DEPARTMENT OF HEALTH

EARLY HEARING DETECTION AND INTERVENTION

GUIDELINES FOR REFERRAL TO EARLY INTERVENTION, MEDICAL SPECIALTIES AND CONNECTION TO PARENT-TO-PARENT SUPPORT

Section 2 of the Early Hearing Detection and Intervention (EHDI) Guidelines for Audiologists

Last Revision Approved: November 2018

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Newborn Screening Program 651-201-5466
www.health.state.mn.us/newbornscreening
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Introduction

This document provides recommendations for audiologists as they proceed with referrals to follow-up care and other medical specialists for infants and young children who are newly identified with permanent/persistent hearing loss. Early intervention is critical in providing children early access to language.

Respect for Identities Statement

Minnesota Department of Health (MDH) recognizes that everyone has their own unique identity, and we respect the terms people want to use to identify themselves. People may self-identify as deaf, deafblind, hard of hearing, a person with hearing loss, Deaf Plus, a person with a hearing difference, Deaf Disabled, etc.

When referring to this population, MDH may use "deaf, deafblind, and hard of hearing (DHH/DB)," in an all-inclusive manner. The term "hearing loss" may be used when talking about a medical diagnosis.

Background

An important goal of early intervention is to support the development of infants and toddlers within their families and communities. Early intervention supports families in helping their child with language development, communicating, moving, interacting, and thinking. Early access to comprehensive

information and resources helps families make decisions about communication opportunities, health, and education for their child that is right for them. For additional information on communication opportunities and access to language see Exploring Communication Opportunities.[1] As indicated in the Joint Committee on Infant Hearing (JCIH) 2019 Position Statement, studies have shown that if hearing levels outside the typical range are identified before 3 months of age and early intervention is initiated by 6 months of age, infants and children can be expected to achieve developmental milestones and reach their full potential.[2] Children who receive intervention very early in their critical language learning years are more likely to have language scores that more closely match their cognitive abilities (Yoshinaga-Itano, et al., 1998).

Guideline for Audiologist Referrals

Following identification of hearing loss, the audiologist plays a critical role in making referrals to early intervention, connecting families to parent-to-parent support and other resources, and discussing medical specialist evaluations.

The following print resources are provided free to audiologists by MDH. The resources support audiologists and professionals in counseling families regarding referrals. Audiologists can use the Early Hearing Detection and Intervention (EHDI) Free Resources Order Form[3] to order the following resources:

- Early Hearing Detection and Intervention: A step-by-step road map for families and caregivers brochure.[4] This brochure contains contact information and explanations of various resources and is available in English, Hmong, Somali, and Spanish on the MDH EHDI Resources for Families webpage.[5]
- Hearing Loss in One Ear: Information for families and caregivers brochure.[6] This brochure has information and resources for parents/caregivers of a child with unilateral hearing loss and is available in English, Hmong, Somali, and Spanish on the MDH EHDI Resources for Families webpage.[5]
- The Beginnings Book: Understanding Your Child's Hearing Loss: A Guide for Parents. This book is available in English and Spanish. MDH provides the Beginnings Book free of charge to audiology clinics to hand out to families at the time of diagnosis. The English version includes additional Minnesota specific information.

MDH also provides online resources:

- MDH EHDI website[7]
  - MDH EHDI Pediatric Audiology[8]
- MDH Early Hearing Detection and Intervention: Information for Families and Caregivers parent resources binder[9] (also available in print; see Selected Links to access electronic binder in Hmong, Somali, and Spanish).
- MDH Newborn Screening[10]
- MDH Children and Youth with Special Health Needs[11]

Referring children for early intervention or educational services

Early intervention (birth through 2 years of age)

The Federal Individuals with Disabilities Education Act (IDEA) Part C Referral Procedures[12] requires all medical professionals to refer every infant and toddler (birth through 2 years of age) who has a condition that has a high probability of resulting in developmental delay or disability to their state's Part C Infant and Toddler Intervention as soon as possible, but no later than seven days after a concern or delay is noted. In Minnesota, these services are provided FREE to every eligible child and family through the local school districts and cooperatives. Once a referral is made, the school district will contact the family to discuss possible next steps. It is the responsibility of the school district to work with the family in determining eligibility for Part C early intervention services.

