



Newborn Hearing Screening Advisory Committee Meeting Minutes

05/27/2015

1:00-4:00 p.m.

Amherst H. Wilder Foundation
 451 Lexington Pkwy. N.
 Saint Paul, MN 55104

Facilitator: Joscelyn Martin

Recorders: Melinda
 Marsolek, Darcia Dierking,
 Cara Weston

Attendees: Kathy Anderson, Joan Boddicker,
 Nicole Brown, Teresa Buck, Mary Cashman-
 Bakken, Kirsten Coverstone, Laura Godfrey
 (representing Candace Lindow-Davies), John
 Gournaris, Joscelyn Martin, Linda Murrans, Anna
 Paulson, Sara Oberg, Emilee Scheid, Jay Wyant

Absent: Dennis Ceminski, Mary Hartnett, Tina Huang, Candace Lindow-Davies, Karleen Maeurer,
 Gloria Nathanson, Peggy Nelson, Lisa Schimmenti, Geoffrey Service, Michael Severson, Rhonda Siv-
 arajah, Emily Smith-Lundberg, Kara Tempel

AGENDA ITEM	DISCUSSION POINTS/DECISIONS/NEXT STEPS
<p>1. Welcome and Announcements Joscelyn Martin</p>	<ul style="list-style-type: none"> • Jocelyn convened meeting and entered motion to approve minutes from February. Linda Murrans moved and Mary Cashman Bakken seconded. Motion passed. • Introduction of new members • Invites have been sent for 2016 meetings. • Member updates: Laura Godfrey shared that Candace is on a trip to China sharing her work with Hands & Voices. You can follow her trip on Facebook.
<p>2. National EHDI Meeting</p>	<ul style="list-style-type: none"> • Nicole Brown: Two highlights—1. NECAP update showing language outcomes for children with unilateral hearing loss. 25-35% demonstrated delayed language at 2 years of age (and the delay did not show up until about 2 years of age). Were not able to identify factors that put children at greater risk for language delay (e.g. degree of hearing loss was not related.) 2. Networking with other states and countries that have D/HH role model programs. BC developed a video explaining the importance of D/HH role models. • Kirsten Coverstone: presentations from conference are available online. 1. CMV was a big theme this year. Utah is doing targeted CMV screening. 2.6% of children were positive for CMV at one site. No programs shared information about parent impressions of CMV screening as of yet. 2. ‘Ear Community’ nonprofit for people born with microtia/atresia. Resource we have not been aware of in MN. Earcommunity.com. 3. New pediatrician video posted in Medscape explaining the importance of following up on a Refer result on hearing screening. • Mark McCann: 1. Surprised that genetics of hearing loss was not talked about at the conference. 2. Importance of early intervention for brain development. Maybe the 1-3-6 model needs to be compressed? 1-3-6 weeks? • Laura Godfrey: 1. Attended many sessions on CMV and H&V is trying to figure out how best to talk about this with families. 2. MN is doing so well compared to other states.

