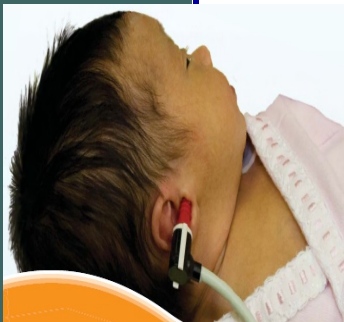


# Michigan Early Hearing Detection and Intervention (EHDI)

Program Report 2013  
2007-2011 Data



Michigan Department  
of Community Health



Rick Snyder, Governor  
James K. Haveman, Director



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and Intervention Program

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## EHDI Background

The Michigan Early Hearing Detection and Intervention (EHDI) Program began in 1997 and is housed in the Michigan Department of Community Health (MDCH). MDCH strives for a healthier state by 1) promoting access to the broadest possible range of quality services and supports, 2) taking steps to prevent disease, promote wellness, and improve quality of life, and 3) striving for the delivery of those services and supports in a fiscally prudent manner. The EHDI Program helps identify infants with hearing loss and follows these infants to enrollment of early intervention services, striving toward achievement of the national EHDI goals. Since 2000, the EHDI Program has been supported by state funding and by grants awarded by the Centers for Disease Control and Prevention (CDC) and the MCHB Grant from the Health Resources and Services Administration (HRSA) in the U.S. Department of Health and Human Services. EHDI has also received funding from the Michigan Newborn Screening Card fees since 2007.

The EHDI Program works in collaboration with hospitals, clinics, parents, and audiologists to identify infants with hearing loss and follows them to enrollment in intervention services. The CDC, along with state representatives and other national agencies, developed national goals, objectives, and performance indicators to improve screening, hearing loss detection, and early enrollment in intervention services.<sup>1</sup>

The national EHDI goals are as follows:

- **Goal 1:** All newborns will be screened for hearing loss no later than **1 month** of age, preferably before hospital discharge.
- **Goal 2:** All infants who screen positive for hearing loss will have a diagnostic audiologic evaluation no later than **3 months** of age.
- **Goal 3:** All infants identified with hearing loss will receive appropriate early intervention services no later than **6 months** of age.
- **Goal 4:** All infants and children with late onset, progressive or acquired hearing loss will be identified at the earliest possible time.
- **Goal 5:** All infants with hearing loss will have a medical home.
- **Goal 6:** Every state will have a complete EHDI Tracking and Surveillance System that will minimize loss to follow-up.
- **Goal 7:** Every state will have a comprehensive system that monitors and evaluates the progress towards the EHDI Goals and Objectives.

The first three national EHDI goals are commonly referred to as the “1-3-6 goals” and the CDC collects EHDI data from each state through the ‘CDC EHDI Hearing Screening and Follow-up Survey’ to assess progress toward these goals.<sup>2</sup>

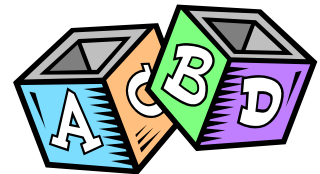
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## Hearing Screening Legislation in Michigan

Since February 23, 2006, with the passing of the Public Act 31, health professionals have been mandated to report results of hearing screens on infants less than twelve months of age and on children who have been diagnosed with hearing loss up to three years of age. The hearing loss report must include type, degree, and symmetry of the hearing loss as well as the site and date of the diagnosis. Along with the mandate to report results of hearing screens and hearing loss diagnoses, Michigan law established a Quality Assurance Advisory Committee which recommends policies and level of fees to support screening follow-up and surveillance efforts for the newborn screening program. In April 2008, the Quality Assurance Advisory Committee recommended that hearing screening be included in the mandatory newborn screening panel. Since 2003, 100% (n=85) of birthing hospitals in Michigan perform newborn hearing screens.

## Medical Home

Medical homes provide comprehensive care by partnering with individuals and their medical providers and allow for better access to care by centralizing information. Medical homes can help to ensure that infants with hearing loss receive appropriate and timely services. EHDI works to provide notification of all hospital hearing screen referrals to providers for care coordination and medical evaluation, but this can be difficult due to incorrect provider information received with the screen result. To help ease this problem, physicians are able to notify EHDI of any incorrect provider information through the EHDI fax system. EHDI is also able to use the Michigan Care Improvement Registry (MCIR), the data system for child and adult immunization and other health information, to correct medical home information. Working with hospitals to identify correct provider and maternal contact information before discharge helps to ensure that all infants receive appropriate services in a timely manner.



## Benefits of Early Detection of Hearing Loss

Infants who are diagnosed with hearing loss should be enrolled in intervention services no later than six months of age. Research has shown that early identification of hearing loss and enrollment in intervention services may lead to significant benefits in childhood development, including improvements in emotional development, language, learning, and social skills.<sup>3</sup> Intervention is needed to maximize the critical period of language development in early childhood. Recent research indicates that children whose hearing losses are identified in the first 6 months of life, and who received intervention services, developed language within the normal range.<sup>4</sup>

## Risk Factors for Hearing Loss

Congenital hearing loss (hearing loss present at birth) can be caused by a variety of factors. About half of all congenital hearing loss cases are caused by genetic factors. Hearing loss can be a characteristic of some genetic disorders such as Down syndrome or Usher syndrome.<sup>5</sup> Some non-inherited risk factors for congenital hearing loss include: prenatal infections such as cytomegalovirus (CMV) or rubella, maternal conditions such as diabetes, maternal exposure to

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toxins during pregnancy, prematurity; or lack of oxygen shortly after birth.<sup>5</sup> Hearing loss can also be acquired or developed any time after birth and can be caused by head injury, noise exposure, or as a result of some diseases such as influenza, chicken pox, or measles.<sup>5</sup> A more complete list of risk factors can be found in Appendix A.

The Joint Committee on Infant Hearing (JCIH) 2007 Position Statement states that all infants with a risk factor for hearing loss should be referred for a diagnostic audiologic evaluation at least once by 24 to 30 months of age, but earlier and more frequent evaluations should be performed on infants with some risk factors such as CMV infections, trauma, or family history of hearing loss.<sup>6</sup> The JCIH Position also states that all infants with or without risk factors should continue to be evaluated for communication development. The complete position statement from JCIH can be found at: [www.jcih.org](http://www.jcih.org).

### Public Health Impact of Hearing Loss

Hearing loss in infants is one of the most common birth defects. In Michigan, the prevalence of hearing loss is about one to three cases per 1,000 live born infants. Each year in the United States, about 12,000 babies (3 in 1,000) are born with some degree of hearing impairment.<sup>7</sup> Nearly a fifth of all Americans 12 years or older have hearing loss so severe that it may make communication difficult, according to a new study led by Johns Hopkins researchers.<sup>8</sup> Infants who are not diagnosed early and do not receive early and appropriate intervention services are at risk of delayed language skills and social development. Of infants with a diagnostic evaluation during 2011 in Michigan, about 52% had an evaluation by three months of age, about 24% by six months of age, and about 24% later than six months of age. Moreover, infants lost to follow-up are at risk of delayed development. High loss to follow-up rates are a significant problem for EHDI programs across the U.S as well as in Michigan. In Michigan, about 52% of infants referring from their final screen did not receive needed follow-up services in 2011.



Hearing loss has a large economic impact for families in the US. In the US, the estimated *lifetime* educational cost (in 2007 dollars) of permanent hearing loss is about 115,600 dollars per child with no other disabilities.<sup>9</sup> Furthermore, the expected total lifetime costs (in 2003 dollars) for all people with hearing loss born in 2000, will be about 2.1 billion dollars. This cost includes direct costs such as doctor visits, assistive devices, home and automobile modifications, and special education, as well as indirect costs such as the value of lost wages due to limited type and amount of work that may be performed by those with hearing loss.<sup>10</sup> Prevention and early intervention services, such as those provided by the EHDI Program, are needed to help decrease the economic costs associated with hearing loss, and to help increase the percentage of children receiving early intervention services which aids in childhood social and language development.



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# Technical Notes and Definitions

## Technical Notes

All EHDI data for infants born from 2007 to 2011 for this report are current as of June 2013. To obtain demographic information, live birth records were linked to EHDI data using the birth certificate number as a common, unique identifier. To date, information on infants born in 2011 is the most current data available to the EHDI Program due to the amount of time needed to receive screening and diagnostic reports from health professionals. Live birth information used to calculate prevalence rates for each year was obtained from the Division of Vital Records and Health Statistics in the MDCH.

## EHDI Data System

The EHDI Program has an electronic data system for tracking results of newborn hearing screens and diagnoses, as well as an early intervention database for infants diagnosed with hearing loss to track enrollment in appropriate services and to provide information on amplification devices. The electronic data system was completed in December 2003 and is contained within the metabolic Newborn Screening (NBS) database system with Perkin Elmer, Inc. The electronic data system has a *data entry* component in which hearing screen and diagnostic results with limited demographic information are scanned and manually entered into the system, and a *follow-up* component in which form letters are generated for all cases needing follow-up. Based on the automated follow-up system, letters for infants with refers, missed screens, and incomplete screens are faxed to parents and providers—physicians, outpatient designated (re)screen sites, otologists, local public health offices, and Part C coordinators (Early On<sup>®</sup>). Monthly reports for missing or incomplete screens are sent to birthing hospitals so that they can follow-up or submit screen results, if available. Quarterly statistical reports are sent to each birthing hospital detailing hospital specific screening and refer rates as well as overall state data as a comparison.

## Reporting Protocols

- **Initial Screens**

There has been 100% participation in universal newborn hearing screening programs within all 85 of Michigan birth hospitals since 2003. Infants are screened for hearing loss using the Auditory Brainstem Response (ABR) or Otoacoustic Emissions (OAE) equipment, or a combination of both. The ABR measures electrical responses which stem from the auditory system from an external stimulus through small electrodes placed on the baby's head. The OAE measures sound generated by the cochlea in response to an external stimulation by placing a probe in the baby's ear. Michigan collects data on the following screening techniques: Auditory Brainstem Response (ABR), Automated Auditory Brainstem Response (A-ABR), Distortion Product Otoacoustic Emissions (DPOAE), and



Infant receiving a hearing screen.

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Transient Evoked Otoacoustic Emissions (TEOAE). Hospitals can report results of the initial screen in one of two methods: 1) via metabolic hearing card that is mailed to EHDI and scanned into the data system or 2) via Electronic Birth Certificate (EBC) hearing report which is manually entered into the EHDI data system. About 1,000 births per year in Michigan occur at home with a midwife. Increased outreach to midwives has been conducted to improve hearing screening for home births. Infants in the Neonatal Intensive Care Unit (NICU) or who are transferred to another hospital also present challenges in follow-up due to tracking difficulties and infants having complex medical issues.

- ***Outpatient (Re)screens***

Results of outpatient hearing screens or re-screens are reported by primary care providers, designated referral sites, audiologists, otolaryngologists (ENTs), and local public health offices. Results can be reported through a variety of methods including: 1) EHDI reporting form, 2) returned hospital reports for missing or incomplete cases, or 3) returned provider follow-up faxes. Re-screen results are then entered into the data system by EHDI staff. A directory of hospital designated referral sites is maintained and updated frequently so that follow-up letters are sent to correct locations to ensure infants are referred to sites with appropriate testing equipment and knowledgeable staff.

- ***Diagnoses***

Results of audiologic diagnostic evaluations are reported by pediatric audiologists and otolaryngologists (ENTs). Children with confirmed hearing loss, undetermined hearing loss, or with normal hearing are reported to EHDI. A complete list of hearing loss diagnoses reported to EHDI can be found in Appendix B. EHDI receives diagnostic results via the following methods: 1) EHDI reporting form, 2) diagnostic reports, 3) Children's Special Health Care Services (CSHCS) reports, and 4) returned provider fax reports. A directory of pediatric audiology sites is maintained and updated quarterly. Reporting of progressive hearing loss continues to be a challenge to EHDI as audiologists often do not report repeat diagnostic evaluation results.



- ***Early Intervention***

EHDI collects early intervention (EI) data for all children diagnosed with hearing loss. Data collected includes enrollment into Part C services (Early On<sup>®</sup>); follow-up for audiological services including audiology monitoring, amplification services, and cochlear implantation; family support; and medical intervention information including genetics, ENT, and ophthalmology visits. EI information is voluntarily reported by Part C county coordinators with parental consent. EI information is also collected through home visits with families of newly diagnosed infants through the Guide By Your Side (GBYS) Program. Because Part C is not mandated to report EI information and because of the Family Educational Rights and Privacy Act (FERPA), receiving this information can be challenging for EHDI.

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## Quality Assurance

The EHDI Program engages in multiple quality assurance activities to ensure accuracy of information and proper security of data. The accuracy and quality of data is monitored through methods such as data linkages with other programs, 100% verification of hearing loss cases by staff, 100% double entry of demographic data, and verification of missing and duplicate cases to vital records and newborn screening records. Activities related to security of information include annual staff Health Insurance Portability and Accountability Act (HIPAA) training, a HIPAA compliant notification release on all faxes, and data disposal and shredding. The EHDI Program has an evaluation plan which ensures effective use of data and can be used to evaluate the program and identify program priorities. The evaluation plan can be found in Appendix C.

To further ensure accurate data and reporting methods, EHDI offers training opportunities to hospital screening staff, physicians, and audiologists. Educational opportunities include:

- The EHDI web page relaying information to pediatricians and primary care providers on objective methods used to complete screenings, action steps for infants who refer from screening, risk factors associated with hearing loss, and available resources.
- A physician's information packet for infants diagnosed with hearing loss containing literature on intervention services, follow-up checklists, audiology sites, amplification devices, and community specific resource brochures.
- A newborn hearing screener online training course, started in January 2009, detailing correct screening methods for hospital screening staff. This course includes a pre-and post-assessment questionnaire to track knowledge before and after completing the course. To date, about 1,553 individuals have completed and passed the training course since 2009.
- Site visits to birth hospitals and audiology diagnostic centers discussing audiology practices, providing information, and educating on referrals to services available to families.
- The State EHDI Conference with speakers presenting on topics related to hearing loss, testing procedures, educational services, and many others, with additional opportunities for parents of children with hearing loss. Over 300 people attended the EHDI annual conference in 2013.

## Linkages to Other Data Systems

EHDI collaborates with other programs and data systems to ensure accurate data and timely hearing loss detection and to help improve follow-up for infants diagnosed with hearing loss. EHDI shares data with the following:

- **Electronic Birth Certificate (EBC) and the Michigan Care Improvement Registry (MCIR)**
    - EHDI relies on data linkage with the newborn screening database to the EBC, or live birth records which allows for the capability of capturing demographic information (such as race, ethnicity, health insurance, and education) on both the mother and child. This additional demographic information allows for
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loading data into MCIR.

- Linkage to EBC allows for identification of missing newborn hearing results in the EHDI system.
- Since June 2009, EHDI results have been available on MCIR. Infants needing hearing screen follow-up are highlighted so that providers and public health nurses know to take action.
- **Early On® (Part C) and Project Find (Part B)**
  - EHDI collaborates with the Michigan Department of Education to identify children enrolled in intervention services for hearing loss.
  - Collaboration can be difficult due to HIPAA and FERPA regulations which control the sharing of confidential information.
- **Children's Special Health Care Services (CSHCS)**
  - Reports of infants born after 1997 and enrolled in CSHCS for hearing loss are shared with EHDI.
- **Local Public Health**
  - EHDI continues to work with local public health offices by referring infants with failed screens who have not had a hearing outcome reported to the state EHDI Program by 60 days of age.

