



Activities of the Newborn Hearing Screening Advisory Committee

REPORT TO THE MINNESOTA LEGISLATURE 2019

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Activities of the Newborn Hearing Screening Advisory Committee

Minnesota Department of Health
Commissioner's Office
625 Robert St. N., PO Box 64975, St. Paul, MN 55164-0975
625-201-4989
www.health.state.mn.us

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Executive Summary

The Minnesota Newborn Hearing Screening Advisory Committee, (hereafter “committee”) was established in 2007 through Minnesota Statute §144.966. The committee is comprised of medical and educational professionals, various community stakeholders, and state agencies and non-profit representatives. It serves as a central source of dialogue, medical and educational recommendations, and oversight for Early Hearing Detection and Intervention (EHDI) activities throughout the state.

The committee provides an essential forum for communication between varied organizations and individuals, which exists in no other setting or capacity. Through the expertise of committee members, the Minnesota EHDI network is able to gather, adapt, and institute system-level advances as they emerge in national discourse. The committee provides the capacity and expertise needed for Minnesota to not only respond to, but also anticipate national trends, in hearing screening and hearing loss interventions.

Clinicians, families, and professionals throughout Minnesota utilize the many guidelines and recommendations produced by the committee. These guidelines inform the procedures and activities of otolaryngologists, educational staff, hearing screeners, the Minnesota Department of Health (MDH), the Minnesota Department of Education (MDE), and others. Input from the committee's experts allows the development of guidelines in a timely fashion. Most importantly, the committee provides a framework within which all stakeholders – most importantly parents of children who are deaf or hard of hearing (D/HH) and adults who are D/HH – can exchange information, and develop policy recommendations and materials, with the goal of better outcomes for Minnesota infants and children.

Background

In May 2007, Minnesota enacted Minnesota Statute §144.966, which mandated reporting of newborn hearing screening results and added hearing loss to the panel of more than 50 rare conditions for which every newborn in Minnesota is offered a screen.

The goal is to provide early hearing detection and intervention in order to maximize linguistic and communicative competence and literacy development for children who are deaf or hard of hearing. Without appropriate opportunities to learn language, these children will fall behind their hearing peers in language, cognition, and social-emotional development. Such delays may result in lower educational and employment achievement levels in adulthood.^{1, 2}

The legislation established an advisory committee to advise and assist the Departments of Health and Education in:

- developing protocols and timelines for screening, rescreening, and diagnostic audiological assessment and early medical, audiological, and educational intervention services for children who are deaf or hard-of-hearing;

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- designing protocols for tracking children from birth through age three that may have passed newborn screening but are at risk for delayed or late onset of permanent hearing loss;
- designing a technical assistance program to support facilities implementing the screening program and facilities conducting rescreening and diagnostic audiological assessment;
- designing implementation and evaluation of a system of follow-up and tracking;
- evaluating program outcomes to increase effectiveness and efficiency and ensure culturally appropriate services for children with a confirmed hearing loss and their families.

In 2013, Minnesota amended §144.966 (subdivision 2(d)) requiring the Commissioner of Health to report to the chairs and ranking minority members of the legislative committees with jurisdiction over health and data privacy on the activities of the Newborn Hearing Screening Advisory Committee that have occurred during the past two years.

Activities of the Newborn Hearing Screening Advisory Committee

Per M.S. §144.966, the Commissioner of Health shall appoint members from various professional, community and parent groups with no less than two of the members being deaf or hard-of-hearing. Currently the Committee consists of 23 members (Appendix B). Of the 23 current members, 5 members identify as D/HH (22%), and 7 members are parents of a child who is D/HH (30%).

The Newborn Hearing Screening Advisory Committee meets quarterly in February, May, August, and November. The full Committee met on eight occasions during fiscal years 2017 and 2018. Meeting attendance varied between 65-95% during this period. On average, 74% of the committee attended.

Each committee meeting opened with a brief presentation from an Early Hearing Detection and Intervention professional or consumer highlighting strengths and weaknesses of the EHDI system. The presentation was paired with a presentation of EHDI data from MDH epidemiologists. MDH data presented included EHDI system outcome measures that focus on screening, early identification, and important interventions for children who are D/HH such as Part C Early Intervention, parent-to-parent support, and amplification (if chosen by the family).

The testimony and data provided set the stage for further agenda-based committee discussion, identification of system gaps and barriers, disparities, and the development of committee priorities.

