

Newborn Hearing Screening Advisory Committee Meeting Minutes

02/10/2016

1:00-4:00 p.m.

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

Facilitator: Joscelyn Martin

Recorders: Jessica Cavazos

Attendees: Kathy Anderson, Nicole Brown, Teresa Buck, Dennis Ceminski, Kirsten Coverstone, Candace Lindow-Davies, John Gournaris, Joscelyn Martin, Abby Meyer, Linda Murrans, Gloria Nathanson, Peggy Nelson, Sarah Oberg, David Rosenthal, Emilee Scheid, Lisa Schimmenti, Michael Severson, Jay Wyant

Absent: Joan Boddicker, Mary Cashman-Bakken, Tina Huang, Anna Paulson, Kara Tempel

AGENDA ITEM	DISCUSSION POINTS/DECISIONS/NEXT STEPS
<p>1. Welcome and Announcements Joscelyn Martin</p>	<p>Joscelyn Martin convened meeting and entered the motion to approve minutes from November 2015. Sara Oberg requests a correction to her name. Peggy Nelson moved and Michael Severson seconded. Motion passed.</p> <p>Thank you to everyone who has served on the advisory committee and welcome to those of you who are new to the committee.</p> <p>Reminder: we still need people for birth hospital representative position on the committee, please encourage applications.</p>
<p>2. EHDI Story Erin Loavenbruck</p> <p>3. Teletherapy Program Northern Voices Erin Loavenbruck</p>	<p>Erin is Executive Director of Northern Voices, Elizabeth Nelson and Jenny Smith are teachers from Northern Voices.</p> <p>Elizabeth and Jenny introduced the Teletherapy program provided through Northern Voices. The program has been offered since September 2014 and has served 8 families.</p> <ul style="list-style-type: none"> • Teletherapy is a specific model of intervention provided through distant technology and provides family- centered services to infants, toddlers and school aged children with hearing loss. Coaching is an essential component. • Allows the provider to model and coach parents in using language facilitation techniques. • Parent learns to become the primary facilitator of the child’s communication, language and behavior. • Services are delivered through Skype or Facetime <p>Coaching is done at every stage and is a vital component of teletherapy. The goals are to teach the caregiver ways to turn everyday interactions into a language rich learning experience, build confidence in the adult, enhance communication, focus on the language not on speech, and focuses on the adult rather than the child</p> <ul style="list-style-type: none"> • Comments and suggestions are given throughout the session before, during and after • Support is provided through suggestions and positive reinforcement while the

adult is engaged with the child.

- Allows for the adult and the child to enhance communication by implementing suggestions.
- Allows for every moment to be a learning opportunity.
- The adult is given immediate feedback with behavior, interactions and language.
- Builds confidence for the adult and the child.

Teletherapy takes a lot of collaboration and has both advantages and some remaining challenges. Parents like the weekly notes that they receive in parent's summary. Things they did well and things that they can work on. They look forward to these notes and it also helps them see progress.

Advantages:

- Families receive similar services that are as good or better than center based
- Eliminates transportation concerns and less cancellations
- Lessens the barrier of having qualified providers and inequality of available services in rural areas.
- More of a "real life" situation
- Helps children generalize goals
- Children and families are more familiar with their surroundings and more comfortable and less distracted
- Empowers and encourages family members to use daily activities and routine to provide intervention
- Receiving positive feedback from other team members
- Increased and improved collaboration with other professionals
- Better parent engagement when compared to in person sessions

Challenges:

- Technology failure
- Managing behavior
- Lack of planning from parents
- Filling the session with enough activities to keep child engaged
- Reimbursement
- Active participation-parent needs to identify activities, strategies, learning opportunities and practices that enhance child's communication development

Q: In what ways do you see the expansion of tele-therapy benefitting the D/HH children in MN?

NV (Linda): One of the children I follow participated in TT through St. Louis. It's a great idea and empowers the family and allows them to continue through everyday listening and learning. It's fabulous.

- Services are provided in the child's natural environment
- Cost effective
- Reduces the number of sessions missed
- Parents become the coach!
- Success!

Comment & Q: (Michael Severson) As a rural pediatrician, this is just where we want to be. The challenges will be as it expands, some of my families live off the grid, physically or economically. How flexible is the time, plans to study the length of time for a session? Some families take more time than others, what is best?