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## Definitions

**Complete initial screen (complete hospital screen):** A pass/refer type of hearing test designed to identify newborns who require additional audiological assessment to rule out or confirm the presence of hearing loss. This is the first hearing screen an infant receives, usually at the hospital, before discharge.

**Hearing loss:** The Joint Committee on Infant Hearing (JCIH) defines hearing loss for universal newborn hearing screening programs as permanent bilateral or unilateral, sensory or conductive hearing loss, averaging 30 to 40 dB or more in the frequency region important for speech recognition (approximately 500 through 4000Hz).

**Hearing re-screen:** A subsequent hearing screen needed after having a refer result on a previous screen or if an infant has any risk factors for hearing loss. This allows for additional screening to determine if a diagnostic audiological assessment is needed.

**Hearing screening rate:** The proportion of infants with a complete hospital screen among the total number of live births in the specific time period.

*Calculation for hearing screening rate: number of infants with a complete initial screen in specific time period / number of live births in the specific time period (X 100).*

**Incomplete initial screen:** The first screen an infant receives at the hospital that is not completed due to a number of factors: infant was in the Neonatal Intensive Care Unit (NICU), transferred to another facility, discharged prior to screening, restless, died, or not tested due to equipment problems, environmental noise, parental refusal, or for another reason.

**Loss to follow-up (LTF):** Infants who do not receive or have no documentation of needed services after referring from the final hearing screen.

*Calculation for LTF: number of infants with no documentation in specific time period / number of infants referring from their final screen in specific time period (X 100).*

**Missed hearing screen:** A hearing screen not performed before hospital discharge.

**Prevalence rate of hearing loss:** The proportion of infants with hearing loss among all infants born in a given time period.

*Calculation for prevalence of hearing loss: number of infants with hearing loss in specific time period / number of live births in specific time period (X 1,000 to determine number of cases per 1,000 live births).*

**Refer:** Screen result when an infant does not pass the hearing screen.

**Referral rate:** The proportion of infants who refer from their initial screen among all those who complete the hospital screen.

*Calculation for referral rate: number of infants failing their last initial screen / number of infants with a complete initial screen (X 100).*

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## EHDI Data Overview: 2007-2011

The Michigan EHDI Program works to progress toward the national EHDI goals to ensure that: 1) all infants are screened for hearing loss no later than one month of age, 2) all infants who screen positive for hearing loss will have a diagnostic audiologic evaluation no later than three months of age, and 3) all infants identified with hearing loss will receive appropriate intervention services no later than six months of age. A brief summary of statistics for the EHDI Program from 2007 to 2011 is shown in Table 1.

**Table 1:** Summary of statistics from the Michigan EHDI Program, 2007-2011.

| Indicator  | Number                    | Percent |
|--|---------------------------|---------|
| <b>Number of live births</b>                           | <b>592,588</b>            |         |
| Complete initial screen                                | 574,000                   | 96.9    |
| Complete initial screen by 1 month                     | 564,183                   | 98.3    |
| Refer from final screen                                | 8,113                     | 1.4     |
| Diagnostic evaluation after referral from final screen | 3,387                     | 41.7    |
| Diagnosis by 3 months                                  | 1,843                     | 54.4    |
| Number with permanent hearing loss                     | 882                       | 26.0    |
| Number with non-permanent hearing loss                 | 771                       | 22.8    |
| Enrollment in Early Intervention Services              | 331                       | 37.5    |
| Enrollment by 6 months                                 | 135                       | 40.8    |
| Loss to follow-up                                      | 4,457                     | 54.9    |
| Prevalence of permanent hearing loss                   | 1.5 per 1,000 live births |         |
| Prevalence of non-permanent hearing loss               | 1.3 per 1,000 live births |         |

In Michigan, from 2007 to 2011, there were 592,588 live births of which 96.9% (n=574,000) had a complete initial screen, and of these infants, 98.3% (n=564,183) were screened no later than one month of age. Of infants with a complete screen, 1.4% (n=8,113) referred (did not pass) from the final screen.

Approximately, 42% (n=3,387) of infants had a diagnostic evaluation after referring from the final hearing screen and of these infants, 54.4% (n=1,843) had an evaluation by three months of age. Of infants who received a diagnostic evaluation, about 26% (n=882) were diagnosed with permanent hearing loss while about 23% (n=771) were diagnosed with non-permanent hearing loss. Overall from 2007 to 2011, the prevalence of permanent hearing loss was 1.5 infants per 1,000 live births and the prevalence of non-permanent hearing loss was 1.3 infants per 1,000 live births.

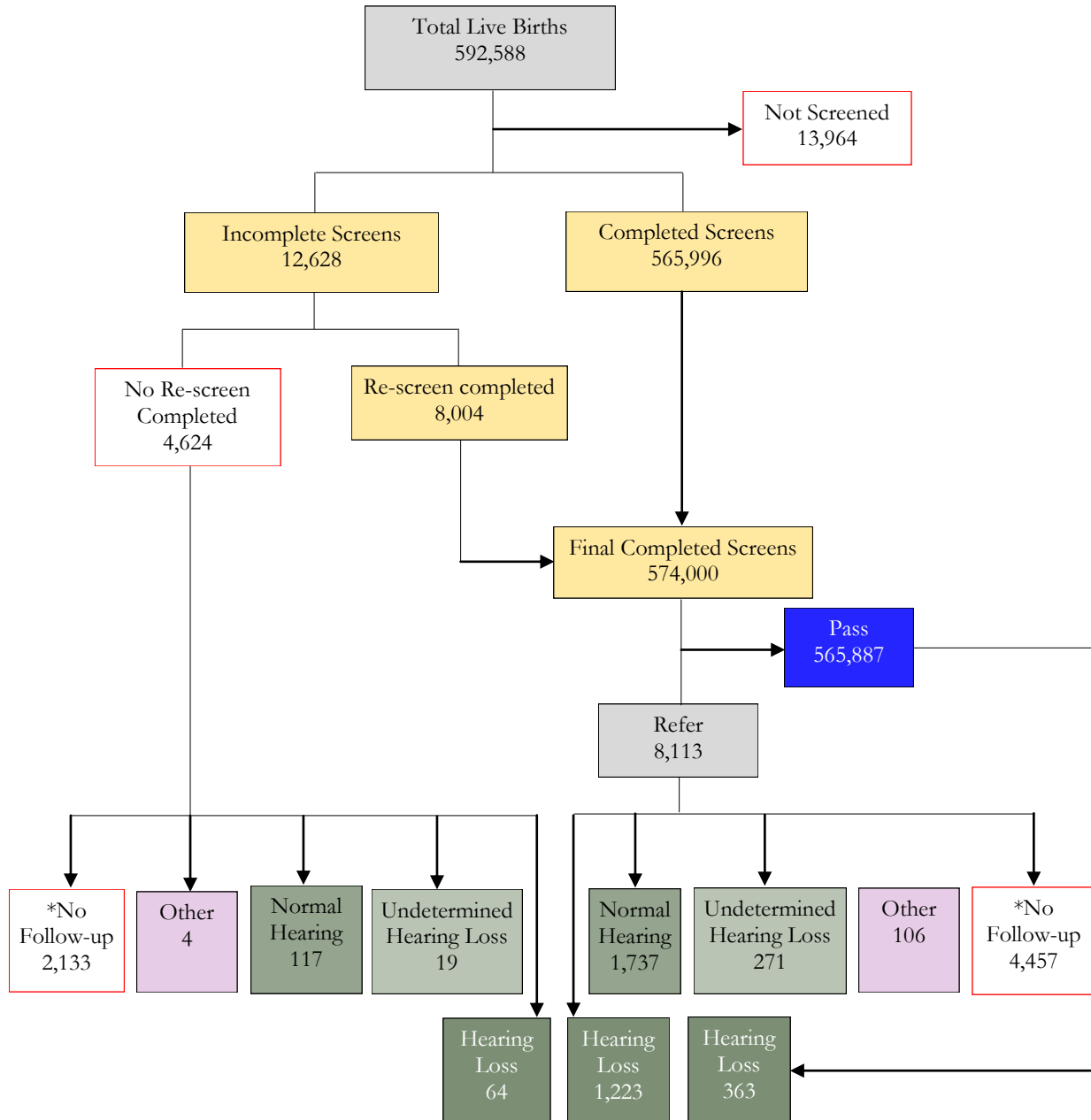
The EHDI Program has limited data on infants enrolled in early intervention services. For those whom the program has intervention data, about 38% (n=331) were enrolled in early intervention services and of those, about 41% (n=135) were enrolled by six months of age.

Infants are considered lost to follow-up (LTF) when they do not receive a diagnostic evaluation after referring from the final screen. About 55% (n=4,457/8,113) of infants were lost to follow up in Michigan from 2007 to 2011.

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This page displays a flowchart showing the flow of infants through the EHDI system from birth to diagnosis. Infants have had diagnostic evaluations at multiple points throughout the EHDI system—after passing or referring from initial screens or re-screens, and after incomplete screens (Figure 1).

**Figure 1:** Flowchart of infants through the Michigan EHDI system, 2007-2011.



\*'No follow-up' excludes infants who are deceased, live out of state, adopted or in foster care, in hospice care, moved out of state, or whose parents refused screening.

**Definitions:**

**Hearing Loss:** Includes both permanent and non-permanent hearing loss.

**Undetermined:** Type of hearing loss was not identified in diagnostic evaluation.

**Pass:** Passed *final* screening test in both ears.

**Refer:** Failed *final* screening test in one or both ears.

**Other:** Includes infants who died or moved out of state.

# Michigan EHDI Statistics, 2007-2011

## Screening Rates

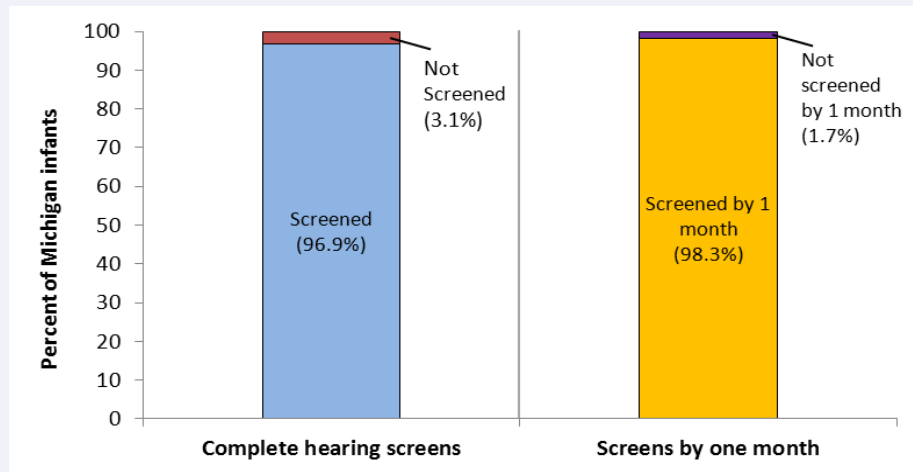
The first national EHDI goal states that all newborns should be screened for hearing loss no later than one month of age, preferably before hospital discharge, and Michigan is successfully meeting this goal. Table 2 summarizes the number of live births, the percentage of infants with a complete hospital screen, and the percentage of infants screened no later than one month of age in Michigan from 2007 to 2011.

In Michigan, the number of live births decreased from 125,172 births in 2007 to 114,159 births in 2011. The percentage of infants with a complete hospital screen increased from 96.1% (n=120,318) in 2007 to 97.6% (n=111,398) in 2011 (Table 2). The percentage of infants with a complete screen remained at about 98% through 2011 primarily due to universal newborn hearing screening becoming a standard of care in 100% of birthing hospitals, since 2003.

The percentage of infants with a complete hospital screen by one month of age remained stable at about 98.3% from 2007 (n=118,326) to 2011 (n=109,539) (Table 2). Figure 2 gives a summary of complete hospital screens and screens completed by one month of age among live births in Michigan from 2007 to 2011. Overall, 96.9% of infants had a complete hospital screen and of those, 98.3% were screened by one month of age (Figure 2).

**Table 2:** Complete hospital hearing screens and screens by one month of age: Michigan EHDI, 2007-2011.

| Birth Year   | Live Births    | Complete Hospital Screen |             | Screened by 1 Month |             |
|--------------|----------------|--------------------------|-------------|---------------------|-------------|
|              |                | Number                   | Percent     | Number              | Percent     |
| 2007         | 125,172        | 120,318                  | 96.1        | 118,326             | 98.3        |
| 2008         | 121,231        | 116,281                  | 95.9        | 114,285             | 98.3        |
| 2009         | 117,309        | 114,246                  | 97.4        | 112,247             | 98.3        |
| 2010         | 114,717        | 111,757                  | 97.4        | 109,787             | 98.2        |
| 2011         | 114,159        | 111,398                  | 97.6        | 109,539             | 98.3        |
| <b>TOTAL</b> | <b>592,588</b> | <b>574,000</b>           | <b>96.9</b> | <b>564,184</b>      | <b>98.3</b> |



**Figure 2:** Overall complete hospital hearing screens and screens by one month of age: Michigan EHDI, 2007-2011.



## Incomplete Initial Screens

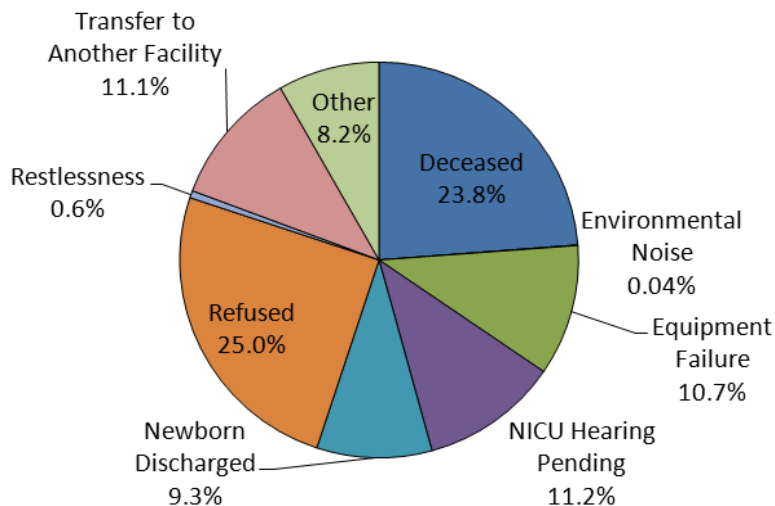
Incomplete hospital screens are those that were not able to be completed due to hospital, parental, and infant related issues, as well as others, as seen in Table 3. A total of 4,624 infants had an incomplete hearing screen with no further screening from 2007 to 2011 (Table 3).

Overall, incomplete screens were due to the following reasons: parental refusal—25.0% (n=1,158); infant died—23.8% (n=1,100); infant was in the Neonatal Intensive Care Unit (NICU)—11.2% (n=517); infant was transferred—11.1% (n=512); equipment failure—10.7% (n=495); infant was discharged—9.3% (n=432); environmental noise—0.04% (n=2); (n=381); infant was restless—0.6% (n=27) or some other reason—8.2% (Table 3 and Figure 3).

Of note, the reasons for incomplete screens changed from 2007 to 2011. With the exception of parental refusal which *increased* by 9.0%, all other reasons *decreased*, ranging from about 5% to 100% (Table 3). These changes demonstrate the successes of midwife education and hospitals completing screens before infant discharge.

