Newborn Hearing Screening Advisory Committee Meeting Minutes

May 11, 2016 1:00 - 4:00 p.m. Amherst H. Wilder Foundation
451 Lexington Pkwy. N
Saint Paul, MN 55104

Facilitator: Joscelyn Martin

Recorders: Darcia Dierking, Cara Weston

Attendees:
Kathy Anderson, Joan Boddicker, Nicole Brown, Mary Cashman-Bakken, Kirsten Coverstone, Candace Lindow-Davies, Joscelyn Martin, Gloria Nathanson, Peggy Nelson, Sara Oberg, Anna Paulson, David Rosenthal, Emilee Scheid, Kara Tempel, Jay Wyant

Absent:
Teresa Buck, Tina Huang, Abby Meyer, Linda Murrans, Lisa Schimmenti, Michael Severson

AGENDA ITEM	DISCUSSION POINTS/DECISIONS/NEXT STEPS
1. Welcome and Announcements a. February 2016 Minutes approval b. Membership Appointment Update Joscelyn Martin	• Jay Wyant: motion to approve February minutes. Gloria Nathanson second. Approval passed. • Nicole Brown: final approval of new advisory members pending commissioner's signature.
2. EHDI Story Impressions From My First EHDI National Conference Joscelyn Martin Chelsea Paulson	• Joscelyn Martin: 1st time at National EHDI conference. Great to get different perspective. Highlights: Idaho's work on a risk monitoring system for later onset of hearing loss. Idaho placed children in two categories for monitoring (more or less often). Texting families for follow-up: being used successfully by other states. State stakeholder's meeting: Minnesota is really a success story in collaboration and looking to future to continue improvement. • Chelsea Paulson: Best part of EHDI conference was the positive atmosphere. I had heard from Deaf community that it would have been more negative and I did not experience that. There was an overwhelming selection of break-out sessions, and they were short (30 minutes each). I do feel like Minnesota is ahead of the game in that we collaborate together and have Role models. • Invitation for other members to reflect on EHDI story: • Candace Lindow-Davies: heard there was an app for parents to walk through the process. Based on text-for-baby. I was wishing we had something like that and now there is! • Kirsten Coverstone: Explained the app more in-depth. MDH is testing the app. It was developed by a high school student, Han Mason. • Melanie Wege: New documentary being produced, following two families through their journey of decisions regarding cochlear implants. The message was that it was a personal choice. • Kathy Anderson: In collaboration with Karl White and Utah State, there will be a series of videos regarding sign language. Free for parents and at a subscription cost for professionals. • Nicole Brown: saw updates about Early Childhood Long Term Data System. Came back from conference wondering how we could also engage speech language pathologists, not just through Part C, but also through clinics, and expand tele-health services.

EHDI Story Continued Impressions From My First EHDI National Conference	• Kirsten Coverstone: Came back with a big to-do list and ideas to consider replicating/modifying in our state. This year focused on CMV sessions. Highlight: Houston study: congenital asymptomatic CMV followed for 18 years. 22% ended up with some permanent hearing loss, a larger number than we have seen. 70% were diagnosed after 4 years of age. It's nice to have a longitudinal study, even though processes have changed over past 18 years. Most states want to do universal CMV screening. Last point: importance of getting hospitals to schedule outpatient appointments before child leaves, and perhaps getting AAP involved. • Joscelyn Martin: next EHDI conference in 2017 in Atlanta GA.
3. D/HH Symposium Summary Anna Paulson	• 247 attendees. Goal to attract professionals. 64% were teachers. This is first time collaborative invited interpreters/intervenors. Other professionals in attendance: administrators, vocational rehabilitation, educational audiologists, speech-language pathologists, parent guides from MNHV and Deaf Mentors. • Discussed World's Greatest Workforce initiative, other variety of topics. • Goal that attendees made new connections. • Majority of teachers that came were itinerant/rural teachers. • Good satisfaction ratings. We had a very Deaf/ASL focus this year and next year we will have to have more hard-of-hearing focus. We will add in some time for the regions to meet together. • Attendees wanted new ideas and skills and evaluations said those goals were met. • Attendees were asked: What else do you want to know? Mental Health and Behavior Strategies was at top of list. She gave a list of other topics teachers want to know, which is on par with what EHDI advisory committee talks about. • Possibly move conference to the fall, add professional groups, including local public health, perhaps add to MDE committee about adding D/HH track to their education conference. • Presentations are online, on the Commission website some will be up forever, others for one more week. • We had a large amount of sponsors, but Commission for of Deaf, DeafBlind and Hard of Hearing Minnesotans provided the most support and Symposium will need increased funding in future. • Sara Oberg: Might advertise to SLPs over ASHA and MEA. • Nicole Brown: It is good for teachers to get together and network but also to broaden to add other professionals and parents as the larger collaborative meeting/summit has been successful in past and is a nice opportunity to talk about EHDI. • Candace Lindow-Davies: broader group is good opportunity and might get more sponsorship. • Anna Paulson: would it be focused on only EHDI age group? • Kathy Anderson: lots to talk about during birth-5, but figuring a way to have school-age available may be important. • Joscelyn Martin: what about every other year? • Anna Paulson: might be a massive event, but important to add track for school age. • Joan Boddicker: Would be good for parents to hear information after the EHDI period, transition