Recommendations and Protocols Approved by the Newborn Hearing Screening Committee and Adopted by the Minnesota Department of Health

Reflecting on system gaps and opportunities for improvement, the committee recognized the need for and prioritized the development of recommendations and protocols to improve the EHDI system. To improve efficiency, the committee maintained two to three ad hoc sub-committees or work groups, which focused on the development of various protocols for screening, rescreening, diagnostic audiological, medical and educational intervention services for children who are deaf or hard of hearing.

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The committee developed, approved, and recommended the following protocols to the Commissioner of Health during fiscal years 2017-2018. All recommendations were adopted by the Minnesota Department of Health.

- Medical Guidelines were updated, providing recommended protocols for medical home providers for a standardized approach to hearing screening, diagnosis and care for infants and young children who are deaf or hard of hearing. *Guidelines for Primary Care and Medical Home Providers* <http://improveehdi.org/MN/library/files/medicalguidelines.pdf>
- Revised *Guidelines for Hearing Screening After the Newborn Period to Kindergarten Age* <http://www.improveehdi.org/mn/library/files/afternewbornperiodguidelines.pdf> Providing best practice guidelines for screening children between the post-newborn period to kindergarten-entry for hearing loss.
- Revision of the *Newborn Hearing Screening Committee Bylaws/Operating Procedures*. Providing rules to direct the operations of the Newborn Hearing Screening Advisory Committee. <http://improveehdi.org/MN/library/files/EHDIBylaws.pdf>
- Audiology Assessment Guidelines were updated, providing recommended protocols for early diagnosis of hearing loss in infants who do not pass their newborn hearing screening for a more standardized approach to follow-up hearing care to ensure consistency in outcomes. *Guidelines for Infant Audiologic Assessment* <http://improveehdi.org/MN/library/files/infantaudassessmentguidelines.pdf>

Committee members have also begun work to review and revise the following documents:

- 2008 Guidelines for Pediatric Amplification
- 2009 Guidelines for Audiologist Referral to Early Intervention & Family to Family Support

Quality Improvement Initiatives

The EHDi program continually works to improve the EHDi system and looks to reportable benchmarks each year to determine areas of improvement. Committee members participated on workgroups and provided guidance to stakeholders throughout the EHDi System. In particular, Committee members analyzed issues and provided guidance to MDH regarding:

- The reduction of disparities for loss to follow-up after not passing newborn hearing screening
- Improving timeliness of diagnosis
- Education, training, and use of screening related to Congenital Cytomegalovirus
- The development, implementation, and recommendations from the D/HH Adult Role Model Mentoring Needs Assessment conducted by Wilder Research
- Deaf and hard of hearing teacher training program at U of M
- The improvement in MDH follow-up protocols and educational materials for children with hearing loss that is presumed transient

- The improvement in MDH follow-up protocols and educational materials for children with permanent hearing loss

Conclusion

The care and education of children who are deaf or hard of hearing motivate the members of the committee to advance Minnesota's EHDI system. Adults who are deaf or hard of hearing and the parents of children with hearing loss join together with professionals from all points in the network of care to realize the best possible outcomes for these children. The knowledge and experience that committee members bring allows the committee to guide MDH and MDE policies, so that families of children who are deaf or hard of hearing can reach better outcomes.

Committee activities are important to the continued functioning of Minnesota's EHDI program. This work includes the sharing of valuable knowledge and experience to MDH and MDE staff, and providing technical expertise and assistance in the development of best practice recommendations and protocols.

Bibliography

1. Honeycutt, A. et al. (2004). Economic costs associated with mental retardation, cerebral palsy, hearing loss, and vision impairment. *Morbidity and Mortality Weekly Report*. Retrieved April 27, 2006, from Centers for Disease Control and Prevention, <https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5303a4.htm>
2. Mohr, P. et al. (2000). The societal costs of severe to profound hearing loss in the United States. *International Journal of Technology Assessment in Health Care*, 16(4), 1120-1135.

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Ingrid Aasan has worked in the field of special education for over 26 years. She is the Director of Special Education at Metro Educational Cooperative Service Unit (ECSU.) As such, she directs the Minnesota Low Incidence Projects (MN LIP) and is the Regional Low Incidence Facilitator (RLIF) for Region 11 (metro area.) As part of her work with the MN LIP, she supervises the Statewide EHDI Specialist, the Statewide DeafBlind Specialist and the staff of the Minnesota DeafBlind Project. She also works in collaboration with the Minnesota Department of Education DHH State Specialist on many state initiatives and projects.

