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# Activities of the Newborn Hearing Screening Advisory Committee

Minnesota Department of Health  
*Report to the Minnesota Legislature 2015*

February 15, 2015

# **Activities of the Newborn Hearing Screening Advisory Committee**

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## **Executive Summary**

The Minnesota Newborn Hearing Screening Advisory Committee (hereafter “committee”) was established in 2007 through Minnesota Statutes §144.966. The committee is comprised of medical and educational professionals, various community stakeholders, and state and non-profit representatives. It serves as a central source of dialogue, medical and educational recommendations, and oversight for early hearing detection and intervention (EHDI) activities throughout the state.

The committee provides an essential forum for communication between varied organizations and individuals which exists in no other setting or capacity. Through the expertise of committee members, the Minnesota EHDI network is able to gather, adapt, and institute system-level advances as they emerge in national discourse. The committee provides the capacity and expertise Minnesota needs to respond to and anticipate national trends in hearing screening and hearing loss interventions.

The many guidelines and recommendations the committee produces are utilized by clinicians, families, and professionals throughout Minnesota. These guidelines inform the procedures and activities of audiologists, otolaryngologists, educational staff, hearing screeners, the Minnesota Department of Health (MDH), the Minnesota Department of Education (MDE), and others. Input from the committee’s experts allows the development of guidelines in a timely fashion. The committee provides a framework within which all stakeholders—most importantly, parents of children who are deaf or hard of hearing and adults who are deaf or hard of hearing—can exchange information and develop policy recommendations and materials, with the goal of better outcomes for Minnesota infants and children who are deaf or hard of hearing.

## **Background**

In May 2007, Minnesota enacted Minnesota Statutes §144.966, which mandated reporting of newborn hearing screening results and added hearing loss to the panel of more than 50 rare conditions screened for in Minnesota. (See Appendix A for the statutory language.)

The goal is to provide early hearing detection and intervention to maximize linguistic and communicative competence and literacy development for children who are deaf or hard of hearing. Without appropriate opportunities to learn language, these children will fall behind their hearing peers in language, cognition, and social-emotional development. Such delays may result in lower educational and employment levels in adulthood.

The legislation established an advisory committee to advise and assist the Departments of Health and Education in:

- developing protocols and timelines for screening, rescreening, and diagnostic audiological assessment and early medical, audiological, and educational intervention services for children who are deaf or hard-of-hearing;

- designing protocols for tracking children from birth through age three that may have passed newborn screening but are at risk for delayed or late onset of permanent hearing loss;
- designing a technical assistance program to support facilities implementing the screening program and facilities conducting rescreening and diagnostic audiological assessment;
- designing implementation and evaluation of a system of follow-up and tracking; and
- evaluating program outcomes to increase effectiveness and efficiency and ensure culturally appropriate services for children with a confirmed hearing loss and their families.

A 2013 amendment to Minnesota Statutes §144.966, subdivision 2(d), requires the health commissioner to report every two years (beginning in February 2015) to the chairs and ranking minority members of the legislative committees with jurisdiction over health and data privacy on the activities of the committee over the previous two years.

### **Activities of the Newborn Hearing Screening Advisory Committee**

Minnesota Statutes §144.966 charges the health commissioner with appointing members from various professional, community, and parent groups, with no fewer than two of the members being deaf or hard of hearing. Appendix B contains a list of committee members.

The Newborn Hearing Screening Advisory Committee meets quarterly in February, May, August, and November. During fiscal years 2013 and 2014, the full committee met on eight occasions with 78% of members in attendance.

Each committee meeting opened with a brief presentation from an Early Hearing Detection and Intervention professional or consumer highlighting strengths and weaknesses of the EHDI system. The presentation was paired with a presentation of EHDI data from MDH epidemiologists. Data presented included Results Based Accountability (RBA) measures, EHDI system outcome measures discussed in the *Quality Improvement Initiatives* section of this report.

The provided testimony and data set the stage for further agenda-based committee discussion, identification of system gaps and barriers, and the development of committee priorities.

### **Recommendations and Protocols Approved by the Newborn Hearing Screening Committee and Adopted by the Minnesota Department of Health**

Reflecting on system gaps and opportunities for improvement, the committee recognized the need for and prioritized the development of recommendations and protocols to improve the EHDI system. To improve efficiency, the committee maintained two to three ad hoc sub-committees or work groups which focused on the development of various protocols for screening, rescreening, diagnostic audiological, and medical and educational intervention services for children who are deaf or hard of hearing.

The committee developed, approved, and recommended the following protocols to the health commissioner during fiscal years 2013-2014. All recommendations were adopted by the Minnesota Department of Health.

- Revisions of Guiding Principles:  
“We work actively and collaboratively with valued stakeholders in the community to build the capacity of families to help their children who have hearing loss achieve optimal growth and competence in the cognitive, communication, social-emotional, functional, and physical domains of early childhood development and literacy. Our activities are investments in the health, social, and educational well-being of children with hearing loss and their families statewide.” (Vision Statement)  
[http://www.improveehdi.org/wi/library/files/Guiding%20Principles\\_rev\\_08222012.pdf](http://www.improveehdi.org/wi/library/files/Guiding%20Principles_rev_08222012.pdf)
- Guidelines for Otolaryngologists:  
“[...] to promote a more standardized approach to care for infants who receive a REFER result on their newborn hearing screen. The document also aims to promote a better understanding of the rationale for early hearing detection and intervention for the general otolaryngologist.”  
<http://www.improveehdi.org/mn/library/files/entguidelines.pdf>
- The committee developed and approved a valuable new resource for hearing screeners, *Guidelines for Hearing Screening After the Newborn Period to Kindergarten Age*:  
“These guidelines provide Minnesota-specific information and resources, including details on screening equipment, protocols, and PASS/REFER criteria, as well as referral and evaluation information for the Individuals with Disabilities Education Act Part C and Part B programs led by the Minnesota Department of Education.”  
<http://www.improveehdi.org/mn/library/files/afternewbornperiodguidelines.pdf>
- The EHDI program’s core Well-Baby Nursery Screening Guidelines were updated, providing recommended protocols for newborn hearing screening in the well-baby nursery in *Guidelines for the Organization and Administration of Universal Newborn Hearing Screening Programs in the Well-Baby Nursery*.  
<http://www.improveehdi.org/mn/library/files/wbnguidelines.pdf>
- Guidelines for the Organization and Administration of Universal Newborn Hearing Screening Programs for Out-of-Hospital Births:  
“This document is intended to provide recommended guidelines for newborn hearing screening programs for midwives delivering newborns in out-of-hospital birth settings, including home births and non-hospital birth centers. Until recently, most Minnesota midwives did not have access to screening equipment and therefore referred their clients elsewhere for screening. Thanks to a successful collaboration between the Minnesota Department of Health (MDH) and the Minnesota Council of Certified Professional Midwives (MCCPM), many Minnesota midwives are now trained as screeners and have access to equipment to screen infants for hearing loss outside of the hospital.”  
<http://www.improveehdi.org/mn/library/files/oohguidelines.pdf>

- Revision of Early Hearing Detection and Intervention (EHDI) Program Goals, Indicators, and Benchmarks:  
“The measures described in this document are based on the National Goals, Program Objectives, and Performance Measures for the Early Hearing Detection and Intervention Tracking and Surveillance System from the CDC. They are intended to be used to evaluate progress toward goals accepted by the Minnesota Newborn Hearing Screening Advisory Committee. Indicators are to be assessed annually for children reported to the Newborn Screening Program between January and December of each calendar year. Results are reported in the EHDI Annual Report.” See pages 18-28 of Appendix C, the 2013 EHDI Annual Report.

## **Evaluation**

Committee members completed a survey at the end of 2014 to report on their satisfaction with the committee and to suggest changes to the group structure or procedures. All members responded with a good, very good, or excellent rating for the committee meetings and their opportunity to participate, and all reported that the committee was moderately, very, or extremely successful in representing all perspectives and stakeholders in the EHDI system.

## **Quality Improvement Initiatives**

In 2014, the committee adopted six Results Based Accountability (RBA) measures to improve Minnesota’s Early Hearing Detection and Intervention System. The six priority population-based indicators were chosen from a set of 32 indicators previously established by the committee.

The goal of using RBA measures is data-driven decision-making. This tool is currently in use to critically examine the quantity and quality of the services provided to customers, as well as the impacts and effects of those activities.

The six measures focus on screening, early identification, and important interventions for children who are deaf or hard of hearing, such as Part C Early Intervention, parent-to-parent support, and amplification, if chosen by the family. See pages 18-28 of Appendix C for detailed information about each of these RBA measures.

The committee has devoted workgroups to focus on “Turning the Curve” (making improvements) and showing measured results in each of the committee RBA measures over the next years.

## **Conclusion**

The care and education of children who are deaf or hard of hearing motivate the members of the committee to advance Minnesota's EHDI system. Adults who are deaf or hard of hearing and the parents of children with a hearing loss join with professionals from all points in the network of care to realize the best possible outcomes for these children. The knowledge and experience that committee members bring allow the committee to guide MDH and MDE policies, so that families of children who are deaf or hard of hearing can reach better outcomes.

Committee activities are important to the continued functioning of Minnesota's EHDI program. This work includes the sharing of valuable knowledge and experience to MDH and MDE staff, and providing technical expertise and assistance in the development of best practice recommendations and protocols.

## **Bibliography**

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**144.966 EARLY HEARING DETECTION AND INTERVENTION PROGRAM.**

Subdivision 1. **Definitions.** (a) "Child" means a person 18 years of age or younger.

(b) "False positive rate" means the proportion of infants identified as having a significant hearing loss by the screening process who are ultimately found to not have a significant hearing loss.

(c) "False negative rate" means the proportion of infants not identified as having a significant hearing loss by the screening process who are ultimately found to have a significant hearing loss.

(d) "Hearing screening test" means automated auditory brain stem response, otoacoustic emissions, or another appropriate screening test approved by the Department of Health.

(e) "Hospital" means a birthing health care facility or birthing center licensed in this state that provides obstetrical services.

(f) "Infant" means a child who is not a newborn and has not attained the age of one year.

(g) "Newborn" means an infant 28 days of age or younger.

(h) "Parent" means a natural parent, stepparent, adoptive parent, guardian, or custodian of a newborn or infant.

Subd. 2. **Newborn Hearing Screening Advisory Committee.** (a) The commissioner of health shall establish a Newborn Hearing Screening Advisory Committee to advise and assist the Department of Health and the Department of Education in:

(1) developing protocols and timelines for screening, rescreening, and diagnostic audiological assessment and early medical, audiological, and educational intervention services for children who are deaf or hard-of-hearing;

(2) designing protocols for tracking children from birth through age three that may have passed newborn screening but are at risk for delayed or late onset of permanent hearing loss;

(3) designing a technical assistance program to support facilities implementing the screening program and facilities conducting rescreening and diagnostic audiological assessment;

(4) designing implementation and evaluation of a system of follow-up and tracking; and

(5) evaluating program outcomes to increase effectiveness and efficiency and ensure culturally appropriate services for children with a confirmed hearing loss and their families.

(b) The commissioner of health shall appoint at least one member from each of the following groups with no less than two of the members being deaf or hard-of-hearing:

(1) a representative from a consumer organization representing culturally deaf persons;

(2) a parent with a child with hearing loss representing a parent organization;

(3) a consumer from an organization representing oral communication options;

(4) a consumer from an organization representing cued speech communication options;

- (5) an audiologist who has experience in evaluation and intervention of infants and young children;
- (6) a speech-language pathologist who has experience in evaluation and intervention of infants and young children;
- (7) two primary care providers who have experience in the care of infants and young children, one of which shall be a pediatrician;
- (8) a representative from the early hearing detection intervention teams;
- (9) a representative from the Department of Education resource center for the deaf and hard-of-hearing or the representative's designee;
- (10) a representative of the Commission of Deaf, DeafBlind and Hard-of-Hearing Minnesotans;
- (11) a representative from the Department of Human Services Deaf and Hard-of-Hearing Services Division;
- (12) one or more of the Part C coordinators from the Department of Education, the Department of Health, or the Department of Human Services or the department's designees;
- (13) the Department of Health early hearing detection and intervention coordinators;
- (14) two birth hospital representatives from one rural and one urban hospital;
- (15) a pediatric geneticist;
- (16) an otolaryngologist;
- (17) a representative from the Newborn Screening Advisory Committee under this subdivision; and
- (18) a representative of the Department of Education regional low-incidence facilitators.

The commissioner must complete the appointments required under this subdivision by September 1, 2007.

