

Meeting Minutes: EHDI Newborn Hearing Screening Advisory Committee

FEBRUARY 19, 2020

Attendance

Present:

Ingrid Aasan, Renae Allen, Kathy Anderson, Joan Boddicker, Nicole Brown, Mary Cashman-Bakken, Kirsten Coverstone, Laura Godfrey, Danelle Gournaris, Hannah Herd, Tina Huang, Colleen Ireland, Joscelyn Martin, Abby Meyer, Jessica Novak, Sara Oberg, Elizabeth Pai, Anna Paulson, Cat Taminga, Katie Warne, Terry Wilding, Jay Wyant

Absent: Gloria Nathanson, Emilee Scheid

Agenda Item Minutes

- Topic/Presenter/Time/Decision Item
- Welcome and Announcements/1:00 to 1:20
 - Introduction of members
 - Please state your name first when speaking to the group, and remember to use the microphone
 - Motion for approval of Nov 2019 minutes by Jay, second by Joscelyn. Minutes approved.
- Family Story, Deaf Mentor Family Program/KaraScheeler/1:20 to 1:35
 - Kara Scheeler and her family have been involved with Mentor program for the last 2 years.
 - Their child didn't pass two hearing screens and was told there was probably fluid in the ears. A 3rd test showed there was not fluid and then they needed to see ENT. There was confusion between hospital and audiology clinic and they were mistakenly scheduled for another rescreen and not a diagnostic ABR. This was devastating when they found out that the diagnostic testing wouldn't be done that day. Once hearing loss was identified, they did not get the *Beginnings* book at the time of diagnosis, and did not know about any of the other resources (like MN Hands & Voices, Deaf Mentor program, etc). They finally got some of this information about 3 weeks later. ASL has often worked better for communicating with their child (due to draining ears, etc). Jesi is their child's Deaf Mentor and also a friend. It's great that she can come out to your home on your time. Their daughter enjoys being around individuals who sign. They value the Deaf Mentor teaching about the DEAF culture. Kara encourages more advertising about the opportunity for DM program. Everyone should know about this instead of the family knowing who to ask and what to ask.
 - *Beginnings* book came from Hands & Voices (along with other materials) about 3 weeks later
 - *Beginnings* book did not have info on Deaf Mentor program. She found out about DM program from Anne Barlow with MN H&V. She (Kara) specifically asked Anne if there were resources to teach ASL, and that is

how she learned about it. The fact that the program is free, was super helpful.

[NOTE: The current parent binder does now include information on the Deaf Mentor Program

- Question about financial support for HA's and if they were given that information. Yes, they were told about a loaner hearing aid option.
- Question if Deaf Mentor works with whole family? Yes, she does. They actually invite other friends/family to participate along with DHH child.
- Family Story, Deaf Mentor Family Program/ Danelle Gournaris, Deaf Mentor Family Program Manager/1:35 to 2:10
 - The program has existed for 8 years. It is focused on teaching ASL in the home, provides resources for community events, connection to other families, etc. The family can connect for 2 years, once a week (or flexible more spaced out time as needed), sometimes at a public location. They use the Ski Hi curriculum designed for hearing parents of Deaf/Hard of Hearing children. One component focuses on environment enhancement for best visual communication. One component focuses on deaf history, and on technology.
 - A Deaf Mentor is a Deaf adult fluent in ASL. They become language models, advocate, and storyteller about personal experiences. 30 mentors are spread out statewide (17 in the metro). 38% of kids they serve are in greater MN.
 - During a session, they typically teach some ASL, then turn it over to the parent to communicate with their child using their new skills. They like to have the whole family involved, not just the mother. They serve children birth to 21, but majority of families have child under age 6 years. 57/97 are Hard of Hearing, and 35 are deaf, 4 are deaf/blind.
 - VCSL (visual communication and sign language assessment) – created by Gallaudet bi-lingual program. Focuses only on ASL, not spoken English. First and only standardized tool for measuring ASL growth. They piloted with 10 families. The tool shows that children in this pilot group are developing, but are typically just behind typical language development for other kids using ASL. Maybe because they are not fully immersed in ASL environment? Bilingualece.org is a resource that was shared. Now you need to be certified to administer this assessment. They won't be continuing to do these unless they receive more funding.
 - Parent satisfaction survey - 92% report that communication between them and their child has improved. 98% were satisfied with this Deaf Mentor Family Program service. 89% indicate their child's quality of life has improved due to being involved with this program. They report their child having more confidence and understanding about the DEAF culture.
 - Benefit of program is improved language acquisition, self-esteem, connections to Deaf community. If older students apply and are struggling in school, they accept older children based on their ability to accommodate birth – 6 kids first.
- EHDI Benchmarks, Proposal and Discussion/Lauren Schwerzler/2:10-2:40
 - EHDI Benchmarks are Indicators used to assess progress towards EHDI goals that are reviewed once annually. They guide work at MDH for quality improvement initiatives and to identify disparities.
 - They were developed and then revised based on Center for Disease Control (CDC) and national goals from the Joint Committee on Infant Hearing (JCIH). In the past there were 7 broad goals and 31 indicators. They were last revised in 2013, and we need to update them again with fewer required basic measures, but also with flexibility to add/change other measures from year to year as needed. MDH proposed goal for new benchmarks is still to follow 1-3-6 main goals, with addition of 9 year goal(educational outcome). So 4 main measures, but then multiple indicators within each bucket.