Special Education for children 3 years and older

Clinical audiologists should refer children with a hearing loss, knowing that the school district will determine eligibility based on a number of factors.

Once a referral is made, the school district will contact the family to discuss possible next steps. Children with hearing loss who are older than 3 years will be evaluated by their school district or cooperative to determine eligibility for educational services based on Minnesota Statute 3525.1331.[13]

How to Refer

All young children with hearing loss from birth up to starting kindergarten should be referred through Help Me Grow Minnesota[14] or through a direct local referral to the child's school district or cooperative as soon as the hearing loss is identified.

- Online: Refer a Child (https://helpmegrowmn.org/HMG/Refer/index.html)[15]
  - The forms are available in English, Hmong, Somali, and Spanish.
- By phone: Call Help Me Grow at 1-866-693-GROW (4769). Interpreters are available.
- Contact the child's local school district. You may need to speak to someone in the school district's Early Childhood Services, Special Education Services, or Audiology Services. See MN Educational Audiologists[16] for a list of educational audiologists and their contact information.

Referrals through Help Me Grow Minnesota made without consent of a parent/guardian may include only the required contact information. Refer to the Help Me Grow Minnesota Professionals form for additional information.[17] With parent/guardian consent, check all applicable boxes in "Reasons for Referral." The following information may also be included in the text box that appears when "Medical Diagnosis" is selected:

- The type and degree of permanent bilateral or unilateral hearing loss (sensorineural, neural, conductive, or mixed hearing loss).
- Any persistent or chronic conductive hearing loss (including hearing loss due to effusion).
- Any other medical conditions (example: congenital cytomegalovirus) that have a high probability of resulting in developmental delay or disability.

See Sharing Child Information to Coordinate Early Childhood Special Education (ECSE) Referrals[18] for additional information on parental consent. **Although not required for referral, clinical audiologists often find it useful to have a family sign a release of information to the school district, to expedite the sharing or records the school will need following the referral.**

The referrals go automatically to the school district or cooperatives based on the child's address entered on the referral form. Someone from the school's early intervention program will contact the family, usually within 7-10 days. To contact a school directly, use Polling Place Finder[19] from the Secretary of State website to locate the child's school district/cooperative, then visit Schools and Organizations (MDE-ORG)[20] on the Minnesota Department of Education website to find the appropriate contact. The school district should reach out to the clinical audiologist for records, as part of their process when families choose to move to the next steps. View the "first steps after identifying a child who is deaf, deafblind, or hard of hearing" video[21] for more information.

For additional resources, see Minnesota Low Incidence Projects EHDI Information Packet for Clinical Audiologists.[22]

Schools and programs serving children who are DHH/DB

In addition to free early intervention and public special education services mentioned above, there are a broad range of schools and programs available for children, some of which may be private and incur a fee. For a comprehensive list that audiologists could share with families, see Educational Resources, Schools, and Programs[23] from Department of Human Services Deaf, DeafBlind, and Hard of Hearing State Services.

Connection to Deaf, DeafBlind, and Hard of Hearing outreach services

The following organizations receive grant support from the Minnesota Departments of Health, Human Services, and Education.

Minnesota Hands & Voices

Following identification of permanent hearing loss and with the family's permission, audiologists should directly connect the family to Minnesota Hands & Voices (MNH&V), a statewide program with trained Parent Guides who will contact the family.

Audiologists making a direct referral to MNH&V will expedite support for parents during a potentially challenging time. MNH&V staff are trained Parent Guides who themselves are parents of children who are deaf and hard of hearing. They provide emotional support for parents from the perspective of someone who knows the joys and challenges of raising a child who is deaf or hard of hearing, knows how to navigate, access, and explain the importance of follow-up services, and can provide valuable connections to community resources. Evidence shows that parent-to-parent support is "necessary and adjunctive to professional services" (Henderson et al., 2014) and family-to-family support is specifically recommended by the Joint Committee on Infant Hearing (2013 and 2019).

MNH&V offers educational workshops and family networking events as well as a periodic newsletter, weekly communication about community events and organizations, family-to-family connections, and links to resources.

