



Early Hearing Detection & Intervention for all Minnesota Children

MDH **EHDI**  
annual report  
2015

# CONTENTS

- 2 Data Snapshots from 2015
- 4 Timely Screening
- 8 Timely Diagnosis
- 12 Timely Intervention
- 18 Program Indicator Data



## GLOSSARY

A few common acronyms you will find throughout the report.

Abbr.	Meaning
D/HH	Deaf or hard of hearing
EHDI	Early Hearing Detection and Intervention
LPH	Local public health
LTF	Lost to follow-up
LTF/D	Lost to follow-up or documentation
MDE	Minnesota Department of Education
MDH	Minnesota Department of Health
MNHV	Minnesota Hands & Voices
REFER	MDH-EHDI term for did not pass screening

\*In an effort to increase timeliness and accuracy, we began instituting an electronic reporting system in 2015. As we transition between systems, it is difficult to pull exact numbers because our data is in two different systems (with some overlap). The numbers presented in this report, may not be exact, but we believe they are a close representation of 2015 data.

# A LETTER FROM THE EHDI TEAM

*Dear Reader,*

The Minnesota Department of Health (MDH) Early Hearing Detection and Intervention (EHDI) Program is working to build a comprehensive and coordinated system of care targeted towards ensuring that newborns and infants are receiving appropriate and timely services, including screening, evaluation, diagnosis, early intervention, and family support.

Each year in Minnesota, approximately 250 infants and children are identified as deaf or hard of hearing. Without early identification and intervention, children with hearing loss often experience delayed development in language and learning.

We can only improve our EHDI system of care through extensive partnerships with our stakeholders including hospitals, midwives, physicians, audiologists, local public health (LPH) departments, early intervention programs, parent support organizations, and others. Together, we strive to achieve the national recommendation of 1-3-6 guidelines:

- 1** Universal hearing screening **before 1 month of age**
- 3** Identification of hearing loss **before 3 months of age** for children who do not pass screening
- 6** Enrollment in early intervention services **before 6 months of age** for children identified with hearing loss

Throughout this report, we share stories of partnerships and initiatives we have undertaken this year, including:

- Improved reporting of screening results with hospitals (pg. 5)
- Collaboration with audiology to achieve EHDI goals (pg. 9)
- An initiative with Ear, Nose and Throat physicians to improve knowledge of 1-3-6 guidelines (pg. 10)
- Identifying the mentoring needs of families with children who are D/HH (pg. 15)

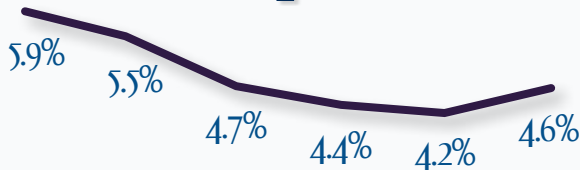
*The EHDI Team*

# DATA SNAPSHOTS

## FROM 2015

# 68,063

newborns screened for hearing loss in 2015, with a REFER rate of **4.6%**



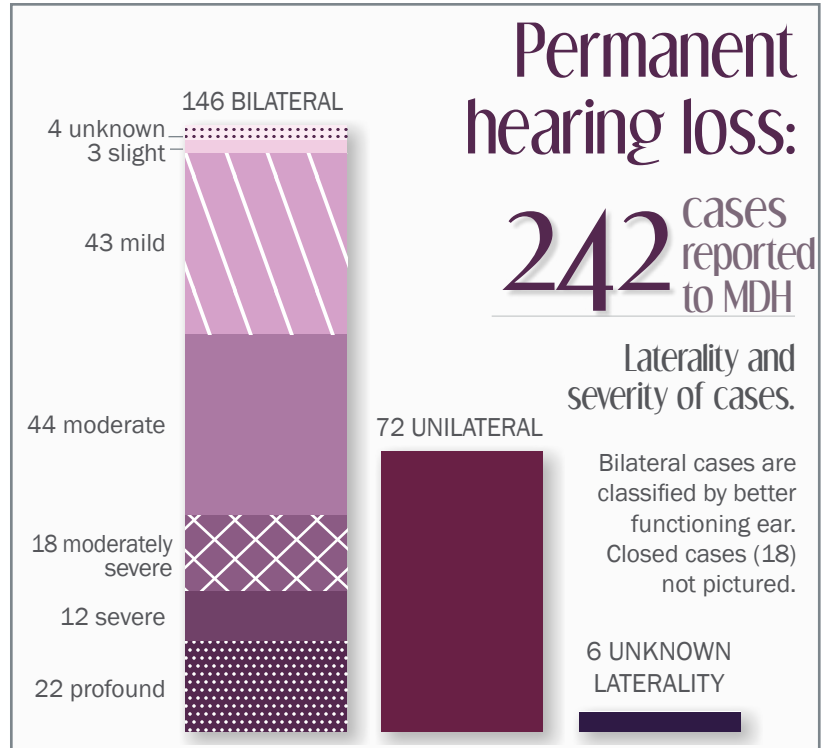
2010 2011 2012 2013 2014 2015

A REFER result means an infant did not pass screening. National guidelines recommend a REFER rate of 4% or less.

**99.1%** of Minnesota newborns were **SCREENED** in 2015. ✓

**144** parents

✗ chose to **OPT OUT** of screening (0.21%).



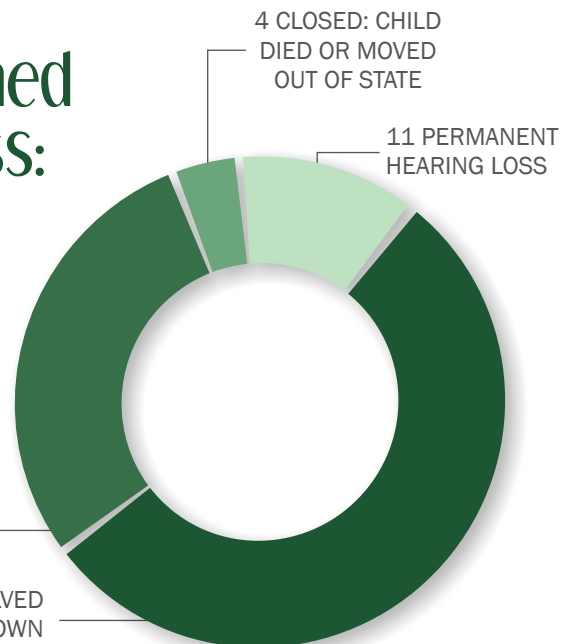
### Transient/undetermined hearing loss:

**91** cases reported to MDH

Status of transient/undetermined cases as of June 2016.