(c) The Department of Health member shall chair the first meeting of the committee. At the first meeting, the committee shall elect a chair from its membership. The committee shall meet at the call of the chair, at least four times a year. The committee shall adopt written bylaws to govern its activities. The Department of Health shall provide technical and administrative support services as required by the committee. These services shall include technical support from individuals qualified to administer infant hearing screening, rescreening, and diagnostic audiological assessments.

Members of the committee shall receive no compensation for their service, but shall be reimbursed as provided in section 15.059 for expenses incurred as a result of their duties as members of the committee.

(d) By February 15, 2015, and by February 15 of the odd-numbered years after that date, the commissioner shall report to the chairs and ranking minority members of the legislative committees with jurisdiction over health and data privacy on the activities of the committee that have occurred during the past two years.

(e) This subdivision expires June 30, 2019.

Subd. 3. **Early hearing detection and intervention programs.** All hospitals shall establish an early hearing detection and intervention (EHDI) program. Each EHDI program shall:

- (1) in advance of any hearing screening testing, provide to the newborn's or infant's parents or parent information concerning the nature of the screening procedure, applicable costs of the screening procedure, the potential risks and effects of hearing loss, and the benefits of early detection and intervention;
- (2) comply with parental election as described under section 144.125, subdivision 4;
- (3) develop policies and procedures for screening and rescreening based on Department of Health recommendations;
- (4) provide appropriate training and monitoring of individuals responsible for performing hearing screening tests as recommended by the Department of Health;
- (5) test the newborn's hearing prior to discharge, or, if the newborn is expected to remain in the hospital for a prolonged period, testing shall be performed prior to three months of age or when medically feasible;
- (6) develop and implement procedures for documenting the results of all hearing screening tests;
- (7) inform the newborn's or infant's parents or parent, primary care physician, and the Department of Health according to recommendations of the Department of Health of the results of the hearing screening test or rescreening if conducted, or if the newborn or infant was not successfully tested. The hospital that discharges the newborn or infant to home is responsible for the screening; and
- (8) collect performance data specified by the Department of Health.

Subd. 3a. **Support services to families.** (a) The commissioner shall contract with a nonprofit organization to provide support and assistance to families with children who are deaf or have a hearing loss. The family support provided must include:

- (1) direct hearing loss specific parent-to-parent assistance and unbiased information on communication, educational, and medical options; and
- (2) individualized deaf or hard-of-hearing mentors who provide education, including instruction in American Sign Language as an available option.

The commissioner shall give preference to a nonprofit organization that has the ability to provide these services throughout the state.

- (b) Family participation in the support and assistance services is voluntary.

Subd. 4. **Notification and information; data retention and destruction.** (a) Notification to the parents or parent, primary care provider, and the Department of Health shall occur prior to discharge or no later than ten days following the date of testing. Notification shall include information recommended by the Department of Health and information regarding the right of the parent or legal guardian to discontinue storage of the test results and require destruction under paragraph (d).

(b) A physician, nurse, midwife, or other health professional attending a birth outside a hospital or institution shall provide information, orally and in writing, as established by the Department of Health, to parents regarding places where the parents may have their infant's hearing screened and the importance of the screening.

(c) The professional conducting the diagnostic procedure to confirm the hearing loss must report the results to the parents, primary care provider, and Department of Health according to the Department of Health recommendations.

(d) The Department of Health may store hearing screening and rescreening test results for a period of time not to exceed 18 years from the infant's date of birth.

(e) Notwithstanding paragraph (d), a parent or legal guardian may instruct the Department of Health to discontinue storing hearing screening and rescreening test results by providing a signed and dated form requesting destruction of the test results. The Department of Health shall make necessary forms available on the department's Web site. If a parent or legal guardian instructs the Department of Health to discontinue storing hearing screening and rescreening test results, the Department of Health shall destroy the test results within one month of receipt of the instruction or within 25 months after it received the last test result, whichever is later.

**Subd. 5. Oversight responsibility.** The Department of Health shall exercise oversight responsibility for EHDI programs, including establishing a performance data set and reviewing performance data collected by each hospital.

**Subd. 6. Civil and criminal immunity and penalties.** (a) No physician or hospital shall be civilly or criminally liable for failure to conduct hearing screening testing.

(b) No physician, midwife, nurse, other health professional, or hospital acting in compliance with this section shall be civilly or criminally liable for any acts conforming with this section, including furnishing information required according to this section.

**Subd. 7. Fees.** The commissioner shall charge a fee so that the total of fees collected will approximate the costs of implementing and maintaining a system to follow up on infants and provide technical assistance, a tracking system, data management, and evaluation. The fee shall be incorporated in the fee charged under section 144.125.

**Subd. 8. Construction.** Notwithstanding anything to the contrary, nothing in this section shall be construed as constituting newborn screening activities conducted under sections 144.125 to 144.128. Data collected by or submitted to the Department of Health pursuant to this section is not genetic information for purposes of section 13.386.

**History:** 2007 c 147 art 16 s 10; 2009 c 79 art 10 s 18; 2009 c 86 art 1 s 18; 2013 c 82 s 13-16; 2013 c 108 art 12 s 34,35

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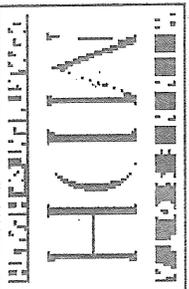
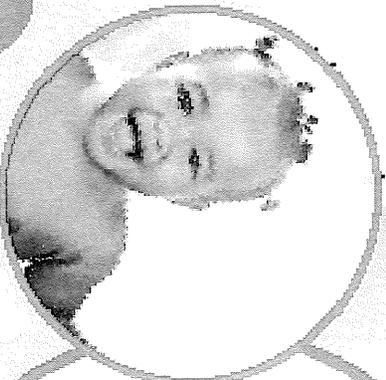
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*A representative of a consumer organization  
representing culturally deaf persons*

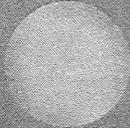
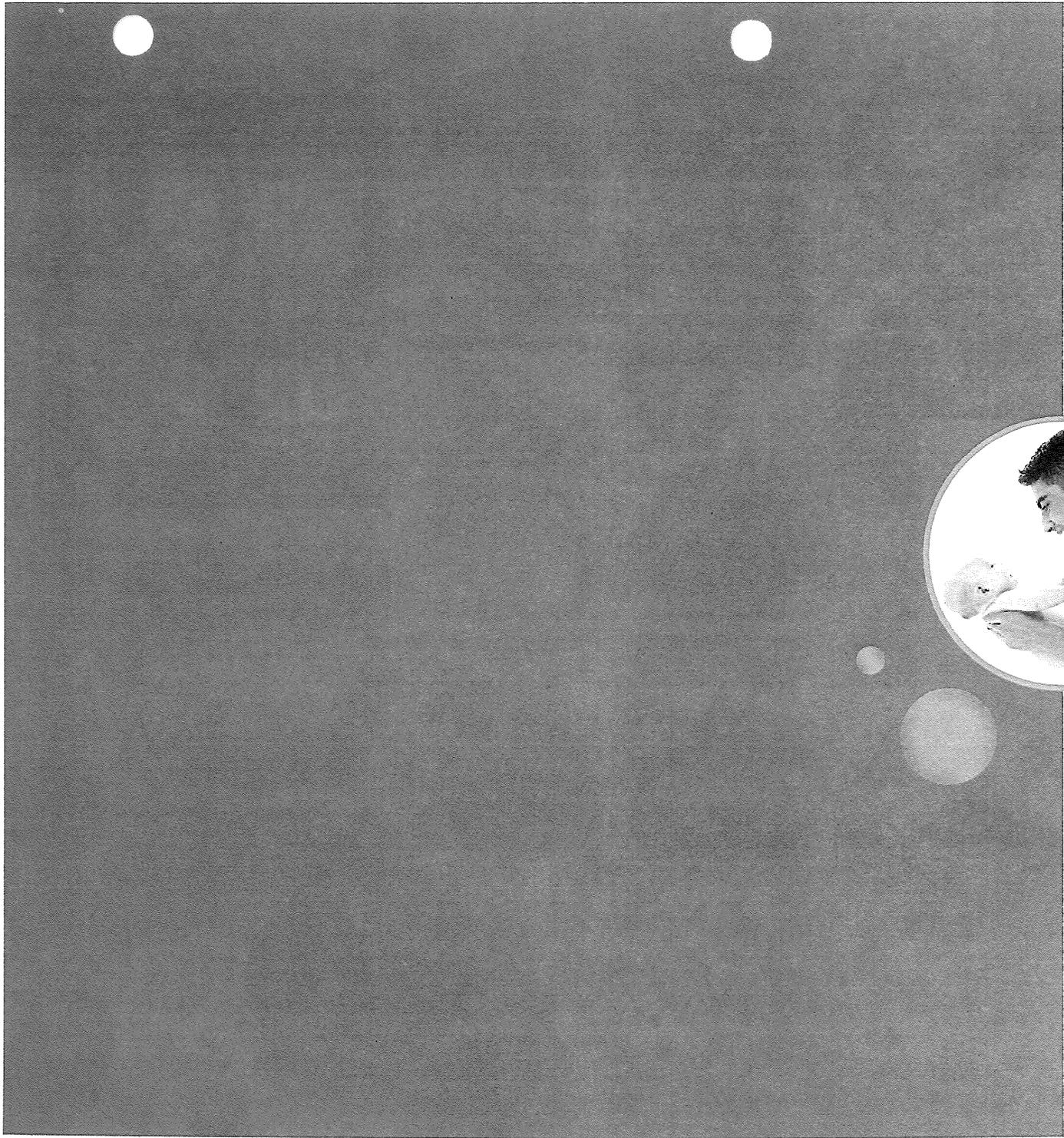
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**EARLY HEARING DETECTION AND INTERVENTION**

# EHDI ! ANNUAL REPORT 2013





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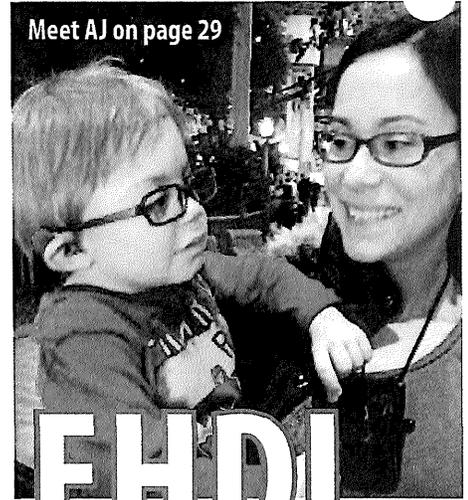
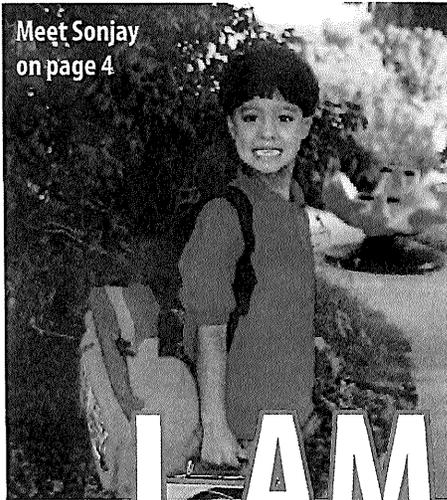
# What is EHDl?

Early Hearing Detection and Intervention (EHDl) programs are state-run programs designed to identify newborns and infants who are deaf and hard of hearing (D/HH) through universal screening so that those infants can receive timely and appropriate interventions to facilitate access to language. Children who are D/HH who receive timely services often develop language skills on par with their typical hearing peers. The ultimate mission of EHDl programs is for all infants and children to develop the language skills — whether they use visual, spoken, or a combination of communication methods — needed to reach their full academic and social potential.