NV: Flexible, if someone isn't engaged we work with shorter sessions, learning to work with these challenges when they come up. Is 60 min too much? Not enough?

NV2: 60 in a starting point, we individualize to what fits the family.

	<p>Q: What's a realistic case load?</p> <p>NV: right now we haven't found that big number, always trying to find more families. As program grows... meet each family 1 a week for an hour, 30 minutes to prepare, 30 minutes to summarize after. So 2 hours for family per week for a provider. Nightly session or early morning sessions. Most sessions are at night. Succeed with this many, will keep expanding until we are told to slow down.</p> <p>Q: (Sara Oberg) I have wanted to do this in the hospital setting for years. Are you running into privacy issues as far as skype and facetime? Are there reimbursement issues?</p> <p>NV (Elizabeth): As D/HH teachers we are not bound to the same requirements needed in a health care setting. . We work with families and these are the services they are comfortable with. Explain that this isn't a private connection and can try something more secure if parents wish, but haven't had to do this yet. Reimbursement, all the families are paying for services themselves. Brainerd school district is contracting it. \$70 per session. Families are paying this because they see the progress their child is making.</p> <p>Q: Do you ever work with insurance?</p> <p>NV: nope, can't bill insurance as we are teachers.</p> <p>Comment: There is a D/HH teacher shortage, some of this can be relieved through tele-therapy.</p> <p>Northern Voices Tele-therapy Program started in 2014. It is still new and working out kinks. Feedback is encouraged and team is looking forward to seeing it grow.</p> <p>Q: Do you work with entire family, both parents and siblings? Helpful to have everyone take part.</p> <p>NV: yes, we have several families who do this, parents, grandparents, siblings. The more people the better. We encourage anyone who wants to be included.</p> <p>Q: Who qualifies for the program? Parents?</p> <p>NV: need internet, computer, email, consistent schedule. Materials/toys/teaching moments are stuff you already have at home.</p> <p>Q: How are you finding these families, how do they participate?</p> <p>NV: contact NV, many find out through word of mouth, we've contacted audiologists or SLPs for recommendations and share our services. Word of mouth is huge.</p> <p>Q: Do you have info on demographics? Education? Socioeconomic? Who is involved?</p> <p>NV: Demographics, education levels, & socioeconomic status is really across the board. We are not turning families away. It's a service that everyone can use. We've become very close with the families. It is a fun and rewarding program.</p>
<p>4. MDH Update EHDl Data and MNScreen Updates Amy Gaviglio</p>	<p>2015 "DRAFT" Screening Data:</p> <p>MDH PHL is working between two systems (some data in one system, some in another, some in both).</p> <p>Of note, previous data reports were done by Received Date (allows snapshot in time at any given time but the addition of MNScreen has necessitated reporting by DOB. Some metrics will change as infants born later in the year still need some time to resolve.</p> <p>Data presented doesn't include midwifery systems, though some are already using MNSCREEN.</p> <p>Facility live dates determine the date the facility began using MNScreen for reporting of EHDl and CCHD results.</p> <p>Babies born in November and December or in NICUs continue to be worked on and were not yet all resolved at the time of this presentation.</p> <p>2015 data will be updated (results from MNScreen added, duplications removed, & late-year born infants resolved. We definitely expect initial screening numbers to go</p>

up as late 2015 NICU babies resolve.

Undocumented Screens:

- NICU and Out Of Hospital (OOH) births remain biggest issue for reporting of initial screen. Some don't have equipment, some don't have screening yet.
- Incomplete: result reported only on one ear
- Missed: didn't receive screen at hospital and couldn't get baby back for screen
- Eq problems: problems with equipment

MN runs higher for initial reported screen, and we breakdown why they haven't had a hearing screen. Some of the "missed" were probably screened but it wasn't reported to us. It is important to note that our overall 'missing' rate continues to decline.

40% of our missing are Out Of Hospital births. As reported previously, this has become much better, but this cohort seems to still have some not participating in screening. Also, MN has a pretty high number of parental births (where the father is listed) and we have no good way of getting these children screened or following up.

Comment (Michael Severson): This is a huge leap to sustain this for the past few years.