A Department of Education regional low-incidence facilitator representative

Renaë Allen has worked in the field of maternal child health for her entire nursing career. For 20 years she provided nursing home visiting services for families who had children with special health needs. As a local public health EHDI team member since 2015 she provides individualized care based on the family's needs. She enjoys interacting with parents to provide EHDI follow-up support & connection to community resources. Renaë also participated in the MDH pilot project to create a plan of care based on the Omaha system, which was implemented for statewide EHDI follow-up.

A representative from the early hearing detection and intervention teams

Kathy Anderson currently works as the Statewide EHDI Specialist under the MN Low Incidence Projects in addition to providing early intervention services to children with hearing loss and their families through Intermediate District 287. Together with the MN Department of Education Part C Coordinator and MDE State Deaf/Hard of Hard of Hearing Specialist, Kathy provides support, information resources, and staff development activities for early intervention programs and professionals statewide. She has worked with young Minnesota children with hearing loss and their families through the public school system for 35 years as a Teacher Deaf, Hard of Hearing, Speech Language Pathologist and LSL Certified Auditory Verbal Therapist. Kathy has been a member/leader of MN's Regional EHDI Team(s) since 1999 and also participated in the MN Centers of Excellence Cultural and Linguistic Diversity (CLD) Master Cadre training initiative.

A Department of Education regional low-incidence facilitator representative

Joan Boddicker is the parent of a child who was diagnosed as being deaf at 10 months and received her first cochlear implant at 18 months. The difficulties arising from the late diagnosis were compounded by her daughter's additional learning disabilities. Believing that literacy was going to be her daughter's main challenge, Joan and her husband researched multiple communication methods before deciding to use Cued Speech. She is a strong

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advocate of early hearing loss detection and supports intervention to assist families in assessing the communication options available. Joan joined the board of the Cued Speech Association of Minnesota in 2004 and is a member of Lifetrack's Deaf/Hard of Hearing Mentor Family Program Advisory Committee.

A consumer from an organization representing cued speech communication options

Nicole Brown is a certified pediatric nurse practitioner and has worked in Minnesota's Maternal and Child Health/Public Health field for over 20 years at both the state and local level. She has coordinated the Maternal Child Health Bureau's Universal Newborn Hearing Screening and Intervention grant at the Minnesota Department of Health since 2005. She is the supervisor of the Newborn Child Follow-up Unit within the Children and Youth with Special Health Needs Section at MDH and is the EHDI Follow-up Coordinator, facilitating ongoing supports and services for infants and children with hearing loss and their families. Nicole is also the parent of two daughters who are deaf.

A Department of Health early hearing detection and intervention coordinator

Mary Cashman-Bakken has been involved in EHDI since she started her current job in 1992. At that time she worked with an informal group and feels MN has come a long way since then. Minnesota now has mandated screening, reporting and Regional EHDI teams but there still is much to do! Mary loves the way many people from inside and outside have come together to make this work. Early Hearing Detection and Intervention continues to be one of the highlights of her job.

A representative from the Dept of Education Resource Center for the Deaf and Hard of Hearing

Kirsten Coverstone is an audiologist with many years of service dedicated to early hearing detection and intervention. She grew up in southern Minnesota, earned her masters degree from the Univ. of Northern Iowa and her doctorate from Salus University. Kirsten has actively worked at the local state and national levels to promote universal newborn screening for hearing. As coordinator of the Lions Infant Hearing Program at the University of Minnesota she worked directly with hospitals to establish effective hearing screening programs and audiologists to confirm hearing loss. In addition, Kirsten implemented a statewide hearing instrument loaner program for infants and young children in Minnesota. She is dedicated to making a difference in the lives of children and their families as the MDH EHDI Screening Program Coordinator.

A Department of Health early hearing detection and intervention coordinator

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Laura Godfrey is the mother of xxxxx She directs services at MN Hands & Voices at Lifetrack. The primary focus of MN Hands & Voices is to provide support and unbiased information by trained Parent Guides to families just learning their child is deaf or hard of hearing, as well as supporting families with children of all ages.

A parent with a child with hearing loss, representing a parent organization

Hannah Herd is a pediatric audiologist at the Lions Children's Hearing and ENT clinic at the University of Minnesota Masonic Children's Hospital. She provides audiological services including auditory brainstem response testing, behavioral audiometric testing, and treatment with hearing aids and cochlear implants. She knows firsthand the importance of working as a team to support families through the diagnostic process. Hannah has always had a passion for working with children and feels fortunate to be working in a pediatric setting that allows her to collaborate and engage with patients and families applying evidenced based practices to improve outcomes of children with various degrees and etiologies of hearing loss.