**Table 3:** Incomplete screens by reason for missing screen: Michigan EHDI, 2007-2011.

| Reason for Incomplete Screen | 2007-2011 Total |         | % Change from 2007-2011 |
|------------------------------|-----------------|---------|-------------------------|
|                              | Number          | Percent |                         |
| Refused                      | 1,158           | 25.0    | 9.0                     |
| Deceased                     | 1,100           | 23.8    | -4.8                    |
| NICU Hearing Pending         | 517             | 11.2    | -27.1                   |
| Transfer to Another Facility | 512             | 11.1    | -23.8                   |
| Equipment Failure            | 495             | 10.7    | -25.3                   |
| Newborn Discharged           | 432             | 9.3     | -18.8                   |
| Other                        | 381             | 8.2     | -31.8                   |
| Restlessness                 | 27              | 0.6     | -18.5                   |
| Environmental Noise          | 2               | 0.04    | -100                    |
| <b>Total Number</b>          | <b>4,624</b>    |         |                         |



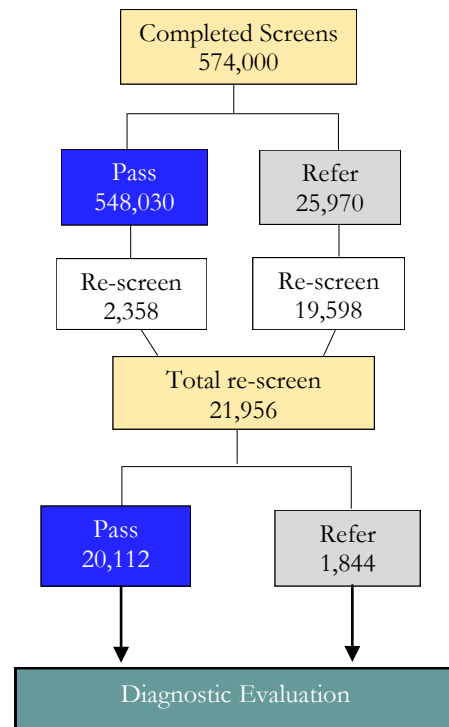
**Figure 3:** Overall reasons for incomplete screens: Michigan EHDI 2007-2011.

## Refer Rates

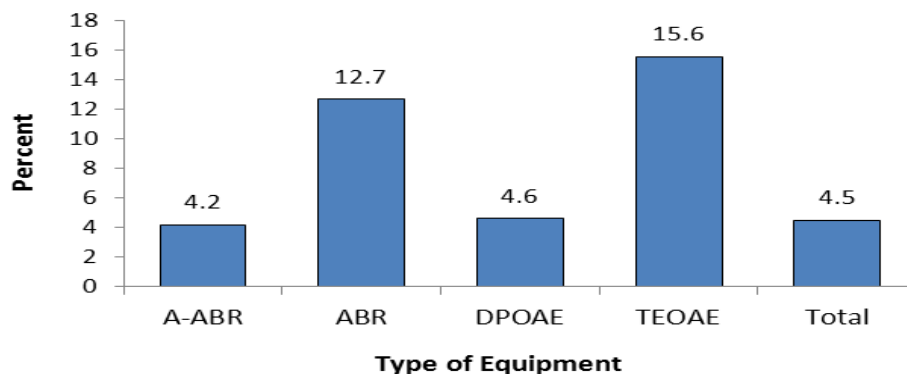
The 'Refer Rate' is the proportion of infants who are referred for a diagnostic evaluation (or refer) following a complete screen among all those with a complete screen. Here, we expand the flow chart found in Figure 1, page 15, to include both the initial complete screens and re-screens (Figure 4). According to EHDI protocol, infants who refer from the complete hearing screen should have had one subsequent re-screen before being referred to determine if a diagnostic evaluation is needed. Nationally, the refer rate is recommended to be below 4%, and Michigan is not meeting this goal.

From 2007 to 2011, 4.5% (n=25,970) referred from the complete screen. The refer rate increased from 4.0% in 2007 to 5.5% in 2011 (Table 4, page 19). It is important that the re-screen rate remains high and the refer rate remains low so that infants do not receive unnecessary testing, as many of those who refer from a complete screen do not in fact have hearing loss. A total of 21,956 infants had a re-screen following a complete screen with 2,358 infants having a re-screen after passing and 19,598 infants having a re-screen after referring from the complete screen (Figure 4). Infants may be re-screened after passing the initial screen if they have a risk factor for hearing loss.

More detailed information on refer rates by type of testing equipment are given in Table 4 and Figure 5. Overall, 4.2% (n=15,145) of those screened with A-ABR referred, 12.7% (n=1,566) of those screened with ABR referred, 4.6% (n=9,109) of those screened with DPOAE referred, and 15.6% (n=150) of those screened with TEOAE referred from the complete hospital screen from 2007 to 2011 (Table 4 and Figure 5). The ABR refer rate may be high because it is usually performed on those in the NICU, who are more likely to have risk factors for hearing loss. The DPOAE refer rate may be low due to infants having repeat screens until receiving a pass result. Refer rates were highest using the TEOAE, which may be due to the low number of times it has been used.



**Figure 4:** Flowchart of infants from complete hospital screen to re-screen: Michigan EHDI, 2007-2011.



**Figure 5:** Refer rates from completed hospital hearing screen by type of screening equipment: Michigan EHDI, 2007-2011.

**Table 4:** Refer rates from completed hospital hearing screen by type of screening equipment: Michigan EHDI, 2007-2011.

| Birth Year   | A-ABR         |            | ABR          |             | DPOAE        |            | TEOAE      |             | Total         |            |
|--------------|---------------|------------|--------------|-------------|--------------|------------|------------|-------------|---------------|------------|
|              | Number        | Percent    | Number       | Percent     | Number       | Percent    | Number     | Percent     | Number        | Percent    |
| 2007         | 2,619         | 3.7        | 286          | 14.1        | 1,806        | 3.9        | 129        | 15.2        | 4,840         | 4.0        |
| 2008         | 2,565         | 3.7        | 268          | 12.0        | 1,863        | 4.2        | 12         | 18.8        | 4,708         | 4.1        |
| 2009         | 2,714         | 3.8        | 284          | 13.8        | 2,041        | 5.0        | 3          | 18.8        | 5,042         | 4.4        |
| 2010         | 2,976         | 4.1        | 372          | 11.9        | 1,914        | 5.2        | 0          | 0.0         | 5,262         | 4.7        |
| 2011         | 4,271         | 5.3        | 356          | 12.3        | 1,485        | 5.2        | 6          | 33.3        | 6,118         | 5.5        |
| <b>Total</b> | <b>15,145</b> | <b>4.2</b> | <b>1,566</b> | <b>12.7</b> | <b>9,109</b> | <b>4.6</b> | <b>150</b> | <b>15.6</b> | <b>25,970</b> | <b>4.5</b> |

## Failed Initial Hearing Screen by Year and Gender

Failed initial hearing screen results were analyzed by gender to assess any disparities between male and female infants who referred from a complete screen. In Michigan, of 25,970 infants who failed the complete initial screen from 2007 to 2011, 54.4% (n=14,139) were boys and 42.2% (n=10,948) were girls (Table 5). Analysis of the EHDI data revealed that more boys failed the initial hearing screen than girls (Table 5). This trend was observed from 2007 to 2011 (Figure 6). Overall, the number referring from the complete initial screen from 2007 to 2011 was about 12% higher for boys compared with girls (Table 5). Trend data also revealed that the number of infants referring from a complete hospital screen increased over the years—from 4,840 in 2007 to 6,133 in 2011 (Table 5).

**Table 5:** Failed complete initial screen (refer) by year and gender: Michigan EHDI, 2007-2011.

| Birth Year       | Refer from completed hospital screen |        | Total         | Percent |
|------------------|--------------------------------------|--------|---------------|---------|
|                  | Gender                               | Number |               |         |
| 2007             | Male                                 | 2,738  | 4,840         | 56.6    |
|                  | Female                               | 2,076  |               | 42.9    |
|                  | missing                              | 26     |               | 0.5     |
| 2008             | Male                                 | 2,540  | 4,708         | 54.0    |
|                  | Female                               | 1,895  |               | 40.3    |
|                  | missing                              | 273    |               | 5.8     |
| 2009             | Male                                 | 2,757  | 5,042         | 54.7    |
|                  | Female                               | 2,070  |               | 41.1    |
|                  | missing                              | 215    |               | 4.3     |
| 2010             | Male                                 | 2,844  | 5,262         | 54.0    |
|                  | Female                               | 2,192  |               | 41.7    |
|                  | missing                              | 226    |               | 4.3     |
| 2011             | Male                                 | 3,260  | 6,133         | 53.2    |
|                  | Female                               | 2,715  |               | 44.3    |
|                  | missing                              | 158    |               | 2.6     |
| <b>2007-2011</b> | Male                                 | 14,139 | <b>25,970</b> | 54.4    |
|                  | Female                               | 10,948 |               | 42.2    |
|                  | missing                              | 898    |               | 3.5     |

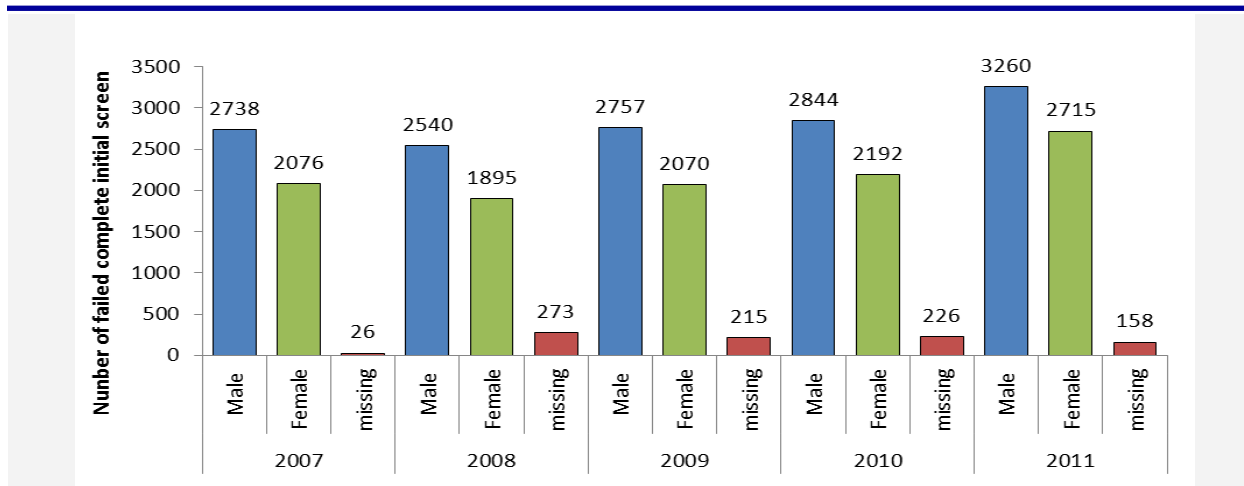


Figure 6: Failed complete initial screen by gender: Michigan EHDI, 2007-2011.

## Multiple Screens

After referring from the complete hospital screen, infants should have **one** subsequent re-screen before one month of age, and should then be referred for a diagnostic audiologic evaluation. If an infant is screened many times, the result of the final screen may be inaccurate or the infant may not be referred to necessary services in a timely manner. Michigan EHDI data revealed that hospitals reported more than one complete hospital screen for about 0.4% (n=2,324) of infants from 2007 to 2011. Of infants with multiple hospital screens, 99.8% (n=2,321) had all screens within one day. Hospitals should only report the result of the final screen to EHDI.

Of the 21,956 infants who had a re-screen from 2007 to 2011, about 6% (n=1,314) had more than one re-screen. Of these infants, the median (middle) length of time between the first and final re-screen was 44.0 days, ranging from 0 to 1,080 days. Of infants with multiple re-screens, about 15% (n=197) had the first and final re-screen on the same day, while about 29% (n=378) had more than 100 days between the first and final re-screen (Figure 7). More detail on the number of days between screens for infants with a re-screen is given in Figure 7. When the number of days between multiple re-screens and diagnostic evaluation increases, infants are not diagnosed with hearing loss or determined to have normal hearing in a timely manner which can result in delayed childhood development and language skills, increased parent anxiety, and increased cost of medical care if the child has hearing loss.

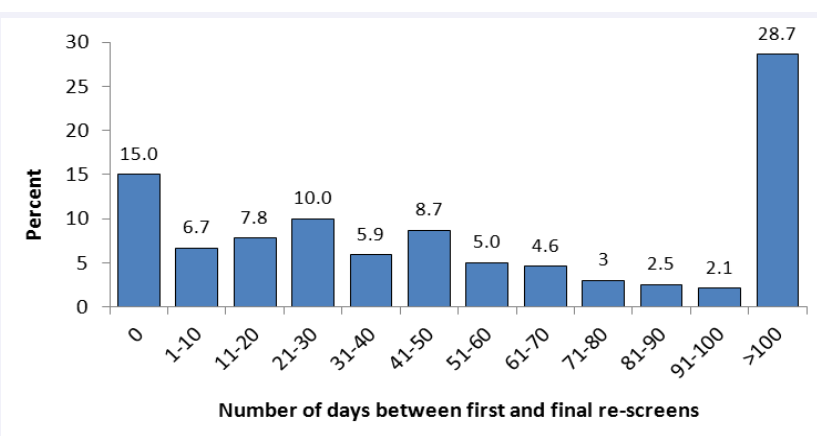


Figure 7: Days between first and final screens for infants with a re-screen: Michigan EHDI, 2007-2011

## Diagnostic Audiologic Evaluations

Information from diagnostic evaluations is reported to EHDI at many stages of the EHDI process. Infants may have a diagnostic evaluation after passing or referring from the complete hospital screen, or after an incomplete screen. Permanent and non-permanent hearing loss by orientation (unilateral or bilateral) and degree are reported to EHDI. Permanent hearing loss includes sensorineural, mixed, conductive permanent, and auditory neuropathy types while non-permanent hearing loss includes conductive transient types. Other diagnostic evaluation results reported to EHDI include hearing within normal limits and undetermined status. Table 6 gives a summary of the percentage of infants with a hearing loss among those who received a diagnostic evaluation and the overall prevalence of hearing loss from 2007 to 2011.

**Table 6:** Prevalence of permanent and non-permanent hearing loss Michigan EHDI, 2007-2011

| Diagnosis            | Number of Infants | Percent | Rate (per 1,000 live births) |
|----------------------|-------------------|---------|------------------------------|
| <b>Permanent</b>     | <b>882</b>        | 26.0    | 1.5                          |
| Sensorineural        | 677               | 20.0    | 1.1                          |
| Mixed                | 75                | 2.2     | 0.1                          |
| Conductive Permanent | 84                | 2.5     | 0.1                          |
| Auditory Neuropathy  | 46                | 1.4     | 0.1                          |
| <b>Non-Permanent</b> | <b>771</b>        | 22.8    | 1.3                          |
| Conductive           | 77                | 2.3     | 0.1                          |
| Conductive Transient | 694               | 20.5    | 1.2                          |

From 2007-2011, of infants in Michigan who had a diagnostic evaluation after referring from the final screen, 26% (n=882) were diagnosed with permanent hearing loss while about 23% (n=771) were diagnosed with a non-permanent hearing loss (Table 6). Percentages are also provided by type of hearing loss in Table 6.

Nationally, about 1 to 3 infants per 1,000 births are diagnosed with permanent hearing loss, and in Michigan, from 2007 to 2011, the prevalence of permanent hearing loss was 1.5 cases per 1,000 live births reported to EHDI.

