



Newborn Hearing Screening Advisory Committee Meeting Minutes

August 10, 2016 1:00 - 4:00 p.m. Amherst H. Wilder Foundation
 451 Lexington Pkwy. N
 Saint Paul, MN 55104

Facilitator: Joscelyn Martin
Recorder: Michelle Gin

Attendees:
 Kathy Anderson, Joan Boddicker, Nicole Brown, Teresa Buck, Mary Cashman-Bakken, Kirsten Coverstone, Tina Huang, Candace Lindow-Davies, Joscelyn Martin, Abby Meyer, Linda Murrans, Gloria Nathanson, Sara Oberg, Anna Paulson, Emilee Scheid, Lisa Schimmenti, Michael Severson, Jay Wyant

Absent:
 Peggy Nelson, David Rosenthal, Kara Tempel

AGENDA ITEM	DISCUSSION POINTS/DECISIONS/NEXT STEPS
<p>1. Welcome and Announcements</p> <p>Joscelyn Martin</p>	<ul style="list-style-type: none"> • Jay Wyant moves to approve the May meeting minutes. Linda seconds. No opposed or abstentions. Passes. • Nominations for 2017 Vice Chair needed • Linda Murrans: Noel Matkin passed away at age of 84 on July 4, 2016 • Gloria Nathanson: Dr. Amy Hiel also passed away.
<p>2. EHDI Story / Tele-Audiology Project</p> <p>Tele-Audiology Project</p> <p>Betsy Schutte, AuD & Maureen Ideker</p> <p>Essentia Health, Duluth</p>	<p>Betsy Schutte</p> <ul style="list-style-type: none"> • Tele-audiology program in Duluth needed to address rural audiology needs. • Background: If an infant does not pass the newborn hearing screening, they go to Essentia Duluth Audiology, usually before 1 month of age. If needing diagnostic testing, they tend to be a little older. Due to being rural, sometimes families are traveling 3 hours to get to appointments. If they do not live near Duluth, then families go to Fargo or the Twin Cities. • Betsy shared a family story of the challenges of rural diagnosis. Challenges include: Family must take a day off of work, cost of gas, babysitter costs, & keeping baby awake during travel so they sleep for the test, etc. This is a typical story. • Plan to add tele-audiology at Essentia Clinic - Virginia • Telehealth has been in place for a number of specialties at Essentia Health • Tele-audiology was launched in Deer River and Betsy Schutte taught primary nurses how to get the patient set up for testing. • How it works: audiology department receives a call that an infant needs diagnostic testing. Patient arrives and gets set- up at the clinic in Deer River. The audiologist in Duluth is notified that patient is ready. The audiologist calls the telehealth cart. All of this is completed over a secure network so there are no privacy concerns. Plan to schedule any rescreens if needed before the family leaves building. • Struggle: reimbursement for tele-audiology services not standard but new legislation in MN is changing that.

<p>Tele-Audiology Project continued</p> <p>Betsy Schutte, AuD & Maureen Ideker</p> <p>Essentia Health, Duluth</p>	<ul style="list-style-type: none"> • Fundraising: Needed to raise \$55,000 for the project • Looking forward: Hoping to test 30 infants in the next year. Hoping to expand to second spoke site in Virginia. In 5 years, hoping to have a strong and expanding program. <p>Maureen Ideker</p> <ul style="list-style-type: none"> • Has worked in telehealth for 24 years • Process map (colored work process map included as handout). Tells everyone what they are responsible for at both rural (spoke) site and specialist's site. Is very detailed. • A deeper look into how Audiologists & Speech Language Pathologists were added as eligible providers for Telemedicine in MN. This means their services are considered reimbursable by insurance. • MN is the first state in the U.S. to have audiology covered in Telehealth • Question: Why did Marshfield Clinic (WI) stop their pilot program? – ran out of funding.
<p>3. EHDI Workgroup</p> <p>Medical & Audiology Guidelines</p> <p>Emilee Scheid & Darcia Dierking</p>	<p>Updated medical guidelines (handout included)</p> <ul style="list-style-type: none"> • Emilee: Developed to be easily useable by primary care providers and emphasize follow-up needed. <ul style="list-style-type: none"> ○ Introduction section: should draw their interest as well as provide a background of importance. ○ Emphasized the concept of a developmental emergency. • Question from Teresa: In the document, the term 'abnormal' is being used in parenthesis after REFER. Is this a term being used with families when informed of the results? <ul style="list-style-type: none"> ○ There was a lot of discussion regarding implications in wording "Abnormal, Refer, Did Not Pass, Positive Result." ○ The discussion centered around parent perception of result and urgency for follow-up, terms that are common & distinctly understandable by providers, & the use of the word 'abnormal' related to a child. • Comment: Families have said that they were confused over the word 'refer' and what that means • Comment: Historically the terms 'refer' / 'did not pass' were requested to be used to describe the result for families because the terms 'normal' / 'abnormal' were considered to be medical jargon • Comment: PCP concerns using 'pass' vs. 'not pass' is too similar and could be skimmed over in paperwork. • Comment: the term 'abnormal' may offend the family. Another choice of words, 'typical' and 'not typical'. • Comment: Words selected are becoming so soft that it can cause harm because families are not following up with the test. • Comment: I strongly feel that we need to change refer to did not pass so that it's clear for everyone because if we're confusing providers, aren't we confusing everyone and making it not seem important, especially mothers who are teenagers having children that are referred, and I just think they're not as educated, and if educated people are confused by the term, what are other states doing? Are they all using pass and refer? Is this nationwide? <ul style="list-style-type: none"> ○ Kirsten: the majority of states use pass/refer.