- Discussion with the group on the proposed main goals.
 - **One month goal:**
 - Terry – Do we need something in between 6 months to 9 years? There is a big space of time in between there. Maybe Kindergarten readiness? We don't want to wait until they are failing before we do something.
 - Nicole – we don't currently have kindergarten data available to us through the ECLDS system. We do have ECLDS at 3rd grade, so that is why this 9 year goal was suggested.
 - Terry – maybe other states do this and we can look at how they look at outcomes of kindergarten readiness?
 - Jesi – is it 1 month gestational age or corrected age? How do you account for premature babies? At 24 weeks they aren't even eligible for a screen yet.
 - Kirsten – Nationally, it is by 1 month of age and that is how we have to report. But looking at corrected age might be a good option to add.
 - Kathy – need to look at disparities of screening data
 - Cat – maybe look at accuracy of people doing screening, and access to high quality screening equipment
 - Jay - do we track if information was provided to family at the time they leave the hospital? And if they had appointment scheduled?
 - Kirsten – hospitals would have to report whether they provide the information. MDH could track whether appointment was made and reported.
 - **Three month goal:**
 - Mary – Look at if they have access to amplification within 1 month of dx
 - Abby – Look at the effect of premature and disparities
 - (not sure who stated this) - How many kids are being tested by a pediatric audiologist versus someone who does not specialize in pediatrics
 - Jesi – Look at whether the Deaf/Hard of hearing child has a diagnosis of any other disability?
 - If they are not screened by 1 month and then there's not follow-up what is the barrier?
 - Have they been educated about education options
 - Sara – I wish that clinical audiologists could give all information out at the time of diagnosis
 - Hannah – confirmed that sites do have Beginnings book available to give out immediately. Sometimes it may be the very next appointment after diagnosis. Some families don't want it right away.
 - Jesi confirmed that educational information is in the binder and that their audiology clinic does refer to MN Hands & Voices, Early Intervention, report to primary care, and report to MDH.
 - Q – Beginnings book is only available in English and Spanish, right? This is standard information that all families should receive. North Carolina created this and MN uses it. After audiologist reports a child who is Deaf/Hard of Hearing, then MDH sends additional information a bit later on (parent binder).
 - Kathy Anderson – North Carolina has updated this, MDE has printed with MN resources included. Darcia is working on additional updates. Teachers do ask the parent if they have received these resources when they meet with the family.