<p>3. EHDl Story Local Public Health Follow-Up Teresa Buck</p>	<ul style="list-style-type: none"> • Teresa Buck provides EHDl follow-up and also works with Home Visiting and is a representative to IEIC for Region 10. • Follow-up of LTFU for EHDl is challenging. Families are sometimes unresponsive, providers are also sometimes not responsive. • Sometimes does home visits for CHL. Teresa went to meet a mom in person who was new to the U.S. • Worked with a mom who had a new dx of Usher for herself and Teresa was able to help her get prior authorization for genetic counseling. • Teresa shared a video clip she developed to help explain her work to the IEIC. • Joscelyn Martin: Who is intended audience for video? Teresa: developed for Early Childhood Special Education directors in the school system, however it could be expanded to others. • Mary Cashman-Bakken requested that the video be captioned prior to video release so that it can be accessible. • Karen Anderson: Another good audience would be primary care providers. • Jay Wyant: Define: Local Public Health as audience members may not be familiar.
<p>4. MDH EHDl Updates a. Local Public Health Update - Melinda Marsolek</p> <ul style="list-style-type: none"> • 2014 Follow-Up Data • Conference <p>b. MNscreen Status Updated - Amy Gaviglio</p>	<p>Melinda Marsolek:</p> <ul style="list-style-type: none"> • Defined Local Public Health: LPH works at community level and is link to MDH • Since 2010, LPH follow-up done for EHDl program • Melinda shared slides regarding LPH contract with MDH from 2010-2015. • All cases notified and documented in web-database • LPH nurses work in many programs and have average of 3 additional roles outside of EHDl • LPH works on lost to follow-up cases (LTFU) and LPH has contributed to reduction in LTFU • 40% of cases sent to LPH are resolved • LTFU cases in less populated counties more likely to be resolved, only 25% resolution rate for Hennepin and Ramsey counties because LPH nurses from these counties may not have access to other programs (WIC, etc). • Quality Improvement project: Two improvement theories: 1) Improved parent education, 2) Improved contact information necessary • Tests of QI: 1) LPH-MDH developed Myth/Fact sheet - successful 2) EHDl Checklist for LPH to contact parents and guardians - successful 3) 2nd phone number from bloodspot card – not successful. • LPH ensures connection to Part C. Data collected on number of referrals made to Part C from LPH and number of times information is provided. • MDH—trying to determine best way to measure work LPH is doing. • Survey for LPH: linking people to services most impactful • Exploring piloting Omaha system to track outcomes of LPH interactions • Mary Cashman-Bakken: wants copy of slides • Sara Oberg Comment re: handout to parents “Your Baby’s Hearing: It is important to test again.” Children may respond to visual cues <p>Amy Gaviglio:</p> <ul style="list-style-type: none"> • Reviewed MNscreen • May 2013 signed contract with vendor for MNscreen reporting platform. • Amy shared slides regarding steps to data collection: Step 1) Baby’s demographic information collected, Step 2) Telepathy; Step 3) MNscreen integrated newborn record • Sara Oberg: Can parents get copies of hearing screen results? Amy: Can print MDH letter from software • Facility roll-out status: see slide • Coverage for births still small – 11 facilities completely implemented in MNscreen covering 6% of births right now • Working with facilities, coordinating with IT departments taking time • MNscreen has ability to collect risk factors, however risk factors not always entered in medical record. Screening staff may not know risk factors. May autopopulate NICU > 5days risk factor based on birth and discharge dates and

	<ul style="list-style-type: none"> • Expanded scope of project at request of facilities, sending results back to facilities' medical records • Mary Cashman-Bakken: Will Early intervention and follow-up to age 21 be involved in MNscreen? Amy: This is to be determined. • Teresa Buck: Can other letters be incorporated in MNscreen to support parents and provide information about more testing needed before parents leave the hospital? Amy: Yes, can include other letters/info. • Nicole Brown: Other states use MNscreen to refer to early intervention. • Amy: Open to enhancements in effort to make end users' work easier. Please contact Amy with ideas for improving system.
<p>5. MDE EHDI Updates Kathy Anderson</p>	<ul style="list-style-type: none"> • 10,000 new referrals to MDE through online system that were then sent to the school districts • Regional EHDI Team Annual Training Day: Handout provided • OAE trainings, piloting service coordinator/provider checklist • Regional EHDI teams create action plans around 4 goal areas • ACRN project with Boys Town National Research Hospital – for staff development of MN public school service providers for children with hearing loss • Analysis of child and family outcomes data. Is there a teacher of the D/HH on IEP teams • Mary Cashman-Bakken—MDE report done soon. Making documents accessible is a requirement. Looking at captioning and full accessibility of materials for general education and special education. Working on Part B agreement with MDH, in July.
<p>6. Commission Serving Deaf, Deafblind, and Hard of Hearing Minnesotans Anna Paulson</p> <ul style="list-style-type: none"> • Symposium for Professional and Parents • EHDI Workgroup • Legislative Update 	<ul style="list-style-type: none"> • Anna shared slides regarding Collaborative plan groups • There are four Collaborative Plan Groups, broken up by age. They meet every other month. The Birth-5 team is developing a resource guide for early interventionists and piloting an EHDI System Self-Assessment Tool that is based on the JCIH recommendations for EHDI programs. • What happens after EHDI: school age groups concerned about MCA scores and progress they are making compared to general education. MCA were not written for children with hearing loss. Doing a study looking at trajectory of reading progress instead of waiting for summative MCA score. • Trying to involve 2 Deaf schools and itinerant teachers • Secondary/Transition Group- next steps when students turn 14. • Student interviews on transition on website. • Goal for next year: Trying to document where children go after high school. • Teacher D/HH and Parent Symposium April 16-18 • Presentations by Mark Marshark, Susan Elliot on the website <ul style="list-style-type: none"> • Legislative Update from Beth Fraser, Government Relations Director at the Commission • Not all legislation was directly related to EHDI • Top priority: \$1 million per year funding for communications access supports for workers and youth [passed during special session] • Central Accommodation Fund: creates a central fund to support hiring deaf, deafblind and hard of hearing state employees (can be used by state agencies to help with the cost of providing accommodations) [passed] • Having a central fund takes that worry away, employer doesn't have to fund accommodations • Also helps people ask for accommodations for acquired disabilities • Starting in July, will exist for all state agencies with \$200k added per year • Additional funding for DHHS division [passed] • will be used for deafblind support services, mental health services in ASL, and updates for the equipment labs. There will also be a study for how services can best be provided statewide (offices being closed) • Technology funding for State Academies [passed in special session] • Pre-K at Metro Deaf School [partial success]