Permanent hearing loss included rates of: 1.1 cases of sensorineural, 0.1 cases of mixed, 0.1 cases of conductive permanent, and 0.1 cases of auditory neuropathy, all per 1,000 live births (Table 6). The prevalence of non-permanent hearing loss was 1.3 cases per 1,000 live births reported to EHDI from 2007 to 2011.

Non-permanent hearing loss included rates of 0.1 cases of conductive and 1.2 cases of conductive transient, both per 1,000 live births (Table 6).

The following pages analyze the results from diagnostic evaluations by a variety of factors, including:

- Permanent hearing loss by result of the final screen—to assess the stages in the EHDI system in which hearing loss is reported.
- Prevalence of permanent and non-permanent hearing loss by orientation (unilateral or bilateral) and degree (slight, mild, moderate, moderately severe, or profound)—to assess varying levels of hearing loss in Michigan infants.
- The percentage of infants with a diagnostic evaluation no later than three months of age—to assess how well the EHDI program is doing in achieving the national EHDI goal.

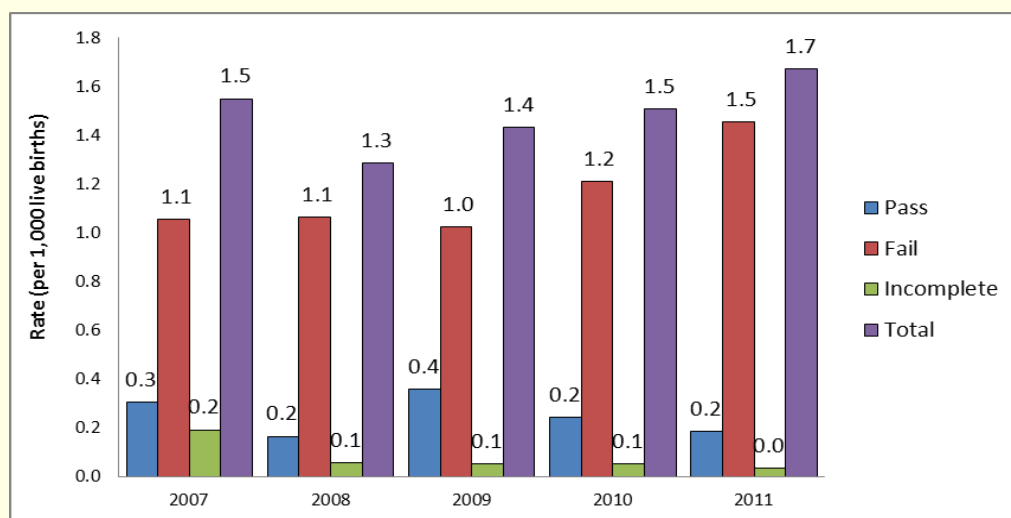
## Permanent Hearing Loss by Result of Final Screen

Prevalence of hearing loss should be analyzed by result of the final screen in order to assess the impact that EHDI has on the detection of hearing loss.<sup>11</sup> Infants diagnosed with hearing loss after a *failed* final screen are considered to be detected by EHDI processes, while infants diagnosed after a *passed* or *incomplete* final screen are considered detected by an outside source. The prevalence of **permanent** hearing loss by result of the final screen for infants born from 2007 to 2011 is shown in Table 7 and Figure 8. More detailed information on permanent hearing loss by result of the final screen for years 2007 to 2011 can be found in Appendix D. In this analysis, hearing loss was defined as permanent hearing loss (sensorineural, mixed, conductive permanent, or auditory neuropathy) of any orientation (unilateral or bilateral) or degree (slight, mild, moderate, moderately severe, severe, or profound).

From 2007 to 2011, a total of 686 infants with hearing loss were detected by EHDI, while an additional 196 (n=149+47) infants were detected by outside sources, for a total prevalence of 1.5 children with permanent hearing loss per 1,000 live births (Table 7). The prevalence of permanent hearing loss detected by EHDI increased from 1.1 children per 1,000 live births in 2007 to 1.5 children per 1,000 live births in 2011. The prevalence of permanent loss detected from outside sources remained stable at about 0.3 children per 1,000 live births from 2007 to 2011 (Figure 8).

**Table 7:** Prevalence of permanent hearing loss by result of final screen: Michigan EHDI, 2007-2011.

| Birth Years  | Final Screen Result   |                | Permanent Hearing Loss |                              |
|--------------|-----------------------|----------------|------------------------|------------------------------|
|              | Result                | Number         | Number                 | Rate (per 1,000 live births) |
| 2007 to 2011 | Pass                  | 565,887        | 149                    | 0.3                          |
|              | Fail                  | 8,113          | 686                    | 1.2                          |
|              | Incomplete            | 4,624          | 47                     | 0.1                          |
|              | <b>Total Screened</b> | <b>578,624</b> | <b>882</b>             | <b>1.5</b>                   |



**Figure 8:** Prevalence of permanent hearing loss by final screen result: Michigan EHDI, 2007-2011.

## Hearing Loss by Degree and Orientation

Audiologists diagnose and report hearing loss by degree and orientation. Orientation refers to hearing loss that is either bilateral (affecting both ears) or unilateral (affecting one ear). Degree of hearing loss focuses on severity and is expressed in decibels (dB) based on the average pure tone for the frequencies 500 to 4,000 Hz.

For this analysis, degree of hearing loss is defined as follows: slight—16-25 dB, mild—26-40 dB, moderate—41-55 dB, moderate severe—56-70 dB, severe—71-90, and profound—91 dB or greater.<sup>12</sup>

Prevalence of permanent and non-permanent hearing loss by degree and orientation is shown in Table 8. For this analysis, those with auditory neuropathy are **not** included as degree is not reported for this type.

For **permanent** hearing loss from 2007 to 2011, there were: 0.4 children with slight-moderate bilateral loss; 0.5 children with moderate severe-profound bilateral loss; 0.3 children with slight-moderate unilateral loss; and 0.2 children with moderate severe-profound unilateral loss, all per 1,000 live births (Table 8).

For **non-permanent** hearing loss, there were 0.8 children with slight-moderate bilateral loss; 0.03 children with moderate severe-profound bilateral loss; 0.5 children with slight-moderate unilateral loss; and 0.02 children with moderate severe-profound unilateral loss, all per 1,000 live births (Table 8). Children are affected by many different degrees of hearing loss and it is important to assess all levels of hearing loss so that appropriate services are available to all children.

**Table 8:** Prevalence of permanent and non-permanent hearing loss by degree and orientation: Michigan EHDI, 2007-2011.

| Prevalence of Hearing loss (per 1,000 live births) |                      |                 |                          |                 |                          |
|--|----------------------|-----------------|--------------------------|-----------------|--------------------------|
| Birth Year   | Type of Hearing Loss | Degree          |                          |                 |                          |
|  |                      | Bilateral       |                          | Unilateral      |                          |
|  |                      | Slight-Moderate | Moderate Severe-Profound | Slight-Moderate | Moderate Severe-Profound |
| 2007   | Permanent            | 0.5             | 0.5                      | 0.3             | 0.2                      |
|  | Non-Permanent        | 0.8             | *                        | 0.4             | *                        |
| 2008   | Permanent            | 0.5             | 0.4                      | 0.3             | 0.1                      |
|  | Non-Permanent        | 0.5             | *                        | 0.4             | *                        |
| 2009   | Permanent            | 0.3             | 0.4                      | 0.3             | 0.3                      |
|  | Non-Permanent        | 0.9             | *                        | 0.6             | 0.01                     |
| 2010   | Permanent            | 0.4             | 0.5                      | 0.3             | 0.2                      |
|  | Non-Permanent        | 1.0             | 0.01                     | 0.5             | 0.01                     |
| 2011   | Permanent            | 0.5             | 0.5                      | 0.2             | 0.3                      |
|  | Non-Permanent        | 0.7             | 0.1                      | 0.4             | *                        |
| Total  | Permanent            | 0.4             | 0.5                      | 0.3             | 0.2                      |
|  | Non-Permanent        | 0.8             | 0.03                     | 0.5             | 0.02                     |

\*No children identified with the degree of hearing loss

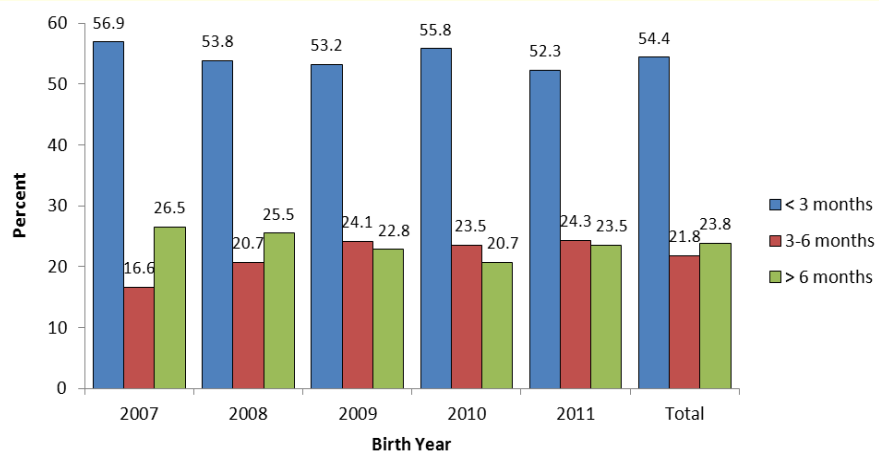
## Diagnostic Evaluation by 3 Months

The second national EHDI goal states that all infants who screen positive for hearing loss should have a diagnostic audiologic evaluation no later than three months of age. Nationally, this goal is not being met with about 43% of infants who refer from their hearing screen having no documented diagnosis.<sup>13</sup> It is important for infants with hearing loss to be diagnosed in a timely manner so that they may benefit from early intervention services.

From 2007 to 2011, a total of 41.7% (n=3,387) of infants referring from the final screen had a diagnostic evaluation in Michigan (Table 9). Overall, for infants referring from the final hearing screen from 2007 to 2011, 54.4% (n=1,843) had a diagnostic evaluation by three months of age, 21.8% (n=737) had an evaluation between three and six months of age and 23.8% (n=807) had an evaluation later than six months of age (Table 9). The percentage of infants diagnosed by **three months** of age decreased from 56.9% in 2007 to 52.3% in 2011. The percentage of infants diagnosed between **three and six months** increased from 16.6% in 2007 to 24.3% in 2011. The percentage of infants diagnosed later than **six months** of age decreased from 26.5% in 2007 to 23.5% in 2011. Although the total percentage of infants with a diagnostic evaluation increased over the years, EHDI is not yet meeting the national EHDI goal and much effort is put into reducing loss to follow-up to ensure that babies who fail the final screen have a diagnostic audiologic evaluation. Activities related to reducing loss to follow-up can be found in the *EHDI Program Highlights* section on page 33 of this report.

**Table 9:** Age at diagnostic audiologic evaluation for infants referring from the final hearing screen: Michigan EHDI, 2007-2011.

| Birth Year   | Age at Diagnostic Evaluation |             |            |             |            |             |              |             |
|--------------|------------------------------|-------------|------------|-------------|------------|-------------|--------------|-------------|
|              | <3 months                    |             | 3-6 months |             | >6 months  |             | Total        |             |
|              | Number                       | %           | Number     | %           | Number     | %           | Number       | %           |
| 2007         | 405                          | 56.9        | 118        | 16.6        | 189        | 26.5        | 712          | 37.1        |
| 2008         | 358                          | 53.8        | 138        | 20.7        | 170        | 25.5        | 666          | 40.9        |
| 2009         | 369                          | 53.2        | 167        | 24.1        | 158        | 22.8        | 694          | 46.2        |
| 2010         | 375                          | 55.8        | 158        | 23.5        | 139        | 20.7        | 672          | 43.7        |
| 2011         | 336                          | 52.3        | 156        | 24.3        | 151        | 23.5        | 643          | 42.0        |
| <b>Total</b> | <b>1,843</b>                 | <b>54.4</b> | <b>737</b> | <b>21.8</b> | <b>807</b> | <b>23.8</b> | <b>3,387</b> | <b>41.7</b> |



**Figure 9:** Age at diagnostic audiologic evaluation for infants referring from the final hearing screen: Michigan EHDI, 2007-2011.



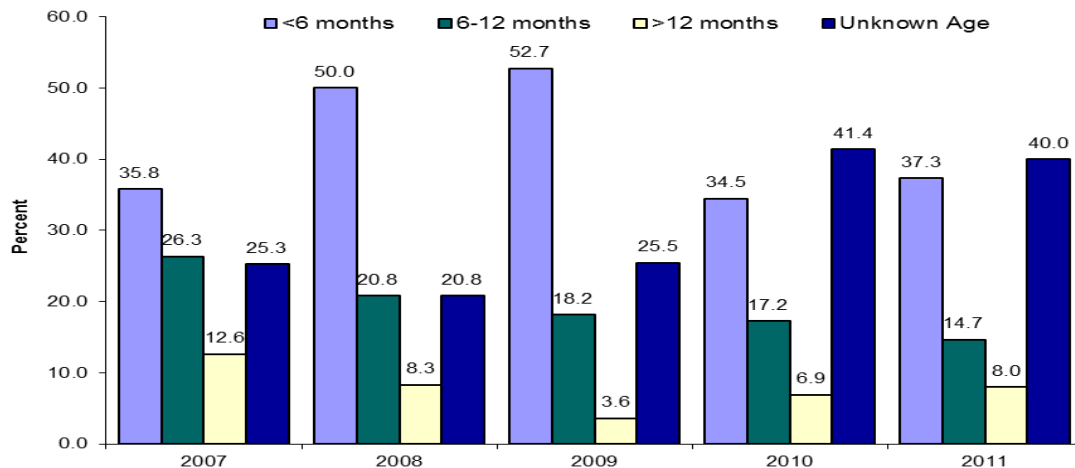
## Enrollment in Early Intervention Services

The third national EHDI goal is that all infants identified with hearing loss should receive appropriate early intervention services no later than six months of age. EHDI collects early intervention (EI) data for children diagnosed with hearing loss from Part C county coordinators and the Guide By Your Side (GBYS) program, with parental consent. Receiving this information can be difficult as Part C is not mandated to report information to EHDI and due to the Family Educational Rights and Privacy Act (FERPA). This section gives information on enrollment into Early On<sup>®</sup> (Michigan's Part C services), which assists children age zero to three years with developmental delays or a diagnosed disability.

Table 10 shows the percentage of infants diagnosed with permanent hearing loss and enrolled in intervention services from 2007 to 2011. From 2007 to 2011, 37.5% (n=331) of infants diagnosed with permanent hearing loss were enrolled in intervention services. Of infants diagnosed with permanent hearing loss from 2007 to 2011, 40.8% (n=135) were enrolled by six months of age, 19.9% (n=66) were enrolled between six and twelve months of age, 8.5% (n=28) were enrolled later than twelve months of age, and 30.8% (n=102) were enrolled at an unknown age (Table 10). In 2011, 39.3% of infants were enrolled in services but this percentage may increase as reports for infants who continue to be enrolled at later dates are sent to the EHDI program. Michigan is currently not meeting the national goal, but data is limited due to FERPA regulations.

**Table 10:** Age at enrollment in intervention services for infants diagnosed with permanent hearing loss: Michigan EHDI, 2007-2011.