- Joan – measure if they’ve received educational information. Maybe at 3 month appointment, ask if they have received all of these things? Maybe this should be at 6 months?
- Laura – MN Hands & Voices asks about this (whether the family received educational information) and they send this information back. They also talk about IFSP and IEP,
- Jay– If something is not checked off on time, does it remain on the “to do list” until it does get done? And do we track kids that are identified later?
- **6 month goal:**
 - Cat -if kids with diagnosis are not receiving early intervention services, then track why not
 - Abby – were they in early intervention late because some of the earlier factors were late which pushed this benchmark date out?
 - Terry– collect baseline data and track outcomes trends
- **9 month goal:**
 - Tina – do we know if they changed their modality? Wearing a hearing aid, or have a cochlear implant?
 - Kathy – track kids who are passed newborn hearing screening and are identified later
 - Sara – are they speaking a different language at home and at school
 - Joscelyn - are we tracking risk factors
 - Anna –Does the child have different primary label (another disability added?)
 - MaryCB – There is a big gap between 6 months and 9 years. Need to look at Kindergarten readiness and the language picture earlier. Need more checklists at 5 years than at 9 years.
 - Cat – look at eligibility category and if there was a change. Look at history of kids at age 9 years. Did they receive early intervention when younger?
 - Ingrid– look at early indicators of mental health concerns? Not sure how to collect that.
- Break
- HRSA EHDI Grant, Proposed Activities for 2020-2021 and Discussion/Darcia Dierking/3:00 to 3:25
 - HRSA is federal funding that goes toward EHDI activities. MDH has applied for next cycle of funding which would be just over \$200,000. If MDH receives this funding the grant cycle would start April 1 of this year. Goal of new grant is to support systems of care to ensure that children who are Deaf/Hard of Hearing are diagnosed and receive appropriate early intervention to optimize language, literacy, cognitive, social, and emotional development.
 - Main Areas of Focus - continued work on 1-3-6 goals, more focus on early intervention, add hearing screening up to age 3 years, EHDI stakeholder engagement, training, and collaboration, identify and address disparities.
 - 16 proposed activities:
 - Equipment for Out of Hospital Births
 - Hearing Screening to age 3
 - Partnerships with professionals
 - Local Public Health Nursing Assessments

- EHDI Advisory Committee
- Diversity and Inclusion
- Quality Improvement
- Websites
- Training for Early Interventionists
- Training for Audiologists
- Training for nurses
- Newsletter and Outreach
- Collaboration with Families and Deaf/Hard of Hearing Adults
- Collaboration with other related HRSA grantees
- Improve Coordination across early childhood programs
- Data Sharing Agreement with MDE and ECLDS
- Terry question on #8 and *Beginnings* book. Can the website be more dynamic for people who prefer to get things online rather than in print? Darcia – the copyright is very specific to only be distributed in MN, so we can't put online.
- Terry, accessibility is also a question, so it would be worth trying to figure that out.
- Discussion regarding Activity #2 (Expand hearing screening to age 3). The goals involve identifying who the stakeholders are, now. By 2024, work on implementing this plan. Initial thoughts from the committee on this? Should this start with a work group from the Newborn Hearing Screening Advisory Committee, since many of the stakeholders are at the table here?
 - Jesi – how would you screen? OAE? Tympanometry and OAE? It's not easy to screen at 15 months. Does this include otoscopy and who will be trained to do this?
 - Darcia, we do have the updated guideline that addresses this. The question would be, how do we roll that guideline out and track sites that are providing that care?
 - Jesi, would this be all children?
 - Kathy – we have typically done a screening for kids referred for early intervention for any reason through early childhood, but the reporting is the issue. School age screening has gone by the wayside, some. Maybe we need an AMA person involved to get pediatrician buy-in.
 - Cat, look at capacity in terms of providers. Yes, start with work-group and add others as needed.
- Educational EHDI Updates/Cat Tamminga, Help Me Connect/3:25 to 3:45
 - Ch 3 is new chapter that deals with early intervention. What are evidence based practices?
 - Help Me Grow will be expanded and Help Me Connect will be added. They are not the same thing. HelpMeGrow will remain as is for the referral system into early intervention
 - HelpMeConnect will be resource for all kids, not just those who are in early intervention.
 - MDE, HHS, Governor Children's Cabinet are partners in addition to Creation in Common, Metro Area Agency on Aging, Revation, Senior Linkage Line (working on building on their website platform to modify a new site for HelpMeConnect)

- HelpMeGrow started in 2012. Preschool Development Grant will help with some of the funding for Help Me Connect. Goal of Help me Connect is to make it easier for families to find what they need (top goal of PDG)
- Phase 1: Need to hire coordinator, develop marketing, and training for website, release navigator website summer/fall 2020, plan for sustainability and accessibility. This will allow family to print list of resources, not directly connect them (yet).
 - Terry – why not using a google platform?
 - Cat - Because we are building onto a site that already exists that doesn't function like google.
- Phase II: Development of online, real-time referral system, built on platform of HMG. The organizations receiving referrals need to be ready to receive referrals. No timeline for development yet, but they will pilot and tweak before they do a full launch.
 - helpmeconnec@state.mn.us
 - PDG website <https://education.mn.gov/mde/dse/early/preschgr/>
- Partner Updates/3:34 to 3:55
 - All members should have received e-mail survey, required by grant. Please complete. Only 4 questions.
 - Turn in ideas form.
- Closure/3:55 to 4:00
- Next Meeting: May 20. 2020 is canceled due to COVID-19