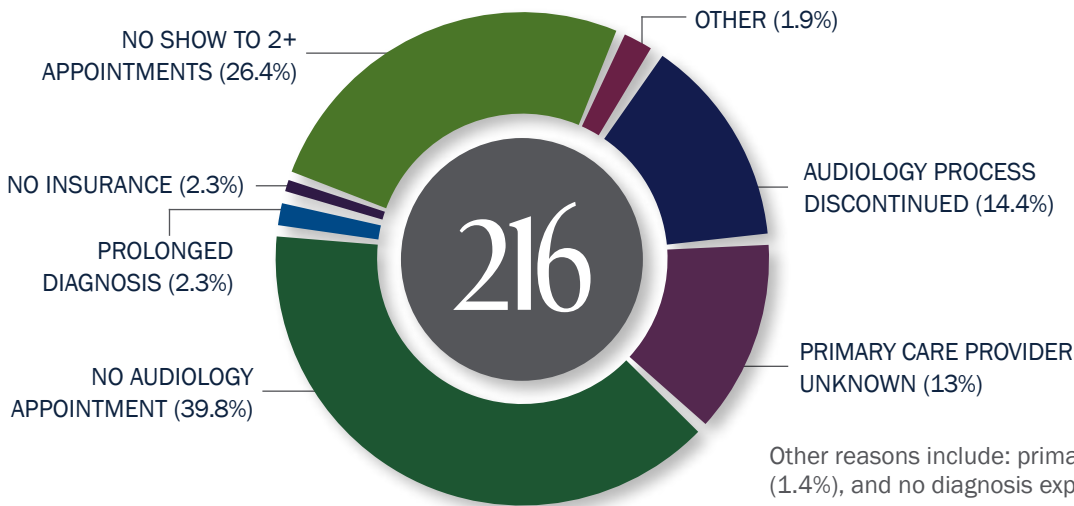
27 CLOSED: HEARING LOSS RESOLVED

49 HEARING LOSS UNRESOLVED OR STATUS UNKNOWN





## Top Reasons for Loss to Follow-up or Documentation (LTF/D)



**216** newborns with REFER results were LTF/D in 2015

Other reasons include: primary care provider chose not to rescreen (1.4%), and no diagnosis expected due to comorbidities (0.5%).

## Time to diagnosis

\* of infants with reported diagnosis

**59%** of infants were diagnosed within 90 days of birth

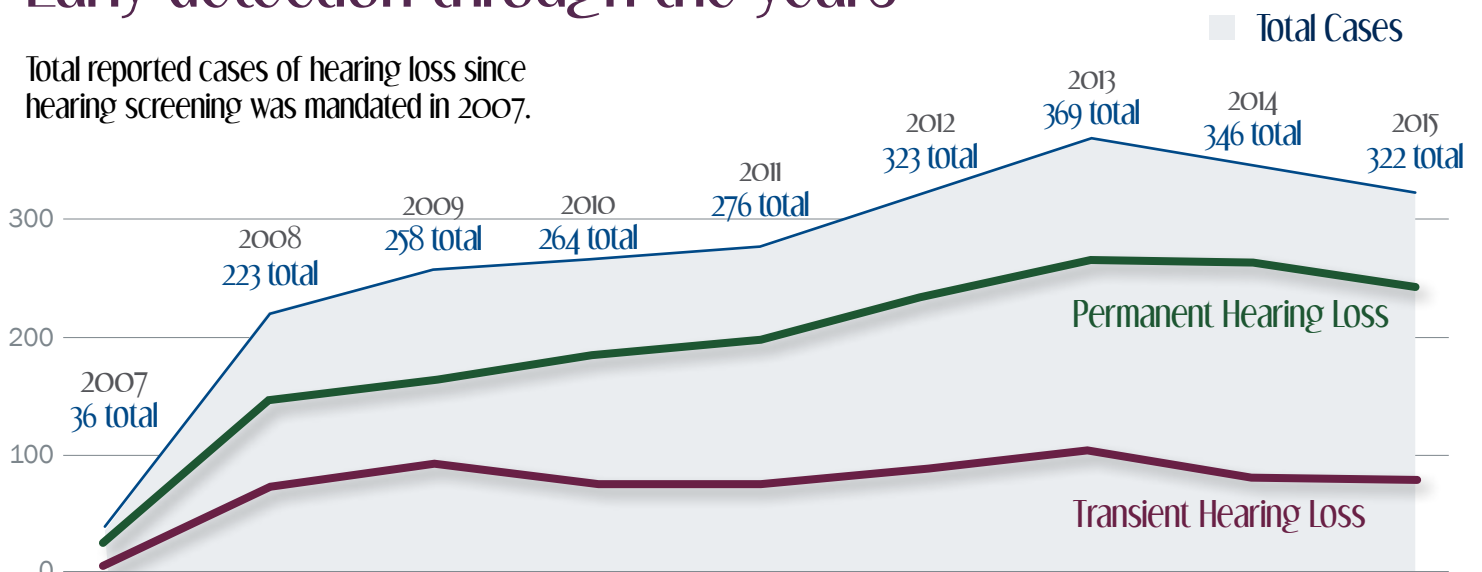
**15%** of infants were diagnosed within 90-180 days of birth

**26%** of infants were diagnosed after 180 days from birth



## Early detection through the years

Total reported cases of hearing loss since hearing screening was mandated in 2007.



# TIMELY SCREENING

The quality and timeliness of screening, reporting results, and follow-up directly impact the diagnosis and intervention options for infants. In 2015, 99.1% of all Minnesota newborns were documented to have had their hearing screened, with 97.3% completing the screen before 1 month of age. Our efforts to increase the number of newborns receiving their initial hearing screen before one month of age continue and we expect further progress in the coming years. Improved documentation and access to hearing screening equipment for our out of hospital births have proven vital.

## Program goal:

**1** All newborns will complete a hearing screening before **1 month of age**, preferably before hospital discharge.\*

\*excludes newborns weighing  $\leq 1800g$  at birth

In 2015, **97.3%\*\*** of newborns received their hearing screen before 1 month of age.