	<ul style="list-style-type: none"> • The Education Finance Bill passed during the special session will allow parents to choose the Metro Deaf School, but prohibits the school from receiving state or school district funding to pay for these services. • Supported Department of Public Safety to get funding to develop technology for people to dial 911 by text, included in Public Safety bill [passed] • Other bills didn't make it through • Q. Emilee – Concern – insurance companies don't cover children over 18 for hearing aids. How will we cover children through college, reduce drop-outs? • A. Commission was instrumental in getting coverage expanded to age 18. Introduced bill to cover HA up to age 26, not successful. • Q. We have eye care coverage, dental, why not hearing insurance coverage? • A. Ins companies tend to see it as cosmetic. • Comment, Jay Wyant – lots of national organizations have been working on insurance coverage, have to pick fights based on climate. Ideally should be done on national level. Hope to see it happen in future. • Commission looking at age-related HL, professor at Johns Hopkins has invented very low-cost HA. One reason for high cost is no competition. Looking at other ways to bring down cost.
<p>7. Workgroup Updates</p> <ul style="list-style-type: none"> • Transient Hearing Loss • Guidelines - Medical and Audiological <p>Joscelyn Martin, Nicole Brown</p>	<p>Transient</p> <ul style="list-style-type: none"> • The term “transient” can be misleading. Some children turn out to have permanent HL or prolonged conductive hearing loss. • Abby Meyer looked at initial reports to see how many transient HL cases turn into permanent and found that it was 1 in 10. Most who developed permanent HL had risk factors. • Currently, MDH doesn't know the final result for 70% of children reported with transient HL • Created educational materials for parents – postcard; still working on wording (fluid? Temporary? Permanent? Diagnosing?), second trial now • Expanded postcard test – Linda Murrans discontinued test until wording is resolved • Also asked Univ of MN Lions Children's Hearing Center to test, don't know results yet • Dr. Severson weighed in – tough balance, not freaking anyone out, but strong enough to get parents to come back • Linda Murrans – use that LPH fact sheet for why to get baby's hearing tested until card is done? • Additional suggestions, workgroup would love to hear <p>Will be starting two new workgroups:</p> <ul style="list-style-type: none"> • Audiological Assessment guidelines – Darcia/Kirsten coordinating • Medical providers guidelines – Nicole coordinating • If interested, watch for email • If you have an idea for a new workgroup, add to the list
<p>8. Closure</p> <p>Joscelyn Martin</p> <p>Next Advisory Committee Meeting: August 12, 2015 1-4pm</p> <p>Location: Amherst H. Wilder Foundation 451 Lexington Pkwy. N Saint Paul, MN 55104</p>	<ul style="list-style-type: none"> • Send partner updates to chair or ehdi@state.mn.us • Adjourn