

# SOUND MATTERS

Audiology Newsletter of the Minnesota Early Hearing Detection & Intervention Program

## Mapping the Journey of Families through Early Hearing Detection & Intervention

In 2019, MDH partnered with Wilder Research to better understand how families perceive their journey from newborn screening and identification of their child as deaf or hard of hearing, through early school age. This project specifically focused on engaging families who are African American, Hmong, and Latino, as well as families who primarily use American Sign Language (ASL). Families were asked to rate their experiences with key touchpoints along their journey on a scale of 1-5 (1=terrible/5=excellent) and they were also able to provide comments.

Families rated their experiences with audiology, ENT, hospital and pediatricians as “good” or “very good.” They also had ideas for improvement: 1. Providers could share a variety of materials in addition to written information (i.e. short online videos), 2. Some providers need to respect parental decisions regarding hearing aids or cochlear implants, 3. More available medical appointments would be helpful.

Parents from all four focus groups mentioned difficulties in the identification phase, specifically that they had to have multiple tests, sometimes results were inconclusive, or sedation felt invasive.

*“... when her tests were coming back negative, it would have been nice to have known what we should expect next. Instead of every time the test came back negative and telling us at that point they will have to do another test. So explain everything, lay it all out before so we have an understanding.”* —African American parent

A few families entered Minnesota’s EHDI system sometime after birth so missed some of the early touchpoints and were unaware of the supports available. A few families who use ASL would like to see their providers educated about Deaf Culture. Some parents highlighted the financial difficulties they faced when paying for hearing technology.

Wilder analyzed this feedback and proposed that MDH and stakeholders/clinics consider adding resources or using tools to help families better understand what to expect with diagnostic testing and how to pay for technology. They proposed that professionals seek opportunities to improve cultural responsiveness when working with Deaf parents and families. The full report will soon be available here: <https://www.wilder.org/wilder-research/research-library>

## Did you know? Resource Updates

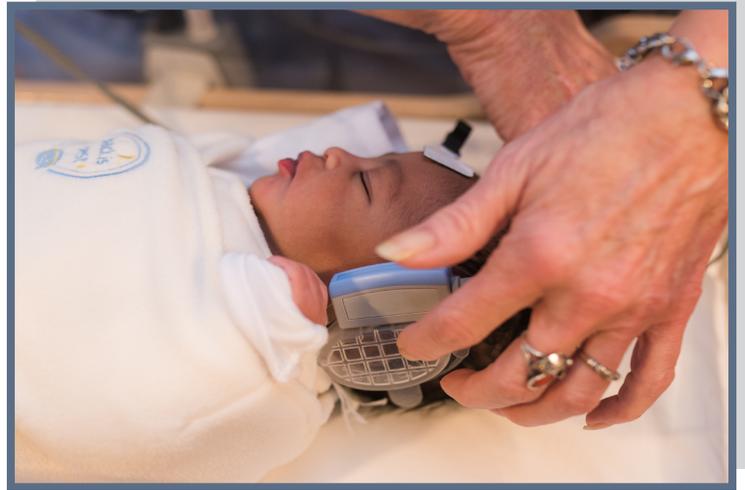
The Guidelines for Hearing Screening After the Newborn Period to Kindergarten Age have been approved and updated, and are located at <https://www.health.state.mn.us/docs/people/childreneyouth/improveehdi/guideafternb.pdf>. Audiologists are encouraged to notify colleagues in the education system and primary care clinic staff in their local communities.

Minnesota Department of Education maintains a list of educational audiologists, including the communities they serve and current contact information. Contact [mary.cashman-bakken@state.mn.us](mailto:mary.cashman-bakken@state.mn.us) to request a copy of this information.

# Have You Heard?

## CMV Study Update

In 2015 MDH began work on a joint study with the University of Minnesota and the Center for Disease Control and Prevention to investigate newer methods of using the newborn bloodspot to screen for cCMV in contrast to existing screening methodologies utilizing saliva analysis. Current partnerships in this endeavor include three hospitals in the Fairview Health system, and two in the Allina Health system. CentraCare St. Cloud is projected to join this collaboration beginning early in 2020. The study's goal was to enroll 30,000 consented participants to gather this data. As of June 2019, just over 12,000 infants were enrolled. The detection rate of cCMV using the newborn bloodspot and current analysis methods used in this study is higher than previously reported. Of the 56 confirmed positive cCMV cases, 51 passed their newborn hearing screening. Diagnosis of cCMV would have been missed for these 51 infants in a targeted cCMV screening approach that only focused on screening infants who do not pass newborn hearing screening. MDH-Newborn Screening Program continues to review these study results, along with other evidence and consider the potential addition of cCMV screening to the current state screening process.



## Last Words from the Advisory Committee

### Meeting highlights...

- Hands & Voices Family Leadership in Language and Learning (FL3) program was highlighted. <http://www.handsandvoices.org/fl3/index.html>  
This new cooperative agreement with the Health Resources and Services Administration (HRSA) promotes the inclusion of families of deaf or hard of hearing infants/children as leaders in their statewide EHDI system
- Minnesota Guidelines for Pediatric Amplification – Section 3 of the Early Hearing Detection and Intervention Guidelines for Audiologists was updated and approved by the Newborn Hearing Screening Advisory. The new version has been posted here <https://www.health.mn.gov/people/childreneyouth/improveehdi/state.html>.

### Next meeting...

**February 19, 2020**  
**1:00 – 4:00 p.m.**  
**Amherst A. Wilder Foundation**  
**451 Lexington Parkway North**  
**St. Paul, MN 55104**

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EHDI Website: [www.improveehdi.org/mn](http://www.improveehdi.org/mn)