Early Hearing Detection & Intervention for all Minnesota Children

MDH EHDI annual report 2014

MINNESOTA MDH DEPARTMENT OF HEALTH

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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
LTFU	Lost to follow-up
LTFU/D	Lost to follow-up or documentation
MDE	Minnesota Department of Education
MDH	Minnesota Department of Health
MNHV	Minnesota Hands & Voices

A LETTER FROM THE EHDI TEAM

Dear Reader,

Hearing loss is one of the most common congenital conditions in Minnesota. Each year, approximately 250 infants are born with hearing loss. Without early identification and intervention, children with hearing loss often experience delayed development in language and learning.

The Minnesota Department of Health (MDH) Early Hearing Detection and Intervention (EHDI) program collaborates with hospitals, midwives, physicians, audiologists, local public health (LPH) departments, early intervention programs, and other partners to ensure that infants with hearing loss are identified early and receive appropriate and timely intervention services for optimal developmental outcomes. The ultimate goal of our program is to maximize linguistic competence and literacy development for children who are deaf or hard of hearing (D/HH).

We strive to accomplish that aim by ensuring that all infants achieve the national recommendation of:

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

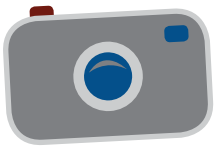
In all of our work—whether it relates to screening, diagnosis, or early intervention services—we strive for continual quality improvement. Throughout this report, we share stories of several quality improvement projects and initiatives we have undertaken this year, including:

- The implementation of MNScreen for electronic reporting of results (page 5)
- Quality assurance reports and open discussions with audiologists (page 9)
- Collaboration with LPH nurses to reduce loss to follow-up (page 11)
- Participation in a national survey to assess Minnesota physicians' current knowledge, attitudes, and practices regarding hearing screening, diagnosis, and intervention (pages 6, 9, and 15)

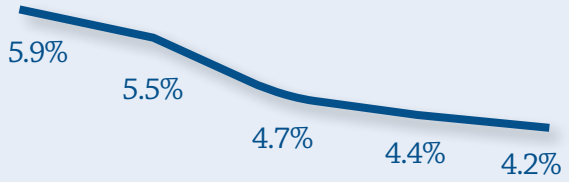
As we continue to strive to make the 1-3-6 goals a reality for all newborns in Minnesota, we look forward to working with you—our stakeholders, our partners, and our public.

The EHDI Team

DATA SNAPSHOTS FROM 2014



67,780 newborns screened for hearing loss in 2014, with a REFER rate of **4.2%**



A REFER result means an infant did not pass screening.

National guidelines recommend a REFER rate of 4% or less. Minnesota has made progress toward this goal each year.

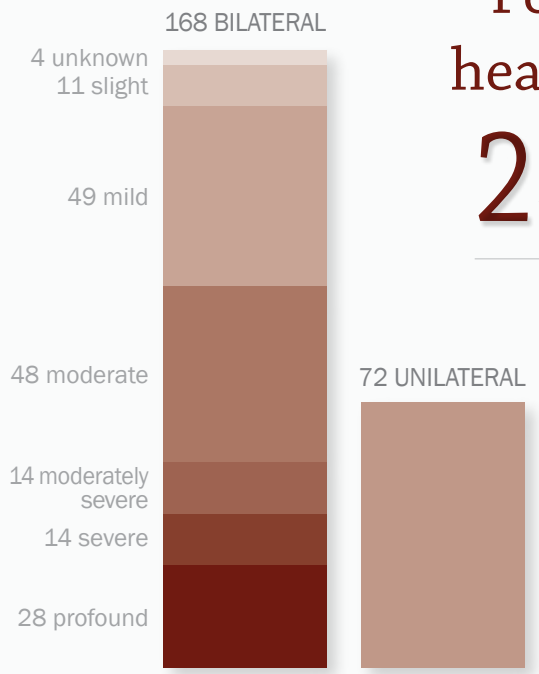
98.9% of Minnesota newborns were SCREENED in 2014.

75 parents chose to OPT OUT of screening (0.11%).

Remaining newborns have no documented screen.

Permanent hearing loss:

259 cases reported to MDH



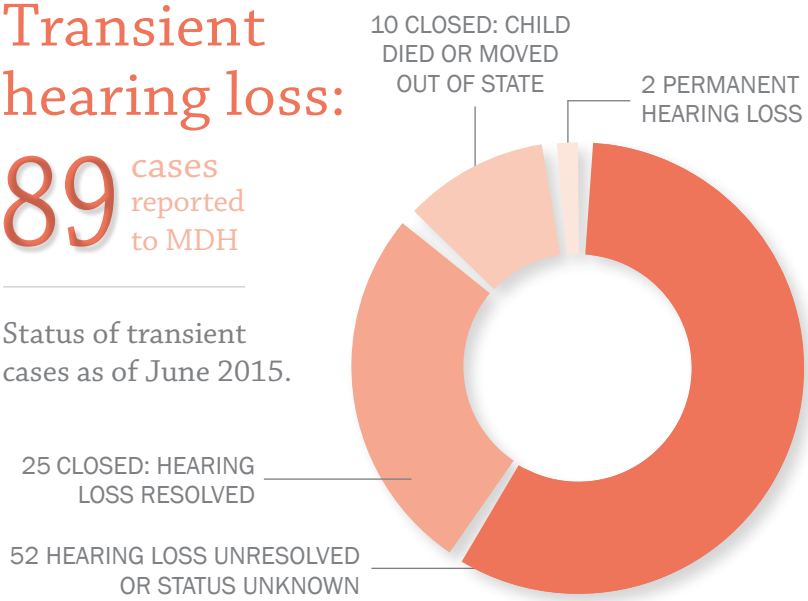
Laterality and severity of cases.

Bilateral cases are classified by better functioning ear. Closed cases (15) not pictured.

Transient hearing loss:

89 cases reported to MDH

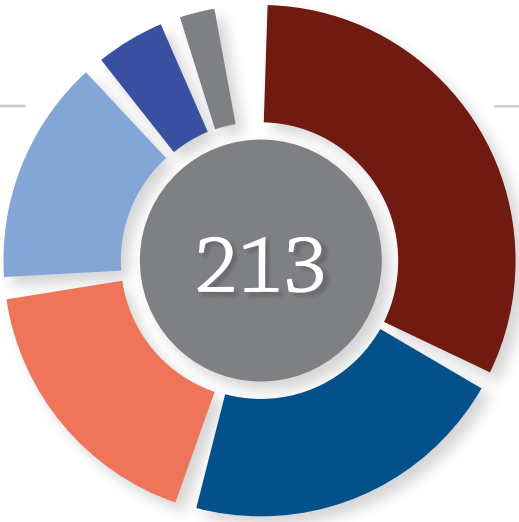
Status of transient cases as of June 2015.



