Meeting Minutes: EHDI Newborn Hearing Screening Advisory Committee

February 20, 2019

Approved 5/15/2019

Minutes prepared by: Annikka Strong
Location: Amherst H. Wilder Foundation, 451 Lexington Pkwy. N, St. Paul MN 55104

Attendance

Present:

Ingrid Aasan, Renae Allen, Kathy Anderson, Joan Boddicker, Nicole Brown, Kirsten Coverstone, Laura Godfrey, Hannah Herd, Kathryn Lein, Joscelyn Martin, Abby Meyer, Gloria Nathanson, Jessica Novak, Sara Oberg, Emilee Scheid, Sonny Wasilowski, Jay Wyant,

Absent:

Mary Cashman-Bakken, Tina Huang, Colleen Ireland, Nathaniel Meuser-Herr, Anna Paulson, Lisa Schimmenti

Agenda Item Minutes

1:00 Welcome and Announcements

- Nicole Brown and Jay Wyant explained the WebEx instructions.
- Meeting was called to order by Kathy Anderson.
- Kathy Anderson presented meeting minutes from November 7, 2018. The minutes were open for discussion. No comments. Open up for motion to accept. Kirsten Coverstone accepts the minutes. Ingrid Aasan seconded the motion to accept the minutes. All say yes.

Newborn Screening Advisory Committee Liaison Update:

- Emilee Scheid will join the meeting late and we will come back to this update.

1:20 PM Advisory Committee Member's "Story"

Each committee member was asked to share 2-3 minutes of their 'story'. What brought you here? What are you hoping we accomplish this year?

Nicole Brown:
Minnesota Department of Health (MDH) Early Hearing Detection and Intervention (EHDI) Coordinator. MDH Newborn Follow-Up Unit Supervisor. Focus mostly on the point of diagnosis and after, long term follow-up. Two daughters that are deaf. Worked at the Health Department prior and had a passion for this program. Excited for new people on the committee. Hoping to accomplish updating benchmarks.

Kirsten Coverstone:
Minnesota Department of Health (MDH) Early Hearing Detection and Intervention (EHDI) Coordinator. MDH Point of Care Audiologist, Short Term Follow-up. Always enjoyed working with children and families. Making a positive impact on their lives. Hoping to accomplish updating benchmarks and going beyond just 99% screened.

Jay Wyant:
I am deaf. I was raised learning spoken language. Past - President of Alexander Graham Bell promoting early awareness of hearing loss. Common Ground trying to bring together all major stakeholders in deaf education, spoken language, ASL. I would see not only success in early identification, but also communication and collaboration with both the health and education field.

Jessie Novak:
Audiologist at Children's. I am really interested in how to help our clinics become better audiologists all around and help to better serve our patients.

Hannah Herd:
Audiologist at the University of Minnesota Children's Hospital. New to the field. I'm excited to learn from this group and bring information back to my clinic to help other audiologists with their patients and families.

Kathryn Lein:
Hearing advisor, 3 year old son that is deaf.
I am hoping to accomplish – how to learn more about advocating for families, what is in place

Ingrid Aasan:
Director of Special Education at Metro ECSU. Representing regional low incidence facilitators or RLIFs for short. Mother of four daughters, has seen the progression of hearing screening at birth.

Renae Allen:
Public Health Nurse Dakota County.
EHDI follow-up with local public health. Looking to bridge the gap of children that pass their newborn hearing screening and later are diagnosed with hearing loss.

Abby Meyer:
Pediatric Otolaryngologist at Children's. Had a mentor that had a lot of deaf and hard of hearing patients. Worked on a research project with Kirsten and Nicole. I am looking at disparities and trying to address disparities so that children have an equal playing field. I would love to improve our process.

Sonny Wasilowski:
I am from Faribault. I am deaf and have deaf family members. I am part of the deaf community. I am aware of EHDI. I have two children and when they were born in 2008 and 2011 they did not have newborn hearing tests. My children are both hearing. I'm interested in early identification. Making sure they have all kinds of resources. I really like the data part.

Gloria Nathanson:
I represent MADC, Minnesota Association of Deaf Citizens, oldest advocacy group for deaf and hard of hearing. I am an audiologist. I am the mother of four children, two of whom are deaf and two can hear. We are doing a great job at progress with early intervention and making great strides.