REFER rates have gone up slightly from 4.2% to 4.7% due to more education (don't screen until they pass, if they refer there might be a reason). However, this number may change with the updated data as well. Overall we are aiming for a statewide refer rate between 3-4%. REFER rate is the percent of babies screened that did not pass in one or both ears at initial hospital screen. Working with hospitals is ongoing at all times regarding annual refresher training, online videos, or MDH training for screeners. We know there is high turnover for nurses and techs who are doing the screening. We closely monitor hospitals, if their refer rate jumps we check in with them to see why. If the refer rate is too low that could be a problem too.

Many facilities have started using AABR technology in the last 6 months which may help contribute to a refer rate drop.

Q: Any technology changes that can help false positive refer rate.

KC: companies are always improving their algorithms. OAEs and AABR are still used. There are some opportunities coming, but the current technology is amazing. We need competent screeners and help them stay competent.

Rescreen timeline Slide: ~62% of infants with an initial 'refer' result received an outpatient rescreen within 1 month of age (not NICU). Historically it has been hard to get a rescreen within 1 month. We have been working specifically with programs to schedule follow-up appointment before discharge (this is what our Guidelines recommend). Hoping to see a jump in 2016.

Diagnostic timeline Slide: 42.7% (not NICU) are reported to have received a comprehensive audiological evaluation by 3 months of age. Hoping our initiatives will help to improve.

Q: Do we have numbers for scheduled appointments where families failed to show up.?

Yes, we are tracking that.

Confirmed hearing loss Slide: Timeliness of confirmed hearing loss diagnosis from 2010 to 2015. Overall diagnosis is still delayed and there has not been much change in the last 3 years. Still have ~16% that are not diagnosed until 3-6 months and another 28% after 6 months of age. This includes permanent and non-permanent hearing loss. We will continue working to find out why and how to fix this in 2016.

LTF/D Slide: 6.8% of infants with initial 'refer/did not pass' result that have an unknown outcome born in 2015. This percent should go down as we resolve cases from late 2015. At least 50 cases we just referred to local public health in January and February.

Reasons why LTF/D Slide: no audiology apt was scheduled (42.9%). No show

(25.9%), started but discontinued (15.1%). Unknown PCP (12.7%). Working with data sharing agreements within MDH to get updated PCP and hope that this will help decrease the unknown PCP group.

LTF/D by mother's education Slide: 56% of known LTF/D are infants with mother's education of High School/GED or lower.

LTF/D by race slide: Orange bar is race indicated on Birth Certificate. Green bar is race on LTF/D. This clearly shows the need to work with communities and H&. Is there cultural barriers to follow-up? Pilot programs at hospitals serving these communities.

2016 initiatives:

- Continue onboarding birth hospitals and midwifery practices to MNScreen
- Begin piloting audiology reporting into MNScreen
- Evaluate new data and identify process gaps and education needs
- Pilot projects with hospitals/clinics to reduce LTFU and health disparities

Q: What are we doing with refused screenings?

Sensitive number, parents in statue have option to refuse. Some in group believe that this right should not be questioned. Some may want to refuse bloodspot, but not refuse everything. Need to train and educate public as well as provider and nursing staff who can educate parents on concerns. Should be given handouts, but it's hard to make sure that provider is giving them the handouts or that they are engaging with them rather than just putting it in a folder and parents see it (may) when they get home. Fact sheet and infographic (INCLUDE PICTURE OF MATERIALS).

Q: When do they decide to do/refuse screen?

Parents can sign a refusal form when at hospital for delivery or they can bring it with them. Hospitals have to provide education about screening so families can decide to refuse at this time too. Probably not best for education, but logistically it's the best (not everyone gets prenatal education/appts), etc.

MNSCREEN

Demographics come from electronic medical record, and results come directly from the screening device. Data integrity increases. As of February 9, 2016:

- 36 hospitals are completely live (38% of births)
- Working with 31 other hospitals and are in some stage of implementation
- 22 not started yet (breakdown from slides)
- Goal is to have everyone live by end of year.

Meaningful Use: provides incentive to eligible hospital to implement and maintain MNSCREEN (and use electronic medical records)> MN is the first state to declare MNSCREEN (and similar programs) as a specialized registry.

- MNScreen (EHDI and CCHD reporting) is now a Specialized Registry!!!
 - As of 1/4/2016
- Provides incentives to Eligible Hospitals to Implement and Maintain MNScreen
- Eligible Providers (e.g, audiologists!) coming soon!