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

- no audiology appointment (33%)
- primary care provider unknown (22%)
- no show to 2+ appointments (19%)
- audiology process discontinued (15%)
- prolonged diagnosis (6%)
- no insurance (3%)

Other reasons include: primary care provider chose not to rescreen (0.9%), primary care provider not returning contact (0.9%), and no diagnosis expected due to comorbidities (0.5%).



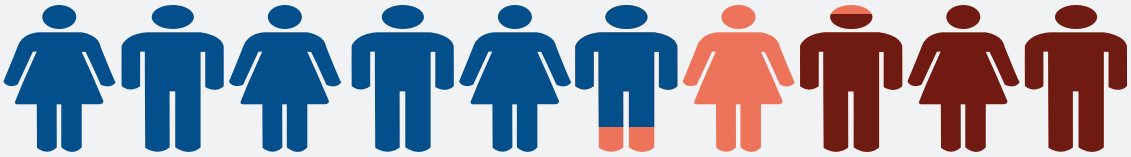
213 newborns with REFER results were LTFU/D in 2014

TIME TO DIAGNOSIS

58% of infants were diagnosed **within 90**

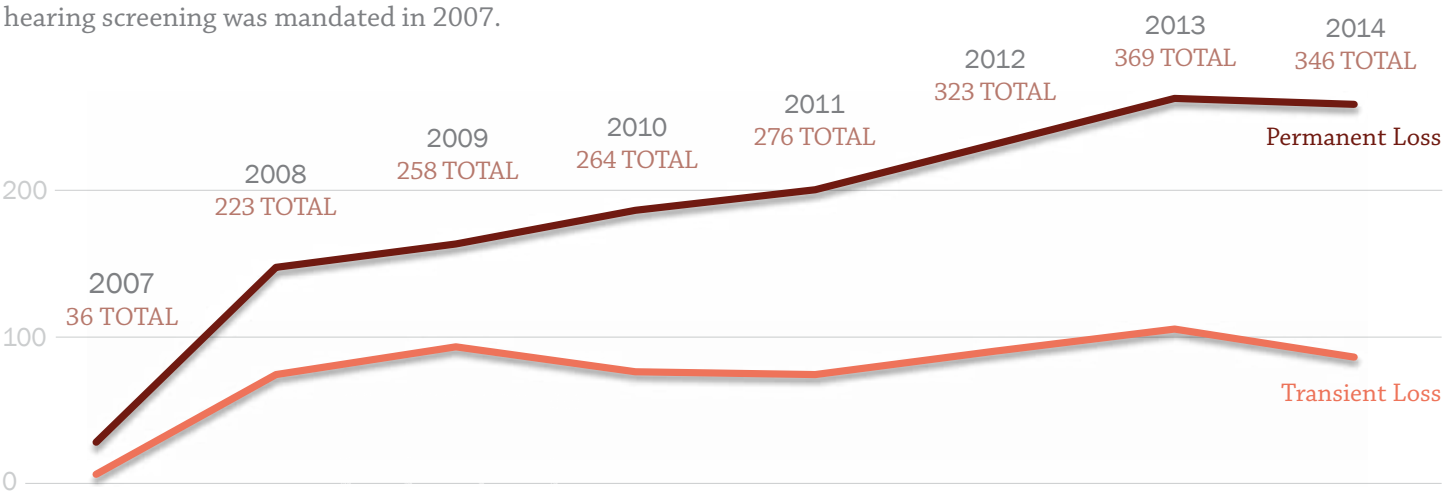
13% of infants were diagnosed **within 90-180 days of birth**

29% 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

TIMELY SCREENING

The quality and timeliness of screening, reporting results, and follow-up directly impact the diagnosis and intervention options for infants. We work continuously to increase the percentage of infants who complete screening (both initial and any rescreens) before one month of age, to improve timely reporting and accuracy of screening results reported, and improve timely follow-up for infants who do not pass the initial screen. This year, statewide data shows improvements in timely reporting, and that 98.7 percent of Minnesota newborns were screened before 1 month of age.

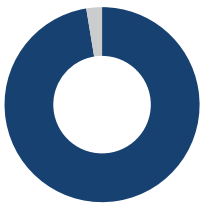
Program goal:

1

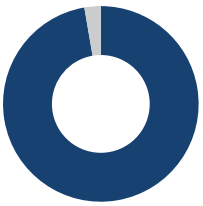
All newborns will complete a hearing screening before 1 month of age, preferably before hospital discharge.

Our progress in recent years:

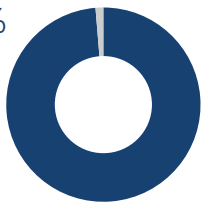
97.4%
2010



97.3%
2012



98.7%
2014



Numbers above do not include newborns weighing ≤ 1800 grams at birth and refer to initial screening only.

"Screening allowed us to communicate appropriately with Bryce right after he was born. Our research indicated that early communication is paramount to socialization and cognitive development.

-Alina and Claude, Bryce's parents"

MNScreen

Results reporting in real time

We took a significant step forward this year in our move toward real-time electronic reporting of hearing and pulse oximetry screening results, a move designed to improve the efficiency of both data collection and follow-up care coordination for children who do not pass the screens.

The Newborn Screening Program contracted with OZ Systems to provide MNScreen, a secure, web-based system for reporting screening results to the Program. As of June 2015, more than half of Minnesota's birth facilities and practices are actively implementing the new system.

MNScreen is made up of three processes. The first collects the infant's information from the facility and securely and automatically sends it to the Newborn Screening Program. This allows the Program to get an accurate and timely count of all newborns who have yet to undergo screening.

The second part of the system electronically captures data from the screening device once screening is complete. This takes the place of manual reporting of results, making accurate screening results available in real time.

The third part of MNScreen is the web-based integrated child health record. This record allows Newborn Screening Program and birth facility staff to view referrals, appointments, and final outcomes all in one place.

