EHDI Advisory Committee Minutes

August 15, 2018

1:00 – 4:00 p.m.

Location: Amherst H. Wilder Foundation, 451 Lexington Pkwy., N Saint Paul

1-1:25 p.m. - Welcome & Introductions

- Went around the table and conducted introductions of everyone's names & roles (see sign-in sheet for attendance list)
- Meeting minutes from May 2018 reviewed. Linda Murrans asked for a correction: page 5, MDH update, EI provider survey, the second bullet. The word 'have' should be changed to 'half'. Right now it says "less than have of interventionists" and I think it's supposed to be "less than half of the interventionists without DHH specific training indicated that their education prepared them well for serving DHH students
- Linda Murrans moved to approved the minutes with the noted correction, motion seconded, committee unanimously voted to approve the minutes.
- EHDI appointments will be up in January 2019 for half of members, Kirsten Coverstone & Nicole Brown will reach out to individuals regarding these appointments
- EHDI Member Survey results presented by Kirsten Coverstone
 - \circ $\;$ Thank you to everyone for their participation.
 - o Overall, advisory committee members are satisfied serving on the committee
 - Meeting productivity is an area of growth and the survey identified that individuals would like to see improvements made
 - Members would like to see how individual participation makes an impact in the community and know how their work makes a difference
 - Members find that the advisory committee is overall successful in representing various participants and stakeholders
 - The executive committee will be taking all of the results into consideration as we move forward.
 - Comments/Questions:
 - Sonny thanked Kirsten & team for their work
 - Jay W. commented that he wasn't very clear about committee influence and drawing a direct line between the advisory committee and process impact. What impact do we have in the community and others?
 - Lisa has been on the committee a long time and responded about her experience in seeing changes and impact over time. For example, this committee helped MN have legislation in place for deaf or hard of hearing individuals in the state. Additionally, working with the commission for deaf or hard of hearing in order to address guidelines and information in place to improve care and individuals' livelihoods and personal/professional achievements.

1:25 – 1:40 p.m. - Early Healthy Deaf Identity—Sonny Wasilowski

- National discussion about shifting EHDI from "Early Hearing Detection and Intervention" to "Early Healthy Deaf Identity."
- Shared a video from Deaf Counseling Center
- Lisa: I appreciated your sharing this Sonny, I recognize this in my practice. Parents are grieving, and I try to reframe this for them. But what advice do you have?
 - Sonny: LIfeTrack has wonderful resources. I'd like to see more referrals happen to provide mentors to this children.

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1:40 - 2:40 p.m. - EHDI Data

Employment data – strictly academic #s, so we may need to work w/ Sonny to dig into early healthy deaf identity

- Higher than other states for graduation and employment rates
- 10 year completion rate for college looked at for all students (not specific to one population)
- ACT scores for D/HH and all students --> D/HH increased ACT score in the last year (from 2 years of data)

Kindergarteners: math & reading proficiency

- 3rd graders who are enrolled in the EHDI program scored higher than SpED students for reading proficiency
- Compared 3rd graders in EHDI & SpED programs have similar scoring for math and reading (not a lot of kids enrolled in the EHDI group, but similar to the general population)
- 2016-17 kindergarten cohort, children identified by EHDI program are enrolled in SpED. 80% of children served by SpED and 60% identified by the EHDI program. Wanting to grow EHDI program identification with D/HH children.
- More children served as D/HH in kindergarten are also identified by EHDI and #s are increasing

Kindergarten readiness

- Three quarters of children with hearing loss are reported "at age level" or above for early literacy and almost 90% are for early numeracy
- The numbers are small, but we are looking at ¾ of students that are going to kindergarten with good language skills want to continue to look at this and increase #s
- Looked at hearing devices that are used and what types of hearing technology is fitted for kids going to kindergarten (most kids use hearing technology)
- Looked at language and communication opportunities chosen by families (families could select multiple options)
- Most families use spoken language, but much smaller percentage using ASL or other spoken languages

• Again, not talking about all the kids being served, but the kids leaving part C and leaving pre-k SpED and going into kindergarten (133 kids) to get an overall look at what the families are like that we are serving

Children getting into Part C Enrollment

- Would like to have children enrolled by 3 years of age (if not sooner)
- About 80% are enrolled in Part C services
- For the children that don't enroll, it's a very small percentage (parents explicitly decline services or can't participate)
- Partnership w/ MDE allows EHDI program to find children and see if there is any record available
- Most kids get in the program within 2-3 mo of diagnosis

Newborn screening reporting system

- 2017 MN births was the first time gathering data about newborn screening reporting through MNScreen
- No big surprises yet w/ # of births
- 1/3 of 2017 births who had diagnostic results reported are permanently D/HH
- Number of children reported as D/HH in 2017 is similar to previous years
- EHDI work extends beyond newborns: one third of children reported as D/HH in 2017 were NOT infants identified through newborn hearing screening
- Age at diagnosis is before 1 year of age, but have reports up to 10 years of age
- Laterality and degree: 70% of children have bilateral hearing loss. Mild and moderate identification is the most common.
- Amplification: 73% of children were fit within 2 months of diagnosis (includes children w/ bilateral hearing loss who did not decline)
- Hands & Voices continues to contact most families. Close to half of families are contacted within 1 month of diagnosis.
- Questions
- Jay had a point of clarification. Early on, Kathy's presentation was talking about those people who were captured by EHDI and those who were not. In other words, EHDI identified, we call that the EHDI group, and then later on we find other people who were not identified by EHDI but are in special ed or deaf education. When children are reported, do they become a part of EHDI? We don't get reports from the education system and they don't join EHDI. We need timely and accurate reporting through audiologists.
- Emily was curious that if MDE is following children identified D/HH, but have we really identified early? Why are we not including these other kids (technically in data it seems like we are) and following these kids more accurately and clearly? Late onset children are going into SpED, but we do have information from the audiologists to connect individuals to resources. We want audiologists to get us information by the age of 10, so we can provide those resources for intervention.