*"My husband and I are so thankful that we live in a time when hearing loss is identified early in life and intervention can begin right away. I know that Max has been given the same opportunities as any other child due to the early diagnosis and intervention."*

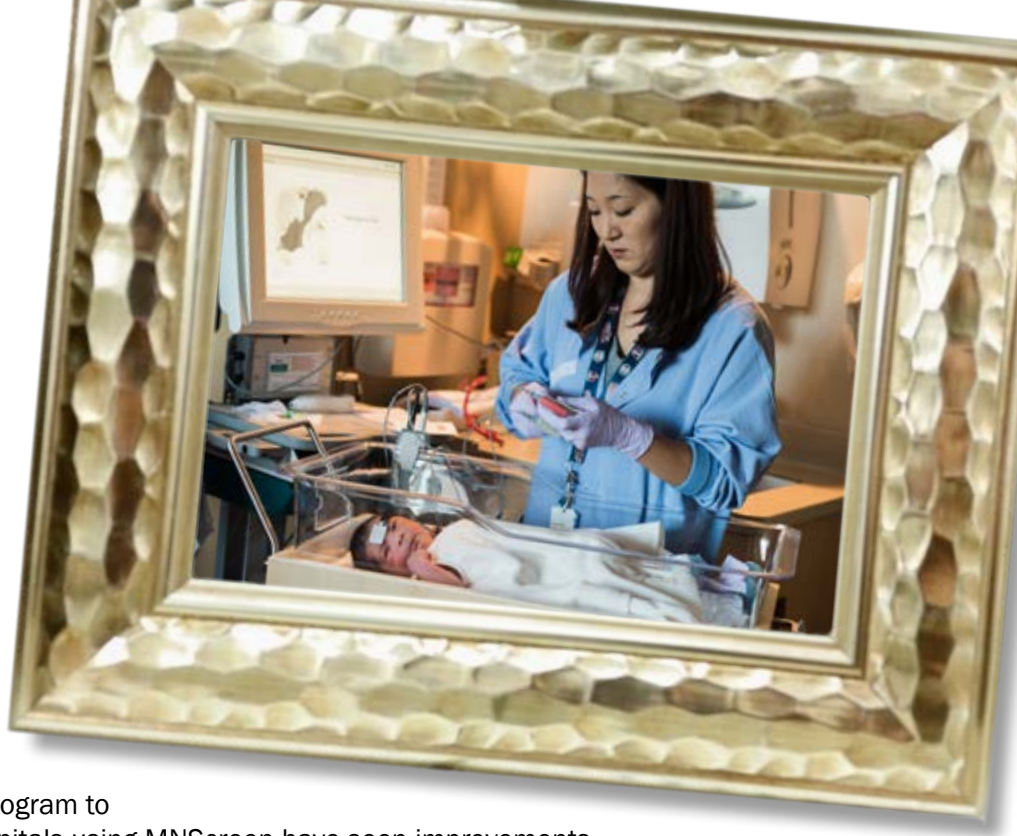
Allison, Max's mom



\*\* This only accounts for cases  $>1800g$  whose cases were in Legacy LIMS. The percentage of cases in Legacy LIMS  $>1800g$  equals about 93% of  $>1800g$  cases.

# MNSCREEN Begins Live Reporting in Minnesota Hospitals

The implementation of MNScreen, the Newborn Screening Program's new system for reporting hearing and pulse oximetry screening results from hospitals directly to the program, continued in 2015 with much success. By the end of 2015, 28 (31%) Minnesota birth hospitals were using MNScreen to report their hearing and pulse oximetry results in real-time. Another 31 (34%) hospitals were actively working with the program to implement the system in their facility. Hospitals using MNScreen have seen improvements both in timeliness of reporting as well as completeness of reporting.

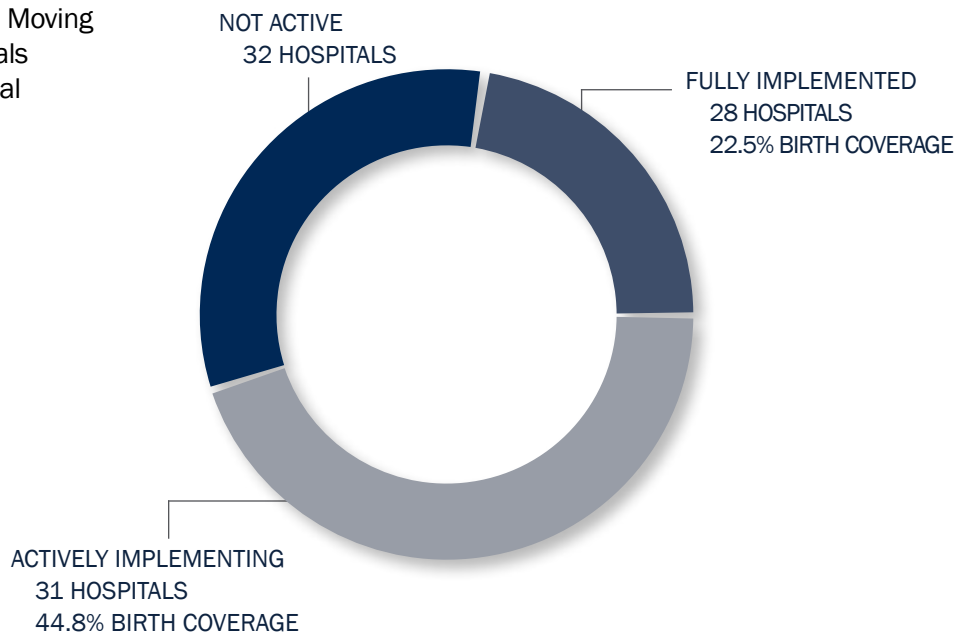


Statewide implementation of such a robust electronic system is a new initiative not only at the program level, but at the agency and national level as well. As such, we have encountered several uncharted challenges, including device networking issues, transitions between Electronic Medical Record systems, competing IT priorities at birth facilities, etc. Despite these obstacles, the MNScreen project continues to pave new ground, and is on pace to be the first statewide electronic newborn screening reporting system in the nation to receive hearing screening data exported directly from the screening equipment.

The program's goal is to have all hospitals fully implemented in MNScreen by the end of 2016. Moving forward, we will continue to reach out to hospitals to begin implementation. We have begun several initiatives in an effort to make statewide implementation a reality:

- Exploring the ability to provide grants to Critical Access Hospitals in Minnesota to aid in implementation costs
- Beginning the process for MDH to declare MNScreen a Public Health Specialized Registry for Meaningful Use Stage 2<sup>1</sup>

We look forward to exploring other improvements to the program that will be made as a result of MNScreen!



<sup>1</sup> A Specialized Registry must collect production data from the providers' EMR using certified electronic medical record (EMR) technology and is used to improve quality, safety, efficiency, and reduce health disparities. By declaring MNScreen a Public Health Specialized Registry for Meaningful Use eligible providers will be able to receive an incentive for electronically reporting what they are already required to report to our program.



# MDH Partners on CMV Study

Cytomegalovirus (CMV) is the most common congenital infection in the U.S. and the most prevalent cause of nonhereditary sensorineural hearing loss.<sup>1</sup> Each year, about 1 in 150 newborns is estimated to be born with CMV, which would be approximately 467 infants in Minnesota.