MNScreen also allows both Newborn Screening Program staff and birth facilities to monitor their own screening programs on an ongoing, real-time basis, which will help improve services for all Minnesota newborns. In the future, outpatient providers will also have access to MNScreen to report diagnostic test results and refer newborns for other early interventions as needed, helping to improve access and reduce disparities in care.

Our staff members have conducted **30** MNScreen trainings as of June 2015. Pictured above, midwives learn how to use MNScreen for out-of-hospital births.

minnesota physicians say...

In 2012, our program participated in a national survey of physicians to assess their knowledge, attitudes, and practices regarding newborn hearing screening. Altogether, 142 Minnesota physicians—primarily pediatricians, family practitioners, and otolaryngologists—completed the survey. The results of the survey were released in 2014. Look for the *Minnesota Physicians Say...* boxes in the following sections for more survey highlights!

Only **16%** of respondents knew that additional testing for newborns who do not pass the initial screen should be completed by 1 month of age.

We continue to work to communicate screening recommendations to primary care providers.

Our EHDI program has published **9 guiding documents** for providers with recommendations regarding early screening, diagnosis, and intervention.

New and revised provider guidelines

Part of our role in improving early hearing detection and intervention in Minnesota is to create and disseminate best practice guidelines for providers. This year, we worked with members of our Newborn Hearing Screening Advisory Committee to revise state guidelines for screening in out-of-hospital birth settings, as well as create a new set of guidelines for otolaryngologists.

The *Guidelines for the Organization and Administration of Universal Newborn Hearing Screening Programs for Out-of-Hospital Births* now include recommendations for teaching and maintaining the skills of qualified screeners, in addition to a new section emphasizing strategies for program quality assurance and improvement.

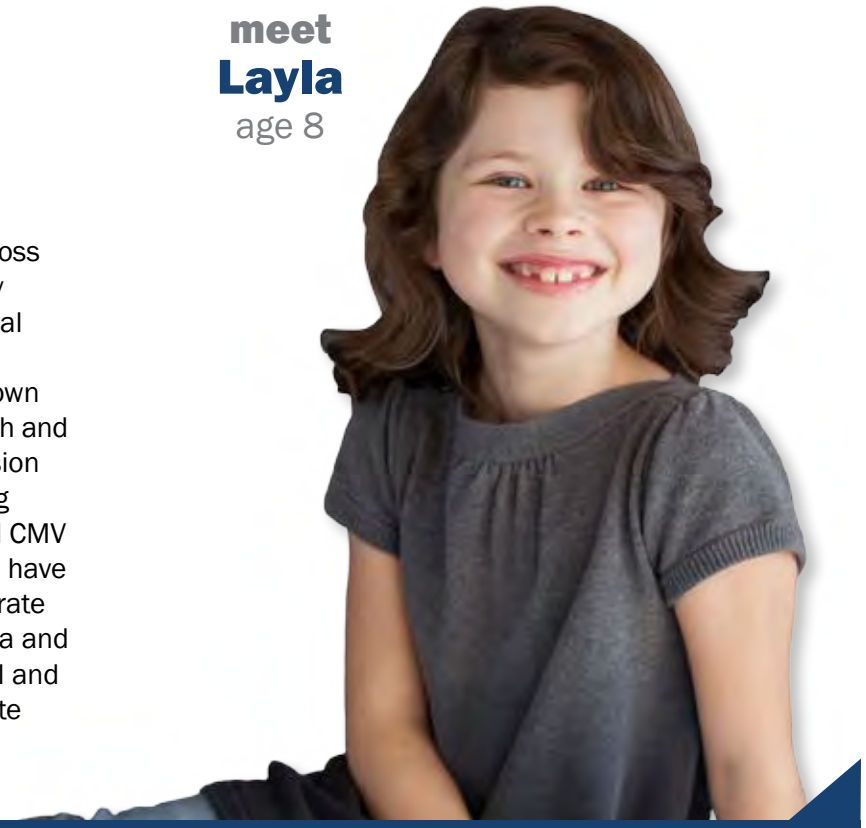
We created the *Guidelines for Otolaryngologists* to highlight several key messages for the providers, including the importance of timely follow-up and definitive diagnosis of hearing loss. These new guidelines were part of a broad outreach plan focused on educating otolaryngologists this year (refer to page 10).

All recommendations align with current state and national standards and are designed to promote consistency and best practices related to early hearing detection and intervention. Guidelines are not only posted on our EHDI website, but we also share them with stakeholders through direct mailings, electronic notifications, and professional associations. The quarterly *Sound Matters* newsletter also includes a notice when guidelines are created or revised to keep audiologists up to date.

Integrating CMV screening with EHDI

Cytomegalovirus (CMV) is the most common congenital infection and the most common nonhereditary cause of sensorineural hearing loss in children. Recognizing this critical opportunity for education, prevention, and screening, several states have begun evaluating how to integrate CMV programs within their EHDI systems. Our own program is currently reviewing the latest research and policies to see how CMV may fit within our mission and vision, and our Newborn Hearing Screening Advisory Committee has added CMV as a standing agenda item. We have also recently agreed to collaborate with the University of Minnesota and the Centers for Disease Control and Prevention in a study to evaluate screening methods for CMV.

~1%
of babies are born with CMV



meet Layla
age 8

Layla was diagnosed with hearing loss shortly after not passing newborn hearing screening. She was fitted with her first pair of hearing aids at just three weeks old from the Lions Infant Hearing Aid Loaner Program. These are her words.

Tell me what it is like to have hearing loss.

Layla: It is fun, exciting, and a tiny bit scary. If I ask myself why is it scary, it's because when you go into public I worry people will react in a way that makes me uncomfortable. But, it is fun and exciting because you have something different from other people. It is really nice being unique. I still make lots of friends easily and I've never had anyone ever tease me.

What are the best parts?

Layla: It is fun to have a unique part of your style. Not everyone in the whole entire universe has hearing loss. I think hearing aids go really well with my unique style.

Also, when someone is saying something I don't want to hear, I can just turn off my hearing aids. That is kind of funny!

What are the hardest parts?

Layla: Taking care of my hearing aids, cleaning them and changing my batteries is a lot of work.

What do you do when other kids ask you about your hearing aids?

Layla: When kids ask me a lot of questions it gets kind of annoying. If I'm not in the mood to explain I tell them, "I'm not in the mood to talk about it right now." Otherwise, I explain it like this, "When I was born I had hearing loss and to help me hear better I got hearing aids. I wouldn't be able to hear you right now if I didn't have my hearing aids."

