MDH Minnesota Department of Health

Newborn Hearing Screening Advisory Committee Meeting Minutes

08/12/2015 1:00-4:00 p.m. Amherst H. Wilder Foundation
451 Lexington Pkwy. N.
Saint Paul, MN 55104

Facilitator: Tina Huang

Recorders: Jessica Cavazos

Attendees: Kathy Anderson, Joan Boddicker, Nicole Brown, Teresa Buck, Mary Cashman-Bakken, Dennis Ceminski, Kirsten Coverstone, Candace Lindow-Davies, John Gournaris, Tina Huang, Joscelyn Martin, Linda Murrans, Gloria Nathanson, Peggy Nelson, Sara Oberg, Lisa Schimmenti,, Geoffrey Service, Kara Tempel

Absent: Karleen Maeurer, Anna Paulson, Emilee Scheid, Michael Severson, Emily Smith-Lundberg, Jay Wyant

AGENDA ITEM	DISCUSSION POINTS/DECISIONS/NEXT STEPS
1. Welcome and Announcements Tina Huang	• Tina Huang convened meeting and entered the motion to approve minutes from May. Linda Murrans moved and Geoff Service seconded. Motion passed. • Committee members received a packet to put into their folder/binder. This includes updated contact sheets and a biography pages. If something is incorrect, please let Kirsten know and they will be updated for the next meeting. You've also received a copy of the EHDI Annual Report, it is currently available online. • Newborn Screening has a booth at the Minnesota State Fair in the HealthFair 11 building, we encourage people to share this with partners, other providers, and patients. • Newborn Screening billboards are now in Greater Minnesota • MDH is partnering with UMN and CDC on cCMV study. IRB met today, approved with some stipulations. Moving forward with year one and talking about year two.
2. EHDI Story: Guided by China National Hands and Voices China Trip Candace Lindow-Davies	**National Hands & Voices China Trip** • Mission: share the latest research and best practice in audiology education and parents support for children who are Deaf and Hard of Hearing. Led by Dr. Christine Yoshinaga-Itano, Professor of Audiology at the University of Colorado Boulder • Included a team of Taiwanese professionals on the trip, American and Chinese Audiologists/ENT. Teamed up with local Chinese team • May 18-June 1, 2015 • Parent support, lots of informational interviews, including a Chinese parent guide from BC Hands & Voices and our own Yaoli Li who wrote a Letter of Introduction to Dr. Bu, chair of China's Newborn Screening Committee • Hearing aid donation ceremony, large donation of hearing aids in Shanghai • National newborn hearing screening forum at provincial people hospital in Nanjing • Tour of Yinchuan Rehab Center and Planning meeting with Yinchuan staff

3. EHDI Story Local Public Health Follow-Up Teresa Buck	• Held clinics at Yinchuan Center – 160 children • Equipment calibration, audiological and medical assessments; hearing aid distribution and fittings; cochlear implant mappings; FM training; teacher and staff training on audiology, speech-language, and education; daily team meetings with Yinchuan Staff; daily parent group. • Most children were severely to profoundly deaf, most with "better" hearing are considered "fine" and aren't seen and rarely receive intervention • Daily parent groups: became a QA parents were eager to learn how they can help their children. • Parent and teacher presentation – 100 participants • Parent to parent support; importance of adult role models; expectation of success; hearing difference not seen as a disability until the system fails the child; communication opportunities and progress in education; resources; parent/child stories • Audiology and speech language seminars – 50 participants latest technologies, research, and best practice's practical advice • Tour of Yinchuan Women and Children's hospital – newborn hearing screening, speech language training, physical therapy • NBS is not universal in China, it's more of a luxury, trying to get that to change. Waiting for government funding to amplify child's hearing can take years, so many parents were worried that their child was developmentally disabled • Next steps: typically the mission visits a new center every other year; suggested returning to Yinchuan to reinforce training; suggested screening and follow-up for children with mild to moderate loss; suggested visual language options for children and families; suggested educating children who are DHH Plus; suggested a larger Chinese Conference on interventions past screening; suggested future collaborations between Taiwan and China; suggested a Chinese delegation visit the US • Exciting new steps: 2 educators, 1 parent, and 1 Chinese translator will attend H&V leadership conference in Sept; Chinese delegation will meet with national cued speech association and also attend join meeting with Russian delegation; Chinese delegation will travel to Colorado to visit education centers, medical facilities, and families representing different choices; hope for awareness of the important role adults who are D/HH to be role models for children and parents • http://guidebychina.tumblr.com
4. D/HH Role Model & Mentor Program Results of the D/HH Adult Role Model Mentoring Needs Assessment Conducted for Lifetrack Beth Quist & Wilder Research	**Results of the D/HH Adult Role Model Mentoring Needs Assessment Conducted for Lifetrack** • Results of the D/HH Adult Role Model Mentoring Needs Assessment Conducted for Lifetrack Beth Quist & Wilder Research • Final report from assessment • Started planning last fall, started data collection in January, final report by June 30 • Project goal: to develop recommendations for a Minnesota specific D/HH adult mentor/role model program that is responsive to the following three JCIH recommendations: •All children who are D/HH and their families have access to support, Mentorship, and guidance from individuals who are D/HH and represent the diversity of the EHDI population (e.g. deaf culture, hard of hearing, cochlear implant and hearing aid users, unilateral hearing loss, auditory neural hearing loss, and cultural diversity.) •Intervention services to teach ASL will be provided by professionals who have native or fluent skills and are trained to teach parents/ families and young children.