Laura Godfrey:
I am the mother of a 16 year old born with a bilateral mild to profound hearing loss. I took a position at MN Hands and Voices and now am the manager. We work closely with the committee and MDH when a child has a confirmed hearing loss. We help families through the journey. I am new to the committee. I was an observer for many years. Looking at disparities and kids at all economic ranges receive help.

Joan Boddicker:
Representative for consumers of cued speech. My daughter is 16 and identified as being deaf. We adopted her when she was 5 months old and we didn't identify the hearing loss until 10 months old. Interested in working with pediatricians with adopted children to see if they are having hearing issues. Make sure we aren't losing kids between identification and then getting connections.

Joscelyn Martin:
Mayo Clinic Rochester Audiologist. Started the program in 1999. This fall our program is 20 years old. I joined this committee to help improve outcomes for families that I work with and for those across the whole state of MN. Looking to improve timeliness at our own clinic and working with others on their projects closer to home.

Sara Oberg:
Speech Language Pathologist. I specialized in aural rehabilitation and have been doing that for 12 years. I am passionate about helping all children reach their full potential by receiving help and resources. I have grandparents that were born hearing and lost all of their hearing in accidents at ages 5 and 14. I have been around people who are deaf and hard of hearing my entire life.

Kathy Anderson:
Trying to help assist this group this year with Laura Godfrey as the chairperson and vice-chairperson. I have been a teacher for deaf and hard of hearing for 40 years. For 10 years doing the statewide EHDI Specialist position and working with now low incidence projects. Member of the regional EHDI teams under the Department of Education since 1998.

2:15 PM EHDI Advisory Committee 101

Handouts –

- Advisory Biographies and contact information.
- Guiding principles that were revised in 2012 – principles that really help guide our work and common beliefs.
- Operating procedures – rules, how we do our work, how many meetings, etc**.**

Legislation

This committee is guided by the legislation that came about in 2007. This legislation really guides our whole EHDI program at MDH. Our legislation includes parent to parent support and the Deaf mentor program and deaf/hard of hearing role models program as well.

Statute 144.966 EHDI Newborn Hearing Screening Advisory Committee

- Nicole Brown - this committee is scheduled to sunset at the end of June this year. Even if this committee sunsets we are committed to continue this group and provide guidance and recommendations to the Department of Health and Department of Education.
- Jay asked if there are changes to language.
- Nicole stated to talk to the commission if you have suggestions or questions.
- Sonny - I know that for some time that this committee has been planning to sunset and I'm wondering if we have really thought about this. What is the impact of changing the advisory committee? I would like to see our advisory committee maybe take a more assertive role. Maybe take other initiatives.
- Kathy Anderson: Today one of the activities on our agenda is really to review what our role is. Discussion about the principles that we have and a little bit about the responsibilities.
- Our vision is really supporting children and families. Our purpose is to provide advice to the Minnesota Department of Health and Department of Education.

Walk through Legislation 144.966

- Mandated newborn hearing screening
- Mandated reporting to MDH
- Added hearing to newborn screening panel
- Required evaluation of program outcomes
- Long-Term Follow-up through 18
- Established Advisory Committee

Purpose of Committee in Statute

- In subdivision 2 – the role of the committee is to develop protocols and guidelines for screening, rescreening, diagnostic assessment, early medical audiological and educational intervention services.
- We also design tracking children birth to 3.
- Providing recommendation to the MDH in designing early intervention and follow-up.
- So each one of you fulfill these roles and go back to who you are representing. Being the liaison.

Statute 144.125: Commissioners duties legislation, birth registration and early hearing detection and intervention legislation.

- Sonny comment: 1. About my two children and that somehow they were overlooked by the screening process and whether children really are screened. Do we have any teeth in our law about requiring screening? Is their consequences if they are not screened? 2. Interested in the educational interventions and description flushing out the statute in specifying educational intervention. If we are to

support the MDH and MDE or any other state agency to see if they are still missing the equation – Should we include the Minnesota State Academy for the Deaf?

