable Zoom's Live Transcription feature for all meetings.*