	•Individuals who are D/HH will be active participants in the development and implementation of EHDI Systems at the national, state/territory, and local levels; their participation will be an expected and integral component of the EHDI Systems. • Methods: [more in the report] Literature review, web survey of parents who have children who are D/HH, focus groups (parents of children who are D/HH and adults who are D/HH), key informant interviews, 118 parents completed web survey • Parent preference for contact; importance of getting in touch right away after diagnosis, repeated follow-up, variety of methods. • Recommendation: expand outreach and contact points: need for clear branding, lack of awareness of the program among families, program benefits; comprehensive plan for family contact, follow-up, use multiple modes of communication. • Finding: Minnesota's D/HH population diversity and change; population of families with young children who are D/HH in Minnesota is very diverse and constantly changing (culture, race, home language, assistive technology) • Recommendations: Future program evaluation: Lifetrack should expand the current program to meet the ever changing needs of family and develop and implement strategies and process for continually assessing the needs of the target population • Types of program evaluation: • Developmental-for any new program model or component that provides real-time feedback loops to Lifetrack and program participants to help refine the programming. • Process-understand experiences with and satisfaction of mentors, families, and other program partners/stakeholders, and how these experiences are contributing to or hindering positive outcomes for participants. • Outcomes-determines impact on children, families and mentors. Could include assessments of language acquisition, family functioning and communication, academic outcomes, etc. • Recommendation: Mentors- training; matching the diversity of families served; study participants form this Lifetrack needs assessment also indicated a need for the program to recruit and hire more mentors of varying ethnicity, mode of communication, range of hearing loss, and language(s) spoken. Suggest continual training • Lifetrack recently increased their tri-lingual staff • Some participants suggested Teen Mentors [see slides for details] • Next Steps: • Create a communications plan in collaboration with Wilder Research for disseminating the D/HH Assessment Report. • Review recommendations and create a crosswalk between the recommendations and Lifetrack's Guiding Principles. • Create an implementation plan, prioritizing items with a timeline. • Review implementation plan with funders and key stakeholders. • Convene an Advisory Committee to provide feedback and guidance on the implementation plan. • Drafting a plan for communication with Wilder Foundation, will come out soon. • Infographic is being created to visually show the report, blog, news pieces to add to newsletters-lots of different ways to communicate the results of the report

	Review recommendations and create a crosswalk between the recommendations and Lifetrack's Guiding Principles. Create an implementation plan, prioritizing items with a timeline. Review implementation plan with funders and key stakeholders. Convene an Advisory Committee to provide feedback and guidance on the implementation plan.
5. Workgroup Updates Transient Hearing Loss Nicole Brown Guidelines Nicole Brown	**Transient Hearing Loss** • Based on feedback, revised the educational materials and will be tested at audiology clinics. Will continue to follow up with families and parents for understanding and if it helps them come back for appointments • Follow-up process for several different scenarios, ran test cases through processes, and may expand testing to include local public health, try to follow-up with children who are lost to audiology and pediatrics, to bring them back in for appointments Guidelines • Finish revisions by November meeting. If you'd like to join a workgroup please contact us.
6. MDE EHDI Update Kara Temple **MDE Students who are D/HH & Part C Data** Mary Cashman-Bakken & Kathy Anderson	**MDE EHDI Update** • [slides] effort to bridge the gap to help connect families to a variety of services that are already available. Working to increase funding via the legislature. Instead of being under the early learning, it's now in the governor's office under the children's cabinet. [need correct updates to this] looking at how to better align the different councils that are doing parallel work and how to make it more efficient. • Leadership team for Help Me Grow – State staff, community members, to help with guiding Help me Grow, open to the public. 4 subgroups that are working on things to give recommendations to the group. Technical assistance contract with Connecticut Children's hospital ends in October. • Candace: Is United Way part of this? • Kara: United Way was part of the small groups, leadership team is figuring out what role they will be having with Help Me Grow **MDE Students Who Are D/HH & Part C** • Mary Cashman-Bakken: {DHH Legislative Report 2015 is in your packet} • Child count for 2015 is 2,450. This is 14 students less than last year. The all-time high was 2,498 in 2012-2013. Gender = 53% male and 47% female. Most of DHH are white (65% or 1,590). 11% are Asian (279).11% are Hispanic(265) • Graduation State Trends (slides) 76.6% for D/HH students in MN (2014), 84.7% general education, 58.4% special education • Dropout rates (slides): MN 2014 – 2.5% D/HH students, 2.4% general education, 4.2% special education • Post school outcomes. Fed Government requires a survey, 5 questions of parents of students who graduated HS past year. Only have to do 5 pockets, just a small piece of the state D/HH population. This year going to try to survey all D/HH who left high school last year. • Post School Outcome data was only 18 students, not all the D/HH students who graduated last year. These numbers are misleading. (slide) • Transition slide. Survey in March, due back by end of April. Hoping to do this survey annually (to survey all D/HH graduated students in MN)