Anything else you would like to share?

Layla: I really enjoy having hearing loss. It is fun, easy, and most of all I love being different from other people in my family.

timely diagnosis

TIMELY DIAGNOSIS

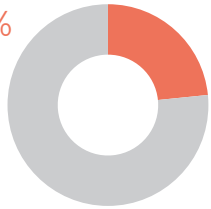
In 2014, nearly all Minnesota newborns were screened for hearing loss at birth. However, 8 percent of infants were considered lost to follow-up or documentation (LTFU/D). A newborn who is LTFU/D did not pass newborn hearing screening and did not complete further hearing tests to confirm or rule out a diagnosis of hearing loss. This year, we worked to decrease time to diagnosis and reduce the number of infants considered LTFU/D through outreach to otolaryngologists, quality assurance reports for audiologists, and partnerships with LPH.

Program goal:

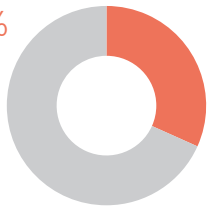
3 All newborns who do not pass screening will have a definitive diagnostic audiologic evaluation before 3 months of age

Our progress in recent years:

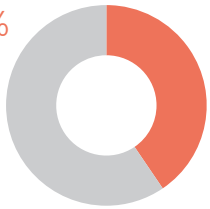
23.4%
2010



31.7%
2012



40.5%
2014



Numbers above do not include newborns weighing ≤ 1800 grams at birth.

"Because we found out so quickly about Kendra's hearing loss, she was able to get cochlear implants in record time. Kendra is now two years old and doing amazing!

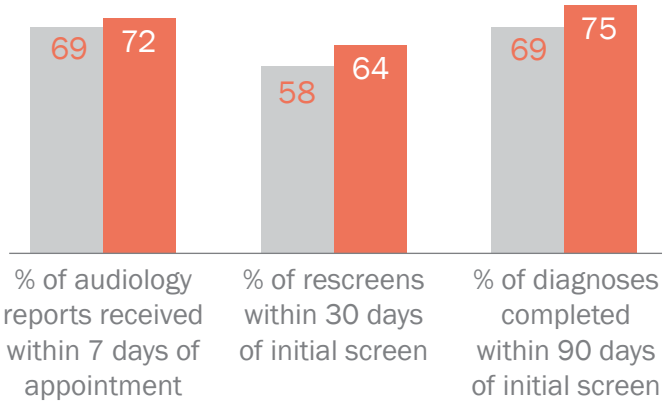
-Jennifer, Kendra's mom"

Audiology quality assurance reports bring statewide results

As part of our goal to promote quality improvement in meeting the national 1-3-6 timeline, we began providing audiology facilities quality assurance reports beginning in 2013. These reports include site-specific data alongside statewide data, allowing facilities to see how they compare. They also highlight the 1-3-6 standards with data showing the percentage of patients receiving a timely audiologic rescreen, percentage of confirmed hearing loss cases diagnosed by three months, and time from diagnosis to connection with early intervention services and hearing aid fitting.

Last year, we met with 24 audiology facilities to share the initial round of quality assurance reports and to encourage open discussion about barriers to follow-up. Since then, we have continued to partner with individual facilities as they work to reduce the time from initial screen to outpatient rescreen. Ideally, reducing the time to final outpatient screen will expedite diagnosis and subsequent connection with early intervention services.

Statewide Performance in 2013 and 2014



From 2013 to 2014, we observed statewide improvements in time to reporting by audiology facilities, the percentage of infants who received a rescreen by 30 days after the initial screen, and the percentage of diagnoses occurring by 90 days from the initial screen. We believe these improvements are due in part to our renewed relationships with audiology facilities and hope that the quality assurance reports will encourage and aid facilities in meeting the 1-3-6 goals.

minnesota physicians say...

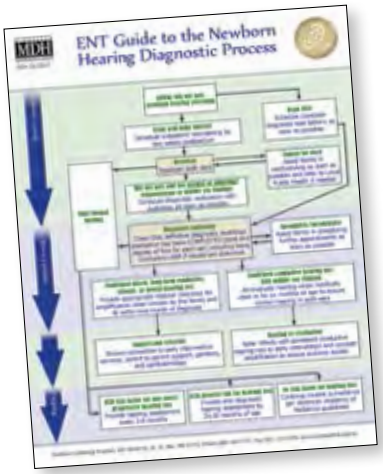
Only **23%** of respondents feel that their training adequately prepared them to meet the needs of infants who are D/HH.

To fill this gap, we provide just-in-time information to all physicians caring for a child newly identified as D/HH.

Reducing delays due to fluid

A review of program data shows that the suspected presence of middle ear fluid often causes delays in diagnosis. Too many infants in recent years who did not pass newborn hearing screening did not receive a diagnosis by three months of age because of a delayed diagnostic referral while waiting for the fluid to resolve. In 2008 and 2009, about 70 percent of infants with unknown hearing status at six to eight months of age were not referred to diagnostic testing because of suspected middle ear fluid, even after multiple audiology or otolaryngology visits.

To reverse this trend, we focused recent outreach efforts on increasing awareness in the otolaryngology or Ear, Nose and Throat (ENT) specialist community that diagnosis must not be delayed due to middle ear dysfunction. Outreach included:



- The development and distribution of EHDI Guidelines for Otolaryngologists
- The development of a quick reference ENT flowchart and guide to the newborn hearing diagnostic process
- An exhibit table at the annual Minnesota Academy of Otolaryngology (MAO) meeting and the distribution of our ENT flowchart and guide to attendees
- A message in the MAO newsletter highlighting key EHDI priorities

In recent years,

70%

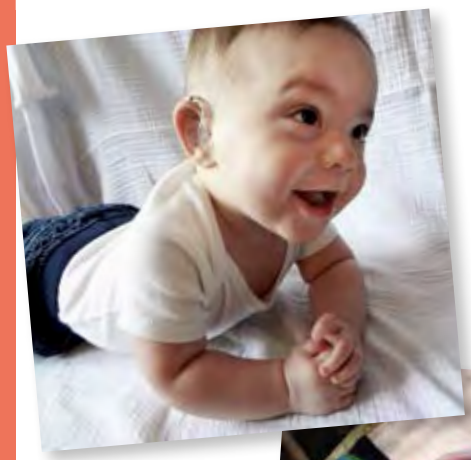
of infants with unknown hearing status at 6-8 months had delayed diagnosis due to middle ear fluid.