In 2015, we continued our collaboration with the University of Minnesota (U of M) and the Center for Disease Control and Prevention (CDC) to evaluate screening methods for universal screening of CMV—comparing dried blood spots versus saliva. As dried blood spots are currently collected on all infants, the most cost effective and streamlined process would be to utilize the system currently in place—to screen for CMV with dried blood spots. However, saliva is considered to be a more sensitive method for screening for CMV currently, as previous studies have reported poor sensitivity for CMV screening by blood spot.

During the study, blood spot samples from infants (whose parents have consented to the study) are sent to the CDC and Dr. Mark Schleiss' lab at the U of M. Dr. Schleiss' lab also receives saliva samples from the same infants, to compare the two detection methods. In the case that an infant has a positive result, the infant's primary care provider is contacted by a Newborn Screening genetic counselor who will discuss the results and recommendations with the provider. Education materials for medical professionals and parents have been developed. Year-one of this study began enrolling study participants from Fairview Riverside. We plan to expand the study to multiple hospitals in 2016 with the goal of enrolling a total of 30,000 infants in three years.

<sup>1</sup> Sensorineural hearing loss (SNHL) occurs when there is damage to the inner ear (cochlea), or the nerve pathways from the inner ear to the brain.

**~1 in 150 infants is  
born with CMV**

**Each year in Minnesota...  
of ~70,000 births**

**467 infants are born with CMV**

**8 in 10  
are unaffected**

**1 in 10  
are asymptomatic and  
will develop hearing  
loss, possibly after  
passing NBHS**

**1 in 10  
are symptomatic  
which may include  
hearing loss**

**\*numbers based on current prevalence data**





## Family Story

# Our CMV Story

The “Dear Parents/REFER Hearing Screening” letter was the beginning of our journey. After a healthy pregnancy and an uneventful planned C-section, we were notified prior to hospital discharge that Harper failed the screening in one ear and we were instructed to follow up in 5-6 weeks. It sounded like fluid in the ears was common with C-section babies so we weren’t worried in the weeks leading up to her follow-up appointment. The follow-up visit confirmed not only hearing loss in one ear, but in both. We were shocked but quickly moved into the process with more testing, new specialists, and terminology foreign to us.

With no family history of hearing loss, we were motivated to understand the cause of Harper’s hearing loss. I had attended a program sponsored by the University of Minnesota – Next Steps for Families with Newly Diagnosed Hearing Loss. In that session, they covered a number of congenital causes of hearing loss – one of which was CMV. I remembered that and called our pediatrician and requested Harper be tested for CMV. After Harper was diagnosed with CMV, she began anti-viral treatment.

We will be forever grateful for the newborn hearing screen and all of our partnering medical professionals along the way. Without this, I’m confident we would have lost several months and perhaps even the opportunity to consider an anti-viral. This screening gives parents the gift of time so that they may have more options for CMV treatment.



## Newborn Screening at the Great Minnesota Get Together

The Newborn Screening Program hosted a booth at the 2015 Minnesota State Fair as part of our general population education initiative. Fairgoers were encouraged to take one of seven different “I’m a fan of newborn screening” fans which included stories from Minnesotans who were identified with a condition through newborn screening. The booth was decorated with banners which detailed each component of newborn screening as well as a history of newborn screening in Minnesota, and included family stories.

Almost 1.8 million people attended the Minnesota State Fair in 2015 and we gave away nearly 22,000 fans and interacted with just over 30,000 people. In addition to the booth, newborn screening billboards were posted near the fairgrounds and posters with newborn screening stories on them were posted in the women’s restrooms around the fairgrounds, expanding the reach of our message.



# TIMELY DIAGNOSIS

In 2015, nearly all Minnesota newborns received a hearing screening at birth. However, 5.8% percent of infants were considered lost to follow-up or documentation (LTF/D). A newborn who is LTF/D did not pass newborn hearing screening and did not complete further hearing tests to confirm or rule out a diagnosis of hearing loss. This year, we worked to decrease time to diagnosis and reduce the number of infants considered LTF/D through outreach to otolaryngologists, collaboration with audiologists and partnerships with LPH. We continue to analyze the data for strengths and gaps and share information with our stakeholders to improve practice. Although there remains work to be done, timely diagnosis continues to improve.

## Program goal:

3 All newborns who do not pass screening will have a definitive diagnostic audiologic evaluation before **3 months of age**.\*

\*excludes newborns weighing  $\leq$  1800g at birth

In 2015, **40.7%\*\*** of newborns who referred on their newborn hearing screen had a definitive diagnosis before 3 months of age.\*



*"I think the audiologist who told us [about Emory's hearing loss] was really good, she didn't put any negative spin on it and she was very encouraging and so it was like, well this is it. It is what it is. You have to go with the flow and find out how you can make sure your child is going to not be left behind in any way."*

Joyce, Emory's mom

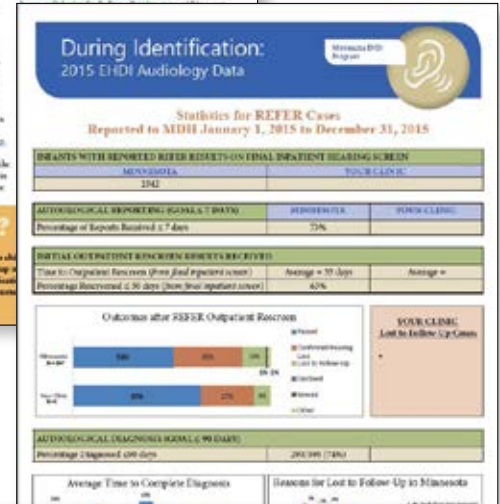
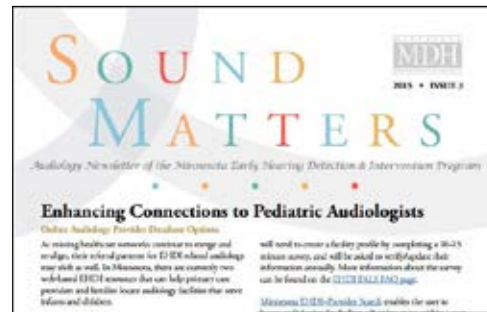
# Audiology Partnerships Support EHDI Goals

Audiologists are key stakeholders when it comes to achieving EHDI goals and the MDH-EHDI partnership with Minnesota audiologists is vital for a successful MN EHDI system. We strive to provide ongoing support, foster effective communication, and encourage collaboration in a variety of ways to keep EHDI goals a priority.