Audiologist with experience in evaluation and intervention of infants and young children

Tina Huang works as a neurotologist at the University of Minnesota, and often treats children with hearing loss. She is also part of the Lions' efforts to provide care to those children identified with hearing loss during newborn screening. Additionally, at least half of the cochlear implant patients in her fellowship in New York were children. These experiences have impressed upon Dr. Huang the importance of newborn screening and early identification of hearing loss.

An otolaryngologist

Colleen Ireland is a pediatric audiologist at the Mayo Clinic Health System in Mankato. She grew up in a rural community and did her doctorate schooling in Madison, WI. She is the coordinator of the newborn hearing screening program at Mayo Clinic Health System-Southwest Minnesota since 2015. This includes training technicians on inpatient screenings, meeting with pediatric physicians, and giving lectures on the importance of screening newborns, especially those that were home-birtherd. She developed an interest in pediatric audiology while fulfilling her externship year through Mayo Clinic. In addition to newborn hearing screening, she is passionate Auditory Brainstem Response testing and cochlear implants.

A birth hospital representative from a rural hospital

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Kathryn Lein is a parent of a child with hearing loss as well as a school Speech-Language Pathologist. As a child with hearing loss herself she had to learn how to advocate and cope with the hearing loss so that she could do her best. Kathryn has a passion for working with people and advocating for their needs.

A speech-language pathologist with experience in evaluation and intervention of infants and young children

Joscelyn Martin is a pediatric audiologist at the Mayo Clinic in Rochester. She developed an interest in pediatric audiology while serving as a faculty member and preceptor at Northwestern University in the late 1990s. She has been coordinator of the newborn hearing screening program at Mayo Clinic since its inception in 1999. In addition to newborn hearing screening, she is passionate about child and family centered counseling, and the positive effect that it has on the diagnostic and re/habilitative process for the families with whom she works.

Audiologist with experience in evaluation and intervention of infants and young children

Abby Meyer is a pediatric otolaryngologist with Children's Hospitals and Clinics of Minnesota. She also serves in a leadership role at Children's as the Associate Medical Director of Audiology Services. She completed residency training in otolaryngology-head and neck surgery at the University of Minnesota followed by a fellowship in pediatric otolaryngology at Seattle Children's Hospital and the University of Washington in Seattle, Washington. In her practice at Children's Minnesota, she cares for many children with hearing loss and other ear-related conditions including performing cochlear implant surgery. She has a special interest in improving the evaluation and management of infants and children with hearing loss.

An otolaryngologist

Nathaniel Muesser-Herr is a pediatrician with Hennepin Healthcare where he teaches and supervises newborn care in their birth center. He has a background in ASL from undergraduate studies and he received his medical degree from SUNY Upstate in Syracuse, NY where he was an advocate for Deaf access in healthcare. He completed his pediatric residency at the University of Minnesota and focuses on primary care practice on supporting children previously cared for in the NICU and also children or families who are Deaf or hard of hearing.

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Gloria Nathanson is a Deaf audiologist and a parent of four children, two of them Deaf. She obtained her self-directed B.S. degree in Language Development with Emphasis on Those with Hearing Loss from University of Minnesota and doctorate of audiology (Au.D) from Gallaudet University. She is an adjunct faculty member at Gallaudet and Associate Professor at St. Catherine University. Her passion for teaching and advocacy is reflected in her long-term goals of continuing to work with the state's EHDI and promoting more culturally sensitive practices in the general field of audiology. She also supports families as a mentor through Life Track's Deaf Mentor Family Program.

A representative of a consumer organization representing culturally Deaf persons

Jessica Novak is a Lead pediatric audiologist at Children's Hospitals and Clinics of Minnesota. Her areas of expertise include comprehensive diagnostic hearing evaluations for children of all ages, fitting and management of amplification, as well as audiology system protocols and procedures. She provides supervision to audiology students, gives presentations locally and nationally, and collaborates frequently with the Department of Health.