"My little Max and Alex came into this world early due to complications of the twin pregnancy. Just before discharge, the nurse performed a second newborn hearing screen on Max because he did not pass the first. Unfortunately, he did not pass once again.

We followed up with an audiologist to have a diagnostic test. When the audiologist told me "Max has severe hearing loss in both ears," I was stunned. This was not what I had expected.

I took a short time to grieve but then dove into the world of hearing loss by learning sign language, searching for community resources, and more. I am so thankful we live in a time when hearing loss is identified early and intervention can begin right away. I know that Max has been given the same opportunities as any other child because of it.

-Allison, Max's mom"



meet Maximus
age 1

In 2014, LPH nurses in Minnesota helped **17 kids** with hearing loss complete diagnosis who otherwise would have been LTFU/D.

Quality improvement with local public health partners

Hearing Loss:
Is it important to test again?

What if my baby reacts to loud sounds, or when I clap next to his head?

Some babies with hearing loss will still look or make a face when there is a loud noise, like clapping or banging pots. This depends on the level of hearing loss in each ear. Even when babies can hear loud noises, they may not be able to hear all of the sounds that are important for speech development.

Hearing loss isn't very common, so my baby is probably fine, right?

Hearing loss is one of the most common conditions that can be identified at birth. Your baby had a "refer" result from the newborn screening test, which means that some level of hearing loss was found. This could be because of some fluid in the ear(s) which might go away, but there could be a permanent cause.

My baby has fluid in his ear, will the test still work correctly?

Yes - it is important to know if the hearing loss is just from the fluid, or if it is permanent. The test can be done before all of the fluid is gone from the ear(s).

My baby can't talk yet, so there isn't a rush to see if he has hearing loss. Can we test again later if we notice anything?

Babies who are identified early can start early intervention and get connected to resources. Interventions (ex. hearing aids) help prevent speech and language delays. Even before a baby can talk they are learning what different words sound like and other important pieces of language and talking.

Newborn Screening Program, 601 Robert St. N., St. Paul, MN 55155. Phone (651) 696-7772. Fax (651) 215-9280
Minnesota Early Hearing Detection and Intervention (EHDI) | www.dhsmnehdi.org/ehdi
Updated 2014 | This photo: shutterstock/Ryan Jorgensen

To reduce the number of infants considered LTFU/D, our program contracts with LPH agencies to provide follow-up, complete documentation, address barriers, and help families receive additional hearing tests when our program is unable to ensure complete follow-up has occurred. This year, we joined forces with six LPH nurses who participated in a quality improvement collaborative aimed at increasing their success.

Between April and December, the nurses used quality improvement tools to identify the likely causes for LTFU/D in Minnesota. They also brainstormed ideas for improvement, including enhanced parent education, improved contact information, and better ways to contact families. Each nurse then developed and tested targeted strategies related to the improvement ideas.

We put several ideas into practice right away, including the development of a parent educational handout stressing the importance of follow-up screening and a checklist for LPH nurses recommending the most successful follow-up strategies.

Our staff also learned that LPH agencies located in relatively small counties have had success in contacting hard-to-reach families by leveraging the connections of local maternal and child health programs. These local partnerships help account for the vast difference in success rates in reducing LTFU/D between large metro counties (22 percent of cases resolved in 2014) and the rest of the counties throughout the state (55 percent of cases resolved in 2014). Our staff are currently looking for ways to improve these connections for all counties.

timely intervention

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 2014, we continued to reduce delays in connecting families to these services. Among children newly diagnosed as D/HH this year, almost 9 of every 10 families were connected to parent-to-parent support through MNHV, and about 8 of every 10 children were connected to early intervention programs.

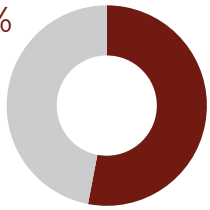
Program goal:

6

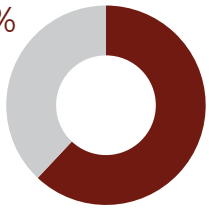
All infants identified as D/HH will receive appropriate early intervention services before 6 months of age.

Our progress in recent years:

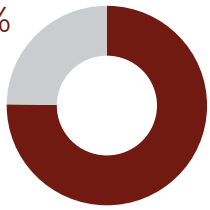
53.0%
2010



62.0%
2012



75.2%
2014



"It gave [me] knowledge of tools and resources to use, now and in the future, to keep my son's learning on track."

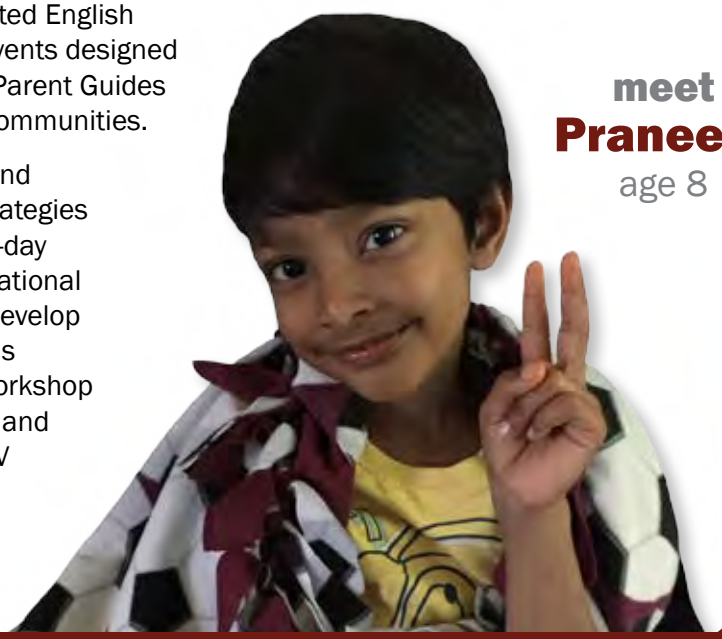
-Parent at ASTra

Parent support through MDH-funded Minnesota Hands & Voices

Funding from our EHDI program allows Minnesota Hands & Voices (MNHV)—a parent-driven nonprofit organization dedicated to supporting families of children who are D/HH—to offer support to families of children who are D/HH in MN. Parents report that they find enormous value in connecting with other parents who share similar experiences in order to learn from each other and gain moral support and encouragement. Data also shows that trained parents who provide emotional support and assistance to families of children who are D/HH can improve family outcomes.