4. MDH Update MNScreen: Amy Gaviglio CMV Study: Maggie Dreon EHDI Pre-session at MAA- Darcia Dierking	• MNscreen: Collects 1) Demographics, 2) screening results directly from the device 3) Integrated newborn record- MDH can do their work and hospitals also have access. On average, a 12 week process to onboard facilities consists of: Kick-off webinar, IT systems/feeds built and tested, devices connected, ongoing support from MDH and Oz, then "Go Live Date" set. Training scheduled between MDH staff and hospitals to build the relationship and keep things working smoothly. After Go Live Date, MDH does a couple of weeks of monitoring. Over 54% of birth rate now captured by new system. We have made a lot of progress since February when we had 37% of birth rate captured. Challenges: We've had some device networking issues. Also smaller hospitals may not have IT support to on-board and CDC grant funds may be used to support these smaller hospitals to get them set-up. This takes a lot of time but will be so worth it in the end to have better quality data. We expect to have all hospitals live by end of 2016. The second part of this is to send information back to the electronic medical record. Sometimes hospitals have the opposite information on screening records if they were manually entered in error. We have tested that and it is working. We are also working on the diagnostic part and hope to get audiologists in that system soon and get rid of paper faxing need. We also want to get risk factor information electronically. Acknowledged MNscreen team. • CMV Study: Launched in February at Fairview Riverside. It is a consented study and existing bloodspot is used along with a saliva sample. Study is comparing sensitivity of test between bloodspot and saliva samples to see what is sufficient. This is tested at U of Minnesota and CDC labs. If there is a positive test, genetic counselor contacts primary care provider. 53% of eligible infants have been enrolled so far. Any healthy newborn is eligible, but not from NICU. There has been barriers to reaching the non-English speaking community and this will be addressed. We also don't have a consenter on the floor on weekends and holidays, which will hopefully be addressed. There are 127 babies tested and 1 has been positive, but family did not choose treatment at this time, and will get hearing testing every 3 months. Fact sheets and study information sheets provided in advisory committee packets. We would like to add 4 additional sites, also hopefully expanding Mother/Baby at Abbott to universal screening. Would like to add parental experience assessment for positive screens, and ongoing educational efforts. • MAA pre-session: Pediatric pre-sessions for the last two years, joint effort between MDH and MAA. Free to clinicians the past 2 years, more than 100 clinical and educational audiologists; MAA had to cap attendance due to room capacity. Close to 80% said session gave idea on how to improve 1-3-6 goals and improved familiarity with EHDI guidelines. Featured presenter – Pat Roush, ANSD presentation, diagnostic assessment; well-received. Pediatric Grand Rounds – 15-min case presentations highlighting specific topics, given by MN audiologists and parent guide. Topics included unilateral and conductive HL, vestibular/balance testing, parent-parent support, educational/clinical audiologist collaboration, pediatric amplification. Over 90% would like to attend similar session in future. Over 60% said would make a change to current practices based on sessions; participants gave long list of immediate changes. Top 3 changes were to: ABR protocol, ANSD protocol and follow-up, and adding vestibular/balance screenings to practice. • Mary Cashman-Bakken – thanks for doing this, educational audiologists love it.
5. ENT Education/Outreach Initiative Update Melanie Wege	• ENT is a very important part of f/u after referring on newborn hearing screen. Important need to ensure consistent message to families when working w/both providers. Of children with delayed diagnosis – 70% had history of fluid, many has multiple re-screens instead of diagnostic ABR, inconsistent recommendations on f/u. If baby is not passing, immediately proceed to diagnostic ABR. Important: want to use bone conduction ABR to detect permanent HL, and earlier = better chance to have baby sleeping. • 2010, created brochure for MN Academy of Otolaryngology • 2012 NCHAM survey: sent to PCPs and ENTs, MN data extracted, sorted by providers. 83% not primarily pediatric. • New educational materials, infographic w/MN-specific data; myths/facts sheet, timeline.