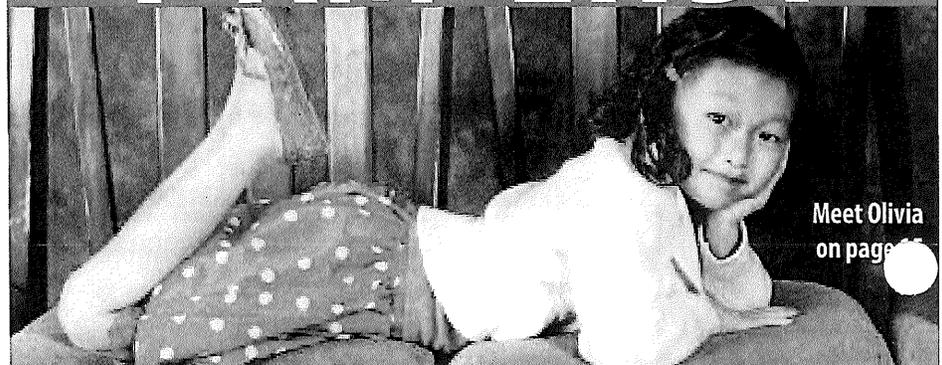
The main objectives of EHDl programs are:

- Early identification of children who are D/HH through universal newborn hearing screening and timely audiological evaluation
- Prompt and appropriate early intervention (medical, audiological, and developmental) and culturally competent social and financial services that result in the best possible outcomes for the infant or child
- Monitoring and evaluation of the EHDl system to improve its effectiveness and impact

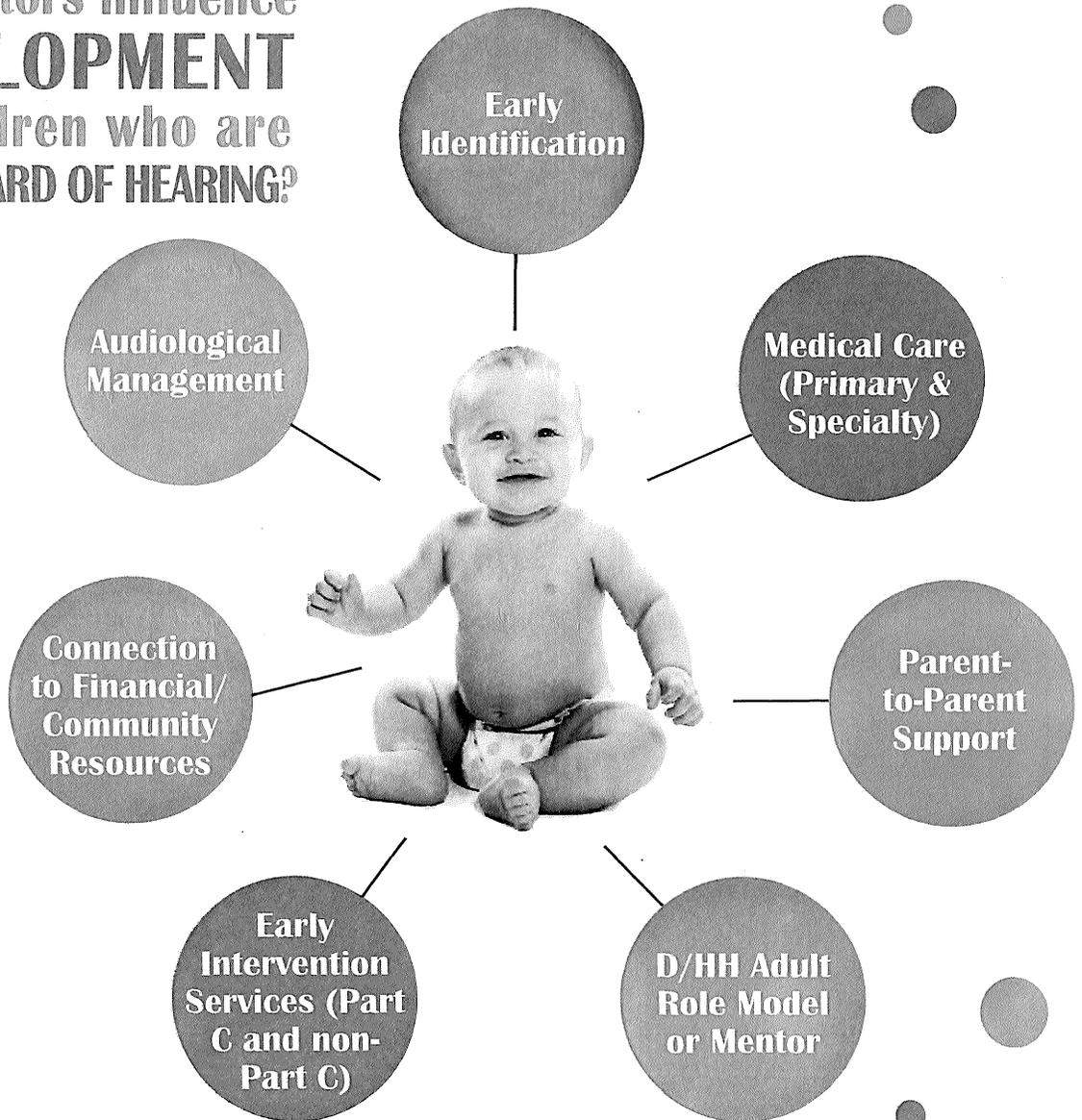
family support  
deaf mentors  
screening  
early intervention  
resources  
medical care  
audiological management  
D/HH adult role models



# I AM EHDl



# What factors influence **DEVELOPMENT** for children who are **DEAF or HARD OF HEARING?**



## **EHDI's beginnings in Minnesota**



Newborn hearing screening in Minnesota began in approximately 1997. Throughout the following decade, the Minnesota Newborn Hearing Screening Program succeeded in increasing the number of infants that received hearing screening across the state, with the goal that all infants, regardless of geographic location, would receive hearing screening and appropriate follow-up services when needed.

In 2007, legislation passed to formalize the Minnesota EHDI program. Importantly, the legislation mandated results reporting to the Minnesota Department of Health (MDH) so that the EHDI program could ensure the screening of all infants, follow-up on missing results, and the timely receipt of appropriate intervention services. The founding legislation also established a Newborn Hearing Screening Advisory Committee (NHSAC) to guide the EHDI program and provided funding for parent-to-parent support through a nonprofit organization.

**Program goals:**



**screening**

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



**diagnosis**

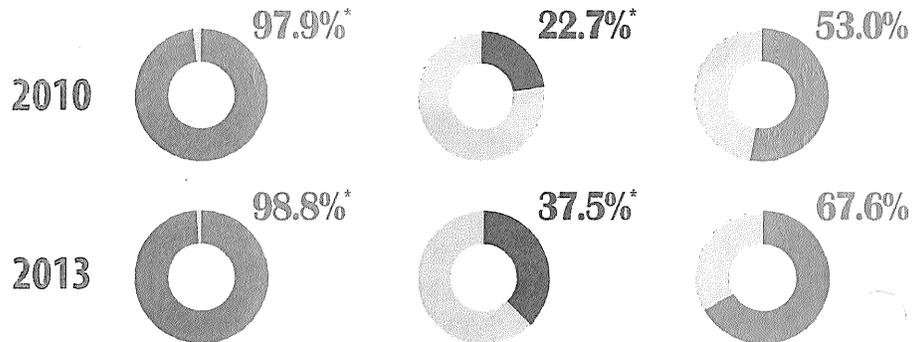
All infants who do not pass screening will have a definitive diagnostic audiologic evaluation before **3 months** of age.



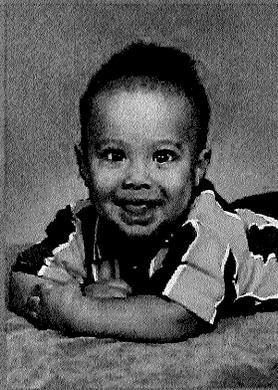
**intervention**

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

**Minnesota's progress in recent years:**



\*Does not include newborns weighing  $\leq 1800$  grams at birth

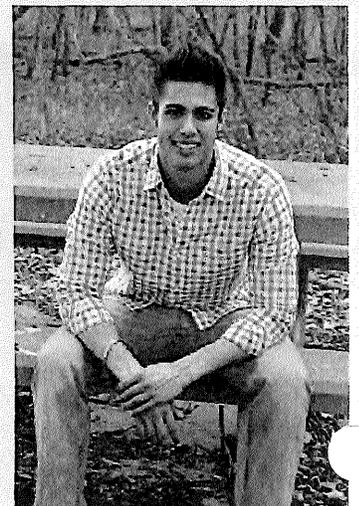


**“Early identification gives families the opportunity to provide their child with access to language during a critical period for speech and language development.”**

-Rhonda, Sonjay's mom

**I AM EHDI: Sonjay's story**

“When our son Sonjay was born, newborn hearing screening was not in place. After having our concerns dismissed repeatedly by his pediatrician, his hearing loss was finally diagnosed when he was nearly 2½ years old. Although Sonjay has achieved great success, his journey has been filled with frustration and challenges—all of which would have been easier had newborn hearing screening been a reality. Early identification gives families the opportunity to provide their child with access to language during a critical period for speech and language development. Newborn hearing screening is a win-win-win situation – for the child, the family, and the taxpayer.”

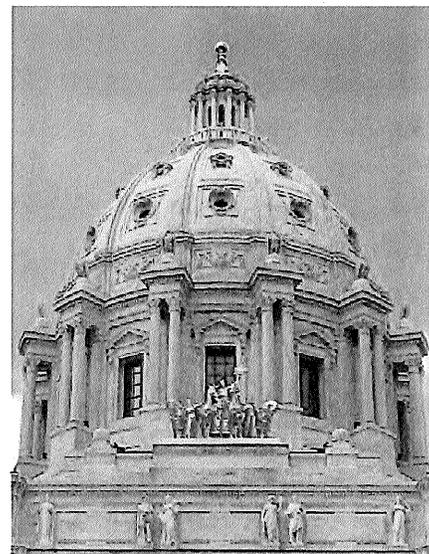


-Rhonda, Sonjay's mom

# LEGISLATIVE UPDATE: What's new in 2013?

The 2013 legislative session brought about several changes to Minnesota's EHDI law, [MN Statute 144.966](#). These changes include the following:

1. The NHSAC mandate that was set to expire in 2013 was extended to June 30, 2019.
2. A provision was added to allow MDH to store hearing screening and rescreening test results for a period of time not to exceed 18 years from the infant's date of birth. This provision also allows parents to opt out of storage of hearing results by MDH at any time.
3. A subdivision was added to clarify that EHDI data is not genetic information. As such, it is not subject to the genetic privacy law, [MN Statute 13.386](#).
4. The newborn screening fee was increased from \$101 to \$150 in [MN Statute 144.125](#). This increase raised the amount of funds set aside for EHDI support services from \$5 to \$15 per screening.



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## Notes from the field

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"My name is Jane, and I'm a public health nurse. I provide follow-up services for children newly identified as deaf or hard of hearing and assure connections to early intervention and resources.



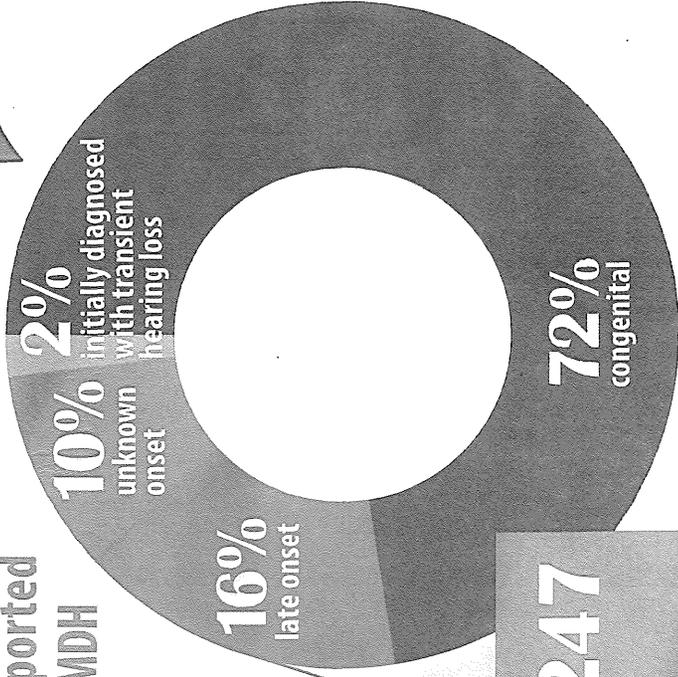
I recently contacted a family whose 4-month-old daughter was identified as hard of hearing. The family had not responded to the school district's attempts to contact the family and offer early intervention services. Fortunately, I was able to connect with mom. She was overwhelmed with her daughter's diagnosis and what it meant for her family. I talked with her about the importance of early intervention and assisted her in connecting with the school district. Although her daughter had loaner hearing aids at the time, she was concerned about how she would pay for her own set of hearing aids. I discovered she was eligible for medical assistance (MA) to help cover her copays and deductibles of her private insurance, and I walked her through the online application.

