Activities of the Newborn Hearing Screening Advisory Committee

REPORT TO THE MINNESOTA LEGISLATURE 2017

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MDH Minnesota Department *of* Health
NEWBORN SCREENING PROGRAM

Activities of the Newborn Hearing Screening Advisory Committee

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Executive Summary

The Minnesota Newborn Hearing Screening Advisory Committee, (hereafter "committee") was established in 2007 through Minnesota Statute**s**, Section 144.966. The committee is comprised of medical and educational professionals, various community stakeholders, and state 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.

The many guidelines and recommendations produced by the committee are utilized by clinicians, families, and professionals throughout Minnesota. 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 who are deaf or hard of hearing.

Background

In May 2007, Minnesota enacted Minnesota Statutes, Section 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 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;
- 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 section 144.966,subdivision 2, 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 Minnesota Statutes, section 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 22 members (Appendix B). Of the 22 current members, 5 members identify as D/HH (23 percent), and 5 members are parents of children who are D/HH (23 percent).

The Newborn Hearing Screening Advisory Committee meets quarterly in February, May, August, and November. During fiscal years 2015 and 2016, the full Committee met on eight occasions with 74% of members in attendance over that time period.

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, 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.

The committee developed, approved, and recommended the following protocols to the Commissioner of Health during fiscal years 2015-2016. All recommendations were adopted by the Minnesota Department of Health.

- The EHDI program's core Neonatal Intensive Care Unit (NICU) Nursery Screening Guidelines were updated, providing recommended protocols for newborn hearing screening in the neonatal intensive care nursery. *Guidelines for the Organization and Administration of Universal Newborn Hearing Screening Programs in the NICU Nursery* http://www.improveehdi.org/mn/library/files/nicuguidelines.pdf
- Revision of Early Hearing Detection and Intervention (EHDI) Program Goals, Indicators, and Benchmarks: "The measures described in this document are based on the National Goals, Program Objectives, and Performance Measures for the Early Hearing Detection and Intervention Tracking and Surveillance System from the CDC. They are intended to be used to evaluate progress toward goals accepted by the Minnesota Newborn Hearing Screening Advisory Committee. Indicators are to be assessed annually for children reported to the Newborn Screening Program between January and December of each calendar year. Results are reported in the EHDI Annual Report."
  See Appendix D: 2015 EHDI Annual Report

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

- 2007 Early Hearing Detection and Intervention Guidelines for Medical Providers
- 2007 Guidelines for Pediatric Amplification
- 2007 Guidelines for Infant Audiologic Assessment

Quality Improvement Initiatives

In 2015, the committee focused on Results Based Accountability (RBA) measures to improve Minnesota's Early Hearing Detection and Intervention system. The goal of using RBA measures is data-driven decision-making. This tool is currently in use to critically examine the quantity and quality of the services provided to customers, as well as the impacts and effects of those activities.

The six measures 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). See Appendix D for detailed information about each of these RBA measures and performance indicators.

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
- The implementation of pilot testing for congenital Cytomegalovirus
- The development, implementation, and recommendations from the D/HH Adult Role Model Mentoring Needs Assessment conducted by Wilder Research
- 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

See Appendices C and D for more information

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 a 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 allow 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*. Retried 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.