



North Carolina Early Hearing Detection and Intervention (EHDI) Program

2018

NCEHDI

Annual Report

Contents

- 3 Program Overview
- 5 Screening
- 8 Diagnosis
- 13 Early Intervention
- 17 Conclusion & Thank You



Glossary

Diagnostic audiological evaluation-

A series of procedures used to determine the type, degree, and configuration of hearing loss.

Freestanding birth center- A facility which is not part of a hospital and provides comprehensive obstetrical care to women whose births are planned to occur away from the mother's usual residence following a normal, uncomplicated low risk pregnancy.

Inpatient screening- A screening that occurs before the newborn has been discharged from the birth facility.

Learning communities- Connect people, organizations, and systems that are eager to learn and work across boundaries in pursuit of a shared goal.

Newborn hearing screening (NBHS)-

Testing of the newborn baby's ability to hear. NBHS is done with automated auditory brainstem response test or otoacoustic emissions.

Outpatient screening- A screening completed after the baby has been discharged from the birth facility.

Primary care provider (PCP)- A physician, nurse practitioner, clinical nurse specialist or physician assistant, as allowed under state law, who provides, coordinates or helps a patient access a range of health care services.

Refer result- Fail/did not pass the screening.

Program Overview

The North Carolina Early Hearing Detection and Intervention Program (EHDI) collaborates with birthing facilities, audiologists, primary care providers, midwives, local public health departments and early intervention programs to ensure that infants with hearing loss are identified early and receive appropriate and timely intervention services for optimal developmental outcomes, regardless of the mode of communication.

The EHDI Program is located in the North Carolina Department of Health and Human Services, Division of Public Health, Women's and Children's Health Section, Children and Youth Branch as part of the state Title V Maternal and Child Health Services Program. The Program is administered by staff in the Genetics and Newborn Screening Unit and functions in close collaboration with a number of other programs for children with special health care needs.

Early identification of hearing loss and early intervention are critical to speech/ language development in children. As a result, North Carolina strives to meet the following national recommendations for all children:

1

All infants are screened for hearing loss prior to discharge from birthing facilities or within **1 month of age.**

3

All infants referred from the screening process complete diagnostic audiological evaluation by **3 months of age.**

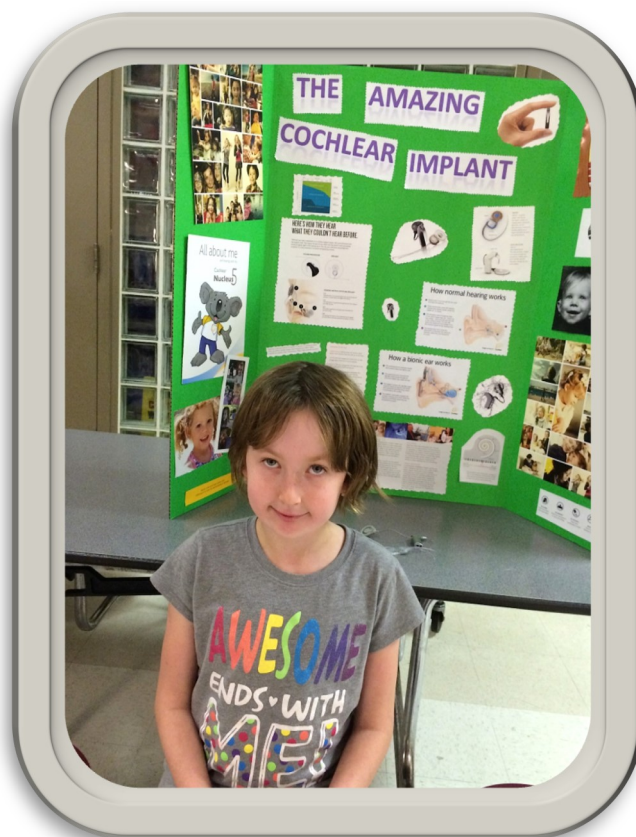
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All infants with diagnosed hearing loss receive appropriate interventions by **6 months of age**, including amplification selection (if appropriate) and early intervention.