Ultimately, she was able to secure MA as her daughter's secondary insurance coverage, was enrolled into early intervention through her school district, and was connected to our local WIC program. I love knowing that I've been able to help families connect to the resources they need."

# SNAPSHOTS FROM

# 2013

Cases of Permanent  
Confirmed Hearing Loss  
Reported  
to MDH



247

# 67,329

NEWBORNS SCREENED  
FOR HEARING LOSS IN  
2013, WITH A REFER  
RATE OF **4.4%**

Cases of Transient  
Hearing Loss  
Reported to MDH

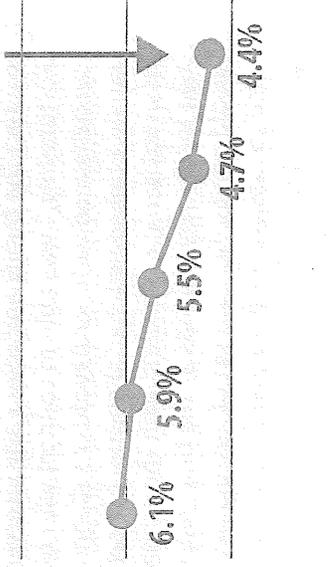
(mild or moderate  
conductive loss)

78

Closed Cases

(hearing loss resolved,  
deceased, or moved  
out of state)

44



2009 2010 2011 2012 2013

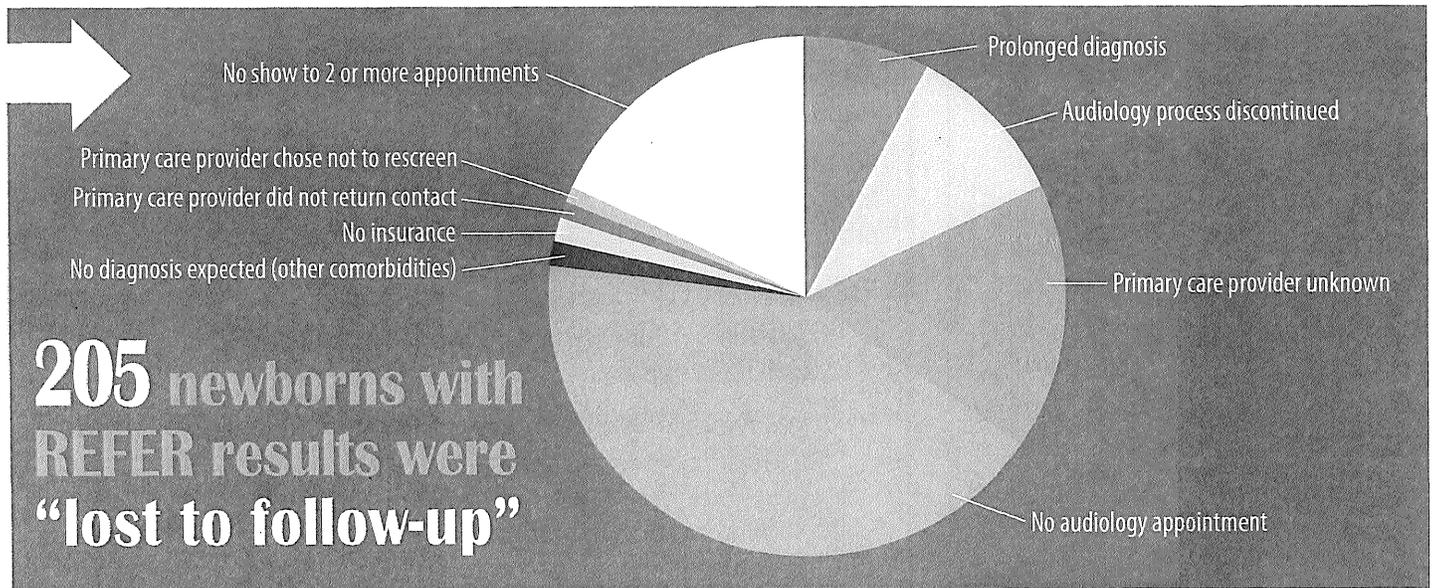
# HEARING AID LOANER PROGRAM

The Lions Infant Hearing Aid Loaner Program, located at the University of Minnesota, was again awarded a sum of \$69,000 by MDH to help to ensure that infants and young children newly-identified as D/HH receive timely intervention services. The program provided 136 hearing devices to children identified as D/HH in 2013, which gave their families time to adjust, assess, and make arrangements for permanent hearing aids or await medical intervention. The loan period also allows families time to gather their own funds, await third party payments, and determine if the device provides benefit for the child. Most importantly, for families who choose listening and spoken language, it provides immediate access to acoustic information.

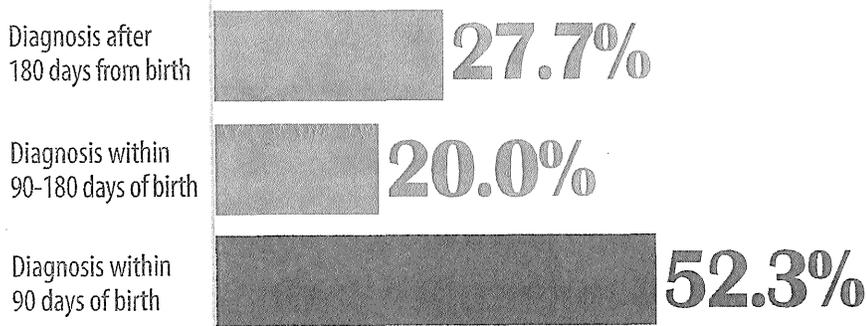
Children fit with a Lion's loaner device are almost **twice as likely** to be fit within **1 month** of an initial diagnosis.

Of children fit with a Lion's loaner device, **58%** were fit within one month of diagnosis.

Of children NOT fit with a Lion's loaner device, **29%** were fit within one month of diagnosis.



## TIME TO DIAGNOSIS



**0.09%**  
OF PARENTS CHOSE TO **OPT OUT** OF HEARING SCREENING



## Newborn Hearing Screening Advisory Committee:

Per MN Statute 144.966, the NHSAC advises and assists MDH and the Minnesota Department of Education (MDE) in developing recommended EHDl protocols. Guidelines developed or updated during 2013 include the following:

- The program's core Well-Baby Nursery Screening Guidelines were updated, providing recommended protocols for newborn hearing screening in the well-baby nursery.
- The Committee also developed and approved a valuable new resource for hearing screeners – the Guidelines for Hearing Screening After the Newborn Period to Kindergarten Age. These guidelines provide Minnesota-specific information and resources, including details on screening equipment, protocols, and pass/REFER criteria, as well as referral and evaluation information for the Individuals with Disabilities Education Act Part C and Part B programs led by MDE.



### **DRIVEN BY RESULTS: Results-based accountability**

This year, the Committee made a new commitment to improving the EHDl system through the use of a data-driven decision-making framework of results-based accountability (RBA) to guide its work. For a detailed explanation of RBA, please see the *Driven By Results* section on page 21.

**These RBAs are explored in-depth on pages 22-28 of this report.**

# Program Activities:

## Expanded Early Intervention and Support

Recommendations published by the Joint Committee on Infant Hearing (JCIH) in the April 2013 issue of *Pediatrics* encourage the establishment of strong early intervention and support systems to meet the needs of children who are D/HH. With new funds appropriated by the Minnesota Legislature in May of 2012, we have enhanced efforts to address three key recommendations:

1. Parent-to-parent support
2. Support, mentorship, and guidance from individuals who are D/HH
3. American Sign Language (ASL) instruction by professionals who have native or fluent skills

### Parent-to-parent support through cultural guides

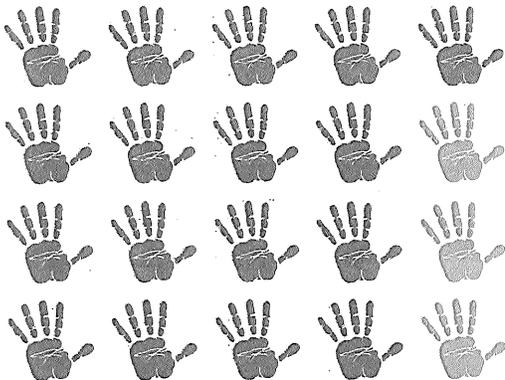
Families report that there is something unique and important about receiving support from other parents and families who have children who are D/HH. After a child is identified as D/HH, families often need assistance getting started in understanding hearing loss and its implications for their child and family.



MINNESOTA  
HANDS &  
VOICES™

Increased funding from MDH allowed Minnesota Hands & Voices (MNHV) – a nonprofit, parent-driven organization dedicated to supporting families of children who are D/HH – to offer unique cultural and linguistic support to diverse families of children who are D/HH. New parent guides represent the Northeast African, Southeast Asian, and Spanish-speaking communities. With increased funding, the program was also able to expand educational opportunities for families of children who are D/HH.

On average, MNHV contacted  
**17 of every 20 families**  
of children newly identified as D/HH in 2013,  
providing direct parent-to-parent support.



“Es bastante util,  
todo gracias.” —  
“Everything is very  
useful, thank you.”

Parent comments  
regarding MNHV

“Love, Love, Love  
Parent Guides!”

“Holy buckets,  
I keep asking  
myself ‘Who  
or what is this  
organization?’  
because it’s so  
amazing.”

“It has absolutely  
been wonderful!  
I can’t thank you  
enough! I’m amazed  
by the support.”

Parent comments  
regarding MNHV

**“Having a deaf mentor makes it possible to learn ASL, but also gain confidence to have conversations with other deaf people and to help our son communicate effectively.”**

**“This program has helped us grow as a family. We spend time together and help each other learn. We also have another way of communicating with our child when hearing is difficult.”**

Parent comments regarding the Deaf Mentor Program

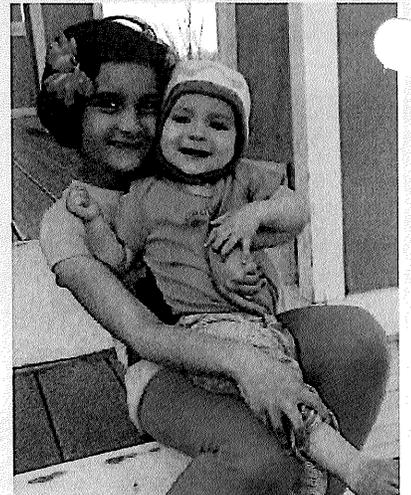
## **Deaf and hard of hearing adult role models and American Sign Language instruction**

MDH awarded funding to Lifetrack’s Deaf Mentor Program in November 2013 to deliver individualized support to families of children who are D/HH through adult role models/mentors. D/HH role models/mentors who represent the diversity of the EHDI population (e.g., Deaf culture, hard of hearing, cochlear implant and hearing aid users, unilateral hearing loss, auditory neural hearing loss, cultural diversity) support language and social development for families by sharing personal experiences and/or information about being D/HH, the deaf community and Deaf culture, educational and communication opportunities, and hearing technology.

For families who have chosen to use ASL, the use of deaf mentors trained through evidence-based deaf mentor models supports a family’s learning of the language. Currently, 19 deaf mentors are trained to serve children who are D/HH throughout Minnesota.

### **I AM EHDI: Rilee & Harrison’s story**

Seven years ago our family was given the shocking news that our baby girl was deaf. Words cannot describe how unprepared, overwhelmed, and scared we were as first-time parents. Yet over time our fears slowly subsided as we found ourselves amidst a strong network of professionals who could provide Rilee with exceptional intervention and allow her to reach her full potential.



Fast forward to last May when our son Harrison was born. Thanks to newborn hearing screening we were quickly able to detect his hearing loss and get him aided by the time he was 1 month old. We were relieved to be able to know such valuable information so quickly and make the appropriate decisions for our family.

Today, Rilee is a happy 7-year-old girl who has caught up to her hearing peers and enjoys being a language model for her baby brother. Harrison is a busy 1-year-old who loves all the attention from his big sister and is working hard on keeping his hearing aids on his ears.

-Lisa & Steve, parents of Rilee & Harrison

# Program Activities:



## Quality Improvement Initiatives

The MDH EHDI program continually works to improve the system for hearing screening, timely follow-up, and interventions for Minnesota children. We strive to incorporate quality assessment and quality improvement within all program areas and activities. This past year, we made special efforts to collaborate with community stakeholders and serve as an ongoing resource for them to reduce "lost to follow-up" (LTFU) at each stage of the EHDI process. The sections on pages 11-13 highlight some of our progress with various stakeholder groups – each of whom plays a critical role in the EHDI process.