To connect:

- Online: Visit Minnesota Hands & Voices (www.lssmn.org/MNhandsandvoices)[24] and choose "Refer a Family."
- Phone: Call 651-265-2435

Deaf and Hard of Hearing Guide Program (through MNH&V)

Families and children who are deaf or hard of hearing are introduced to Deaf and hard of hearing Adult Role Models from the deaf or hard of hearing community who use a variety of communication modalities and are able to share a vast array of lived experiences. Parents have opportunities to address practical questions in casual personal settings at home, at school, or at a community event. Families can visit the Deaf and Hard of Hearing Guide Program website[25] to learn more.

To connect:

- Online: Contact MNH&V via their website.[24]
- Phone: Call 651-265-2435

Deaf Mentor Family Program

This program provides a trained Deaf mentor to work closely with families to facilitate early learning of American Sign Language (ASL), early visual communication, Deaf Culture, and Deaf History, using a research-based curriculum and flexibly scheduled home visits. Families have the opportunity to ask questions and learn directly from their Deaf Mentor, helping build understanding, connection, and confidence on their journey. The presence of a Deaf adult as a language and cultural role model has been shown to significantly improve child language

outcomes in deaf and hard of hearing children and improve parent confidence (Watkins et al., 1998). Families can visit the Lutheran Social Services of Minnesota Deaf Mentor Family Program website[26] to learn more.

To connect:

- Families can contact DMFS@lssmn.org.

Connection to Minnesota DeafBlind Project

The Minnesota DeafBlind Project provides technical assistance to families, education teams, and service providers to support children (birth-21 years) who have a combined vision and hearing loss or are highly suspected of having both vision and hearing losses. Mild losses may qualify. Services are in addition to those provided by schools and other state and local agencies. Families can visit the Minnesota DeafBlind Project website[27] to learn more.

To connect:

- Online: Families can register their child at Register Your Child (https://www.dbproject.mn.org/registerChild.html)
- Phone: Call 612-638-1531 (toll free 800-848-4905)

Recommendation for medical specialist evaluations

The JCIH (2019) recommends that children with permanent hearing loss:

- Be evaluated by an otolaryngologist who has knowledge of pediatric hearing loss.
- Have at least one examination to assess visual acuity by an ophthalmologist who is experienced in evaluating infants.
- Be offered a genetics consultation.

Audiologists can help families understand the importance of these evaluations and communicate with primary care providers and otolaryngologists to facilitate making these referrals. Audiologists should consider additional referral to a speech-language pathologist, an expert in language development, in a clinic setting as well as what might be provided by the local school program. Cost varies by clinic and insurance programs.

Selected Links

[1] Exploring Communication Opportunities, Minnesota Low Incidence Projects https://mnlowincidenceprojects.org/Projects/ehdi/ehdiCommunicationOpp.html

[2] Joint Committee on Infant Hearing (JCIH) Year 2019 Position Statement https://digitalcommons.usu.edu/jehdi/vol4/iss2/1/

[3] MDH Early Detection and Intervention Free Resources Order Form https://survey.vovici.com/se/56206EE35D330692

[4] MDH Early Detection and Intervention: A Step-by-Step Road Map for Families and Caregivers (English) https://www.health.state.mn.us/docs/people/childrenyouth/improveehdi/roadmap-eng.pdf

- Hmong: https://www.health.state.mn.us/docs/people/childrenyouth/improveehdi/roadmap-hmg.pdf
- Somali: https://www.health.state.mn.us/docs/people/childrenyouth/improveehdi/roadmap-som.pdf
- Spanish: https://www.health.state.mn.us/docs/people/childrenyouth/improveehdi/roadmap-spa.pdf

[5] MDH EHDI Resources for Families https://www.health.state.mn.us/people/childrenyouth/improveehdi/resources.html

[6] MDH Hearing Loss in One Ear: Information for Families and Caregivers (English) https://www.health.state.mn.us/people/childrenyouth/improveehdi/hearlossone.pdf

- Hmong: https://www.health.state.mn.us/people/childrenyouth/improveehdi/hearlinglossone_hmo.pdf
- Somali: https://www.health.state.mn.us/people/childrenyouth/improveehdi/hearlinglossone_som.pdf
- Spanish: https://www.health.state.mn.us/people/childrenyouth/improveehdi/hearinglossone_spa.pdf

[7] MDH EHDI website https://www.health.mn.gov/improveEhdi

[8] MDH EHDI Pediatric Audiology https://www.health.state.mn.us/people/childrenyouth/improveehdi/pediatric.html