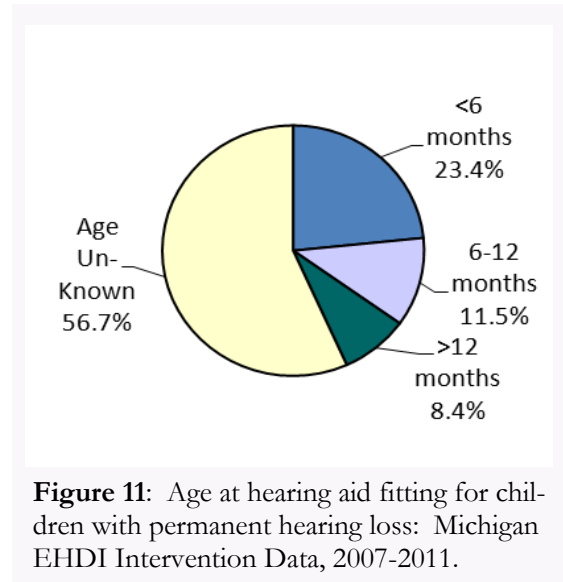
| Birth Year   | Age at Enrollment |             |             |             |            |            |             |             | Infants Enrolled |             |
|--------------|-------------------|-------------|-------------|-------------|------------|------------|-------------|-------------|------------------|-------------|
|              | <6 months         |             | 6-12 months |             | >12 months |            | Unknown Age |             | Total            |             |
|              | Number            | %           | Number      | %           | Number     | %          | Number      | %           | Number           | %           |
| 2007         | 34                | 35.8        | 25          | 26.3        | 12         | 12.6       | 24          | 25.3        | 95               | 51.6        |
| 2008         | 24                | 50.0        | 10          | 20.8        | 4          | 8.3        | 10          | 20.8        | 48               | 30.8        |
| 2009         | 29                | 52.7        | 10          | 18.2        | 2          | 3.6        | 14          | 25.5        | 55               | 32.7        |
| 2010         | 20                | 34.5        | 10          | 17.2        | 4          | 6.9        | 24          | 41.4        | 58               | 33.5        |
| 2011         | 28                | 37.3        | 11          | 14.7        | 6          | 8.0        | 30          | 40.0        | 75               | 39.3        |
| <b>Total</b> | <b>135</b>        | <b>40.8</b> | <b>66</b>   | <b>19.9</b> | <b>28</b>  | <b>8.5</b> | <b>102</b>  | <b>30.8</b> | <b>331</b>       | <b>37.5</b> |



**Figure 10:** Age at enrollment in intervention services for infants diagnosed with permanent hearing loss: Michigan EHDI, 2007-2011.

## Additional Intervention Services

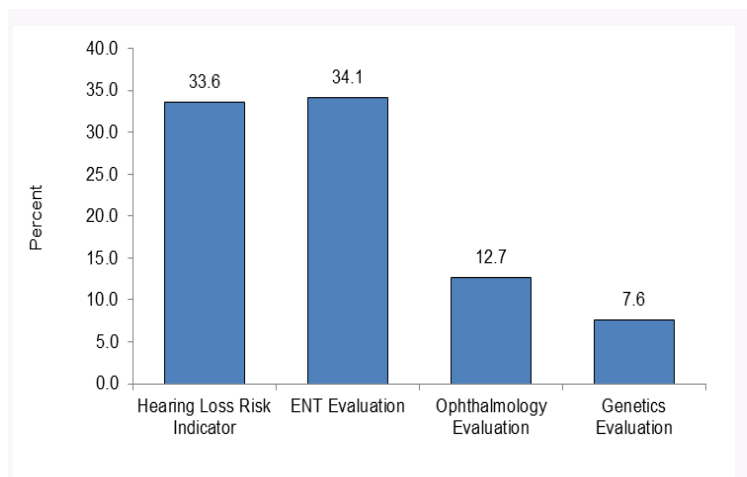
The EHDI Program receives information on amplification devices, cochlear implants, family support programs, as well as medical intervention information including genetics, ENT, and ophthalmology visits for infants with permanent hearing loss. Families may choose which services are appropriate for them and their children. From 2007 to 2011, 29.6% (n=261) of infants with permanent hearing loss had a hearing aid fitting. As shown in Figure 11, of those with a hearing aid fitting from 2007 to 2011, 23.4% (n=61) were fit by 6 months of age, 11.5% (n=30) were fit between 6 and 12 months of age, 8.4% (n=22) were fit after 12 months of age, and 56.7% (n=148) were fit at an unknown age. From 2007 to 2011, 6.8% (n=50) of infants with permanent hearing loss had a cochlear implant.



**Figure 11:** Age at hearing aid fitting for children with permanent hearing loss: Michigan EHDI Intervention Data, 2007-2011.

A variety of support programs and resources are offered to families of children with hearing loss. From 2007 to 2011, 13.7% (n=121) of families were referred to or enrolled in the Parent Infant Program, 1.0% (n=9) were referred to or enrolled in Community Mental Health Services, 37.5% (n=331) were referred to or enrolled in Children’s Special Health Care Services (CSHCS), 2.5% (n=22) were referred to or enrolled in Family-to-Family Support and 8.7% (n=77) were referred to or enrolled in GBYS. More information about these programs can be found on the EHDI website at: [www.michigan.gov/ehdi](http://www.michigan.gov/ehdi). From 2007 to 2011, 9.6% (n=85) of families with children with permanent hearing loss received EHDI resource guidebooks, which contain information on support programs and state and national resources available to families.

The EHDI Program receives limited medical intervention information on children with hearing loss. Figure 12 shows the percentage of infants with permanent hearing loss with medical interventions from 2007 to 2011. Of those with permanent hearing loss, 33.6% (n=296) had a risk indicator for hearing loss, 34.1% (n=301) had an ENT evaluation, 12.7% (n=112) had an ophthalmology evaluation, and 7.6% (n=67) had a genetic evaluation from 2007 to 2011. These categories are not mutually exclusive and children could have had more than one type of medical intervention. It is important for children with hearing loss to have these evaluations as those with hearing loss may have other medical issues.



**Figure 12:** Medical intervention services for children with permanent hearing loss: Michigan EHDI Intervention Data, 2007-2011.

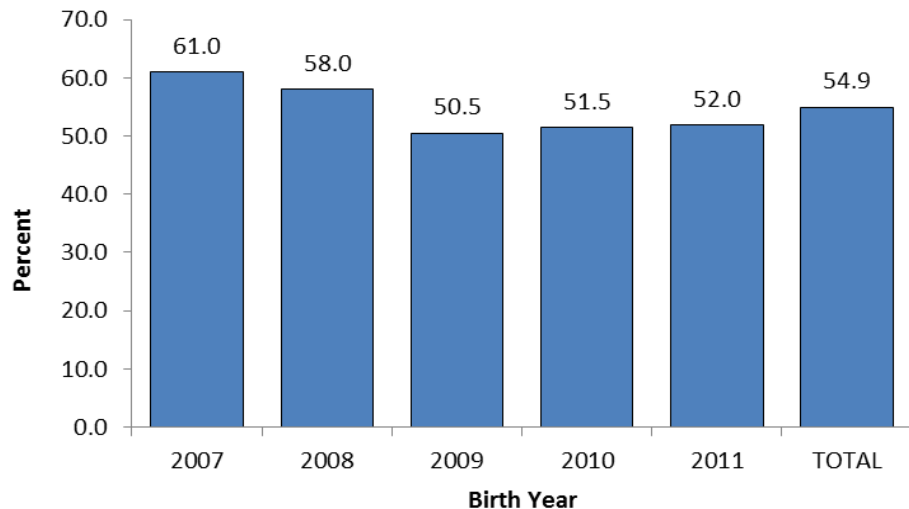
## Loss to Follow-Up

An infant is considered lost to follow-up (LTF) when he or she does not receive appropriate services, or does not have documentation of services, after referring from the final hearing screen. Loss to follow-up is a problem for most EHDI programs across the US with about 35% of all infants referring from their final screen not receiving appropriate services.<sup>14</sup> Factors that may contribute to high LTF rates include poor communication between EHDI personnel and families, poor data management, lack of facilities, and lack of well-trained personnel.<sup>15</sup> Research has shown that LTF rates were highest among infants of mothers who were non-white, had public insurance, or smoked during pregnancy.<sup>16</sup> LTF rates must be reduced so that all infants receive appropriate and timely care.

Overall in Michigan from 2007 to 2011, 54.9% (n=4,457) of infants referring from the final screen were lost to follow-up. The LTF rate decreased from 61.0% in 2007 to 52.0% in 2011 (Table 11 and Figure 13). The Michigan EHDI Program was awarded a supplemental grant from the Maternal and Child Health Bureau (MCHB) in 2010 to assist in lowering the loss to follow-up rate. EHDI activities related to reducing the loss to follow-up rate are given in the *EHDI Program Highlights* section.

**Table 11:** Loss to follow-up rates: Michigan EHDI, 2007-2011.

| Birth Year   | Number Referring from Final Screen | Loss to Follow-up |             |
|--------------|------------------------------------|-------------------|-------------|
|              |                                    | Number            | Percent     |
| 2007         | 1,916                              | 1,168             | 61.0        |
| 2008         | 1,625                              | 942               | 58.0        |
| 2009         | 1,501                              | 758               | 50.5        |
| 2010         | 1,539                              | 793               | 51.5        |
| 2011         | 1,532                              | 796               | 52.0        |
| <b>TOTAL</b> | <b>8,113</b>                       | <b>4,457</b>      | <b>54.9</b> |



**Figure 13:** Loss to follow-up rates: Michigan EHDI, 2007-2011.

LTF rates were analyzed by selected demographic variables including: maternal race, ethnicity, age, and education and the source of payment for delivery of the baby. The percentage of infants lost to follow-up in each category is shown in Table 12.

Loss to follow-up rates were **highest** among those who:

- Were black, non-Hispanic (73.6%).
- Were less than 20 years old when they had their baby (69.7%).
- Had less than a high school education (71.3%).
- Had “other” methods to pay for the delivery of their baby (71.2%).

Loss to follow-up rates were **lowest** among those who:

- Were Hispanic (43.2%).
- Were 35 years or older when they had their baby (48.0%).
- Had some college education or a college degree (45.4%).
- Had private insurance for the payment of delivery of their baby (55.4%).

**Table 12:** Loss to follow-up rates by selected demographic variables: Michigan EHDI, 2007-2011.

| Demographic Variable                  | Number Referring from Final Screen | Loss to Follow-up |         |
|---------------------------------------|------------------------------------|-------------------|---------|
|                                       |                                    | Number            | Percent |
| <b>Mom's Race, Ethnicity</b>          |                                    |                   |         |
| White, Non-Hispanic                   | 3,106                              | 1,599             | 51.5    |
| Black, Non-Hispanic                   | 2,415                              | 1,778             | 73.6    |
| Other, Non-Hispanic*                  | 387                                | 222               | 57.4    |
| Hispanic                              | 444                                | 192               | 43.2    |
| missing                               | 1,761                              | 666               | 37.8    |
| <b>Mom's Age</b>                      |                                    |                   |         |
| <20                                   | 1,064                              | 742               | 69.7    |
| 20-24                                 | 2,079                              | 1,351             | 65.0    |
| 25-29                                 | 1,678                              | 933               | 55.6    |
| 30-34                                 | 1,068                              | 551               | 51.6    |
| 35+                                   | 627                                | 301               | 48.0    |
| missing                               | 1,597                              | 579               | 36.3    |
| <b>Mom's Education</b>                |                                    |                   |         |
| <HS                                   | 1,883                              | 1,342             | 71.3    |
| HS diploma/GED                        | 2,218                              | 1,424             | 64.2    |
| Some College/College degree           | 2,322                              | 1,055             | 45.4    |
| missing                               | 1,690                              | 636               | 37.6    |
| <b>Source of Payment For Delivery</b> |                                    |                   |         |
| Private insurance                     | 2,879                              | 1,596             | 55.4    |
| Medicaid                              | 3,452                              | 2,156             | 62.5    |
| Self Pay                              | 102                                | 70                | 68.6    |
| Other                                 | 59                                 | 42                | 71.2    |
| Unknown                               | 19                                 | 13                | 68.4    |
| missing                               | 1,602                              | 580               | 36.2    |

\*Other race category encompasses women who do not define themselves as black or white and includes Native American, Asian/Pacific Islander, etc.

Of note, other ethnicities were not included due to too small numbers and potential privacy issues

LTF rates by region of birth place and maternal residence are shown in Appendix E.

Loss to follow-up rates after refer from final screen were:

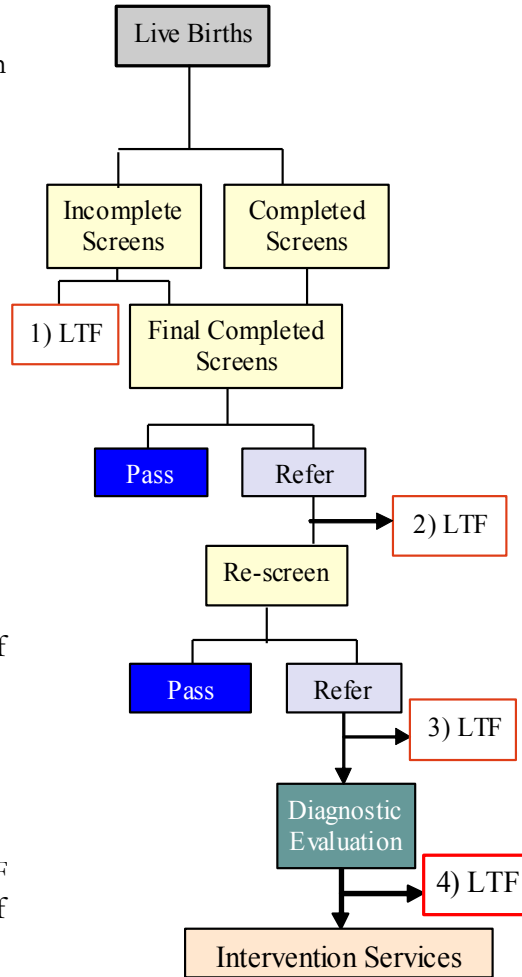
- Highest in Region 1
- Lowest in Region 8

## Loss to Follow-Up Stages

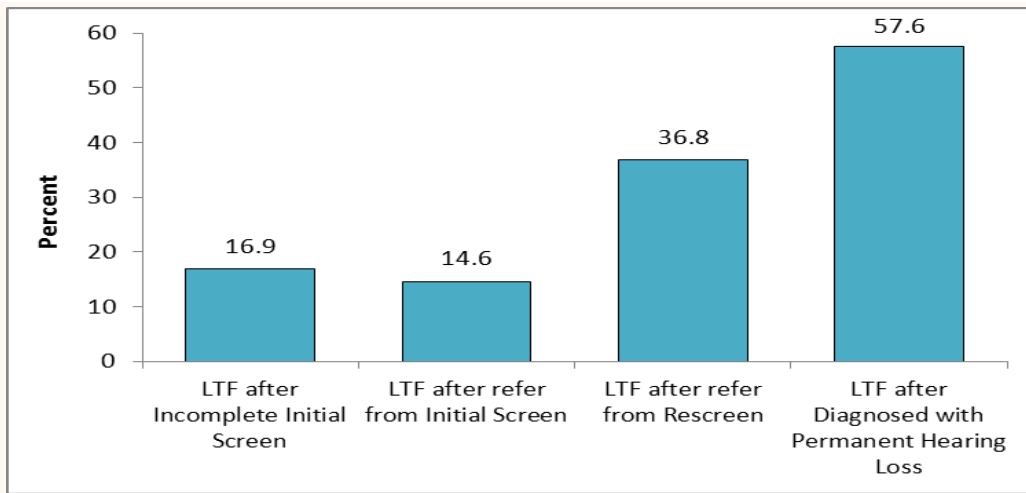
The **overall** LTF rate is defined as the percentage of infants not receiving needed services after referring from the *final* screen. In addition, it is important to analyze LTF rates at multiple stages throughout the EHDI system. Here, LTF rates were assessed at the following stages, as seen in Figure 14:

- 1) When a baby has an incomplete screen but does not have documentation of a subsequent completed hearing screen.
- 2) When a baby refers from the initial screen but does not have documentation of a re-screen to determine if more tests are needed.
- 3) When a baby refers from the re-screen, but does not have documentation of a diagnostic evaluation.
- 4) When a baby is diagnosed with permanent hearing loss but does not have documentation of enrollment in early intervention services.