- Sonny had a question for Anna: do you have any recommendations of the blue ribbon school and their excellence, by their deaf and hard of hearing students? Do you Mary? Mary said that we have blue ribbon schools, but we don't know how many are in the special ed or that are partaking in those classes, but that's kind of the difference there academically. The report will say which schools are doing well and that should show you what you're looking for in the academics, so that the schools that are performing well will show up on the report. And you can pick that information for yourself.
- Kirsten asked what a blue ribbon school? It is a special honor given to some schools. Mary isn't sure specifically how a school is given the blue ribbon identification, but will look into it.
- Mary was asked what kind of school participates and Mary responded that any school can participate. It is a government program started in 1982 to recognize schools closing the achievement gap in student sub-groups (someone looked this up online and read it to the group).
- When a student is reported to a school as being D/HH, for example, are schools encouraged the not contact MDH to report or have the families like education audiologists reported to in order to close the loop? Hands & Voices helps with this.
- Are there benchmarks as far as time to amplification for kids that are all ages not just identified as newborns? Some of them would apply, like timeliness to Hands & Voices, and early intervention under the age of 3. We want to revise our benchmarks, that's our goal, and I think that would be something to think about, are there things that we want to include that would be more relevant for older children?
- Does the CDC have benchmarks? CDC specifically right now has still focused on the 1, 3, 6 because we still have work to do on that. It's not a done deal. Not meeting all milestones.
- Kathy added information about guidelines for hearing screening for the newborn to kindergarten period and that work is still being done to recommend ongoing follow-up for hearing screening for kids.
- 2:11 2:30 p.m. Break (ended presentation ½ hour early)
- 2:35 3:10 p.m. Audiology Assessment Guidelines
 - Thank you to our workgroup for their diligent work on the Audiology Guidelines (Infant Assessment, Referral to Early Intervention, Amplification)
 - Today we are focusing on the Infant Assessment portion
 - o Included MN specific information and national information
 - Compared other guidelines to determine what topics to include
 - Stakeholder review (EHDI Advisory Committee Workgroup, MN Dx Center Audiologists, EHDI Advisory Committee Workgroup, now for full committee review)
 - Response to Jay's question about if this is tied to training: this is tied closely to what new audiology graduates are learning (Peggy from the U was part of the workgroup). But this guideline is for everyone, including new grads and currently established audiologists
 - Darcia briefly walked through the guideline and reviewed the new topic sections.

- Sonny: should we consider using a QR code for the entire document so you can have the paper document and easily access the QR code.
- Plan for final vote:
 - Distribute final updated document (after changes made based on comments here), allow 2 weeks for review, then final vote by email.
- Additional sections (Referral and Pediatric Amplification)
 - Revisit Guidelines for Referral to Early Intervention, Medical Specialties, and Connection to Parent-to-Parent Support
 - Begin work on Guidelines for Pediatric Amplification
- Suggestion to refer to the Medical guidelines for wording when it comes to similar sections between guidelines
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3:10 – 3:20 p.m. - EHDI Educational Update

- Foundations for Literacy is a curriculum that has been in development for 10-11 years with Georgia State University
- This can be useful for teachers to build early literacy for children who are D/HH
- Takes 45 min 1 hour/day and was created for classroom use
- Targets overall language of building vocabulary, narrative skills, storytelling skills, alphabetic knowledge, phonological awareness for the beginning readers and reading decodable words
- Accessible and provides lots of visuals and is very auditory based (but there are adaptations available)
- 33 MN participants and 2-day intensive training in July and reviewing materials 8/16 to plan for the upcoming school year (21 teams exist; some people are doing it individually and some people are coming in groups)
- Talking about data collection over this year
- Many different implementations in classrooms to allow for variability
- Is this just being used with D/HH kids? This is being used with D/HH kids, but this is built for all children learning to read and it can be used with any early childhood programs.
- Training has been done with providers who have hearing differences and we're using a variety of different communication modes. We have teams that used cued speech and transliterators.
- We did a pilot study for 1 year and we had two MN teachers who were part of the pilot and those two people will be helping us and the rest of the team with their information too.
- The district 916 (WBL, Roseville, Shoreview, etc.) was one of the trial schools and showed significance difference.
- Any schools outside of the metro? We have representation from every region from the state.

3:20 – 3:25 - Topics/Partner Updates for Next Agenda

- Sonny: On TV, this coming month, A&E, will have a show called Deaf Outloud, spotlighting stories of different families and children
- Mary: On the MDE D/HH website, there is a new biannual legislative report
- There is a national conference about CMV in September, we will be trying to pull together some data from our pilot study.

- Anna: Collaborative Plan Summit is XXXX, we have contracted with Wilder to do an environmental scan of the D/HH landscape in Minnesota. If you get an email from Wilder, it's not spam, we are asking you to participate for an interview.
 - Results will be available as a report, infographic, etc.
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3:30 - Closure

Move to adjourn

Joan motioned

Kirsten second