ENT Education/Outreach Initiative Update, cont. Melanie Wege	• ENT outreach efforts: worked w/Dr. Geoffrey Service to have EHDI-related segments in MN Academy of Otolaryngology newsletter, mailed hard copies of new materials to top 25 ENT sites, 250 physicians. ENT advisory committee members worked w/MDH. • Last 3 years, EHDI booth at MN Academy of Otolaryngology conference. Some ENTs loved new guidelines, wanted them sooner. Some ENTs also want simpler 3-point checklist w/no fluff. • Did we make a difference? Things starting to shift, providers making referrals more quickly; wanted to do a new survey. • 2016 survey – mailed/emailed Feb 2016, plus reminder. Online and paper responses, better response rate (30/160 in 2012 vs 53/147 in 2016). Practice location – got more variety of locations than 2012. Some choices did not best represent their location. % of practice including children – similar to 2012, majority had 20% or less. # infants/children identified w/permanent congenital HL? Not many. Reinforces need to get info out to clinics. Saw improvement from 2012 for most questions—most ENTs answered in closer alignment with EHDI goals. Some work still to be done, but definitely improvement. An application question was also added- a scenario was given and ENTs asked to pick their intervention. • ENTs also asked what types of info they would like to receive. Preferred method of communication: email 80%, then MDH website, mailed copies, webinars, presentations at meetings. • Future planning: get copies of audio clinic data report to ENTs, email blasts, etc • Jay Wyant: Is there a specialist portion for ENT or audiology in toolkit? Yes, specialist portion of toolkit, is basic and could be developed more. • Thank you to advisory committee's help developing materials and guiding process, thanks to Jessie Cavazos who was key in helping design survey, helped with materials
6. BREAK	
7. Minnesota Early Childhood Longitudinal Data System and EHDI Anita Larson and Nicole Brown	• Nicole: Introduction of Anita Larson from MDE to talk about ECLDS. National Disability Research Dissemination Center put out grant opportunity for looking at outcomes for D/HH children related to EHDI systems. Objective to match records from EHDI and Education for 100 children. Learned that MDH did not receive grant, but while developing proposal decided that whether we receive it or not, we will move forward with project to input EHDI data into ECLDS. • Anita: MDE and MDH have been working together for last 3 years under a race to the top early childhood grant. MN wants MN-specific data. Fed gov't has started funding integrated data systems, 49 states doing it. SLDS systems, where all funding started, K12-higher ed. P20 = lifespan of integrated data system. P=preschool, 20=everything else. • Systems being built target teachers and parents, secure portals for parents to see child's info; some states for teachers, too. Another audience – state/local planners, higher-level info for broader view. This is MN targeted group; stakeholder group = legislators, advocates, state agency staff, leadership, local planners; school district and county are focus right now. • Background: governing body: formal representation from all 3 state agencies, also from professional associations. Research and data committee – know data and policy and service delivery. Reliability and validity of data elements, make recommendations to governing body. Everything is documented, and public. Charter between state agencies, do our best to have fair representation.