Overall, from 2007 to 2011, 16.9% of infants with an incomplete screen were LTF; 14.6% of infants referring from the initial screen were LTF; 36.8% of infants referring from the re-screen were LTF; and 57.6% of infants diagnosed with permanent hearing loss were LTF (Figure 14). Parents must be aware of the importance of screening and be encouraged to return for follow-up services. More information on these stages of LTF, including rates by birth place and maternal residence regions, can be found in Appendix E.



**Figure 14:** Four stages of loss to follow-up in the EHDI system.



**Figure 15:** Loss to follow-up rates at three stages of the EHDI system: Michigan EHDI, 2007-2011.

## Michigan vs. National Statistics

The CDC compiles national statistics from state EHDI programs through the ‘CDC EHDI Hearing Screening and Follow-up Survey (HSFS)’. Individual states can use national statistics to assess their achievements in timely detection of hearing loss and enrollment in early intervention services. Here, we compare Michigan with the Nation on the ‘1-3-6’ goals, using data from 2011.

**Table 13:** Michigan vs. National Statistics, 2011.

| Indicator  | Michigan | Nation* |
|--|----------|---------|
| Percent with complete hospital screen                  | 97.6     | 97.9    |
| Percent screened no later than 1 month                 | 98.3     | 94.9    |
| Percent diagnosed after referral from final screen     | 42.0     | 56.9    |
| Percent diagnosed no later than 3 months               | 52.3     | 70.8    |
| Percent with hearing loss enrolled in EI services      | 39.3     | 62.9    |
| Percent enrolled in EI services no later than 6 months | 37.3     | 67.6    |

*\*National data was obtained from the 2011 National CDC EHDI Hearing Screening & Follow-up Survey and is limited to those states, territories, and districts that respond to the survey*

Currently, Michigan is meeting the first national goal with 98.3% of infants screened for hearing loss no later than one month of age in 2011. This compares to the Nation with 94.9% of infants screened no later than one month.

For the second national EHDI goal, in 2011, Michigan had 52.3% of infants who referred from the final screen with a diagnostic evaluation no later than three months of age. This is lower than the Nation which had 70.8% of infants diagnosed no later than three months of age. The percentage of infants diagnosed in Michigan may increase in the future as late reports are received from facilities who do not report diagnostics in a timely manner.

Michigan is lower than the Nation on the third goal of having all infants with permanent hearing loss enrolled in early intervention (EI) services no later than six months of age. Michigan had 37.3% of infants enrolled by six months while the Nation had 67.6% of infants enrolled by six months in 2011. The percentage of infants enrolled in EI services in Michigan may be underestimated due to FERPA regulations that limit EI service personnel from sharing enrollment information with EHDI.

Additional national statistics as well as statistics for other states can be found on the CDC website at: <http://www.cdc.gov/ncbddd/hearingloss/ehdi-data.html>.

## Barriers to Services: A View of Michigan Families

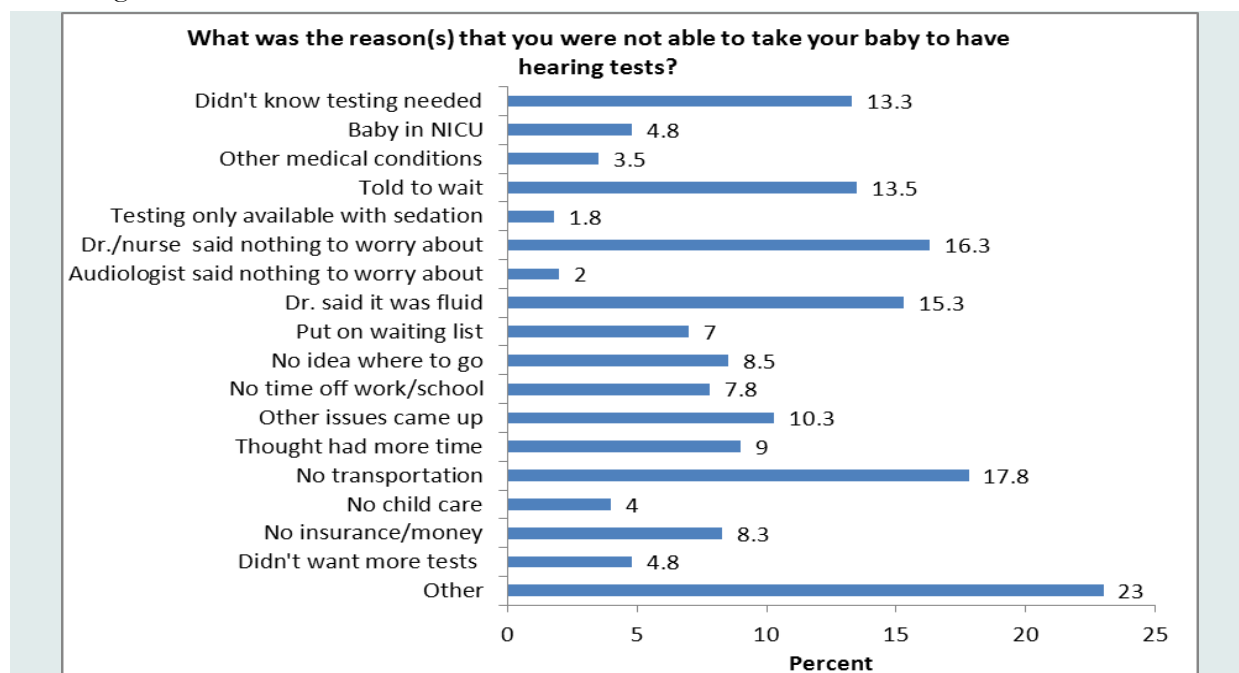
The Michigan EHDI Program continues to have high loss to follow-up or documentation (LTF) rates with about 50% of infants lost in the EHDI system. Community involvement is essential in making effective changes aimed at reducing loss to follow-up rates in the EHDI Program. A survey for those LTF after referring from the hearing screen was developed to identify barriers to accessing services. Families who were LTF from 2009 to 2013 were surveyed and offered a \$10.00 gift card for completing the survey. Results from the survey summarized below are used to help improve EHDI processes for follow-up.

Responses were obtained from 400 families. Overall, the majority of respondents were mothers (97%), 25 years or older (61%). Over half the respondents had more than a high school education (53%), and were white (55%) and 40% were married. About 72% had government health insurance (Medicare, Medicaid, or Military health care) for paying medical expenses and about 40% lived in a suburban area.

Of respondents, 83% thought that hearing testing was important. However, only 41% were concerned about their baby's hearing. Sixty percent had been given information about hearing tests and the majority (82%) had a support system.

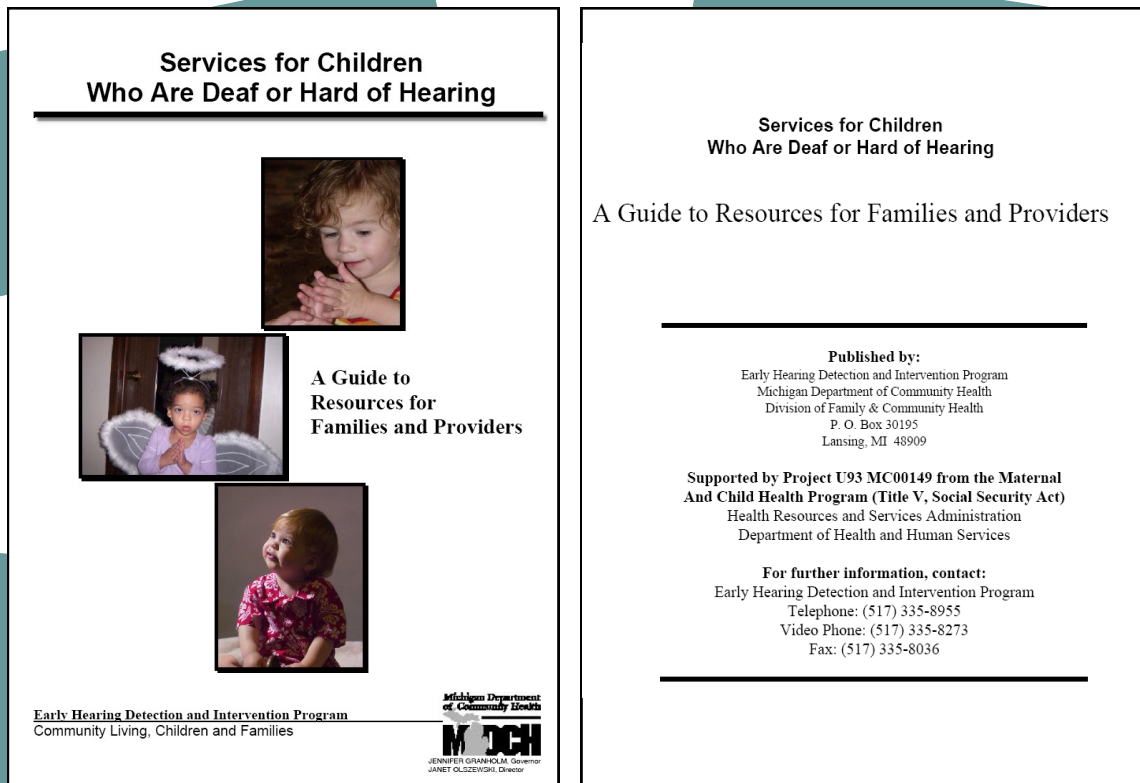
Overall, top reasons families did not have their baby's hearing tested included: **Other** reasons (23.0%) such as 'hearing test is unnecessary,' 'baby had ear infection,' 'did not know,' 'waiting for baby to get older,' 'crying baby,' 'not covered by insurance,' 'testing center far away,' and 'waiting to be called'; **No transportation** (17.8%); and **Dr./Nurse said it was nothing to worry about** (16.3%). (Figure 16).

This survey gave insight to better understand barriers to access. Based on the analysis of the survey, it is clear that more provider education on messages sent to parents and the importance of hearing screening is needed.



**Figure 16:** Reasons for not taking baby for hearing test: Michigan EHDI Barriers Survey Data, 2009-2013

# State and National Resources



The 'Guide to Resources for Families and Providers' contains state and national resources on the following topics:

- Advocacy
- Assistive Technology
- Cochlear Implant Centers
- Customer Support
- Deaf-Blind Services
- Early Intervention
- Educational Programs and Services
- Genetic Services
- Hearing Dogs
- Information and Referrals
- Interpreter Services
- Language Assessment
- Mental Health Services
- Parent Networks and Support Organizations
- Professional Associations
- Public Health Services
- Service Clubs
- Speech/Language Therapy
- Vocational Training
- Sibling Support

The resource guide can be found online at:  
[http://www.michigan.gov/documents/a\\_unhsmmanual\\_53441\\_7.pdf](http://www.michigan.gov/documents/a_unhsmmanual_53441_7.pdf)

or contact the EHDI Program to obtain a copy at:  
(517) 335-8955



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## EHDI Program Highlights

EHDI Program activities revolve around many areas including provider education, data management, family support, and loss to follow-up. Highlighted below are some of the major activities the EHDI Program has been able to accomplish in 2013:

- Offering provider education at multiple conferences and locations in 2013, including:
  - Michigan EHDI Conference & Parent Dinner
  - Michigan Midwives Association Conferences (2)
  - Michigan Care Improvement Registry Conferences
  - Michigan Audiology Conference
  - Fall Regional Immunization Conferences in Michigan
  
- Attending conferences for professional development, exhibiting EHDI displays, and presenting on important EHDI topics including screening, loss to follow-up and early intervention, to promote the EHDI Program and to educate physicians, nurses, and other conference attendees at the following conferences/Exhibitions:
  - Association of Public Health Laboratories (APHL) Michigan State Banner
  - Newborn Screening Capitol Event
  - Michigan American Academy of Pediatrics
  - National EHDI Conference
  
- Administering the National Center for Hearing Assessment and Management (NCHAM) Physician Survey in Michigan to assess primary care physician's (including pediatricians, family practitioners and ENTs) knowledge, attitudes and practices related to newborn hearing screening.
  
- Reducing the loss to follow-up (LTF) rate by:
  - Providing mini-grants to eight hospitals to replace aging, broken, or recalled screening equipment.
  - Encouraging best practice methods in quarterly meetings with the two largest birth hospitals in Wayne County.
  - Visiting and contacting primary care providers and parents of infants who are LTF.
  - Visiting hospitals around the state to review statistics, improve quality compliance, and promote the online training module and use of the Michigan Hands and Voices "Loss & Found"™ DVD.
  - Surveying families who are lost to follow-up to assess barriers to accessing hearing screens and diagnostic evaluations.
  - Collaborating with Michigan Coalition for Deaf, Hard of Hearing and DeafBlind People to obtain a grant to purchase 15 A-ABR machines for babies born out of the hospital.

Providing EHDI updates, highlights, and educating physicians, nurses and audiologists through: the quarterly EHDI newsletter (for birth hospitals).

- Contributing to Hands and Voices and Guide By Your Side (GBYS) through the following activities:
  - Participating in the Michigan Hands and Voices picnic for families in the program.

- 
- Providing two GBYS trainings a year for the parent guides.
  - Producing new and revised brochures and documents for the programs.
  - Working together with ten guides throughout Michigan who make home visits to families with children diagnosed with hearing loss.
  - Publishing a quarterly Michigan Hands and Voices Newsletter
- 
- Enhancing hearing screen and diagnostic results to physicians and nurses by displaying results on the Michigan Care Improvement Registry (MCIR), and creating a document detailing follow-up action steps for all screening results.
  - Collaborating with the Michigan Newborn Screening Program to conduct a survey of midwives to learn more about both blood and hearing screening among the homebirth community in the hopes of devising strategies to improve screening rates for both programs.
  - Surveying professionals to assess their knowledge and receive feedback on the program in order to maintain or improve customer satisfaction, efficiency, and service quality.
  - Surveying families of children who are diagnosed with hearing loss to assess EHDI processes and reactions to failed screenings and diagnoses to help improve the EHDI Program.
  - Meeting with the EHDI Advisory Committee two times per year, collaborating with audiologists, primary care providers, otolaryngologists, birthing hospital EHDI liaisons, parents of children with hearing loss, representatives from early intervention programs, Children's Special Health Care Services (CSHCS), and others. The EHDI Advisory members may participate in the Diagnostic, Early Intervention, or Provider Education Subcommittees.