Personal contact, print & electronic media, formal education sessions, data, and quality improvement initiatives have been utilized to engage audiologists in working toward timely hearing diagnosis, referrals, and overall EHDI best practices. We also rely on Minnesota audiologists to shape guidelines by participating in workgroups.

Examples of resources that offer timely information specific to MN EHDI include:

- *SoundMatters* – a quarterly e-newsletter for pediatric audiologists that provides topic discussion, audiology highlights, data, and advisory committee highlights.
- Audiology Clinic EHDI Data Reports – provide data back to audiologists specific to their clinic to illustrate their improvements and where improvement may still be needed.
- *Improve EHDI Website* – shares information specific to audiology, but is also used as a reference by audiologists to learn what EHDI is providing to other stakeholders, giving audiologists the ‘big picture’ right at their fingertips.
- In 2015, MDH had the opportunity to partner with the Minnesota Academy of Audiology (MAA) to sponsor a pediatric pre-session to MAA’s annual Upper Midwest Audiology Conference. Speakers Dr. Gail Whitelaw and Dr. Ryan McCreery presented best practices in pediatric audiology and maximizing outcomes for children with hearing loss. Round table forums following the lectures provided the opportunity for pediatric audiologists to discuss essential topics in pediatric audiology.



97.7% of attendees agreed/strongly agreed that the MAA pre-session gave them ideas to improve practices to meet EHDI goals



# ENT Education Initiatives

## Improve Knowledge of 1-3-6 Goals

Otolaryngologists (Ear, Nose & Throat physicians, or ENTs) play an important role in supporting timely and complete audiological diagnosis of infant hearing loss. In 2009, we found that 70% of children with unknown hearing status at 6-8 months had a history of middle ear fluid. The presence of middle ear fluid often led to 4-6 rescreens, delayed referral for diagnostic ABR, complex diagnostic procedures, and becoming lost to follow-up. Identifying common reasons for delayed diagnosis led to an outreach initiative to the otolaryngology community to improve EHDI knowledge.

In 2010, with a team of stakeholders that included two ENT physicians, MDH-EHDI began an improvement project targeting the ENT community. The team conceived and implemented several strategies for improving ENT knowledge of EHDI, including:

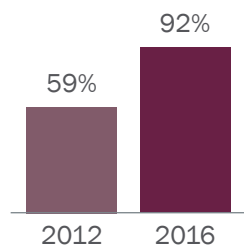
- New educational materials designed specifically for the ENT community
  - EHDI Guidelines for Otolaryngologists
  - EHDI Infographic including Minnesota EHDI data
  - Timeline of the recommended 1-3-6 hearing follow-up process
  - Myths and Facts about EHDI, including Minnesota EHDI data
- EHDI article submitted to state Academy of Otolaryngology for dissemination
- Information booth at state ENT professional meetings
- Presentations and discussions on EHDI at ENT clinic staff meetings and grand rounds sessions



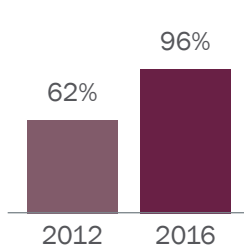
ENT understanding of the 1-3-6 guidelines has increased dramatically since implementation of these strategies.

### Percent of ENTs who choose an answer in-line with EHDI recommendations

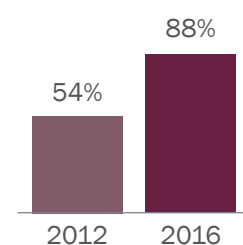
REFER infants should be rescreened by 1 month of age



Definitive diagnosis of permanent hearing loss by 3 months of age



Infants can begin wearing hearing aids within 1 month of diagnosis



In 2012, the National Center for Hearing Assessment and Management (NCHAM) conducted a survey of physicians that revealed that 33% of Minnesota ENT's did not clearly understand recommended timing for hearing screening follow-up and diagnostic testing. Using that survey as a baseline, MDH-EHDI conducted a follow-up survey of Minnesota ENT's in 2016. The graphs above highlight improvements in understanding of key EHDI goals between 2012 and 2016.



## Family story

# Cultural Parent Guides Make a Difference with Families

Por's daughter, Iris, was identified with hearing loss through newborn hearing screening. Through her Parent Guide and interpreter, Mai, Por shares her feelings about Iris' journey and the difference Minnesota Hands and Voices has made.

### **What was the first thought you had when you found out Iris had hearing loss?**

At first I denied it, because she was so little, maybe the doctors and nurses were wrong. I didn't really believe it.

### **How did your family make the decision to get Iris hearing aids?**

At first we weren't quite sure what to do... By talking with Mai (our Parent Guide, whose daughter has hearing loss) and Hands and Voices, we realized that even babies can wear hearing aids and that it makes a difference. That's what made me change my mind and go in and get Iris hearing aids.

### **Has it been helpful to have a parent guide from your own culture?**

Yes! It definitely helps when someone understands the culture—not just the language—but our culture. I've seen other children with hearing loss, but not in the Hmong community, so having someone like Mai, who's daughter has gone through the same things my daughter is going through, makes me realize that there is help out there and there are things I can do to help Iris. Having someone from my culture who has a child with hearing loss (like Mai), her experiences have helped us so much.

### **What is your biggest hope when looking forward to Iris growing up?**

I have a lot of hope for Iris. I hope that as she grows up she will be a strong role model for other people in the community, especially in the Hmong community itself. That eventually she will help other children or other families who are going through the same thing she did growing up with hearing loss.

### **Is there anything you would want other parents or providers to know?**

To parents, don't lose hope. To providers, it's important to encourage families to build a support network and to encourage people to support these families—especially children—to get to where they need to be. When a family doesn't have support or a clear understanding, it can limit the child and the family from getting where they need to be. Family-to-family support programs are a great benefit to families, providers, and the community as a whole.



*Having someone from my culture who has a child with hearing loss, her experiences have helped us so much.*

# TIMELY INTERVENTION

For children who are D/HH to reach their full potential, it is critical that they and their families are connected to comprehensive family support and quality early intervention programs as soon as possible after diagnosis. In 2015, we continued to connect families to these services as soon as possible. Among children newly identified as D/HH this year, almost 9 of every 10 families were connected to parent-to-parent support through MNHV, and about 7 of every 10 children were connected to early intervention programs.

## Program goal:

# 6

All infants identified as D/HH will receive appropriate early intervention services before **6 months of age.**

In 2015, **67.8%** of infants identified as D/HH enrolled in early intervention services before 6 months of age.