Minnesota Early Childhood Longitudinal Data System and EHDI, cont. Anita Larson and Nicole Brown	• Structure: MDE, DHS, MDH. Linking and deidentification process, decision-making on questions we want to know. Very simple questions. • No data elements that do not have a purpose. Start w/questions, identify programs that could identify elements. • Privacy: data integrated only if allowed by law. Not creating new data, all existing data. Linking data because have legal right to. Long list of data sharing agreements. Identified data used only at time of linking. Only 5 people see identified data. • Q: If numbers are suppressed, with small numbers will that limit what we can learn? A; Have talked about that – analytics around 3 and 5-year averages. Have to be careful. • Departments decide what goes in; what it means, how we should rely on it. • Data sources: K12 enrollment, childcare assistance, MfIP, K12 assessment, ECSE, Family and Child Outcomes survey, ParentAware, teacher licensing, district school readiness. Need 30 agreements and have done 3. • Policy Q: what children are participating in what combos of programs? • Website is Mobile-first tech, (looks best on phone/tablet) • Using ECLDS name now, may rebrand in future. • Site: looks similar to SLDS site. • Decision – anchored around a kindergarten cohort, looks back. New way of looking at data is birth cohort. • In system, will not always have complete data. For example, private childcare – not likely will get all to participate in system. • Dropdowns: participation by program. Bar graph and percentage tables. CTSTR = counts too small to report. • Information at bottom of charts – glossaries. • Spreadsheets – children participating in various public programs (family home visiting, etc). • Second policy Q: for each service received, initiation, intensity and duration of each service + status, progress, outcome from birth – 3rd grade. Identified risk factors. • Integrating new sources – received IES grant, put in request for site to be funded by state, no. Need money to pay for maintenance every year. • Future: birth cohort going forward, outcomes by mother's ed, disability status, ECSE, other things. • Funding ends in December, extension didn't go through. Need to get going, must move quickly. Data sharing agreement exists, can be amended, need members from these groups on committees. • Jay: Could we have a copy of the presentation? A: Yes! Now that we have website we can share it and people can understand it.
8. MDE EHDI Update Mary Cashman Bakken	• Mary: Advisory board has been meeting 4x/year, 15 members. World's Best Workforce 2014 – goals for students, everyone getting into it now. Can find info on plan by district. How do D/HH students fit into this? • No Child Left Behind vs Every Student Succeeds Act: went over comparison chart. Still have state standards, now secretary of state does not have authority over that. More flexibility, MN has state standards we are following, just more flexible. Allows alternative standards for students with significant cognitive disabilities. Signed in December, impact? Unknown. • Interpreters: huge. Registry for Interpreters of Deaf, moratorium for RID testing. MN law based on testing by RID or EIPA, how to react? Waiting for decision, focusing on EIPA. Only 3% of interpreters were passing, why are passing rates so low? Other states rates lower than 3%. RID received a lot of pressure, taking time to figure things out. Not the best solution but waiting. MDE met with interpreter training programs (all 4), talked about what's happening in programs, turning out good candidates. From that meeting decided to do a mentor training for mentors working with new interpreters, will happen in August, ready to go. Will give the EIPA free to new interpreters. Registering all interpreters through MCB; asking school districts for list of interpreters throughout state.

MDE Update, Cont.	• Q: Is this only for ASL or cued speech transliterating? A: Only for ASL interpreters. • Q Gloria: Word game, some places label them a language facilitators when job duties are interpreting? A: Difficult - parents or someone in the district can file a complaint. Right now school district will receive no money to do training if they're not labeled an interpreter. • Doing a pilot for deaf mentor for interpreter, work with interpreter in classroom, give notes, figure out gaps. • Richard Lorean from St Kate's talking about priority of interpreters for D/HH in school, how can St Kate's help more? • Teachers of D/HH love the D/HH collaborative plan. • Strategies for reading and writing, how to get scores up? • Mentoring for D/HH teaching, 4 tried and loved it. More people interested in participating, looking to double it to 8 next year. Becca Jackson helping, sending out newsletter. • D/HH/DB survey, legislative report will be out in July. • Early Childhood, Kathy going through Boys Town modules. • Race to the Top funding ends this year. Menu of assessment tools. Kindergarten entry profile = KEP, new tool. Formative assessment system for teachers = FAST. Did pilot, ongoing. • Legislative report – possibly every 2 years. Added BBI to report, am finishing up this month. MMB • Parent concerns: not all parents aware of choices for DHH kids. Looking at those questions, develop new materials? Invited Candace and PACER to talk about resources out there for parents. Do we really have issues, or just a few parents not understanding? • Advisory board has several openings, will be filled this summer.
9. Workgroup Updates Nicole Brown – Medical Guidelines Update Darcia Dierking – Audiological Guidelines Update	• Nicole: Thank you to Emily for extensive work on medical guidelines, lots of good feedback on medical guidelines. Hoping guidelines will be ready for approval next meeting. • Darcia: Comprehensive document, assessment, referrals, and amplification. Have all components listed out for review/development, sent out to workgroup to get preferences, and work will begin.
10. MDE Update Part 2 Kara Tempel	• New Help Me Grow website – used to be landing page and now is full-blown website. Not an ECSE-specific website, geared toward parents and professionals. • HMG expanding to match national model. • Kara will send out link; helpmegrowmn.org.
11. Closure	Next Advisory Committee Meeting: August 10th, 2016 Amherst H. Wilder Foundation 451 Lexington Pkwy. N Saint Paul, MN 55104