Providers, this will be eventually come to you end of 2016, start of 2017

Observations:

- Electronic reporting does not solve all problems
 - Serial screening, mis-entry into EMR, etc.
- Target continues to move
 - Timeline, risk factors, return of results to EMR

We are currently working on the ability for results to go to both MDH and also be

	<p>sent directly to the electronic medical record to prevent mis-entry, serial screening, etc. Also first state to do this.</p>
<p>5. Loaner Hearing Aid Program</p> <p>Lion's Program Update Robert Margolis/ Heather Gilbert</p> <p>Website and Discussion Darcia Dierking</p>	<p>Lions Hearing Aid Program</p> <p>In the 90s, there was still opposition to universal NBHS, in MN there wasn't a mandated program, just a few hospitals and providers doing newborn hearing screening.</p> <p>In 1999 the U of M got grant from the Lion's (half million over 5 years) to begin NBHS in hospitals across the state. The program hired Kirsten and she drove around the state training and educating hospitals.. Funding also helped to provide matching grants to hospitals. In early 2000s, Penny Hatcher (MDH), wrote two big grants. One from the US Dept of Maternal Child Health and one from CDC to develop a UNHS program and included some initial funding for a hearing aid loaner program. In 2007 the universal NBHS mandate was passed by MN legislature. Mary Harnett was the hero for this. Funding for the Hearing aid loaner bank was also included in 2007 by the legislature. Some of this activity was transferred to MDH and Kirsten started working for MDH too. A graduate assistant position for this program was created to administer the loaner bank under the direction of an audiologist.</p> <p>HEATHER GILBERT 3rd year Dr of Audiology student is administering the program now.</p> <p>The Loaner program provides hearing aids to newly identified children in MN (some cases from Border States too) at no charge to the family for up to 6 months. This allows families time to figure things out and the child doesn't have to wait for access to language. Some families have limited or no insurance coverage for hearing aids. Some families have deductible needs to be met, so we help fill that gap. The loaner program is able to provide hearing aids as a trial period to families who aren't sure if they will be of benefit. We also provide a lot of loaner hearing aids for children that are Cochlear Implant candidates to use before CI surgery.</p> <p>In order for families to obtain hearing aids through the program, the Audiologist contacts the Lions Loaner Hearing Instrument Program, selects the appropriate hearing aid and provides the fitting.</p> <p>Audiologist sign up through the website, can view inventory, and request hearing aids. (SLIDES)</p> <p>Word of mouth is how audiologists are currently made aware of loaner bank. Presence at conferences may be helping. There were 110 devices loaned in 2015.</p> <p>GOALS: family and audiologist satisfaction- every hearing aid that comes back gets a survey sent to the family, audiologists are surveyed yearly. 100% of respondent indicate satisfaction (4-5 on a scale of 5)!</p> <p>Current inventory: keeping current technology in loaner bank to help with transitions between loaner and permanent aid.</p> <p>INVENTORY MANAGEMENT: getting aids in timely and checking them in timely (and checking function) and putting back into online inventory quickly.</p> <p>DEVLEOP NEW WEBSITE: update website and streamline process for audiologists.</p> <p>Future: barrier to access, insurance and funding, trial periods are required (parents want to try intervention before committing to expense), Outreach (family outreach, D/ HH teachers, Ed Aud?)</p> <p>IDEAS FOR IMPROVEMENT? QUESTIONS?</p> <p>Contact email: Lionsear@umn.edu</p> <p>Q: Does the program continue to get support?</p> <p>HG: work with many manufacturers to get reduced pricing, or work with them to get granted aids through foundations, or to get new products that need review on a trial basis.</p>