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# Appendices

## A. Risk Factors for Hearing Loss

## B. Hearing Loss Diagnoses Reportable to EHDI

**Table 1:** Permanent hearing loss reportable to EHDI.

**Table 2:** Non-permanent hearing loss and other conditions reportable to EHDI.

## C. EHDI Evaluation Plan

**Table 1:** EHDI Evaluation Plan.

## D. Permanent Hearing Loss by Result of the Final Screen

**Table 1:** Prevalence of permanent hearing loss by result of final screen.

## E. Loss to Follow-Up (LTF) Rates

**Figure 1:** Geographic regions approximate pediatric specialty care service areas.

**Table 1:** Infants LTF after referring from the final screen by birth and maternal residence regions in Michigan.

**Table 2:** LTF rates by EHDI stages and by selected demographic variables.

**Table 3:** LTF rates by EHDI stages and by birth and maternal residence region in Michigan.

**Table 4:** LTF from diagnosis of permanent hearing loss to enrollment in early intervention services by maternal residence region.

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## Appendix A

### Risk Factors for Hearing Loss

The Joint Committee on Infant Hearing, Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs ([www.jcih.org](http://www.jcih.org)) recommended the 11 risk indicators listed below that are associated with either congenital or delayed-onset hearing loss. All infants with a risk indicator for hearing loss should be referred for an audiological assessment at least once by 24 to 30 months of age. Children with risk indicators that are highly associated with delayed-onset hearing loss, such as having received ECMO or having CMV infection, should have more frequent audiological assessments.

Risk indicators associated with congenital, delayed-onset, or progressive hearing loss in childhood are listed below. Risk indicators that are marked with an asterisk\* are of greater concern for delayed-onset hearing loss.

1. Caregiver concern\* regarding hearing, speech, language or developmental delay.
2. Family history\* of permanent childhood hearing loss.
3. Neonatal intensive care of more than 5 days or any of the following regardless of length of stay: ECMO (extracorporeal membrane oxygenation)\*, assisted ventilation, exposure to ototoxic medications (gentamicin and tobramycin) or loop diuretics (furosemide/Lasix), and hyperbilirubinemia that requires exchange transfusion.
4. In utero infections, such as CMV (cytomegalovirus)\*, herpes, rubella, syphilis and toxoplasmosis.
5. Craniofacial anomalies, including those that involve the pinna, ear canal, ear tags, ear pits and temporal bone anomalies.
6. Physical findings, such as white forelock, that are associated with a syndrome known to include a sensorineural or permanent conductive hearing loss.
7. Syndromes associated with hearing loss or progressive or late-onset hearing loss\*, such as neurofibromatosis, osteopetrosis, and Usher syndrome; other frequently identified syndromes include Waardenburg, Alport, Pendred, and Jervell and Lange-Nielson.
8. Neurodegenerative disorders\*, such as Hunter syndrome; or sensory motor neuropathies, such as Friedreich ataxia and Charcot-Marie-Tooth syndrome.
9. Culture-positive postnatal infections associated with sensorineural hearing loss\*, including confirmed bacterial and viral (especially herpes viruses and varicella) meningitis.
10. Head trauma, especially basal skull/temporal bone fracture\* that requires hospitalization.
11. Chemotherapy\*.

## Appendix B

**Table 1:** Permanent hearing loss reportable to the Michigan Early Hearing Detection and Intervention Program.

| Permanent Hearing Loss |   |
|------------------------|---|
| Diagnostic Code        | Meaning   |
| AN                     | Auditory Neuropathy                                   |
| BSNSL                  | Bilateral sensorineural slight                        |
| BSNMILD                | Bilateral sensorineural mild                          |
| BSNMOD                 | Bilateral sensorineural moderate                      |
| BSN M-S                | Bilateral sensorineural moderate severe               |
| BSNSEV                 | Bilateral sensorineural severe                        |
| BSNPRO                 | Bilateral sensorineural profound                      |
| RUSNSL                 | Right unilateral sensorineural slight                 |
| RUSNMILD               | Right unilateral sensorineural mild                   |
| RUSNMOD                | Right unilateral sensorineural moderate               |
| RUSN M-S               | Right unilateral sensorineural moderate severe        |
| RUSNSEV                | Right unilateral sensorineural severe                 |
| RUSNPRO                | Right unilateral sensorineural profound               |
| LUSNSL                 | Left unilateral sensorineural slight                  |
| LUSNMILD               | Left unilateral sensorineural mild                    |
| LUSNMOD                | Left unilateral sensorineural moderate                |
| LUSN M-S               | Left unilateral sensorineural moderate severe         |
| LUSNSEV                | Left unilateral sensorineural severe                  |
| LUSNPRO                | Left unilateral sensorineural profound                |
| BMIXMOD                | Bilateral mixed moderate                              |
| BMIX M-S               | Bilateral mixed moderate severe                       |
| BMIXSEV                | Bilateral mixed severe                                |
| BMIXPRO                | Bilateral mixed profound                              |
| RUMIXMOD               | Right unilateral mixed moderate                       |
| RUMIX M-S              | Right unilateral mixed moderate severe                |
| RUMIXSEV               | Right unilateral mixed severe                         |
| RUMIXPRO               | Right unilateral mixed profound                       |
| LUMIXMOD               | Left unilateral mixed moderate                        |
| LUMIX M-S              | Left unilateral mixed moderate severe                 |
| LUMIXSEV               | Left unilateral mixed severe                          |
| LUMIXPRO               | Left unilateral mixed profound                        |
| BCONDPRMNTMILD         | Bilateral conductive permanent mild                   |
| BCONDPRMNTMOD          | Bilateral conductive permanent moderate               |
| BCONDPRMNT M-S         | Bilateral conductive permanent moderate severe        |
| BCONDPRMNTSEV          | Bilateral conductive permanent severe                 |
| RUCONDPRMNTSL          | Right unilateral conductive permanent slight          |
| RUCONDPRMNTMILD        | Right unilateral conductive permanent mild            |
| RUCONDPRMNTMOD         | Right unilateral conductive permanent moderate        |
| RUCONDPRMNT M-S        | Right unilateral conductive permanent moderate severe |
| RUCONDPRMNTSEV         | Right unilateral conductive permanent severe          |
| LUCONDPRMNTMILD        | Left unilateral conductive permanent mild             |
| LUCONDPRMNTMOD         | Left unilateral conductive permanent moderate         |
| LUCONDPRMNT M-S        | Left unilateral conductive permanent moderate severe  |
| LUCONDPRMNTSEV         | Left unilateral conductive permanent severe           |

**Table 2:** Non-permanent hearing loss and other conditions reportable to the Michigan Early Hearing Detection and Intervention Program.

| <b>Non-Permanent Hearing Loss</b> |   |
|-----------------------------------|---|
| <b>Diagnostic Code</b>            | <b>Meaning</b>  |
| BCONDMILD                         | Bilateral conductive mild                                       |
| BCONDMOD                          | Bilateral conductive moderate                                   |
| RUCONDMILD                        | Right unilateral conductive mild                                |
| RUCONDMOD                         | Right unilateral conductive moderate                            |
| LUCONDMILD                        | Left unilateral conductive mild                                 |
| LUCONDMOD                         | Left unilateral conductive moderate                             |
| BCONDTRANSSSL                     | Bilateral conductive transient slight                           |
| BCONDTRANSMILD                    | Bilateral conductive transient mild                             |
| BCONDTRANSMOD                     | Bilateral conductive transient moderate                         |
| BCONTRANS M-S                     | Bilateral conductive transient moderate severe                  |
| BCONDTRANSSEV                     | Bilateral conductive transient severe                           |
| RUCONDTRANSSSL                    | Right unilateral conductive transient slight                    |
| RUCONDTRANSMILD                   | Right unilateral conductive transient mild                      |
| RUCONDTRANSMOD                    | Right unilateral conductive transient moderate                  |
| RUCONDTRANSSEV                    | Right unilateral conductive transient severe                    |
| LUCONDTRANSSSL                    | Left unilateral conductive transient slight                     |
| LUCONDTRANSMILD                   | Left unilateral conductive transient mild                       |
| LUCONDTRANSMOD                    | Left unilateral conductive transient moderate                   |
| LUCONDTRANSSEV                    | Left unilateral conductive transient severe                     |
| <b>Other</b>                      |   |
| <b>Diagnostic Code</b>            | <b>Meaning</b>  |
| WNL                               | Within normal limits bilaterally, determined via diagnostic ABR |
| UNDETERMINED                      | Left or right ear result is undetermined or blank               |



## Appendix C

**Table 1:** Michigan EHDI Evaluation Plan.

| <b>Evaluation Purpose:</b>   |  |  |   |   |                                      |  |
|--|--|--|---|---|--------------------------------------|--|
| To assess and improve the ability of the EHDI Surveillance System to meet the data needs of the EHDI program and stakeholders. |  |  |   |   |                                      |  |
| <b>Evaluation Design and Implementation:</b>   |  |  |   |   |                                      |  |
| <b>Design</b>  |  |  | <b>Implementation</b>   |   |                                      |  |
| Attribute  | Question(s)  | Indicators   | Methods   | Sources   | Timeline                             | Responsible  |
| Data Quality   | What is the quality of data entered in to the EHDI-IS system and what hospitals are not reporting accurately?          | % of missing initial screen date fields                    | Data review<br><br>Report to individual hospitals and on overall system                               | EHDI-IS   | Quarterly                            | Data Analyst   |
| Data Quality   |  | Reasons for incomplete screen                              | Review at staff and advisory committee meetings   | EHDI-IS<br><br>Hospital Site Visit reports  | Annually                             | Data Analyst<br><br>Follow-Up Consultant   |
| Data Quality   |  | % agreement of 10% data verification by EHDI staff         | Routine calculation   | Review at staff meetings  | EHDI-IS                              | Quarterly  |
| Data Quality   | Can LTF rates be improved using addresses from other DCH program data sources through linkage or notification systems? | 1 new system reviewed annually<br><br>New routine linkages | Key informant interviews<br><br>Pilot data linkage for cases with returned letters or other materials | Expert knowledge of programs<br><br>Live birth, Medicaid, CSHCS, WIC, MHP or other program data | Jun-Nov 2013<br><br>Nov-May annually | Follow-Up Consultant/<br>Epidemiologist<br><br>Epidemiologist<br><br>Epidemiologist/<br>Data Analyst |

|                    |  |  |   |   |                     |  |
|--------------------|--|--|---|---|---------------------|--|
| Timeliness         | Is the timeliness of reporting of screens and audiometric evaluations adequate for action and is data entered into EHDI system in a timely manner? | <p>% of reports received by 14 days after completion of screen or diagnosis.</p> <p>Median days between date of screen or evaluation and EHDI receipt, Median days between receipt and entry</p> | Review during staff meeting and advisory committee meetings | EHDI-IS   | Every 6 months      | Data Analyst<br>Follow-Up Consultant<br>Epidemiologist |
| Representativeness | What subpopulations are most frequently missed/lost by each phase of the EHDI process and why?   | <p>% of missed screens &amp; evaluation/ LTF by demographic, geographic, risk factor, and birth site characteristics.</p> <p>Barriers identified for missed screens</p>                          | Review during staff meeting and advisory committee meetings | EHDI-IS linked to live birth file<br>Site visit report<br>Family barrier survey   | Annually            | Epidemiologist<br>Follow-Up Consultant                 |
| Acceptability      | To what extent are hospital staff satisfied with and using surveillance data made accessible to them   | # hospital and partner quality improvement or other initiatives utilizing system data or reporting   | Track utilization and discuss satisfaction results          | Site Visit reports<br>Calls/web requests from providers requesting data/information<br>Survey of hospital coordinators (once) | Once a grant period | Follow-Up Consultant                                   |

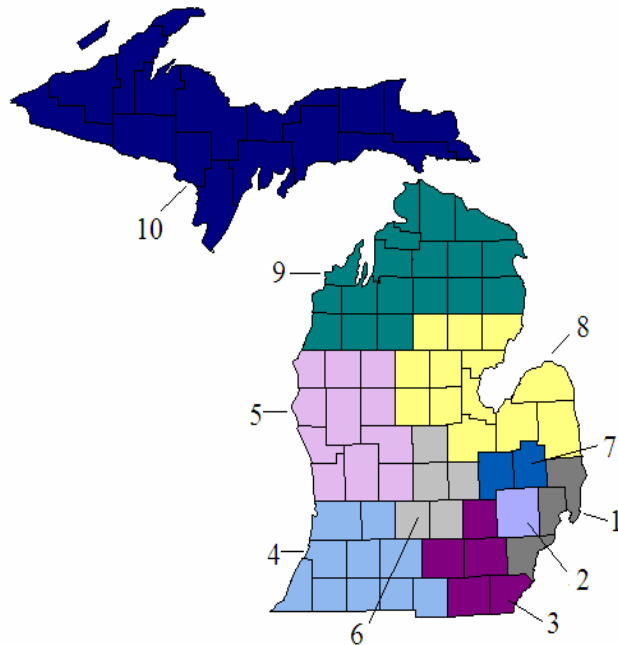
|               |   |   |  |                                |           |   |
|---------------|---|---|--|--------------------------------|-----------|---|
| Usefulness    | What barriers are faced by families of children who failed a hearing screen and never received follow-up (LTF/LTD) that the system could be used to overcome? | Barriers identified<br>Solutions  | Barriers identified and discussed with partners              | Survey of families of children | Annually  | Follow-Up Consultant/<br>Epidemiologist |
| Usefulness    | What barriers are faced by families of children diagnosed with hearing loss that the system could be used to overcome?  | Barriers identified<br>Solutions  | Barriers identified and discussed with partners              | Survey of families of children | Annually  | Follow-Up Consultant/<br>Epidemiologist |
| Effectiveness | What is the ability of EHDl-IS system to identify true cases?   | False Negative rate   | Linkage of cases found outside EHDl system to EHDl screening | EHDl-IS                        | Annually  | Epidemiologist                          |
| Effectiveness | Does the system meet 1-3-6 national guidelines?   | % diagnosis in 3 months<br>% with intervention services within 6 months | Review at staff and advisory meetings                        | EHDl-IS                        | Quarterly | Epidemiologist                          |

## Appendix D

**Table 1:** Prevalence of permanent hearing loss by result of final screen: Michigan EHDI, 2007-2011.

| Birth Year | Final Screen Result   |                | Permanent Hearing Loss |                              |
|------------|-----------------------|----------------|------------------------|------------------------------|
|            | Result                | Number         | Number                 | Rate (per 1,000 live births) |
| 2007       | Pass                  | 118,402        | 38                     | 0.3                          |
|            | Fail                  | 1,916          | 132                    | 1.1                          |
|            | Incomplete            | 1,231          | 24                     | 0.2                          |
|            | <b>Total Screened</b> | <b>121,549</b> | <b>194</b>             | <b>1.5</b>                   |
| 2008       | Pass                  | 114,656        | 20                     | 0.2                          |
|            | Fail                  | 1,625          | 129                    | 1.1                          |
|            | Incomplete            | 1,174          | 7                      | 0.1                          |
|            | <b>Total Screened</b> | <b>117,455</b> | <b>156</b>             | <b>1.3</b>                   |
| 2009       | Pass                  | 112,745        | 42                     | 0.4                          |
|            | Fail                  | 1,501          | 120                    | 1.0                          |
|            | Incomplete            | 783            | 6                      | 0.1                          |
|            | <b>Total Screened</b> | <b>115,029</b> | <b>168</b>             | <b>1.4</b>                   |
| 2010       | Pass                  | 110,218        | 28                     | 0.2                          |
|            | Fail                  | 1,539          | 139                    | 1.2                          |
|            | Incomplete            | 750            | 6                      | 0.1                          |
|            | <b>Total Screened</b> | <b>112,507</b> | <b>173</b>             | <b>1.5</b>                   |
| 2011       | Pass                  | 109,866        | 21                     | 0.2                          |
|            | Fail                  | 1,532          | 166                    | 1.5                          |
|            | Incomplete            | 686            | 4                      | 0.04                         |
|            | <b>Total Screened</b> | <b>112,084</b> | <b>191</b>             | <b>1.7</b>                   |
| 2007-2011  | Pass                  | 565,887        | 149                    | 0.3                          |
|            | Fail                  | 8,113          | 686                    | 1.2                          |
|            | Incomplete            | 4,624          | 47                     | 0.1                          |
|            | <b>Total Screened</b> | <b>578,624</b> | <b>882</b>             | <b>1.5</b>                   |