*"When Elise was first diagnosed, someone from Hands and Voices came over. She spent hours with us, poring over information, meeting and spending time with Elise, answering all of our questions, reassuring us. She was amazing. I was so thankful for that whole experience and for Hands and Voices."*

Greg, Elise's dad

# What is Early Intervention?



medical care  
(primary +  
specialty)

parent-  
to-parent  
support

D/HH adult  
role model or  
mentor

services  
(part C +  
non-part C)

connection  
to financial/  
community  
resources

audiological  
management

## Identifying the Unique Needs of Families with Children Who are Deaf or Hard of Hearing

The Minnesota Department of Health continues to partner with local public health (LPH) agencies across the state to better identify and address the needs of families when a child is newly identified as deaf or hard of hearing. Since 2010, LPH nurses have contacted families of children who are D/HH to identify family needs through a nursing assessment and then connect families to available resources. In 2015, six LPH agencies began piloting an improved system to guide their nursing assessments and standardize the documentation of family needs. Pilot nurses focused their assessment on the following areas: growth and development, health care supervision, income, caretaking/parenting, and communication with community resources. Data from the pilot are beginning to provide powerful insights into the most common difficulties that families are facing after identification of hearing loss, such as the financial burden of uninsured medical expenses. This information will help MDH and stakeholders develop local and statewide strategies to address the most common barriers that families face.





# Minnesota Hands & Voices Initiatives for Providers and Families

Minnesota Hands & Voices (MNHV), an MDH-EHDI program-funded, parent-driven nonprofit organization, continues to offer effective support to families of children who are D/HH in Minnesota. MNHV outreach to families comes in many forms, including one-on-one support from parents of children who are D/HH, connections to resources, and coordinated events. Parents find enormous value in connecting with other parents with shared experiences, which provides the opportunity to learn from each other, as well as gain moral support and encouragement. Emotional support and assistance from trained parents have been shown to improve outcomes for families of children who are D/HH.

In 2015, MNHV launched the Hands & Voices' League of Heroes™. This effort aims to raise awareness about the importance of adult role models in the lives of children who are D/HH. MNHV recruited and trained adults with diverse backgrounds who are D/HH to attend MNHV events and engage with families. These Adult Role Models provided families with information about programs that offer services such as the Deaf Mentor Family Program and the Adult Role Model Program at Lifetrack. Wearing capes, the Adult Role Models handed out "League of Heroes" trading cards, described the superpower on the card and how they discovered that particular power (i.e. resiliency, advocacy, courage), and then encouraged the children to harness the same power within themselves.

Minnesota Hands and Voices supports families throughout the year in several ways:

- Networking and educational events – providing information on topics such as new technology available for children who are D/HH, early intervention opportunities, educational advocacy for diverse communities, strategies for communication, and working with providers
- Social events – facilitating playgroups for children for are D/HH, family social events, annual picnics
- Information, support, and referral – connecting parents with other families, Deaf Mentor program, parent guides



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**In 2015, Minnesota  
Hands and Voices  
connected with nearly  
90% of families who  
had a child recently  
identified as D/HH**

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*[Our daughter] does not know very many people with hearing aids and so we treasure the picnic every year as an opportunity for her to see other kids who are just like her. As adults, my husband and I enjoy seeing adults and reading their stories so we can see what the future may hold for her.*

Parent of a child who is D/HH



# Study Provides Insight on Mentoring Needs of Families with Children Who are D/HH

In June 2015, Wilder Research published the results of a study made possible through grant support from MDH that focused on the needs and preferences of Minnesota families with young children who are D/HH related to family mentoring programs. Researchers talked with parents of children who are D/HH, adults who are D/HH, and experts from other mentoring programs around the country to find out what types of mentoring and support are most helpful for families with young children who have hearing loss. Deaf Mentors are uniquely qualified to share their personal experiences or information about being D/HH, educational and communication opportunities, experiences using hearing technology, and about the Deaf community and Deaf culture.

Wilder Research found that one of the most important functions of an adult mentor who is D/HH is to give the parents hope for their child's future. Mentors also provide the child a positive adult role model who can help the child learn life skills related to their hearing loss and develop a positive self-identity.

The results of this study will help Minnesota expand its D/HH mentor outreach and offerings—particularly in terms of reaching populations that may currently be underserved, such as families in rural Minnesota, culturally diverse families (especially those who do not speak English at home), and families who choose modes of communication for their child other than American Sign Language.

*"Our Deaf Mentor had a cochlear implant. Since we were going through the process of deciding about a cochlear implant for our son while we were in the program, we valued having an adult in our life who we could talk to about the experience. It really helped put us at ease."*

Parent of a child who is D/HH



*"I wondered what careers would be available for the Deaf. Where will he go to school? Will he drive? It's these random thoughts that flooded my mind. Knowing the Deaf Mentor and becoming part of the community, you see the capabilities of these great people and it gives you hope. My mentor gives me hope."*

Parent of a child who is D/HH

Parents of young children who are D/HH most commonly need:

- Emotional support to help them through this initial stage of grief
- To connect with other families participating in D/HH mentoring programs
- A role model the child can look up to—parents need hope for the future
- To learn American Sign Language (ASL) and communication skills and tools—many parents also want to know more about other communication tools (e.g., Cued Speech)
- Information about assistive technologies—cochlear implants and hearing aids

From *Families with Young Children who are Deaf and Hard of Hearing in Minnesota*

## Family Story

# Learning to be Our Own Advocate

Chad and Joyce's daughter, Emory, was born in Massachusetts where her hearing loss was identified by newborn hearing screening. When she was three months old, Emory got her first pair of hearing aids. Now in Minnesota, Chad and Joyce talk about Emory's journey.

### **Emory completed her D/HH preschool program and will be moving to mainstream preschool, how has this changed your role as parents?**

Now we are getting into the understanding what it means for us needing to be more of an advocate for her. It puts more responsibility on our shoulders, to make sure that we are asking Emory, 'Can you hear what the teacher is saying? Can you understand what they are saying? Are your hearing aids working? Does your teacher have her microphone on, and does she give the microphone to other teachers when they are in circle time?' All of these things we now have to be our own advocate for, and she is learning to advocate for herself.

### **What other communication methods have you learned?**

We took sign language through Lifetrack's Deaf Mentor program and now we are doing sign language classes online. We wanted to develop another way of communication, just in case Emory wanted to sign and communicate that way. So far, she seems to prefer the verbal route. If later in life she wants to use sign language, at least we have a background and we will be able to help her with that. Maybe she'll want to connect to that part of her culture.

We took cueing classes from a speech language pathologist. Cueing uses hand signals for sounds the child might now be able to hear. These hand signals help her to differentiate sounds that she can't differentiate herself due to her hearing loss. You might have two sounds that sound the same to someone who is hard of hearing but if you pair that sound with a hand signal then they can differentiate between them. Emory doesn't cue anymore, but because of it, she's developed what she needs to develop language.