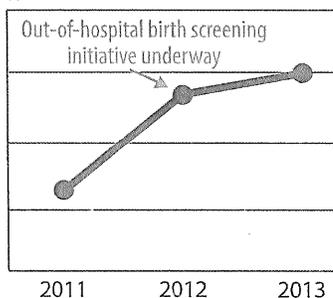
### Out-of-hospital birth midwives

After reviewing our data, we identified that babies born in out-of-hospital birth settings accounted for a large percentage of the infants who never received a hearing screening. Beginning in 2012, we met with local midwives to share the data trends observed and brainstorm ways to improve the out-of-hospital birth hearing screening rate. Here are some of the activities that followed:

- The creation of a hearing screening program for midwives with guidance from our staff
- Hands-on screening and EHDI training for midwives
- New educational materials designed specifically for out-of-hospital birth providers and parents
- 13 pieces of hearing screening equipment and supplies secured for use by Minnesota midwives

**2011: 34.2%**  
**2012: 67.4%**  
**2013: 74.7%**

OUT-OF-HOSPITAL BIRTH HEARING SCREENING RATES:



The families I work with are so grateful to access the hearing screen at home, rather than take a trip to the local hospital with a newborn in weather or over distances. Any time I have a question, the staff at the Newborn Screening Program have been prompt, clear, and happy to hear from me. The partnership we've created is just one more step to making sure every baby in Minnesota receives best practice newborn care.

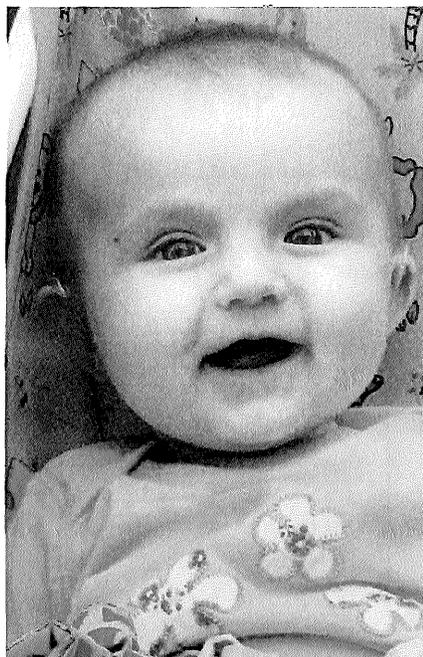
-Jana Studelska  
 CPM/ LM, Birth Duluth Midwifery, LLC

"I love that I can now offer hearing screening to all of my families. In years past, before MDH issued us hearing screening machines, almost none of the families had access to something as simple as a hearing screen for their baby. Now, all families have access!"

-Nickie Kerrigan, CPM  
 Helping Hands Birth Services, LLC

"The Minnesota Council for Certified Professional Midwives is so grateful for the partnership that MDH has built with us. Through our work together, midwife members have been able to offer hearing screening as part of routine newborn care in all of our practices!"

-Kate Saumweber Hogan, CPM, LM  
 Twin Cities Midwifery, LLC



## Audiologists

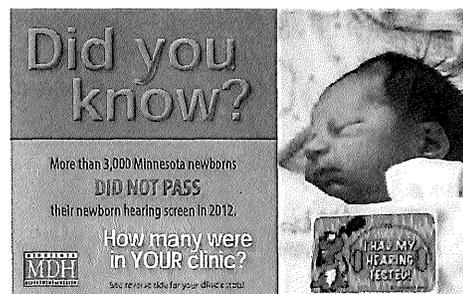
Data showed that we weren't meeting our goal of identifying hearing loss by three months of age. To help reduce the number of infants who are LTFU and increase timely diagnosis, reporting, and referrals, we worked to engage audiologists in new evaluations and data sharing processes. Activities included:

- 24 collaborative meetings with audiology clinics to share data, identify barriers, and brainstorm solutions
- New annual quality assurance reports developed and used to track progress by clinic
- An exchange of resources through an exhibit at the Minnesota Academy of Audiology Upper Midwest Audiology Conference
- A presentation at a statewide meeting of audiologists who work in Minnesota schools to help increase reporting and create partnerships

## Primary care providers

Because of the unique role of the medical home in the EHDI process, we strive to continually improve working relationships with providers to decrease the time to outpatient rescreening and increase timely referrals. This year, our activities with primary care providers (PCPs) included:

- A survey of physicians to better understand their knowledge, attitude and practices regarding EHDI
- The annual *Did You Know?* mailing of clinic-specific LTFU data
- A live and recorded [webinar](#) as well as five on-site presentations for PCPs and their staff on their role in the Minnesota EHDI process
- Direct calls and informational packet sent to providers with "just in time" information for new diagnoses



## Birth hospitals

To ensure effective screening for all newborns, we continually review our data to identify trouble areas and work with hospitals to make improvements in the screening, referral, and reporting process. This year, some of our ongoing activities included:

- Biannual quality assurance reports highlighting screening and referral rates and timeliness of reporting
- Targeted assistance for more than 20 hospitals to improve identified goals
- Four on-site equipment and EHDI process training for screeners
- The development of a new transfer form to reduce the incidence of LTFU among infants who are transferred to another hospital/unit

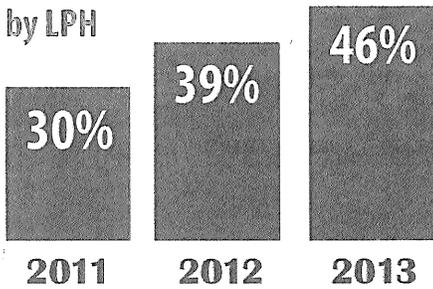


## Local public health

To reduce LTFU rates and assure connection to services for children who are D/HH, we have worked to create and sustain partnerships with local public health (LPH) agencies since 2010. Currently all counties within Minnesota participate in this partnership, as well as one tribal government – the Mille Lacs Band of Ojibwe.

In 2013 alone, our LPH partners were able to resolve 46 percent of the cases we sent to them that otherwise would have been classified as LTFU. Fourteen of those children were identified as D/HH. LPH also contributed to a significant rise in the percentage of reported Part C Early Intervention status for children identified as D/HH – from 22 percent in 2009 to 76 percent in 2013.

Percentage of LTFU cases resolved by LPH

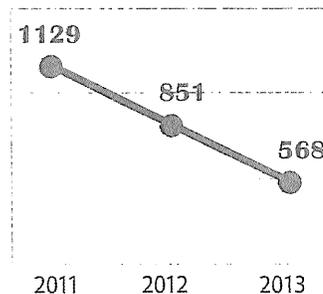


**250%**  
increase in reported Part C Early Intervention status from 2009 to 2013 thanks to local public health

## Internal processes

To improve reporting of hearing screening results, we took an in-depth look at cases of Minnesota newborns with no reported screening results who are assumed not to have been screened. We identified that 80 percent of those classified as “missing” were actually screened, but the birth facility failed to report the results within the standard time frame or after follow-up requests. To help address this issue, we revised our internal follow-up protocol to include the following:

- Two additional attempts at contact with submitters to provide opportunities to report results
- A fax to PCPs when a newborn has been classified as “missing”
- The designation of a primary program staff contact for each submitter to improve consistency in communication and relationship building



These three steps decreased “missing” by **33 percent** from 2012 to 2013.



# Program Activities:

## Publications, Communications, and Training

MDH EHDI program staff members continually provide presentations, trainings, and resources to stakeholders in the EHDI process. In 2013, we provided 46 in-person or live web-based trainings and/or presentations to PCPs, audiologists, hospital screeners, and LPH nurses in Minnesota. In addition, our staff members gave three presentations regarding Minnesota's EHDI program at the national EHDI meeting in Glendale, Arizona.

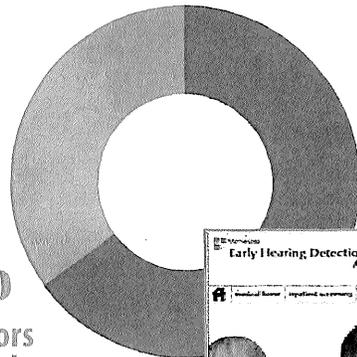
### Minnesota EHDI website

We created the [Minnesota EHDI website](#) in 2012 after a survey indicated that only 10 percent of stakeholders utilized our [MDH website](#) often. With this in mind, we designed the Minnesota EHDI website to offer more audience-specific information with easy provider-friendly navigation. The site houses Minnesota EHDI data, best practice guidelines, and tools for improvement for primary care physicians, screeners, audiologists, early intervention providers, and other stakeholders.

In April 2013, we were awarded the 2012 [Best of EHDI Website](#) at the 12th Annual National EHDI meeting in Glendale, Arizona.

# 46

in-person or live web-based trainings and presentations were given to EHDI stakeholders in 2013.



This year...

**65%** of site visitors were located in the Twin Cities

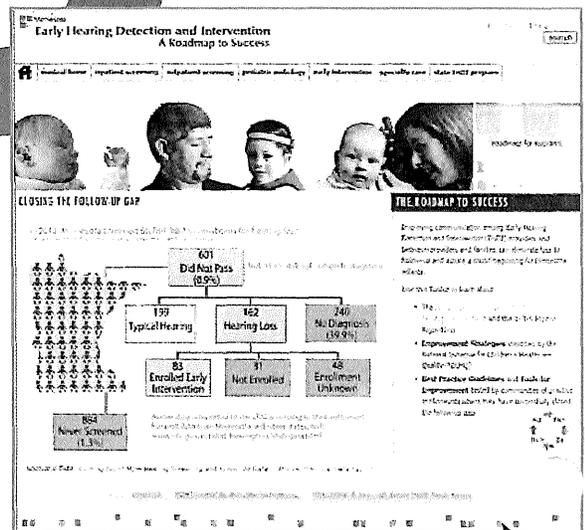
**35%**

of site visitors were located outside of the Twin Cities\*

\*Includes greater Minnesota and visitors from 47 other states

**1,962** SITE VISITS

**901** INDIVIDUAL USERS



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



## Program Activities:

### Continuing Challenges

Despite our successes over the past year, we continue to face challenges. Here are a few things we will continue to prioritize in the years ahead:

- **Increasing health equity, so that all infants and children born in Minnesota – regardless of geography, race, ethnicity, or income – receive timely interventions that result in best possible outcomes**

Analysis of key indicators suggests that significant health disparities exist in early hearing detection and intervention. We are committed to finding ways to eliminate these health disparities.

- **Database collection, storage, and use — particularly missing, incomplete, or inaccurate hearing screening results**

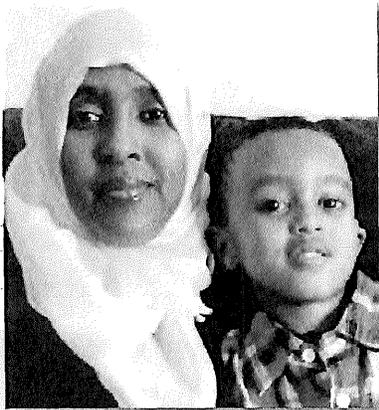
A new project is underway that will send hearing screening data from birth centers and diagnostic testing results from audiologists electronically to the EHDI program. We look forward to greater efficiency and better data quality with this new system.

- **Increased adoption of best practice guidelines**

Multiple best practice guidelines have been developed by the JCIH and the NHSAC. We plan to improve education efforts regarding these guidelines and encourage universal adoption among stakeholders.

- **Appropriate reporting and tracking of individual children from audiologic confirmation to developmental outcomes**

We continue to face barriers in accessing the data needed to identify system gaps or needs. We are currently working with partners to develop pathways for secure data sharing so that we can ensure the best possible outcomes for children.



### I AM EHDI: Abdulkadir's story

Newborn screening is very important to me because my son did not pass hearing screening when he was born. If he did not have a hearing screening, it would have been difficult to identify a bilateral hearing loss at such a young age. It would have delayed my son's hearing aids and the services he needed.

During his diagnosis and after, my family faced many challenges while learning about options for my son's communication choices. Fortunately, Minnesota Hands & Voices reached out to me in 2009, and through this organization we quickly learned more about the options and opportunities for my son. MNHV was a way for my family to connect with a parent guide who explained the options and shared personal experiences. Through sharing my emotions and concerns, we were able to relate with a support team of parents helping parents.