	<ul style="list-style-type: none"> • Nicole: these terms were picked early on because that's what parents wanted. It may be time to revisit this. • Solution: Workgroup will take document back to revise for more edits. Will bring it back for more discussion. <p>Audiology guidelines</p> <ul style="list-style-type: none"> • Still under review
<p>4. BREAK</p>	
<p>5. MDE Update</p> <p>MDE Legislative report & Post Outcome Survey</p> <p>Mary Cashman-Bakken</p>	<ul style="list-style-type: none"> • The 2016 Legislative Report states what's going on educationally for our students who are deaf and hard of hearing with a primary disability category of hearing loss. • Emilee: As a parent of a child who is D/HH...how do I use this information to improve services for our children? • Mary: Concerns about interpreter shortages. Should we lower the requirements for interpreters? • Question from Jay: The interpreter issue is a pretty significant one. How many students have been using or requesting an interpreter for their IEP? <ul style="list-style-type: none"> ○ Mary: Not a whole lot are using it. Most of our kids are hard of hearing. • Question from Jay: But does the report contain the data as to which use interpreters, which use CART, which use an FM system? <ul style="list-style-type: none"> ○ Mary: No, we don't have that information. • Emilee commented on the importance of having access to what their peers are saying. How can that be improved so that this is a consistent service for all students who are D/HH? • Sara: There's research on voice amplification to benefit all children. Though, understand there is a monetary constraint for schools. Dr. Peggy Nelson has a lot of research on amplification in classrooms • Last year, we did the first annual post-secondary transition statewide survey with a n=57 (Results are in the back of the included report) • MN resource library has been growing. Last year, over 1,000 people borrowed materials.
<p>6. MDH EHDI Update</p> <p>2015 Long-Term Follow-up Data</p> <p>Nicole Brown</p>	<ul style="list-style-type: none"> • Nicole: Handout included of the slides presented. Number of children reported is similar to previous year with 242 kids report as having permanent hearing loss in 2015. • Birth prevalence remains stable as 2 in 1,000. • Majority of kids identified in MN are hard of hearing. • Significant number of kids with unilateral hearing loss. • The number of kids reported with presumed transient-conductive hearing loss remains about the same as well. We have been working on a follow-up protocol for these kids. Of those with reported follow-up for Transient Hearing loss we are seeing ~8% end up as permanent hearing loss. However, 1/3 of the cases do not have updated status reported. • Data on referrals to Genetics & Ophthalmology has remained the same. A large number are just not getting referred. We have decided to take a hiatus from tracking down specialty evaluations for the next 2-3 years and instead focus on quality improvement to improve referrals.

<p>MDH EHDI Update continued</p>	<ul style="list-style-type: none"> • Most EI data is coming from match with MDE, although data is incomplete for 2015. Part C status is unknown for close to one third of children. Would we want to do preliminary data or should we do lagged data? For example, report 2014 instead of 2015 next year? • About half of children who enroll in Part C Services are enrolled within 2 months of diagnosis • 39% of infants were fit with amplification within 1 month of diagnosis (includes children with bilateral hearing loss who did not decline). Percentage has remained stable over time. 75% of children were fit within 2 months of diagnosis. • Parent to Parent support contact by MN Hands & Voices remains high. They do a great job connecting with almost every family. • We are approved to add EHDI data into the Early Childhood Longitudinal Data System (ECLDS). Will be able to look at child outcomes over time. www.eclds.mn.gov
<p>7. D/HH Collaborative Project Update</p> <p>Providing Resources and Information to families of children who are D/HH</p> <p>Candace Lindow-Davies & Anna Paulson</p>	<ul style="list-style-type: none"> • Tabled to another time.
<p>8. Closure</p> <p>Joscelyn Martin</p>	<p>Remember to submit nominations for vice chair. We will be voting during the November meeting.</p> <ul style="list-style-type: none"> • Next Advisory Committee Meeting: November 9, 2016 <p><i>LOCATION:</i> Amherst H. Wilder Foundation 451 Lexington Pkwy. N Saint Paul, MN 55104</p> <ul style="list-style-type: none"> • Notify Chair if there are any Partner Updates to put on the agenda • Adjournment