### **How does Emory feel about her hearing loss?**

She's proud. She'll tell people, "I'm a hard of hearing kid!" I think because of the way we've lived our lives, as parents, we've made it not any different than us needing eye glasses. I'm hoping in the future, she won't feel like she has to hide it.

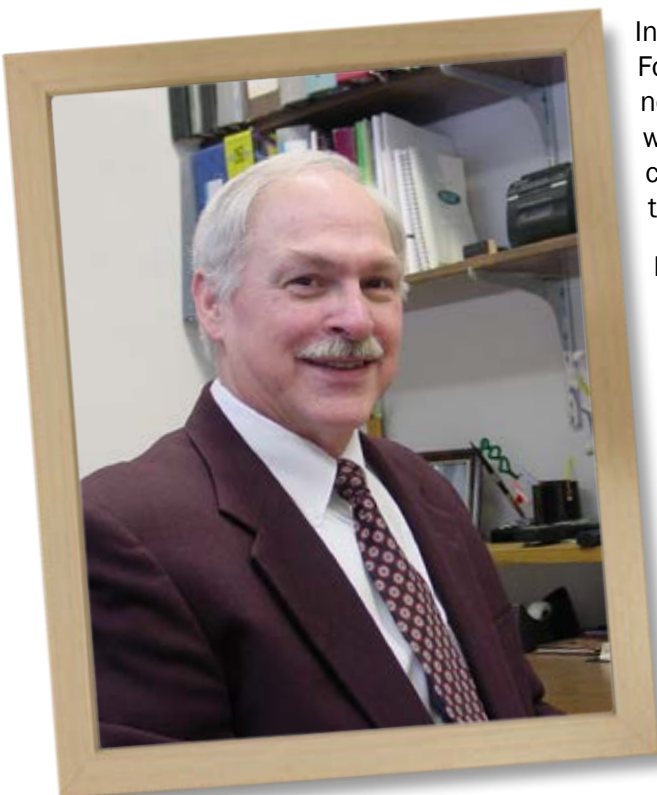
*My hopes and dreams for her are that same as for my other kids, I don't see any reason or way that her hearing loss is going to have any negative effect on her or her potential level of achievement. It doesn't worry me anymore.*

## Continued Funding for Lions Loaner Program

For the eighth consecutive year, MDH-EHDI awarded grant support to the University of Minnesota Lions Infant Hearing Device Loaner Program. The program provides loaner hearing devices to families who choose amplification. For these families, the program helps ensure infants have immediate access to sound soon after diagnosis. This gives families time to arrange payment for permanent devices, wait for medical or surgical treatment, or determine if devices will benefit their child. The program provided 110 hearing devices to children identified as D/HH in 2015. Of that total, 23 loans were for bone-conduction devices which have seen higher demand in recent years.

## Longstanding Partnerships Essential for EHDI Success

Dr. Bob Margolis, professor at the University of Minnesota (U of M) and former Director of Audiology at the University of Minnesota Medical School shares the story of the birth of EHDI in Minnesota and the continued partnerships between the U of M and MDH.



In 1999, the U of M received a grant from the Lion's 5M Hearing Foundation. The \$500,000 grant was awarded to begin universal newborn hearing screening in Minnesota. Dr. Margolis and his team worked to improve training and statewide infrastructure, ensuring children born with hearing loss received a higher standard of care and the resources needed to foster the best outcomes.

Later, MDH-EHDI staff authored Minnesota's first grant from the Center for Disease Control (CDC), and the United States Department of Maternal and Child Health, which ultimately shifted the administrative role of the hearing screening program over to MDH in the early 2000s. The U of M continued to serve MN EHDI with administration of the UMN Lions Infant Hearing Device Loaner Program. This program, started with grant funding from Lions 5M, has provided short term device loans to over 800 families to date. The program was started under a Lions grant and continues to receive funding from MDH. The Loaner Program depends on partnerships with manufacturers, who donate the hearing instruments that are loaned out to children.

## From thankful parents...

*"Hearing the sounds of speech at this influential age is so important. We are very grateful to have had loaners two times now while choosing an appropriate aid for our infant son!"*

From a parent in the process of choosing technology

*"We were undergoing evaluation for cochlear implants, which we eventually pursued. Also, our child was 2 months old when first fit. A few months later, we were able to switch to larger aids."*

From a family awaiting surgery

*"So thankful for this service. You truly made a difference for our daughter and our family!"*

Parents of a child who is D/HH

*"It has been a terrific partnership, all along the way, between the University of Minnesota and MDH. It could not have been better."*



# PROGRAM INDICATOR DATA



Indicator	Annual Percentages					5-Year Trend
	2011	2012	2013	2014	2015	
1.1 Percentage of infants screened for hearing loss	98.5%	99.1%	99.1%	98.8%	99.1%	
1.2 Percentage of infants >1800 grams screened before 1 month of age	97.3%	97.3%	98.8%	98.7%	-	
1.3 Percentage of infants ≤1800 grams screened before 4 months of age	97.1%	91.5%	93.6%	92.3%	-	
1.4 Percentage of infants that did not pass initial screening	5.5%	4.7%	4.4%	4.2%	4.6%	
2.1 Percentage of infants >1800 grams given a REFER on initial hearing screening that were rescreened by 1 month of age	61.1%	61.8%	61.8%	61.1%	-	
2.2 Percentage of infants >1800 grams who have a REFER on rescreen and receive an audiology evaluation by 3 months of age	23.0%	31.7%	37.6%	40.5%	-	
2.3 Percentage of infants with a REFER who were lost to follow-up (LTF)	6.6%	5.7%	5.9%	5.6%	5.8%	
2.4 Percentage of infants >1800 grams with a REFER who were LTF	8.4%	5.6%	5.9%	5.6%	5.9%	
2.5 Percentage of infants ≤1800 grams with a REFER who were LTF	6.3%	4.7%	5.5%	5.4%	3.2%	
2.6 Percentage of all infants with a REFER who were lost to documentation	3.4%	2.4%	2.1%	2.3%	1.1%	
2.7 Percentage of infants >1800 grams with a REFER who were lost to documentation	3.0%	1.9%	2.0%	2.3%	1.2%	
2.8 Percentage of infants ≤1800 grams with a REFER who were lost to documentation	3.2%	3.8%	5.5%	2.7%	0.0%	