-Sahara, Abdulkadir's mom

# Working with Program Partners:

## Minnesota Collaborative for Children who are Deaf, DeafBlind, and Hard of Hearing

Through the Minnesota Collaborative for Children who are Deaf, DeafBlind, and Hard of Hearing, stakeholders are working to better understand and improve educational outcomes for children who are D/HH and deafblind. As a member of the steering committee, we continually provide leadership, direction and financial assistance to the collaborative. In 2012-2013, our staff members were instrumental in conducting a survey of parents of young children who are D/HH. Other Collaborative partners worked to conduct a survey of teachers of students who are D/HH. Survey results were shared at the Collaborative's annual retreat in April 2013 and are being used to direct future work.

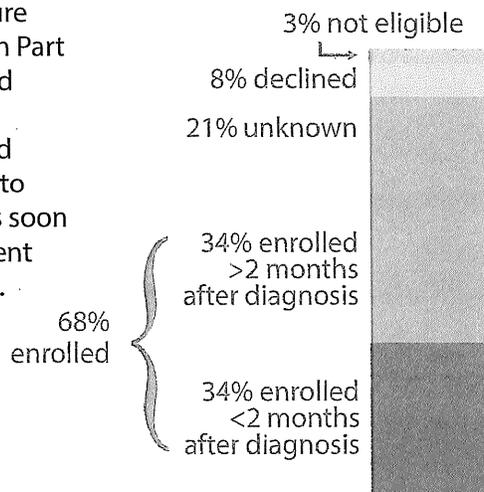
**66%** of teachers of the D/HH say they have adequate resources and training to meet the needs of students age 0-5 years, according to the survey.

## American Academy of Pediatrics Chapter Champion

We continued to work closely this year with Dr. Lisa Schimmenti, our state American Academy of Pediatrics Chapter Champion, to support EHDI educational efforts among physicians. This year's efforts included presentations at a national EHDI meeting, a national American Academy of Audiology conference, and a local conference of pediatric physicians at the University of Minnesota. We also supported Dr. Schimmenti in working with local residents and medical students on the importance of timely follow-up and early detection.

## Minnesota Department of Education

In late 2013, we worked with our partners at MDE to improve our ability to ensure children who are D/HH are enrolled in Part C Early Intervention services designed to meet their unique language and communication needs. This enhanced partnership will allow both agencies to get children connected to services as soon as possible and ultimately to document outcomes for children who are D/HH.



## Part C Status for Children as Reported to MDH in 2013

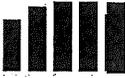
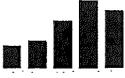
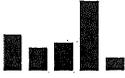


**24%** of parents feel that their child is not developing language skills like other children his/her age.

-MN Collaborative survey

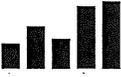
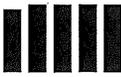
# Program Indicator Data:

Indicator	Annual Values					5-Year Trend
	2009	2010	2011	2012	2013	
<i>more on page 22!</i> <b>1.1</b> Percentage of infants screened for hearing loss	97.9%	98.4%	98.5%	99.1%	99.1%	
<b>1.2</b> Percentage of infants >1800 grams screened before 1 month of age	97.8%	97.4%	97.3%	97.3%	98.8%	
<b>1.3</b> Percentage of infants ≤1800 grams screened before 4 months of age	81.5%	87.9%	97.1%	91.5%	93.6%	
<b>1.4</b> Percentage of infants that did not pass initial screening	6.1%	5.9%	5.5%	4.7%	4.4%	
<b>2.1</b> Percentage of infants >1800 grams given a REFER on initial hearing screening that were rescreened by 1 month of age	56.2%	55.6%	61.1%	61.8%	61.8%	
<i>more on page 23!</i> <b>2.2</b> Percentage of infants >1800 grams who have a REFER on rescreen and receive an audiology evaluation by 3 months of age	20.1%	23.4%	23.0%	31.7%	37.6%	
<i>more on page 24-25!</i> <b>2.3</b> Percentage of infants with a REFER who were LTFU	13.9%	10.8%	6.6%	5.7%	5.9%	
<b>2.4</b> Percentage of infants >1800 grams with a REFER who were LTFU	13.9%	13.9%	8.4%	5.6%	5.9%	
<b>2.5</b> Percentage of infants ≤1800 grams with a REFER who were LTFU	16.6%	16.6%	6.3%	4.7%	5.5%	
<i>more on page 24-25!</i> <b>2.6</b> Percentage of all infants with a REFER who were LTFU/D	6.2%	3.4%	3.4%	2.4%	2.1%	
<b>2.7</b> Percentage of infants >1800 grams with a REFER who were lost to documentation	6.2%	6.2%	3.0%	1.9%	2.0%	
<b>2.8</b> Percentage of infants ≤1800 grams with a REFER who were lost to documentation	7.6%	7.6%	3.2%	3.8%	5.5%	

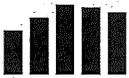
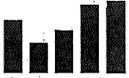
Indicator	Annual Values					5-Year Trend
	2009	2010	2011	2012	2013	
<b>3.1</b> Percentage of infants with congenital hearing loss who received an ENT/ORL evaluation by 4 months of age	35.6%	44.0%	48.7%	50.8%	49.7%	
<b>3.2</b> Percentage of infants with congenital hearing loss who received a genetics evaluation by 1 year of age	13.6%	16.0%	27.4%	38.5%	34.2%	
<b>3.3</b> Percentage of infants with congenital hearing loss who received a pediatric ophthalmology evaluation by 6 months of age	15.3%	10.0%	11.8%	29.4%	7.1%	
<b>3.4*</b> Percentage of infants with bilateral hearing loss whose parent(s) chose personal amplification and who were fit within 1 month of diagnosis	12.5%	38.3%	34.5%	35.3%	32.7%	
<b>3.5</b> Percentage of children diagnosed before 3 years of age who were reported to be enrolled Part C Early Intervention services	22.0%	67.0%	67.3%	82.3%	76.0%	
<b>3.6</b> Percentage of infants with congenital hearing loss who were reported to be enrolled in Part C Early Intervention services by 6 months of age	69.0%	53.0%	70.3%	62.0%	67.6%	
<b>3.7</b> Percentage of children diagnosed before 3 years of age who were reported to be enrolled in the Deaf Mentor or Deaf/Hard of Hearing Role Model Program	Data not available					
<b>3.8</b> Percentage of children diagnosed before 3 years of age who were reported to be receiving private speech therapy	Data not available					

more on page 26!

more on page 27!

Indicator	Annual Values					5-Year Trend
	2009	2010	2011	2012	2013	
<b>3.9</b> Percentage of children diagnosed before 3 years of age who reported to be enrolled in Part C Early Intervention services within two months of initial hearing loss diagnosis	11.0%	37.0%	54.2%	52.9%	50.0%	
<b>3.10*</b> 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	23.8%	24.6%	24.1%	21.2%	45.3%	
<b>3.11</b> 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					
<b>4.1</b> Percentage of infants and children identified with late onset, progressive, or acquired hearing loss	5.3%	9.0%	6.6%	13.6%	14.8%	
<b>5.1</b> Percentage of infants/children who had a PCP at the time of diagnosis	96.9%	99.0%	98.9%	98.6%	96.4%	
<b>6.1</b> Percentage of newborn hearing screening records matched with vital records	99.5%	99.4%	99.4%	99.8%	99.7%	
<b>6.2</b> Percentage of audiology reports received by MDH within 10 days of appointment	76.4%	83.2%	84.4%	83.2%	83.8%	
<b>6.3</b> Percentage of infants who had incomplete or unreported hearing screening	2.6%	2.1%	1.4%	1.2%	0.8%	

more on page 28!

Indicator	Annual Values					5-Year Trend
	2009	2010	2011	2012	2013	
6.4 Percentage of requested follow-up reports received from audiologists identified as caring for infants/children with permanent hearing loss	61.5%	75.0%	95.4%	90.4%	84.0%	
6.5 Percentage of requested follow-up reports received from PCPs identified as caring for infants/children with permanent hearing loss	71.1%	39.0%	57.2%	91.8%	94.0%	

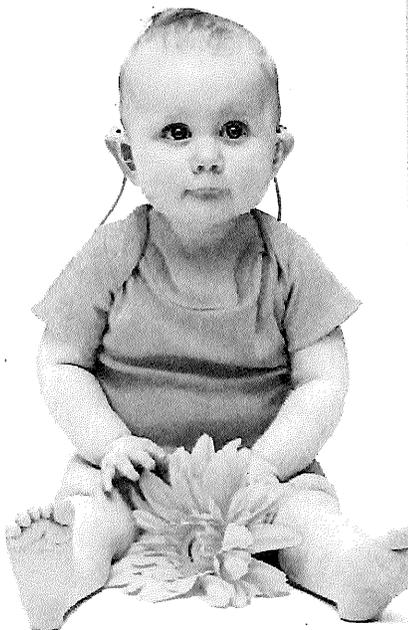
\*The definitions for these indicators have changed. Values from previous years have been updated to reflect these changes, so they may not match previous reports. To view definitions for all indicators, please visit the [Minnesota EHDI website](#).

## DRIVEN BY RESULTS:

With guidance from the NHSAC, our program adopted six RBA measures to guide our work to improve Minnesota’s EHDI system. The six priority population-based indicators were chosen from a set of 32 indicators previously established by the Committee. Measures focus on screening, early identification, and important interventions for children who are D/HH such as Part C Early Intervention, parent-to-parent support, and amplification, if chosen by the family.

The goal of using RBAs is data-driven decision-making. This tool is currently in use by all state agencies to critically examine the quantity and quality of the services provided to customers, as well as the impacts and effects of those activities.

**These six RBAs are explored in-depth on pages 22-28.**



# DRIVEN BY RESULTS

# 1.1

**Our goal: All newborns will be screened for hearing loss.**

### Story behind the curve:

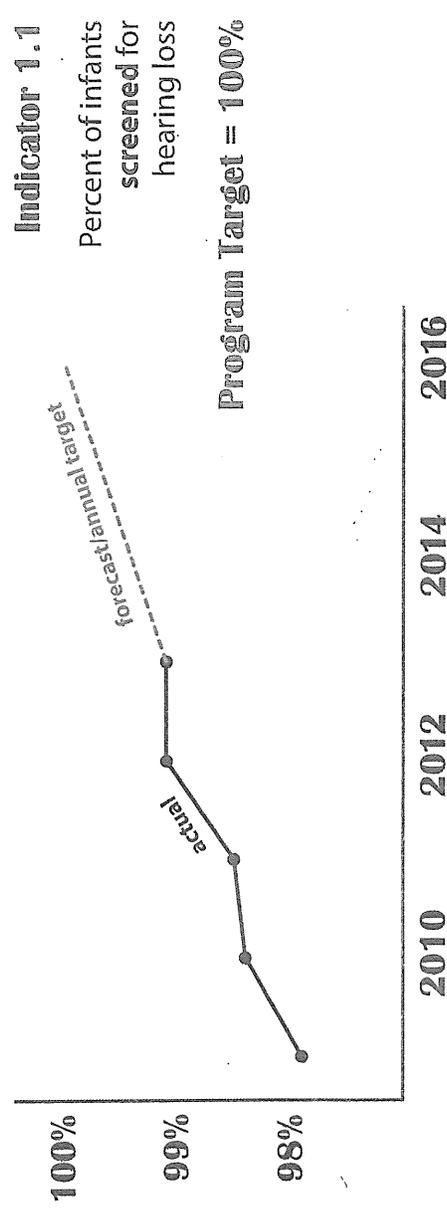
- The reporting of hearing screening results to MDH was mandated in September 2007. Consequently, we added several staff members to our Newborn Screening Program who would be dedicated to hearing screening follow-up.
- In 2011, we added hearing data (e.g., number of screens vs. birth rate) to our biannual Birth Center Quality Assurance reports.
- In 2011, our program staff increased the number of attempts at contact with birth providers to obtain missing results for initial screens. Staff members also began contacting PCPs when a facility indicated that the child was truly “missed.”
- In 2012, we worked with Minnesota midwives to help them obtain screening equipment and trained them on screening and result reporting.
- In 2013, we assigned each hospital a designated MDH contact for follow-up on missing results. This allows staff members to develop closer working relationships with facilities and identify trends in reporting.

### Partners:

Our partners in hearing screening and reporting results are **birthing facilities** and **out-of-hospital midwives** who educate families, provide screening, and report results to MDH.