MNHV outreach to families comes in many forms, including one-on-one support, connections to resources, and coordinated events. Group events provide opportunities for families to learn about their child's hearing loss, connect with each other, and meet adult role models who are D/HH. Because MNHV offers unique cultural and linguistic support, these coordinated events are particularly valuable for families with limited English proficiency. This year, nearly 200 people attended events designed and lead by Spanish-speaking, Hmong, and Somali Parent Guides for families of children who are D/HH within these communities.

MNHV also hosted its first-ever Advocacy, Support, and Training (ASTra) event in April for parents to learn strategies for addressing the needs of D/HH learners. The one-day workshop included sessions with experts from the national Hands & Voices headquarters who helped parents develop their advocacy skills and increase their confidence as advocates for their children's unique needs. Each workshop session was recorded and is available with captions and American Sign Language interpretation on the MNHV website for families who could not attend.



meet Praneeth
age 8

"Greetings to all those who are reading my story. We are a close-knit Indian family of four who moved to the U.S. recently for work. As though moving to a country roughly 9,000 miles away from family was not enough, we soon learned my six-year-old son Praneeth had moderate to severe unilateral sensorineural hearing loss.

In the midst of my depression, I got a call from Anne of MNHV. My usually reclusive demeanor just disappeared, and a flood of emotions came out. Her visit to my home was nothing short of Santa visiting a small child. She was like a counselor, family, friend, and guide all in one.

It's true that I might have to tread rocky terrain in the future with my son. But with the army of support I have, I am lot stronger and a lot more confident, willing to take on any challenge that may arise to help my son.

-Valli, Praneeth's mom"

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

The impact of local public health nurses

Theresa's story

"I recently worked with a young mother who is a recent immigrant to the U.S. and has a daughter with confirmed hearing loss. Mom met with MNHV and connected with a parent guide from her native country. She also began participating in an early intervention group at her child's school. Mom shared how difficult it had been to find out about her daughter's hearing loss, but that she was very appreciative of the supports she and her child were receiving.

One day, I met Mom at her daughter's school to discuss other community resources. When we stopped in to see her daughter at her early intervention group, the three-year-old greeted her mom, but she was having so much fun that she didn't want to go home. It was clear how much her daughter enjoyed this opportunity to be with other children.

Mom shared how happy her daughter was and that she wanted her to have opportunities like this in the summer when the group would not meet. I was able to give Mom information and also—with Mom's consent—contacted the Early Intervention Team at her school to see what ideas they had. These resources made a big difference in the mother and daughter's lives. But the brightest part of the experience was the look on that little girl's face as she played with the children in the early intervention group."

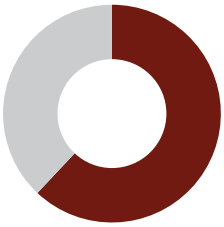
Loaner hearing devices

For the seventh consecutive year, our program awarded grant support to the Lions Infant Hearing Aid Loaner Program at the University of Minnesota. The Lions Program provides families who choose amplification access to loaner hearing devices to help 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 124 hearing devices to children identified as D/HH in 2014.

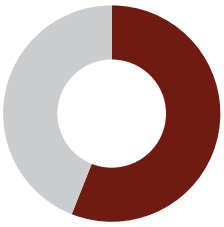
Parent hearing aid survey results

To better understand the experiences and needs of children in Minnesota who use hearing aids and their families, we participated in a seven-state survey this year by the National Center for Hearing Assessment and Management. Recent research has shown that hearing aid experiences vary greatly among young children and are dependent in part on parent knowledge, skills, and support related to their amplification.

The survey of 78 Minnesota parents—all with children with bilateral hearing loss who wore hearing aids—collected information about parent needs and desires for information, training, and support in overcoming barriers. Overall, parents reported receiving adequate support. However, we found several areas for improvement, which we shared with clinical and educational audiologists in early 2015. A few of these areas are shown in the graphs below.



62% reported receiving information about loaner hearing aids



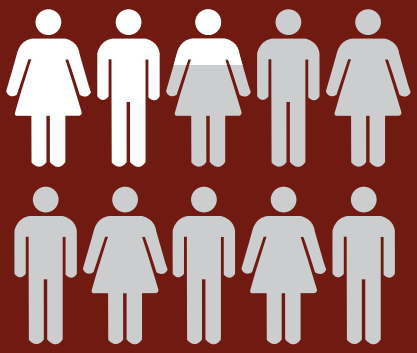
56% reported receiving training on hearing aid maintenance

25% reported wanting their **audiologist** to check in with them more often to see if they need support

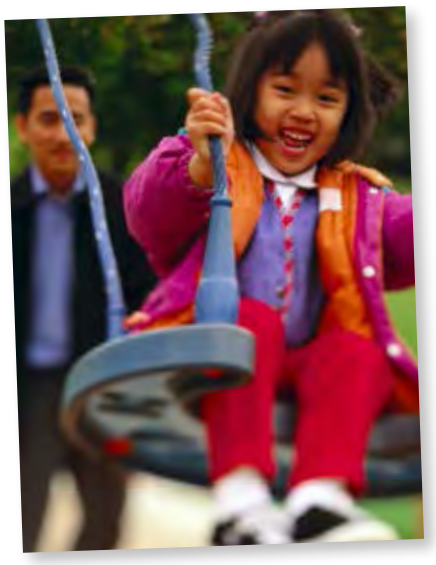
minnesota physicians say...

The Joint Committee on Infant Hearing recommends that all children who are D/HH receive an evaluation by a geneticist to determine etiology and to identify related conditions.

Only **23%** of respondents routinely refer to a geneticist.