National Guidance

Joint Committee on Infant Hearing (JCIH)

JCIH statements: 1971, 1973, 1982, 1994, 2000, 2007

- 2007 statement provides guidance on screening, diagnosis, and interventions
- 2013 supplement provides Principles and Guidelines for Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing
- Three Key Components of EHDI programs Birth Screening before 1 month, Diagnosis before 3 months, Early intervention before 6 months of age.

CDC EHDI Program and Funding = Data System Focus

- CDC EHDI has supported jurisdictions in implementing a broad range of EHDI activities. Nationally, these activities have resulted in over 95% of newborns screened and improved identification of deaf and hard of hearing students. *(Screening data focused)*
- Even with these successes, the capabilities of these EHDI-IS vary and some infants are not documented as having received recommended follow-up diagnostic testing and intervention services. *(Follow-up, Diagnosis, & Intervention data focused)*

HRSA EHDI Program and Funding

GOAL: children are identified through newborn and infant screening and receive evaluation, diagnosis, and appropriate intervention that optimize their language, literacy, and social-emotional development.

- increase health professionals' engagement and knowledge
- improve access to early intervention & language acquisition
- improving family engagement, partnership, and leadership

EHDI Advisory Committee 101 – Purpose (on website) led by Kathy Anderson:

History of beginning and looking at how we can improve, expand to the diversities of families and the discrepancies. Continue to improve tracking, technical assistance to support hospitals, physicians, screeners, public health, etc. Highlight the purpose to focus the group.

Operating procedures and the guiding principles – this group determined this back in 2012. Review and commit ourselves to this. Family focus. We work together in this committee to support.

Accomplishments

- MN guidelines for Hospital screening, out of hospital screening, audiologists, medical professionals, & screening beyond the newborn period.

- Website: EHDI improved website includes:
    - Parts of EHDI – information about the EHDI Advisory Committee, meetings, purpose, annual reports, etc.
    - National Guidelines (JCIH, CDC, HRSA) really guide a lot of our work. In the beginning, we were looking at guidelines and recently we have looked at revising the guidelines.
    - Please explore the website for information.
- Committee recommendations go far beyond guidelines
- Relationships with Other Committees
    - Minnesota Commission of the Deaf, Deafblind, and Hard of Hearing
    - D/HH Collaborative Plan
    - Deaf/Hard of Hearing Advisory Committee
    - Lifetrack, MN Hands and Voices and Deaf Mentor Advisory Committees
    - Others

2:45 – 3:00 Break

Please provide one or two words that come to mind as a focus of our advisory committee for this coming year.

- **Kirsten:** Updated benchmarks
- **Nicole:** Collaboration
- **Joscelyn:** Continued Collaboration
- **Jessie:** Identifying and reducing barriers to follow-up
- **Abby:** The data for long-term outcome – ECLDS Early childhood longitudinal data system. So continuing, expanding, putting information in that.
- **Sara:** As a member of Minnesota speech and language hearing (MNSHA). I will continue to share what we are doing here.
- **Kirsten:** Good reminder to keep in mind to share with your organizations.

3:00pm Overview of MDH's Role in the EHDI Process

Kirsten: we start with electronic reporting from the hospital or birth center. Our data system is called MNScreen. Having an electronic system reduces documentation errors that are often seen with manual reporting. Screening results sent from the hearing screening equipment by the birth facility match to the record in MNScreen electronically. We have a short-term follow-up team at MDH working on follow-up every day. If hearing screening results are missing MDH staff are contacting the hospital. If a family has refused hearing screening we need written documentation. We follow-up on all of the refer results and infants who missed the screen and try to connect with primary care provider so kids don't fall through the cracks.

<u>2017 Data Snapshot</u>

- Statewide screening continues to meet benchmark goals with 99.5% overall screen rate and 97.3% screened by 1 month of age.

- 52.6% of infants with a reported diagnosis have it by three months of age which is the benchmark. The next group within 90 to 180 days 22.7%. Our priority is to improve this timeliness.
- 8% Loss to follow-up/documentation: 238 Infants with no diagnosis – (refer results with no reported diagnosis)
    - Biggest reasons documented
        - Referred by PCP and did not make an audiology appointment.
        - No showed to at least 2 audiology appointments.
- 234 children reported as D/HH in 2017. This is similar to the previous several years.

Nicole: Role in follow-up

Once audiologist report a child with a hearing loss, we work with audiologists to provide information. We work with LPH to connect them to services. Connect them to community resources and family support.