## Appendix E



**Figure 1:** Geographic regions approximate pediatric specialty care service areas.

|   |  |   |  |
|---|--|---|--|
| <p><b>Region 1</b><br/>Macomb<br/>St. Clair<br/>Wayne</p>   | <p><b>Region 5</b><br/>Ionia<br/>Kent<br/>Lake<br/>Mason<br/>Mecosta<br/>Montcalm<br/>Muskegon<br/>Newaygo<br/>Oceana<br/>Osceola<br/>Ottawa</p> | <p><b>Region 8</b><br/>Arenac<br/>Bay<br/>Clare<br/>Gladwin<br/>Huron<br/>Iosco<br/>Isabella<br/>Midland<br/>Ogemaw<br/>Roscommon<br/>Saginaw<br/>Sanilac<br/>Tuscola</p> | <p>Leelanau<br/>Manistee<br/>Missaukee<br/>Montmorency<br/>Oscoda<br/>Otsego<br/>Presque Isle<br/>Wexford</p>  |
| <p><b>Region 2</b><br/>Oakland</p>  | <p><b>Region 6</b><br/>Clinton<br/>Eaton<br/>Gratiot<br/>Ingham<br/>Shiawassee</p>   | <p><b>Region 9</b><br/>Alcona<br/>Alpena<br/>Antrim<br/>Benzie<br/>Cheboygan<br/>Charlevoix<br/>Crawford<br/>Emmet<br/>Grand Traverse<br/>Kalkaska</p>                    | <p><b>Region 10</b><br/>Alger<br/>Baraga<br/>Chippewa<br/>Delta<br/>Dickinson<br/>Gogebic<br/>Houghton<br/>Iron<br/>Keweenaw<br/>Luce<br/>Mackinac<br/>Marquette<br/>Menominee<br/>Ontonagon<br/>Schoolcraft</p> |
| <p><b>Region 3</b><br/>Jackson<br/>Lenawee<br/>Livingston<br/>Monroe<br/>Washtenaw</p>  | <p><b>Region 7</b><br/>Genesee<br/>Lapeer</p>  |   |  |
| <p><b>Region 4</b><br/>Allegan<br/>Barry<br/>Berrien<br/>Branch<br/>Calhoun<br/>Cass<br/>Hillsdale<br/>Kalamazoo<br/>St. Joseph<br/>Van Buren</p> |  |   |  |

**Table 1:** Infants loss to follow-up (LTF) after referring from the final screen by birth and maternal residence regions in Michigan: Michigan EHDI, 2007-2011.

| Region                            | LTF after referring from Final Screen |              |             |
|-----------------------------------|---------------------------------------|--------------|-------------|
|                                   | Number referring from Final Screen    | LTF          |             |
|                                   |                                       | Number       | Percent     |
| <b>State of Michigan</b>          | <b>8,113</b>                          | <b>4,457</b> | <b>54.9</b> |
| <b>Birth Place Region</b>         |                                       |              |             |
| Region 1                          | 3,060                                 | 2,352        | 76.9        |
| Region 2                          | 546                                   | 252          | 46.2        |
| Region 3                          | 468                                   | 236          | 50.4        |
| Region 4                          | 355                                   | 209          | 58.9        |
| Region 5                          | 533                                   | 253          | 47.5        |
| Region 6                          | 179                                   | 94           | 52.5        |
| Region 7                          | 354                                   | 184          | 52.0        |
| Region 8                          | 795                                   | 208          | 26.2        |
| Region 9                          | 163                                   | 59           | 36.2        |
| Region 10                         | 62                                    | 31           | 50.0        |
| <i>Missing Region Information</i> | 1,598                                 | 579          | 36.2        |
| <b>Maternal Residence Region</b>  |                                       |              |             |
| Region 1                          | 3,189                                 | 2,396        | 75.1        |
| Region 2                          | 430                                   | 207          | 48.1        |
| Region 3                          | 416                                   | 214          | 51.4        |
| Region 4                          | 374                                   | 221          | 59.1        |
| Region 5                          | 496                                   | 243          | 49.0        |
| Region 6                          | 190                                   | 97           | 51.1        |
| Region 7                          | 334                                   | 172          | 51.5        |
| Region 8                          | 825                                   | 222          | 26.9        |
| Region 9                          | 157                                   | 55           | 35.0        |
| Region 10                         | 63                                    | 33           | 52.4        |
| <i>Missing Region Information</i> | 1,639                                 | 597          | 36.4        |

Table 2: Loss to follow-up (LTF) rates by EHDl stages and by selected demographic variables, Michigan EHDI, 2007-2011.

| Demographic Variable                  | LTF after Incomplete Initial Screen |              |             | LTF after Refer from Initial Screen  |              |             | LTF after Refer from Rescreen   |            |             |
|---------------------------------------|-------------------------------------|--------------|-------------|--------------------------------------|--------------|-------------|---------------------------------|------------|-------------|
|                                       | Number with Incomplete Screen       | LTF          |             | Number Referring from Initial Screen | LTF          |             | Number Referring from Re-Screen | LTF        |             |
|                                       |                                     | Number       | Percent     |                                      | Number       | Percent     |                                 | Number     | Percent     |
| <b>Birth Year</b>                     |                                     |              |             |                                      |              |             |                                 |            |             |
| 2007                                  | 2,748                               | 723          | 26.3        | 4,840                                | 1,033        | 21.3        | 347                             | 143        | 41.2        |
| 2008                                  | 2,388                               | 682          | 28.6        | 4,708                                | 822          | 17.5        | 316                             | 133        | 42.1        |
| 2009                                  | 2,277                               | 293          | 12.9        | 5,042                                | 618          | 12.3        | 340                             | 140        | 41.2        |
| 2010                                  | 2,571                               | 274          | 10.7        | 5,262                                | 662          | 12.6        | 404                             | 131        | 32.4        |
| 2011                                  | 2,644                               | 161          | 6.1         | 6,118                                | 665          | 10.9        | 437                             | 131        | 30.0        |
| <b>Total</b>                          | <b>12,628</b>                       | <b>2,133</b> | <b>16.9</b> | <b>25,970</b>                        | <b>3,800</b> | <b>14.6</b> | <b>1,844</b>                    | <b>678</b> | <b>36.8</b> |
| <b>Mom's Race, Ethnicity</b>          |                                     |              |             |                                      |              |             |                                 |            |             |
| White, Non-Hispanic                   | 6,609                               | 1,067        | 16.1        | 14,025                               | 1,463        | 10.4        | 346                             | 144        | 41.6        |
| Black, Non-Hispanic                   | 3,181                               | 445          | 14.0        | 6,443                                | 1,723        | 26.7        | 145                             | 63         | 43.4        |
| Other, Non-Hispanic                   | 555                                 | 102          | 18.4        | 1,727                                | 208          | 12.0        | 26                              | 16         | 61.5        |
| Hispanic                              | 845                                 | 210          | 24.9        | 1,684                                | 154          | 9.1         | 108                             | 38         | 35.2        |
| Missing                               | 1,438                               | 309          | 21.5        | 2,091                                | 252          | 12.1        | 1,219                           | 417        | 34.2        |
| <b>Mom's Age</b>                      |                                     |              |             |                                      |              |             |                                 |            |             |
| <20                                   | 1,244                               | 214          | 17.2        | 3,104                                | 706          | 22.7        | 76                              | 39         | 51.3        |
| 20-24                                 | 2,985                               | 543          | 18.2        | 7,125                                | 1,276        | 17.9        | 182                             | 82         | 45.1        |
| 25-29                                 | 3,156                               | 480          | 15.2        | 6,986                                | 870          | 12.5        | 179                             | 69         | 38.5        |
| 30-34                                 | 2,480                               | 378          | 15.2        | 5,006                                | 513          | 10.2        | 96                              | 39         | 40.6        |
| >34                                   | 1,640                               | 264          | 16.1        | 2,866                                | 269          | 9.4         | 94                              | 33         | 35.1        |
| Missing                               | 1,123                               | 254          | 22.6        | 883                                  | 166          | 18.8        | 1,217                           | 416        | 34.2        |
| <b>Mom's Education</b>                |                                     |              |             |                                      |              |             |                                 |            |             |
| <HS                                   | 2,717                               | 456          | 16.8        | 5,297                                | 1,273        | 24.0        | 150                             | 76         | 50.7        |
| HS diploma/GED                        | 3,454                               | 583          | 16.9        | 7,828                                | 1,342        | 17.1        | 196                             | 88         | 44.9        |
| Some College/College Degree           | 5,233                               | 809          | 15.5        | 11,661                               | 965          | 8.3         | 270                             | 94         | 34.8        |
| Missing                               | 1,224                               | 285          | 23.3        | 1,184                                | 220          | 18.6        | 1,228                           | 420        | 34.2        |
| <b>Source of Payment for Delivery</b> |                                     |              |             |                                      |              |             |                                 |            |             |
| Private Insurance                     | 5,627                               | 737          | 13.1        | 11,679                               | 1,489        | 12.7        | 294                             | 114        | 38.8        |
| Medicaid                              | 4,977                               | 936          | 18.8        | 12,813                               | 2,025        | 15.8        | 319                             | 142        | 44.5        |
| Self-Pay                              | 673                                 | 154          | 22.9        | 278                                  | 67           | 24.1        | 7                               | <5         |             |
| Other                                 | 37                                  | <5           |             | 236                                  | 40           | 16.9        | 3                               | <5         |             |
| Unknown                               | 180                                 | 46           | 25.6        | 67                                   | 13           | 19.4        | 2                               | <5         |             |
| Missing                               | 1,134                               | 256          | 22.6        | 897                                  | 166          | 18.5        | 1,219                           | 417        | 34.2        |

\*Other race category encompasses women who do not define themselves as black or white and includes Native American, Asian/Pacific Islander, etc. Of note, other ethnicities were not included due to too small numbers and potential privacy issues

**Table 3:** Loss to follow-up rates (LTF) by EHDI stages and by birth and maternal residence region in Michigan: Michigan EHDI, 2007-2011.

| Region                            | LTF after Incomplete Initial Screen |                          | LTF after Refer from Initial Screen  |                          | LTF after Refer from Rescreen   |                          |
|-----------------------------------|-------------------------------------|--------------------------|--------------------------------------|--------------------------|---------------------------------|--------------------------|
|                                   | Number with an Incomplete Screen    | LTF<br>Number<br>Percent | Number Referring from Initial Screen | LTF<br>Number<br>Percent | Number Referring from Re-Screen | LTF<br>Number<br>Percent |
| <b>State of Michigan</b>          | <b>12,628</b>                       | <b>16.9</b>              | <b>25,970</b>                        | <b>14.6</b>              | <b>1,844</b>                    | <b>36.8</b>              |
| <b>Birth Place Region</b>         |                                     |                          |                                      |                          |                                 |                          |
| Region 1                          | 3,776                               | 20.3                     | 9,426                                | 23.8                     | 214                             | 51.9                     |
| Region 2                          | 608                                 | 15.6                     | 2,888                                | 8.0                      | 63                              | 41.3                     |
| Region 3                          | 1,272                               | 18.4                     | 1,922                                | 11.3                     | 50                              | 38.0                     |
| Region 4                          | 1,739                               | 10.6                     | 1,739                                | 10.4                     | 60                              | 46.7                     |
| Region 5                          | 1,468                               | 12.4                     | 2,944                                | 7.6                      | 94                              | 37.2                     |
| Region 6                          | 607                                 | 17.0                     | 1,472                                | 5.6                      | 37                              | 29.7                     |
| Region 7                          | 489                                 | 16.6                     | 1,226                                | 14.1                     | 41                              | 29.3                     |
| Region 8                          | 665                                 | 15.2                     | 1,540                                | 13.2                     | 32                              | <5                       |
| Region 9                          | 513                                 | 12.9                     | 1,526                                | 3.4                      | 24                              | 37.5                     |
| Region 10                         | 367                                 | 18.0                     | 399                                  | 6.0                      | 12                              | 58.3                     |
| <i>Missing Region Information</i> | 1,124                               | 22.6                     | 888                                  | 18.7                     | 1,217                           | 34.2                     |
| <b>Maternal Residence Region</b>  |                                     |                          |                                      |                          |                                 |                          |
| Region 1                          | 3,848                               | 19.0                     | 10,073                               | 22.7                     | 224                             | 50.0                     |
| Region 2                          | 608                                 | 18.4                     | 2,280                                | 8.2                      | 58                              | 41.4                     |
| Region 3                          | 1,025                               | 22.0                     | 1,736                                | 11.3                     | 42                              | 42.9                     |
| Region 4                          | 1,770                               | 11.1                     | 1,822                                | 10.6                     | 63                              | 42.9                     |
| Region 5                          | 1,381                               | 12.8                     | 2,811                                | 7.6                      | 88                              | 39.8                     |
| Region 6                          | 598                                 | 15.7                     | 1,318                                | 6.6                      | 30                              | 33.3                     |
| Region 7                          | 475                                 | 16.4                     | 1,189                                | 13.6                     | 37                              | 29.7                     |
| Region 8                          | 721                                 | 15.8                     | 1,815                                | 11.7                     | 49                              | 20.4                     |
| Region 9                          | 523                                 | 12.0                     | 1,374                                | 3.6                      | 22                              | 31.8                     |
| Region 10                         | 364                                 | 18.7                     | 432                                  | 6.0                      | 12                              | 58.3                     |
| <i>Missing Region Information</i> | 1,315                               | 45.2                     | 1,120                                | 16.3                     | 1,219                           | 34.2                     |



**Table 4:** Loss to follow-up (LTF) from diagnosis of permanent hearing loss to enrollment in early intervention services by maternal residence region: Michigan EHDI Intervention Data, 2007-2011.

| Region                            | LTF after Diagnostic Evaluation    |            |             |
|-----------------------------------|------------------------------------|------------|-------------|
|                                   | Number with Permanent Hearing Loss | LTF        |             |
|                                   |                                    | Number     | Percent     |
| <b>State of Michigan</b>          | <b>882</b>                         | <b>508</b> | <b>57.6</b> |
| Region 1                          | 162                                | 88         | <b>54.3</b> |
| Region 2                          | 81                                 | 49         | <b>60.5</b> |
| Region 3                          | 67                                 | 39         | <b>58.2</b> |
| Region 4                          | 46                                 | 26         | <b>56.5</b> |
| Region 5                          | 95                                 | 38         | <b>40.0</b> |
| Region 6                          | 19                                 | 10         | <b>52.6</b> |
| Region 7                          | 29                                 | 18         | <b>62.1</b> |
| Region 8                          | 42                                 | 24         | <b>57.1</b> |
| Region 9                          | 11                                 | 7          | <b>63.6</b> |
| Region 10                         | 12                                 | 7          | <b>58.3</b> |
| <i>Missing Region Information</i> | <i>318</i>                         | <i>202</i> | <i>63.5</i> |