### Best ideas for how to maintain the trend:

1. Continue to work with and support out-of-hospital midwives with hearing screening
2. Consider referring “missed” infants to LPH to facilitate screening
3. Continue to monitor trends and identify gaps in screening
4. Implement electronic reporting of screening results from birth providers and audiology facilities



# DRIVEN BY RESULTS:

# 2.2

**Our goal: All infants who do not pass the hearing screening will have a diagnostic audiology evaluation before three months of age.**

## Story behind the curve:

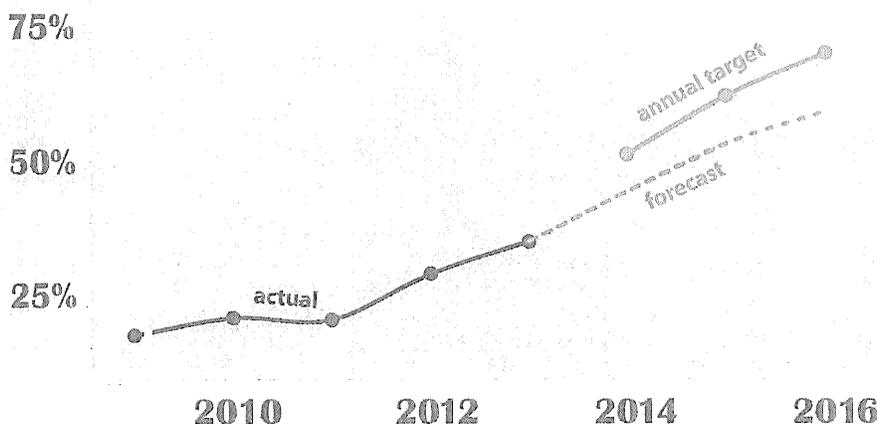
- The reporting of all hearing results (initial, rescreen, and diagnostic) was mandated in September 2007.
- We currently work with LPH to help find families when follow-up is not complete.
- We initiated a *Lunch N Learn* project with PCPs who had a high number of REFER results or LTFU cases. These sessions provided clinics with site-specific data and training by MDH audiologists, which resulted in a reduction of LTFU in sites visited. A webinar version of this project was completed in 2012.
- We now offer audiology and otolaryngology site visits with site-specific data. These visits focus on reporting, complete diagnosis by three months age, and reducing LTFU.
- We continue to encourage specialists to follow Minnesota best practice guidelines and not delay diagnosis because of issues such as middle ear fluid.

## Partners:

Our partners in improving the timeliness of diagnosis include: **PCPs** who make referrals to audiology, provide consistent messages to parents, and report to MDH; **audiologists** and **otolaryngologists** who provide timely services and definitive diagnosis, schedule follow-up, and report to MDH; and **LPH** who connects families to services and reports to MDH.

## Best ideas for how to change the trend:

1. Expand the quality assurance data report to include annual reports to all pediatric audiology sites
2. Develop a plan to promote our new EHDl best practice guidelines and supporting documents for otolaryngologists
3. Work with audiology and primary care clinics to increase the number of infants who receive an outpatient rescreen by one month of age



## Indicator 2.2:

Percent of infants >1800 grams with a REFER result on the initial hearing screen who receive a **comprehensive audiology evaluation** by three months of age

**Program Target  $\geq$  90%**

# DRIVEN BY RESULTS:

**Our goal: All infants who do not pass the hearing screening will have a diagnostic audiology evaluation before three months of age.**

2.3  
&  
2.6

## Story behind the curve:

- After the 2007 reporting mandate, we developed a robust follow-up flowchart and hired four full-time staff to ensure that children with REFER results receive recommended follow-up and that all rescreen/diagnostic results are reported to MDH.
- In order to get a better idea of where “lost to follow-up/documentation” (LTFU/D) occurs, we developed tracking codes to be able to document and quantify the reason for closure of each case.
- We are working with LPH to help find families when follow-up is not complete.
- We initiated a *Lunch N Learn* project with PCPs who had a high number of REFER results or LTFU/D cases. Refer to page 23 for more details on this project.
- Clinic-specific LTFU/D data, best practice guidelines, and tips for reducing LTFU/D are sent to primary care clinics annually.
- We utilize staff audiologists to follow-up on cases where the diagnosis is prolonged by specialty care.
- We now provide an Audiology Clinic Data Report that includes data on LTFU/D.

## Partners:

Our partners in ensuring complete diagnosis for all infants who do not pass the initial hearing screen include: **PCPs** who make referrals to audiology, provide consistent messages to parents, and report to MDH; **audiologists** and **otolaryngologists** who provide timely services and definitive diagnosis, schedule follow-up, and report to MDH; and **LPH** who connects families to services and reports to MDH.

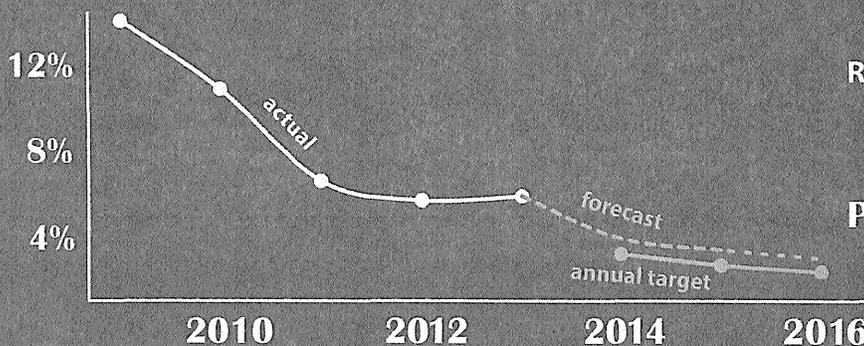
## Best ideas for how to change the trend:

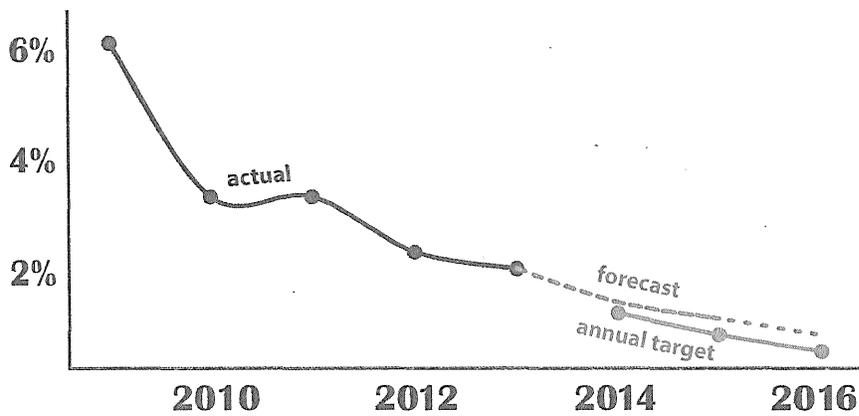
1. Educate and promote best practice guidelines and EHDl goals to stakeholders
2. Look for disparities in LTFU/D and develop a plan to target high-risk groups
3. Promote quality improvement within individual clinics

### Indicator 2.3

Percent of infants with a **REFER result** on the initial hearing screening who were **lost to follow-up**

**Program Target ≤ 1%**





**Indicator 2.6**

Percent of infants with a **REFER** result on the initial hearing screening who were **lost to documentation**

**Program Target  $\leq$  0.5%**

# DRIVEN BY RESULTS

# 3.4

**Our goal: All infants with permanent hearing loss will receive timely and appropriate early intervention services.**

## Story behind the curve:

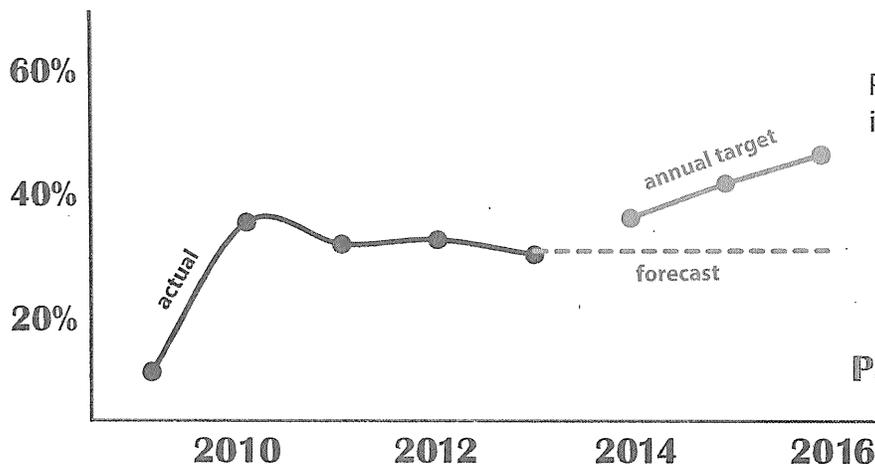
- For children with permanent bilateral hearing loss whose parent(s) choose to pursue amplification, many factors influence how quickly a child is fit. For example:
  - » Children who are older at initial diagnosis or who have a more severe hearing loss tend to be fit more quickly.
  - » The average fit time at larger clinics ranges from 34 to 75 days after diagnosis.
  - » Children fit with a loaner device from the Lion's Infant Hearing Aid Loaner Program are fit an average of three weeks sooner than children who are not fit with a loaner.
  - » Children in families whose first language is not English are fit an average of three weeks later than children whose families use English.
- Many audiologists have expressed that getting patients scheduled for clearance from otolaryngology is a barrier to timely hearing aid fitting.
- Estimates for 2011-2013 are more reliable than earlier years due to more complete data collection.

## Partners:

Our partners in improving the timeliness of fitting include **audiologists** who make recommendations for amplification and **otolaryngologists** who give clearance for amplification.

## Best ideas for how to change the trend:

1. Continue to share clinic-specific data with audiologists and disseminate promising practices from clinics where hearing aid fitting is timelier
2. Promote the use of the Lion's Infant Hearing Aid Loaner Program



## Indicator 3.4

Percent of children with an initial diagnosis of bilateral permanent hearing loss whose parent(s) chose personal amplification and who were fit within one month of diagnosis

**Program Target ≥ 90%**

# DRIVEN BY RESULTS:

# 3.5

**Our goal: All infants with permanent hearing loss will receive timely and appropriate early intervention services.**

## Story behind the curve:

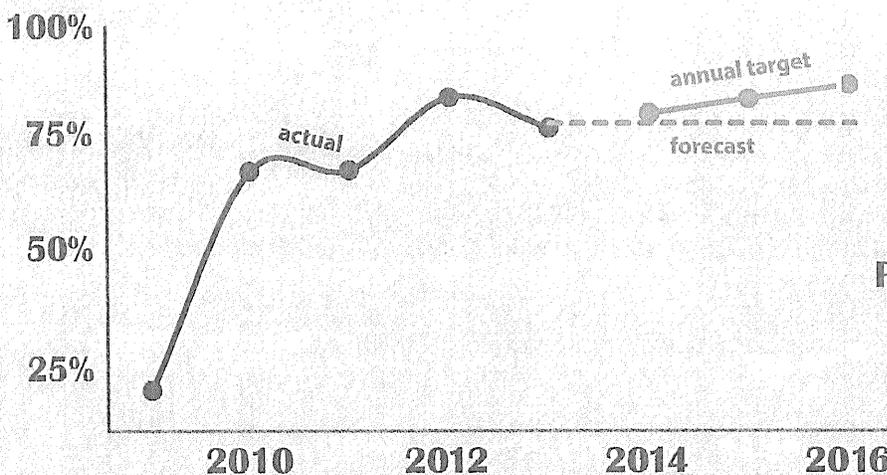
- We began contracting with LPH in 2010 to ensure families are connected to Part C Early Intervention and to report enrollment information to MDH. LPH reporting to MDH accounts for the large jump from 2009 to 2010.
- We recently established an agreement with MDE that allows us to verify and augment the enrollment information collected by LPH. Data received through the new agreement shows that for children reported in 2010-2012, just 6 percent had unknown Part C Early Intervention enrollment status (complete 2013 data from MDE will be available in December 2014).

## Partners:

Our partners in improving enrollment in Early Intervention and reporting to MDH include: **LPH** who ensure connection to Part C and report enrollment information; **MDE** and **Part C service coordinators** who share enrollment information when appropriate; **audiologists** and **PCPs** who make referrals to Early Intervention; and **MNHV Parent Guides** who discuss the importance of Early Intervention with parents.