An audiologist with experience in evaluation and intervention of infants and young children

Sara Oberg is a certified speech-language pathologist at Regions Hospital and for over nine years at the University of Minnesota Medical Center, Fairview. She is specialized in evaluating and providing aural rehabilitation and speech–language therapy to children and adults who are deaf or hard of hearing and have hearing aids and/or cochlear implants. She is further specialized in voice disorders and provides evaluations, laryngeal exams (with videoendoscopy and videostroboscopy), and therapy for individuals with voice disorders. She previously conducted evaluations and provided therapy for individuals who have had traumatic brain injuries, strokes, and dysphagia. The majority of her time is spent giving aural rehabilitation and speech–language therapy at Regions Hospital. She received her bachelor's degrees in Vocal Performance and Music Education (grades K-12) and master's degree in Speech-Language-Hearing Sciences from the University of Minnesota. Sara has also earned a Certificate in Vocology from the National Center for Voice and Speech in Denver, Colorado, through the University of Iowa as well as a Certificate in Vocal Pedagogy from the University of Minnesota. For over five years she evaluated children to see if they were cochlear implant candidates for the Lions Children's Hearing Center. In 2011, Sara started and continues to lead as a volunteer an Adult Cochlear Implant Social Group, because many individuals expressed feeling isolated and/or the desire to connect with others who have hearing loss or have lost their hearing and have received a cochlear implant. Sara has personally been involved with the Deaf community since she was born, because her grandparents had accidents and lost their hearing at ages 5 and 14. She considers herself

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proficient, but not fluent in American Sign Language. Sara has been immersed in the Deaf culture her entire life and is very passionate about this community and making a positive difference in helping all of them reach their full potential.

A speech-language pathologist with experience in evaluation and intervention of infants and young children

Anna R. Paulson is the Coordinator of Educational Advancements and Partnerships with the Commission for Deaf, Deaf Blind and Hard of Hearing Minnesotans. Anna's role within the commission is to coordinate the priorities and initiatives of the fifty stakeholders who participate in the Minnesota Collaborative Plan. The purpose of the Collaborative Plan is to improve educational outcomes so that each student, upon graduation, is prepared to enter the adult workforce or continue his/her education and be a productive member of the community. Prior to joining the commission, Anna was an Educational Specialist at the University of Minnesota; Department of Educational Psychology in the teacher preparation program for deaf/hard of hearing education. Anna has been involved in Part C and the EHDI system since its inception and is passionate about the collaborative work necessary to further advance EHDI for children and families.

Minnesota Commission Serving Deaf and Hard of Hearing People representative

Emilee Scheid is a Physician Assistant-Certified and has worked in Family Medicine for 10 years. She also has experience in NICU and Pediatrics both as a PA-C and EMT-B. In addition to her professional experience, she is a parent of 8 year old Elizabeth who has moderate-severe bilateral sensorineural hearing loss. She personally has experience with the healthcare system, school system and local resources that have helped her child grow. She is a strong advocate in Family Medicine to guide the providers to educate and promote follow up for the newborn hearing screen.

A primary care provider with experience in the care of infants and young children

Lisa A. Schimmenti is a Professor of Pediatrics and Senior Associate Consultant in the Departments of Otorhinolaryngology and Clinical Genomics at the Mayo Clinic. Dr. Schimmenti received her undergraduate degree from Johns Hopkins University in Baltimore, Maryland. She received her medical degree from Albert Einstein College of Medicine in New York. She completed her pediatric residency at Harbor-UCLA Medical Center, Torrance, California and her fellowship in Genetics and Metabolism at the University of Minnesota. She provides genetic services for children and adults with hearing loss and other genetic conditions. Dr. Schimmenti conducts research in understanding the genetic basis of

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hearing and vision loss. Her research efforts have been funded by the National Institutes of Health and the March of Dimes.

A pediatric geneticist

Sonny Wasilowski is treasure of the Faribault Deaf Club. He attended Minnesota State University and Gallaudet University. Sonny worked closely with the Commission Serving Deaf/Deaf-Blind/Hard of Hearing Minnesotans for universal newborn hearing screening legislation in Minnesota. Sonny is currently an account executive at Communication Service for the Deaf in Faribault, MN.

A representative of a consumer organization representing culturally Deaf persons

Jay Wyant is a past president of the board of the Alexander Graham Bell Association for the Deaf and Hard of Hearing (AG Bell), Northern Voices, and the Hearing Society, a non-profit audiology clinic. For over a decade, he wrote a monthly technology column for AG Bell's national magazine, *Volta Voices*. Passionate about accessibility and maximizing opportunities for people with disabilities, Jay has presented on self-advocacy and communications technology, among other topics. Since 2012, Jay has served as the State's first Chief Information Accessibility Officer, or CIAO! Profoundly deaf since birth, Wyant was mainstreamed in first grade and wishes CART had been around when he was in college.

A consumer from an organization representing oral communication options