[9] MDH Early Hearing Detection and Intervention: Information for Families & Caregivers Parent Resource Binder https://www.health.state.mn.us/people/childrenyouth/cyshn/ehdibinder.pdf

- Hmong: https://www.health.state.mn.us/people/childrenyouth/cyshn/ehdibinder_hmong.pdf
- Somali: https://www.health.state.mn.us/people/childrenyouth/cyshn/ehdibinder_som.pdf
- Spanish: https://www.health.state.mn.us/people/childrenyouth/cyshn/ehdibinder_spa.pdf

[10] MDH Newborn Screening Program https://www.health.state.mn.us/people/newbornscreening/index.html

[11] MDH Children and Youth with Special Health Needs https://www.health.state.mn.us/people/childrenyouth/cyshn/index.html

[12] The Federal Individuals with Disabilities Education Act (IDEA) Part C Guidelines https://www.ecfr.gov/current/title-34/subtitle-B/chapter-III/part-303/subpart-D/subject-group-ECFR1ed4257564f6445/section-303.303

[13] Minnesota Statute 3525.1331 https://www.revisor.mn.gov/rules/3525.1331/

[14] Help Me Grow Minnesota http://www.helpmegrowmn.org/

[15] Help Me Grow Refer a Child - Refer a Child https://helpmegrowmn.org/HMG/Refer/index.html

[16] MN Educational Audiologists, Minnesota Low Incidence Projects https://mnlowincidenceprojects.org/Projects/audiologists/index.html

[17] Help Me Grow Refer a Child: Professional Form https://public.education.mn.gov/hmg/pro.html

[18] Sharing Child Information to Coordinate Early Childhood Special Education (ECSE) Referrals https://www.health.state.mn.us/docs/people/childrenyouth/ctc/devscreen/ecserefer.pdf

[19] Polling Place Finder https://pollfinder.sos.mn.gov/

[20] Schools and Organizations, Minnesota Department of Education https://education.mn.gov/mde/about/SchOrg/

[21] First steps after identifying a child who is deaf, deafblind, or hard of hearing https://www.youtube.com/watch?v=yRCxi-dPGZM

[22] EHDI Information Packet for Clinical Audiologist, Minnesota Low Incidence Projects https://mnlowincidenceprojects.org/Projects/ehdi/EHDI_InfoPacketClinicalAudiologists.html

[23] Educational Resources, Schools and Programs, Deaf, DeafBlind and Hard of Hearing State Services https://mn.gov/deaf-hard-of-hearing/hearing-loss/children/education/

[24] Minnesota Hands and Voices https://www.lssmn.org/mnhandsandvoices/

[25] Minnesota Hands and Voices Deaf and Hard of Hearing Guide Program https://mnhandsandvoices.lssmn.org/about-us/deaf-and-hard-hearing-guide-program

[26] Lutheran Social Services of Minnesota Deaf Mentor Family Program https://www.lssmn.org/services/families/deaf-hard-of-hearing/mentor-services

[27] Minnesota DeafBlind Project https://www.dbproject.mn.org/index.html

Colorado Established Condition Database https://docs.google.com/spreadsheets/d/1AkysbUYoJSXn0US_DHw-ZIkn22xU0d8l_99fEBy7NV8/edit?gid=1292800278#gid=1292800278

Hearing Loss as an Established Condition - Eligibility Under Developmental Delay in Part C https://helpmegrowmn.org/cs/groups/communications/documents/document/ag1n/mdaw/~edisp/hmg000753.pdf

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Joint Committee on Infant Hearing. (2013). Supplement to the JCIH 2007 position statement: Principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing. *Pediatrics*, 131(4), e1324–e1349.

Joint Committee on Infant Hearing (2019). Year 2019 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. *Journal of Early Hearing Detection and Intervention*, 4(2), 1-44.

Referral Procedures. 34 CFR 303.303. Code of Federal Regulations, CFR 34, Sec 303.303(a)(2)(i).

Watkins, S., Pittman, P., & Walden, B. (1998). The Deaf Mentor Experimental Project for Young Children Who Are Deaf and Their Families. *American Annals of the Deaf* 143(1), 29-34.

Yoshinaga-Itano, C., Sedey, A. L., Coulter, D. K., & Mehl, A. L. (1998). Language of early- and later-identified children with hearing loss. *Pediatrics*, 102(5), 1161–1171.