Indicator	Annual Percentages					5-Year Trend
	2011	2012	2013	2014	2015	
3.1 Percentage of infants with congenital hearing loss who received an ENT/ORL <sup>1</sup> evaluation by 4 months of age	48.7%	50.8%	49.7%	57.6%	60.5%	
3.2 Percentage of infants with congenital hearing loss who received a genetics evaluation by 1 year of age	27.4%	38.5%	34.2%	34.1%	26.9%	
3.3 Percentage of infants with congenital hearing loss who received a pediatric ophthalmology evaluation by 6 months of age	11.8%	29.4%	7.1%	27.1%	22.2%	
3.4* Percentage of infants with bilateral hearing loss whose parent(s) chose personal amplification and who were fit within 1 month of diagnosis	34.5%	35.3%	32.7%	34.2%	39.4%	
3.5 Percentage of children diagnosed before 3 years of age who were reported to be enrolled in Part C Early Intervention services <sup>2</sup>	67.3%	82.3%	76.0%	79.5%	69.6%	
3.6 Percentage of infants with congenital hearing loss who were reported to be enrolled in Part C Early Intervention services by 6 months of age	70.3%	62.0%	67.6%	75.2%	67.8%	
3.7 Percentage of children diagnosed before 3 years of age who were reported to be enrolled in the Deaf Mentor or D/HH Role Model Program	Data not available			1.6%	3.5%	
3.8 Percentage of children diagnosed before 3 years of age who were reported to be receiving private speech therapy	Data not available			3.8%	2.4%	
3.9 Percentage of children diagnosed before 3 years of age who reported to be enrolled in Part C Early Intervention services within 2 months of initial hearing loss diagnosis	37.0%	52.9%	50.0%	61.3%	46.7%	

<sup>1</sup> Otolaryngology

<sup>2</sup> Part C Early Intervention provides services that promote early learning and development for children 0-3 with disabilities.

# DATA CONTINUED



Indicator	Annual Percentages					5-Year Trend
	2011	2012	2013	2014	2015	
3.10* Percentage of families of infants/children ages 0-10 years who received direct family-to-family support within one month of their child's diagnosis	24.1%	21.2%	45.3%	46.3%	47.3%	
3.11 Percentage of families of children ages 0-6 years who requested a mentor from the Deaf Mentor Family Program and began the SKI-HI curriculum <sup>1</sup> with a mentor within 30 days of their request	Data not available			50.0%	16.7%	
4.1 Percentage of infants and children identified with late onset, progressive, or acquired hearing loss	6.6%	13.6%	14.8%	25.0%	21.4%	
5.1 Percentage of infants/children who had a primary care provider at the time of diagnosis	98.9	98.6%	96.4%	96.3%	99.1%	
6.1 Percentage of newborn hearing screening records matched with vital records	99.4%	99.8%	99.7%	99.4%	99.1%	
6.2 Percentage of audiology reports received by MDH within 10 days of appointment	84.4%	83.2%	83.8%	84.3%	86.3%	
6.3 Percentage of infants who had incomplete or unreported hearing screening	1.4%	1.2%	0.8%	1.2%	0.9%	
6.4 Percentage of requested follow-up reports received from audiologists identified as caring for infants/children with permanent hearing loss	95.4%	90.4%	84.0%	97.5%	95.5%	
6.5 Percentage of requested follow-up reports received from primary care providers identified as caring for infants/children with permanent hearing loss	57.2%	91.8%	94.0%	95.7%	95.9%	

\*The definitions for these indicators have changed. Values from previous years have been updated to reflect these changes, so they may not match previous reports. To view definitions for all indicators, please visit the Minnesota EHDI website.

<sup>1</sup>SKI-HI (Sensory Kids Impaired Home Intervention) program offers support and resources in natural environments for families with children 0-5 who are D/HH

# THINGS TO LOOK FOR IN 2016

Our work to ensure that all Minnesota newborns and infants who are D/HH are identified early and receive appropriate and timely intervention services is far from finished. We continue to partner with our EHDI stakeholders, engage in quality improvement projects, and strive to reduce disparities in our EHDI system. Here are a few things to watch for in 2016 as we work to make the 1-3-6 goals a reality for all newborns in Minnesota and improve outcomes for children who are D/HH.

## Enhanced MDH-EHDI data to guide efforts and improve outcomes

The use of information can be a powerful vehicle for improving the health of a community. It can highlight both the existence of problems and opportunities for improvement. It can also guide and improve effectiveness. In 2016, watch for exciting improvements in how MDH's EHDI program is able to use data to answer important questions related to both the most common difficulties that families face after identification of hearing loss and the development and learning of children who are D/HH in Minnesota.

## Engagement of parents and professionals in quality improvement (QI) initiatives

QI consists of systematic and continuous actions that lead to measurable improvement in health care services and the health status of targeted groups. In 2016, watch for news on EHDI related QI initiatives that have engaged both parents and professionals to reduce time to diagnosis, decrease disparities for children born to mothers from diverse communities, and improve access and coordination of materials provided to families of children who are D/HH.

## Support the use of technology to improve the EHDI system

The use of health information technology (HIT) can improve the quality of care by reducing errors, providing reminders and alerts for health care providers and patients, enhancing clinical decision support, and decreasing the cost of care. In 2016, watch for information on how the MDH-EHDI program has utilized HIT to improve reporting of hearing screening data and provide an opportunity for hospitals and clinics to receive incentive payments. In addition, the 2016 report will include information on partnerships that use HIT to improve care for children who are D/HH by linking families to providers through the use of tele-health and improving access to loaner hearing aids.



*I'm so glad we live in Minnesota I know that not everyone is so lucky to have the support that we do. We've really taken advantage of it. There is so much available, right from the very beginning. It's made a huge difference, we could have never done this without the support of the states that we've lived in and all the programs.*

Joyce, Emory's mom





Minnesota  
Department  
of Health

# EARLY HEARING DETECTION & INTERVENTION

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## 2015 ANNUAL REPORT

For more information, contact:

The Early Hearing Detection and Intervention Program  
Minnesota Department of Health  
601 Robert Street North  
Saint Paul, MN 55155

Phone: (651) 201-5466

Toll-free: (800) 664-7222

Fax: (651) 215-6285

Email: [ehdi@state.mn.us](mailto:ehdi@state.mn.us)

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

Newborn Screening:

[www.health.state.mn.us/newbornscreening](http://www.health.state.mn.us/newbornscreening)

Children and Youth with Special Health Needs:

[www.health.state.mn.us/cyshn](http://www.health.state.mn.us/cyshn)



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## THANKS

A special thank you to all of the stakeholders who work to improve Minnesota's EHDI system. This system is made up of *many* dedicated people and programs all working to improve the lives of Minnesota's children. The MDH-EHDI program is just one part of this important system.

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