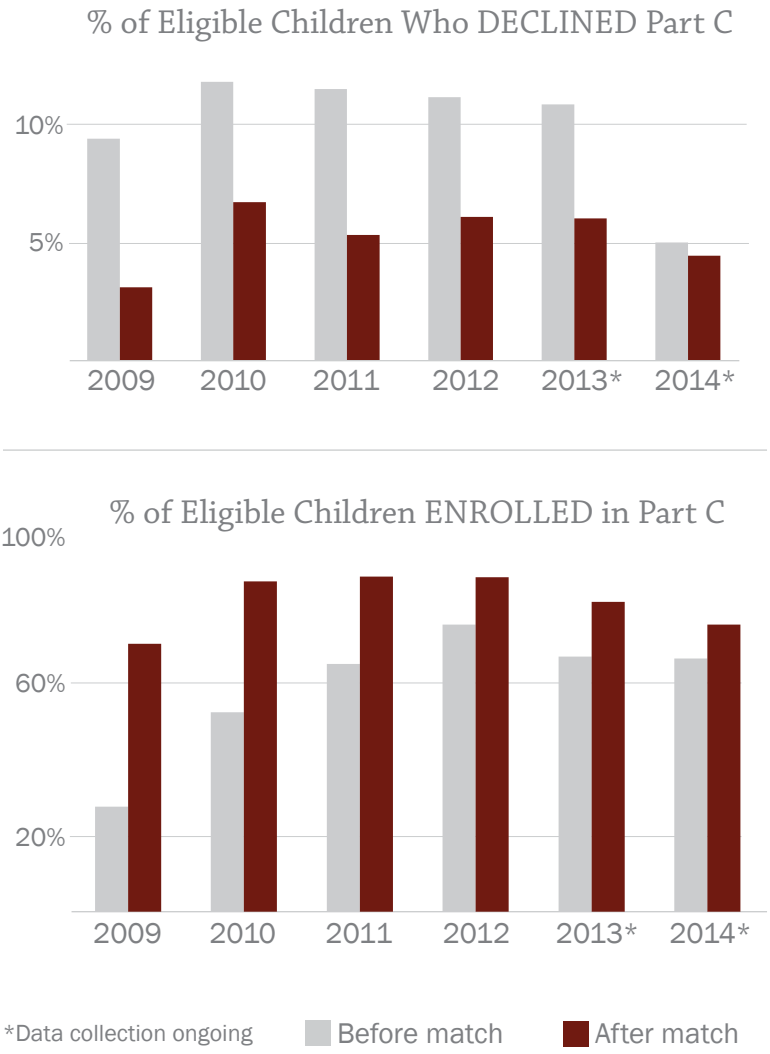
To increase referrals, we developed education materials for providers and families to highlight the importance of evaluation by geneticists.



Enhanced enrollment information through Department of Education

We are working with our partners at the Minnesota Department of Education (MDE) to improve our ability to ensure that children who are D/HH are enrolled in Part C Early Intervention services designed to meet their unique language and communication needs. Thanks to this partnership, we have a better understanding of enrollment patterns for children who are D/HH and have begun evaluating developmental outcome information as well.

In general, when we receive a report that a child is diagnosed as D/HH, we make a referral to LPH to ensure that the child is connected with Early Intervention. LPH also collects and reports enrollment information back to our program. This is the timeliest way for us to get enrollment information, but relying on this process alone has left our enrollment data incomplete. Since late 2013, however, we have begun an additional process to annually match data with MDE to update records for children whose status has changed or was previously unknown.



Before case matching with MDE, we were missing Early Intervention enrollment information for about one third of eligible children. Now we know that close to 90 percent of children do enroll in services. We have also learned that among children for whom services are initially declined, close to half enroll later on.

In reviewing the matched data, we have found that children whose families initially decline are more likely to have a less severe hearing loss and are more likely to have a mother who is Asian. However, there is no evidence of a relationship between decline of Part C services and mother's level of education, mother's age, family's preferred language, or residence in the metro area.

Children who enroll after initially declining services are more likely to have a more severe hearing loss. On average, these children enroll at around 16 months of age, though some enroll as early as three months of age and some were over two years old.

So far, developmental outcome information is only available for a small number of children. As we continue to collaborate with MDE and collect outcome information for more children, we will be able to explore how factors such as age at diagnosis, characteristics of the hearing loss, and sociodemographic characteristics are associated with developmental outcomes. We will use this information to help make sure our EHDI system meets the needs of all children and families.

A FOCUS ON DISPARITIES

This year, we took a critical look at disparities in hearing screening, diagnosis, and intervention in Minnesota based on the age, race/ethnicity, and education level of mothers. This data will help inform our efforts and interventions in years to come, so that all Minnesota newborns have access to the care and support they need for healthy development. Here are a few of our most notable findings.

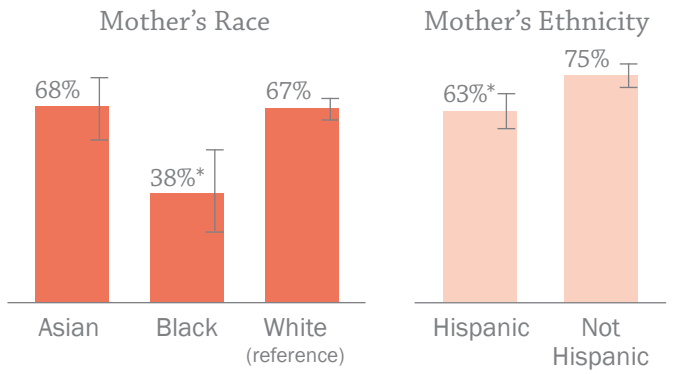
Timely Screening

Although minor disparities exist, data from 2012 shows close to 100 percent of newborns—regardless of mother's age, race/ethnicity, or education level—meet the goal of screening by one month of age. We are committed to ensuring that this trend continues in the future.

Timely Diagnosis

Data shows that significant disparities are present for all characteristics we examined—mother's age, race/ethnicity, and education level. The largest disparities are based on race/ethnicity. Children whose mother is black or American Indian are significantly less likely to be diagnosed by three months of age than children whose mother is white. Some of these disparities are depicted below.

Newborns Diagnosed by 3 Months of Age



Note: Graph combines data from 2011 and 2012. Gray bars indicate 95% confidence intervals. We will continue to compile data as it becomes available so that we can make more reliable estimates. American Indians were excluded from graph because there were too few cases.

*Statistically significant

Timely Intervention

Data on Part C Early Intervention enrollment shows important disparities by mother's race/ethnicity and age. Children whose mother is Asian or under the age of 25 are significantly less likely to enroll in Early Intervention than children whose mother is white or over the age of 25. Data also shows that infants whose mother is black or has less education are less likely to be enrolled in Early Intervention by six months of age.

Once diagnosis is complete, however, timeliness to Early Intervention showed no significant disparities. Therefore, we believe the disparities in Early Intervention enrollment by six months of age is a reflection of the disparities present in timely diagnosis.