- Math and reading slides: reading test has changed three times, so it's hard to compare from year to year.
- Sara Oberg: Suggest that the survey include information on the school and school district and the resources that the school has/uses to prepare and motivate students for life after graduation to achieve higher education or employment.
- Strategic Instructional Model (SIM) slide: helping teachers of D/HH students learn new skills for teaching their students the skills they need.
- Recommendations:
  - 1. Continue the work of the MDE Educational Interpreter Performance Assessment Task Force to address interpreter issues and consider possible statutory changes to current interpreter law.
  - 2. Continue collaboration with the MN Collaborative Plan, including the Advisory Committee's interest in the decision making framework used by school districts and educational teams in determining educational placement options for students with hearing loss.
  - 3. Continue representation by an Advisory Committee member on the Olmstead Plan subcabinet.
  - 4. Provide information to families of students with hearing loss regarding transition options and develop a pilot study of the differences and similarities between high school and adult services for students with hearing loss.
  - 5. Continue efforts to raise academic achievement of students with hearing loss in reading by providing teachers with online reading/writing strategies in Strategic Instruction Methods (SIM).
  - Passing rate for interpreter performance assessment is 3%, task force to see why this is

Kathy Anderson: Part C Data

- Number of children exiting Part C Services between 7/1/13 and 6/30/14
  - All children exiting Part C: 2778
  - Children with Hearing Loss exiting Part C: (N=113 children reported)
  - Cognitive Delay = 32 28.32%
  - Typical Cognitive Skills = 81 71.68%
- Types of hearing loss reported
  - Sensorineural 81 71.68%
  - ANSD 6 5.31%
  - Conductive 15 13.27%
  - Mixed 11 9.73%
  - Bilateral/Unilateral Hearing Loss Reported
- Children with hearing loss exiting Part C (N=113)
  - Bilateral 81 71.68%
  - Unilateral Right 17 15.04%
  - Unilateral Left 15 13.27%
- Degree of Hearing Loss Reported
  - Exiting Part C; Bilateral Hearing Loss (N=81) (About 54 demonstrate a sloping hearing loss, with ear specific information reported)
  - Bilateral Slight-Mild: About 29
  - Bilateral Moderate- Moderately Severe: About 30

	• Severe or Profound: About 22 • Number of children fit with hearing aid technology • Children exiting Part C: Fit with Hearing Technology 94 of 113 (83.1%) • Hearing Aids: 71.28% (67) • Cochlear implants: 13.83% (13) • Bone Conduction Aid: 9.57% (9) • HA and CIs: 5.32% (5) • See slides for more information
7. MDH EHDI Updates 2014 Long-Term Follow-up Melinda Marsolek	• Number of children reported is similar to last year (259 permanent, 87 transient) • Over half of children identified in 2014with transient hearing loss through newborn hearing screening have not yet been reported as resolved • Greater reporting of late onset hearing loss (59 in 2014) • 2 out of every 1000 children screened are identified as D/HH • 70% of children have bilateral hearing loss, mild and moderate are the most common • One third of infants were fit with amplification by 1 month of diagnosis • 73% of children were fit within 2 months of diagnosis • Most children see ENT< but over 40% are not referred to genetics and ophthalmology • Close to half of children who declined Part C services are enrolled later on • About 60% of children who enroll in Part C services are enrolled within 2 months of diagnosis • Hands & Voices continues to contact around 90% of families. Close to half of families were contacted by 1 month of diagnosis in 2013 and 2014.
8. Closure TIna Huang	Next Advisory Committee Meeting**: Nov. 4th, 2015 1-4pm** • LOCATION: Amherst H. Wilder Foundation 451 Lexington Pkwy. N Saint Paul, MN 55104 • Notify Chair if there are any Partner Updates to put on the agenda • Adjournment – Candace moved to adjourn, Linda Murrans seconded