Family Resource Organizer provided to all families

MDH provided nearly a million dollars in grants to support our EHDI system

- LifeTrack for MN Hands and Voices, Deaf mentors, and hard of hearing role model programs.
- Hearing Aid Loaner Program
- Tele-audiology pilot program in Northern MN
- Local Public Health

Goals in the future = expanding follow-up of our audiological management. Connecting data from test scores to services.

3:25pm Demographic Factors Associated with Delayed Identification of Infants who are Deaf or Hard of Hearing in Minnesota, 2012 – 2016 – Dr. Abby Meyer

Dr Meyer, Pediatric ENT at Children's worked with the MN EHDI program to explore data in order to investigate what factors are associated with the delayed identification of hearing loss within a cohort of infants identified as deaf or hard of hearing (DHH). Question: Do disparities exist among DHH children with regards to timeliness of identification of hearing status and if so, what are they?

- Multivariate logistic regression showed that infants identified as DHH with low birthweight, who had public insurance, whose mother had a lower level of education, or whose mother was aged <25 or >34 years were significantly more likely to have delayed identification.

- Three factors were found to be associated with a decreased likelihood of delayed identification of infants who are born DHH:

    – American Sign Language use as the primary language in the home=0.14; 0.008–0.74

    – Having a mother who is Somali=0.29; 0.07–0.97

    – Having a mother who is Hispanic=0.37; 0.16–0.85

Discussion:

- Disparities in timely identification of hearing loss exist among infants who are DHH in Minnesota.
- With delayed identification there might be a delay in initiation of Early Intervention services which has been shown to result in poorer language outcomes in children identified as DHH.
- The information obtained from this study might justify the development of public health initiatives to target these populations.
- Possible initiatives:
    - Partnering with birth and primary care providers to improve messaging about the need for follow-up after newborn hearing screening and improvements in scheduling follow-up appointments for further testing = promising
    - Other possibilities: information in different formats that do not depend upon literacy---online videos, podcasts, etc; strengthen partnerships within public health (LPH, WIC)

Conclusion:

- Socioeconomic factors are well documented determinants of health and in this study, several socioeconomic indicators were associated with increased risk for delayed identification of infants who are born DHH.
- More work is needed to understand the barriers to audiological follow-up for persons with lower socioeconomic status.
- Despite achievements of EHDI programs, disparities exist in timely identification of hearing loss.
- Using this information to develop public health initiatives that target these populations could improve timely identification and enhance outcomes in children who are DHH.

Questions:

Jessie: When looking at low birth weight did you look at corrected age? Abby: We did not use corrected age – we have the data.

Sonny: Where did this info come from? Abby: MDH – entire state.

Ingrid: Is there data to suggest if these were the mother's first baby? Abby: No

Ingrid comment: Region 11 Help me grow does an amazing job of reaching families that are typically very difficult to work with. There charge is to improve early detection and raise public awareness.

Question: was it divided into deaf and deaf plus? Abby: No, it was all together.

Kirsten comment: We are not collecting risk factors in a consistent manner at this time.

Abby comment: Sometimes the plus factors are diagnosed later or identified later.

Question: Why do Somali and Hispanic babies have earlier identifications.

Kirsten: Do they have more resources right away.

Abby comment: I would like to thank Nicole, Kirsten and Melinda. We are doing revisions to be published in the CDC.

3:50pm Closure

Topic/Partner Updates?

Kathy Anderson: Is there something additional any stakeholders would like to add?

Sonny: Deaf Awareness Day – Gloria does EHDI plan to have a booth? Is that something we could do?

Gloria: Yes, Deaf Awareness Day is 4/27/19 at Stillwater High School. Attend as a visitor. Nice opportunity to get the word out.

Kirsten: Laura said, Hands and Voices will have a booth there.

Kathy: EHDI Meeting is coming up in Chicago.

We have a few topics to talk about at upcoming meetings.

Next Meeting

Date: May 15, 2019
Time: 1:00 – 4:00 pm
Location: Amherst H. Wilder Foundation, 451 Lexington Pkwy. N, St. Paul MN 55104
Agenda items: submit proposed agenda items to ehdi@state.mn.us

4 PM Closed/Adjourned.