In coming years, we will continue to promote diagnosis by three months of age so that all infants may receive Early Intervention services in a timely manner.

PROGRAM INDICATOR DATA

	Indicator	Annual Values					5-Year Trend
		2010	2011	2012	2013	2014	
1.1	Percentage of infants screened for hearing loss	98.4%	98.5%	99.1%	99.1%	98.8%	
1.2	Percentage of infants >1800 grams screened before 1 month of age	97.4%	97.3%	97.3%	98.8%	98.7%	
1.3	Percentage of infants ≤1800 grams screened before 4 months of age	87.9%	97.1%	91.5%	93.6%	92.3%	
1.4	Percentage of infants that did not pass initial screening	5.9%	5.5%	4.7%	4.4%	4.2%	
2.1	Percentage of infants >1800 grams given a REFER on initial hearing screening that were rescreened by 1 month of age	55.6%	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	23.4%	23.0%	31.7%	37.6%	40.5%	
2.3	Percentage of infants with a REFER who were lost to follow-up (LTFU)	10.8%	6.6%	5.7%	5.9%	5.6%	
2.4	Percentage of infants >1800 grams with a REFER who were LTFU	13.9%	8.4%	5.6%	5.9%	5.6%	
2.5	Percentage of infants ≤1800 grams with a REFER who were LTFU	16.6%	6.3%	4.7%	5.5%	5.4%	
2.6	Percentage of all infants with a REFER who were lost to documentation	3.4%	3.4%	2.4%	2.1%	2.3%	
2.7	Percentage of infants >1800 grams with a REFER who were lost to documentation	6.2%	3.0%	1.9%	2.0%	2.3%	
2.8	Percentage of infants ≤1800 grams with a REFER who were lost to documentation	7.6%	3.2%	3.8%	5.5%	2.7%	

	Indicator	Annual Values 2010	2011	2012	2013	2014	5-Year Trend
3.1	Percentage of infants with congenital hearing loss who received an ENT/ ORL evaluation by 4 months of age	44.0%	48.7%	50.8%	49.7%	57.6%	
3.2	Percentage of infants with congenital hearing loss who received a genetics evaluation by 1 year of age	16.0%	27.4%	38.5%	34.2%	34.1%	
3.3	Percentage of infants with congenital hearing loss who received a pediatric ophthalmology evaluation by 6 months of age	10.0%	11.8%	29.4%	7.1%	27.1%	
3.4*	Percentage of infants with bilateral hearing loss whose parent(s) chose personal amplification and who were fit within 1 month of diagnosis	38.3%	34.5%	35.3%	32.7%	34.2%	
3.5	Percentage of children diagnosed before 3 years of age who were reported to be enrolled Part C Early Intervention services	67.0%	67.3%	82.3%	76.0%	79.5%	
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	53.0%	70.3%	62.0%	67.6%	75.2%	
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%	
3.8	Percentage of children diagnosed before 3 years of age who were reported to be receiving private speech therapy	Data not available				3.8%	
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%	54.2%	52.9%	50.0%	61.3%	

DATA CONTINUED

	Indicator	Annual Values					5-Year Trend
		2010	2011	2012	2013	2014	
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	24.6%	24.1%	21.2%	45.3%	46.3%	
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 with a mentor within 30 days of their request	Data not available				50.0%	
4.1	Percentage of infants and children identified with late onset, progressive, or acquired hearing loss	9.0%	6.6%	13.6%	14.8%	25.0%	
5.1	Percentage of infants/children who had a primary care provider at the time of diagnosis	99.0%	98.9%	98.6%	96.4%	96.3%	
6.1	Percentage of newborn hearing screening records matched with vital records	99.4%	99.4%	99.8%	99.7%	99.4%	
6.2	Percentage of audiology reports received by MDH within 10 days of appointment	83.2%	84.4%	83.2%	83.8%	84.3%	
6.3	Percentage of infants who had incomplete or unreported hearing screening	2.1%	1.4%	1.2%	0.8%	1.2%	
6.4	Percentage of requested follow-up reports received from audiologists identified as caring for infants/ children with permanent hearing loss	75.0%	95.4%	90.4%	84.0%	97.5%	
6.5	Percentage of requested follow-up reports received from primary care providers identified as caring for infants/children with permanent hearing loss	39.0%	57.2%	91.8%	94.0%	95.7%	

*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.

INDICATOR HIGHLIGHT: 2.2

This year, approx. **40%** of newborns weighing >1800 grams who did not pass newborn hearing screening received an audiology evaluation by 3 months of age.

APPROXIMATE 3 PERCENTAGE POINT INCREASE FROM LAST YEAR.

INDICATOR HIGHLIGHT: 3.6

This year, approx. **75%** of infants diagnosed with congenital hearing loss were reported to be enrolled in Part C Early Intervention by 6 months of age.

APPROXIMATE 8 PERCENTAGE POINT INCREASE FROM LAST YEAR.

INDICATOR HIGHLIGHT: 3.10

In 2013 and 2014, almost **5** out of every **10** families of children under the age of 10 received direct family-to-family support within 1 month of D/HH diagnosis.

UP FROM AROUND 2 OUT OF EVERY 10 FAMILIES IN PREVIOUS YEARS.

"The early intervention teacher is wonderful. She helps me navigate my daughter's education.

I am a single mom who works seven day a week, but MNHV supports my family. Thank you for the resources that you provide.

-Anab, Ryan's mom"

"My daughter's hearing loss was detected at birth, when the doctors told us that she did not pass her hearing screening. We did not expect this, since no one on my side of the family or my husband's side has hearing loss.

I think early screening for babies is good because without early screening, I wouldn't have known my daughter has hearing loss. Plus, without early screening, you wouldn't get help from the doctors or the community—you would think your child is fine.

The second thing that was a benefit for our family was the early intervention with the school district. They provided us information and support, as well as an audiologist to go to if something went wrong with my daughter's device. Early intervention helped my daughter a lot. My daughter has had her implant for six months now, and she can already count to three and say a lot of words such as thank you, bye, and ready, set, go!

-Nasifo, Layla's mom"

EARLY HEARING DETECTION & INTERVENTION

2014 ANNUAL REPORT

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Newborn Screening:
www.health.state.mn.us/newbornscreening

Children and Youth with Special Health Needs:
www.health.state.mn.us/cyshn

THANKS

We would like to give 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.