## Best ideas for how to maintain the trend:

1. Continue to utilize the new agreement with MDE that allows MDE to report enrollment status directly to MDH
2. Provide support to LPH to get signed releases from parents for sharing data with MDH
3. Work with local school districts to explain the importance of sharing information and obtaining parental consent



### Indicator 3.5

Percent of children enrolled in Part C Early Intervention as reported to MDH

**Program Target  $\geq$  95%**

# DRIVEN BY RESULTS:

# 3.10

**Our goal: All infants with permanent hearing loss will receive timely and appropriate early intervention services.**

### Story behind the curve:

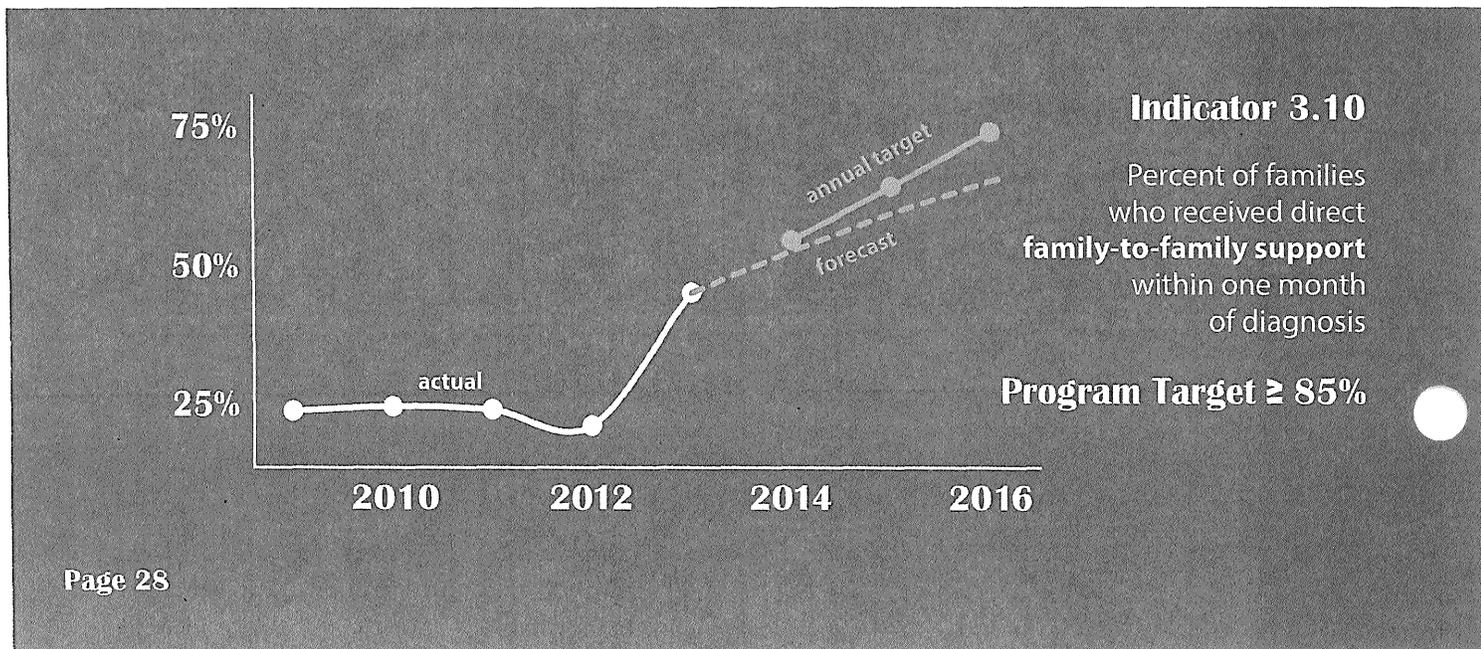
- Delayed referral to MNHV contributed significantly to the lack of progress on this indicator through 2012. The large increase in 2013 is due in part to timelier referral by MDH. Overall, we have reduced referral time from about one month to the current average of nine days.
- During our visits with audiology clinics in 2013, we reinforced the importance of direct referral to MNHV by audiologists at the time of diagnosis.
- Case volume has increased by more than 60 percent since 2009. Despite a growing number of referrals, the contact rate continues to be high, with 85 percent of families contacted by MNHV in 2013.
- In 2013, we nearly doubled state funding for MNHV. With these funds, MNHV hired a new metro area parent guide and culturally specific parent guides for the Northeast African, Southeast Asian, and Spanish-speaking communities in Minnesota.

### Partners:

Our partners in making further improvements include **audiologists** and **PCPs** who make direct referrals at the time of diagnosis, and the **MNHV parent guides** who contact families.

### Best ideas for how to change the trend:

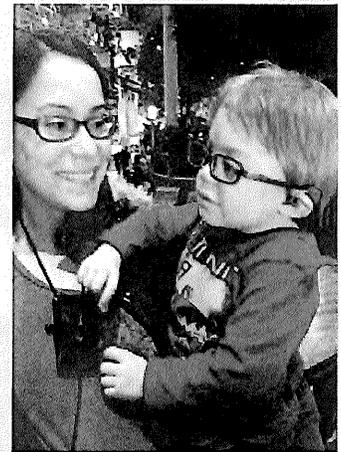
1. Further reduce the time to referral from MDH by making referrals daily rather than weekly
2. Continue to encourage audiologists to make direct referrals to MNHV at the initial diagnosis
3. Develop talking points for audiologists to use when explaining the services that are routinely offered to families with children who are D/HH



## I AM EHQDI: AJ's story

My boy was just a few days old when I learned that he has hearing loss. He was also diagnosed with CHARGE syndrome and had several health conditions that we had to tackle right away. There was a lot to learn and I didn't know where to start.

That's why I was grateful to have received support from services like Minnesota Hands & Voices, which made me feel like things were going to get easier and things were going to be ok. The early intervention team came to our house when he was still a little tiny baby to talk about ways to communicate with him, but they also did so much more than that. They taught me things about development in the first three years of life, they gave me encouragement and hope, and we shared fun times watching my boy accomplish milestones.



He is now 3½ years old, and he signs, speaks English, and is also using some words in Spanish. Because I'm from Mexico and my husband from Minnesota, we use English and Spanish at home. And because we chose to also learn ASL, we are a trilingual home. I think it's amazing that at three years of age, with hearing loss plus multiple disabilities, he understands the difference between three languages and uses them appropriately. He rarely becomes frustrated when he needs something because he is able to tell us if something is bothering him or what he wants to do. We have fun little conversations and he even has one very simple joke he likes to tell us.

He would not have gotten this far if it wasn't for the fact that we knew right away that he had a hearing loss and that the early intervention team came right away to our home to help us. We feel very lucky to have had that support and we continue to have support through different programs.

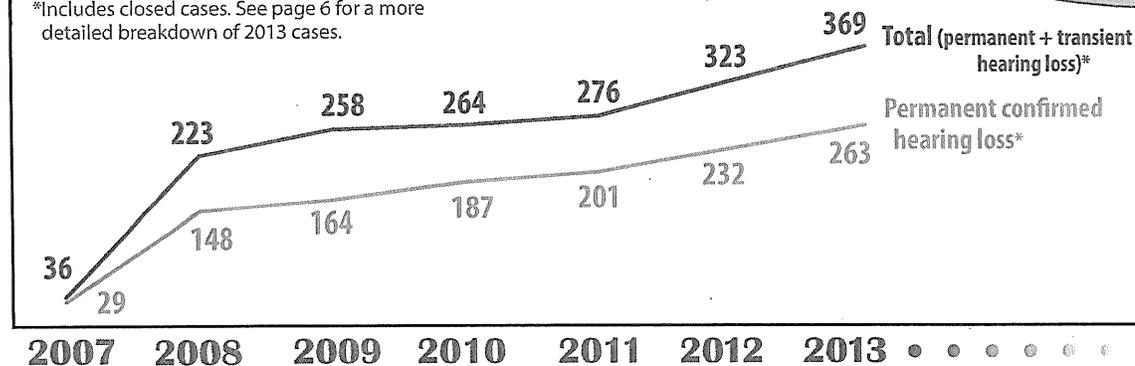
-Judy, AJ's mom

## THROUGH THE YEARS

2007-2013

### Reported cases of children newly identified as D/HH

\*Includes closed cases. See page 6 for a more detailed breakdown of 2013 cases.



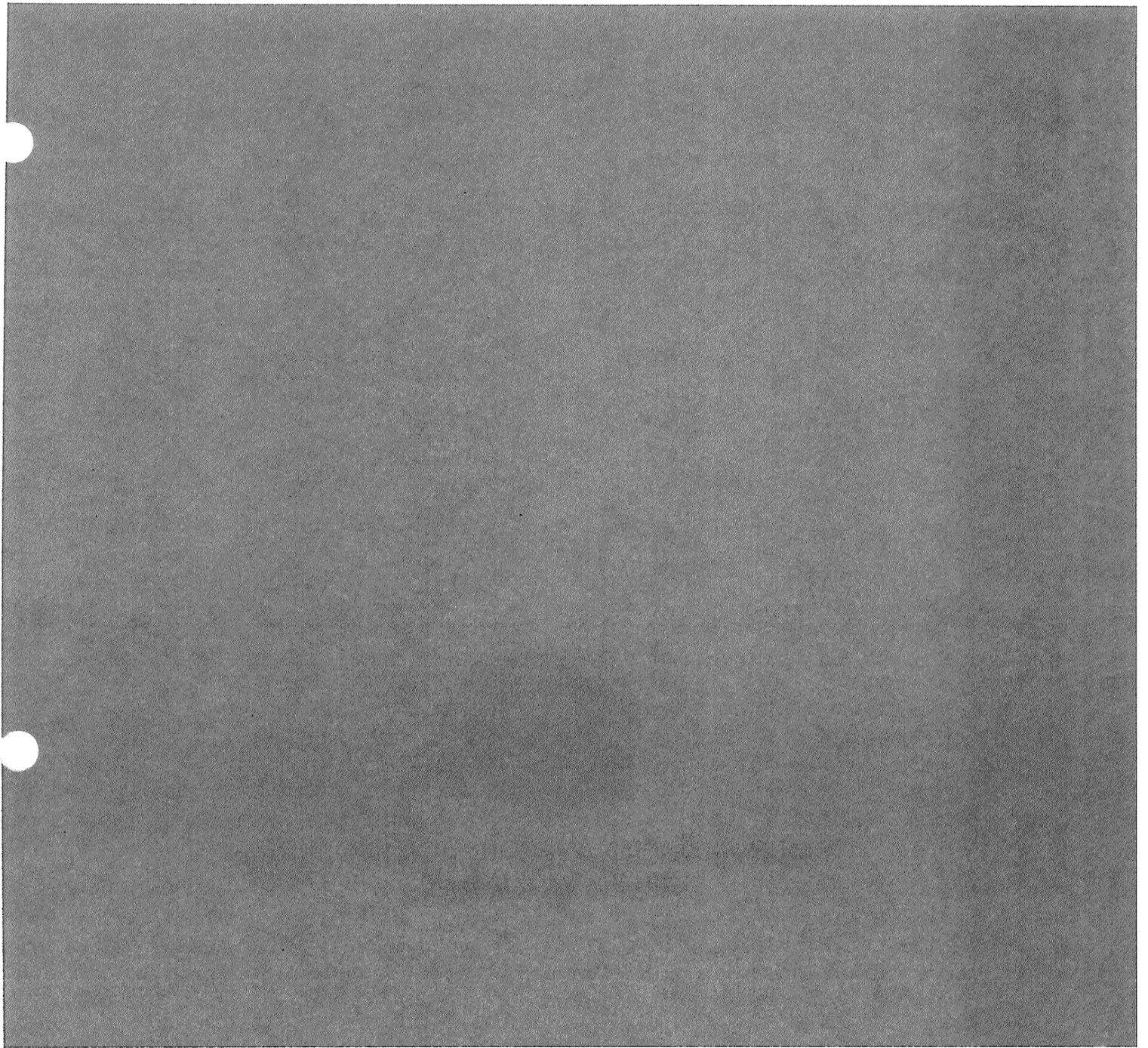
**369**

total cases of children newly identified as D/HH by MDH EHQDI and partners in 2013

# GLOSSARY

<b>Abbr.</b>	<b>Meaning</b>
ASL	American Sign Language
D/HH	Deaf or hard of hearing
EHDl	Early Hearing Detection and Intervention
JCIH	Joint Committee on Infant Hearing
LPH	Local public health
LTFU	Lost to follow-up
LTFU/D	Lost to follow-up/documentation
MDE	Minnesota Department of Education
MDH	Minnesota Department of Health
MNHV	Minnesota Hands & Voices
NHSAC	Newborn Hearing Screening Advisory Committee
PCP	Primary care provider
RBA	Results-based accountability





# THANKS

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



## **MDH Early Hearing Detection and Intervention 2013 Annual Report**

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