	<p>Q: Is hearing covered under health insurance mandate? HG: No, it's usually a separate insurance policy. DARCIA DIERKING: There is a project underway to update the Lions Infant Hearing Instrument Loaner Program website. Audiologists will be testing new site as it is developed to make sure it meets their needs. Planning to launch sometime in 2016, but still waiting on timeline from MN.IT. Infant Loaner Hearing Instrument Program Grant Renewal:</p> <ul style="list-style-type: none"> • Current grant period ends June 30, 2017 • Per state guidelines, will not be sole source in the next grant cycle, necessitating a Request for Proposals (RFP) process • RFP to go out later in 2016, and all eligible entities including the current grantee are encouraged to apply
<p>6. Minnesota CMV Project Mark Schleiss</p>	<p>MARK SCHLEISS: CMV PROJECT cCMV is a DNA herpes virus. If we rely solely on NBHS then we will be missing a lot of babies who might have cCMV progressive hearing loss, which is why we need universal cCMV screening and a robust follow-up program. Why not test for cCMV after there is a problem? Can't be accurately diagnosed in a newborn beyond 14-21 days (they can acquire cCMV after birth due to things like breast feeding). Only cCMV infections acquired before birth lead to hearing loss, after birth seems to have little-no clinical significance. Best way to screen newborns? Bloodspot? Convenient, but possible less sensitive. Urine samples, very sensitive but time consuming, labor intensive and expensive. Mouth swab, appears to be sensitive and specific enough, and does have some false positives (due to breastfeeding, but this is rare in the first 48 hours). Study is currently comparing bloodspot to mouth swab. Follow-up will take place with PCP and Mark Schleiss. Most babies with cCMV will be "normal" - does this fit the classic paradigm of NBS? It's not something that has to be treated immediately. But NBS makes sense. Handouts available. Parallel study: targeted screen, identify infants who have a "Refer/Did Not Pass" after NBHS (urine and saliva, and consent for blood spot). Children's has a questionnaire gauging parent's knowledge and perceptions on cCMV. Mark Schleiss's Lab was awarded the Vikings grant to fund "If you don't pass, screen" \$250,000 grant for community health impact in pediatrics. Legislative advocacy, focus groups, surveys, retreat, etc. Tennessee, Illinois, Texas, Hawaii, Utah all have similar mandated CMV programs. Iowa recently suggested a CMV mandate. There will be a Pediatric Grand Rounds March 9th at UMN on cCMV screening in Utah. Comment (Amy Gaviglio): On a national level NBS programs are concerned about the increase in legislative efforts to mandate conditions to be screened.</p>
<p>7. MDE Update Educational EHDI Team 2016 Plans & Activities</p>	<p>Kathy Anderson provided an update on the Educational EHDI teams and their work. Current membership includes Teachers DHH, Educational Audiologists, ECSE Teachers, Speech-Language Pathologists, an ECSE Coordinator, IEIC representative, and a Part C Service Coordinator. Their purpose is to build Capacity and encourage Evidence-based Practices. The Annual EHDI Teams training was completed Oct, 2015. During this training teams reviewed EHDI system resources</p>

	<p>and developed regional plans for the year.</p> <p>Additional activities that the teams participated in included:</p> <ul style="list-style-type: none"> • Boys Town / MN Low Incidence Projects online course for public school educators • Hearing Screening – OAE Training activities (OAE Training Teams, EHDI Team members)
<p>8. Workgroup Update</p> <p>Medical Guidelines Update Nicole Brown</p> <p>Audiological Guidelines Update Darcia Dierking</p>	<p>Medical guidelines: the second revision is out to the workgroup for review. The workgroup has had discussions regarding things like including specific information about where rescreening can occur, what type of equipment should be used, and specific recommendations when children have OME with effusion. Once the workgroup has all agreed on the guidelines they will be sent out to committee members for review. There will be an opportunity for discussion by the full committee before full committee vote on guidelines.</p> <p>Audiological guidelines:</p> <ul style="list-style-type: none"> • EHDI advisory committee workgroup voted to integrate the 3 audiology guidelines into one combined document (infant diagnostic, pediatric amplification, and referrals). • Workgroup has given preliminary input on scope, level of detail, components to add or delete • New document will be formatted similarly to the Newborn Screening Provider Manual • Workgroup to begin revision of individual sections
<p>9. Closure Joscelyn Martin</p>	<p>Next Advisory Committee Meeting: May 11th, 2016, 1-4pm</p> <p>LOCATION:</p> <p>Amherst H. Wilder Foundation 451 Lexington Pkwy. N Saint Paul, MN 55104</p> <ul style="list-style-type: none"> • National EHDI Meeting in March, look for updates/information at the May 11th Meeting • As always, please notify chair to add any partner updates on the meeting agenda.