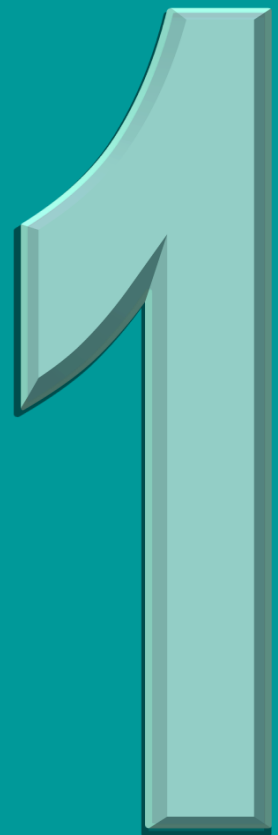
The EHDI Program receives hospital newborn hearing screening results through the WCSWeb, a secure web-based database that is commonly referred to as "Hearing Link". Screening, rescreening, and diagnostic results are entered into this system, along with early intervention enrollment information. EHDI works closely with early intervention program partners to assure timely referrals upon diagnosis, and to receive information about the enrollment status of infants referred for early intervention services.

The EHDI Program is funded, in part, through two federal grants from the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA). The CDC grant is focused on the development, maintenance, and enhancement of the EHDI information system and surveillance programs. The HRSA grant is focused on improving the number of children in NC who receive screening, diagnosis, and early intervention services by the 1, 3, and 6 month milestones.

Each year the NC EHDI Program participates in the CDC national survey, providing data on the number of infants screened, diagnosed with hearing loss, and enrolled in early intervention.

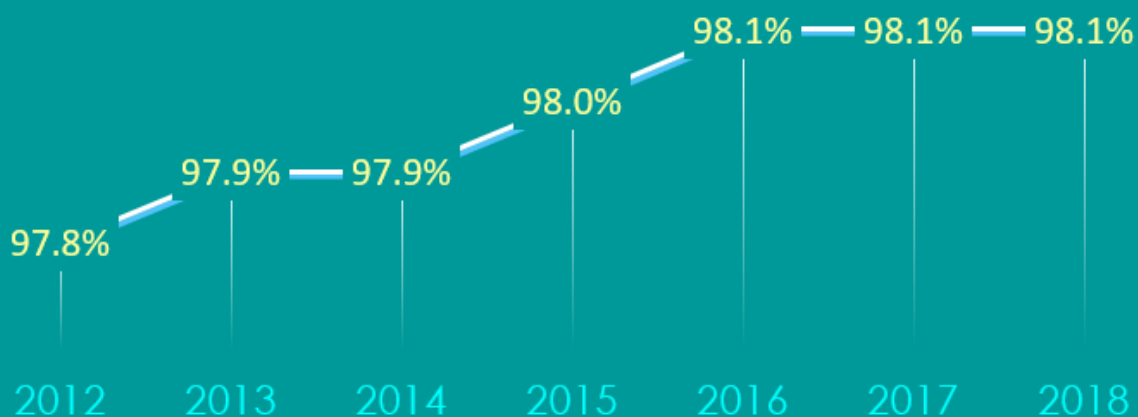


Screening



The NC EHDI Program works to ensure that all infants receive a hearing screening, and a rescreening if necessary, by one month of age. In 2018, hearing screenings were completed on 119,980 babies, or 99.8% of the 120,809 infants born in North Carolina (excluding infants that died or cases where the parent declined screening). In addition, 117,665 infants, or 98.1%, had their screening completed before the age of 1 month.

PERCENT SCREENED BY
ONE MONTH OF AGE BY YEAR



Program Goal:

All infants are screened for hearing loss prior to discharge from birthing facilities or by **one month of age.**



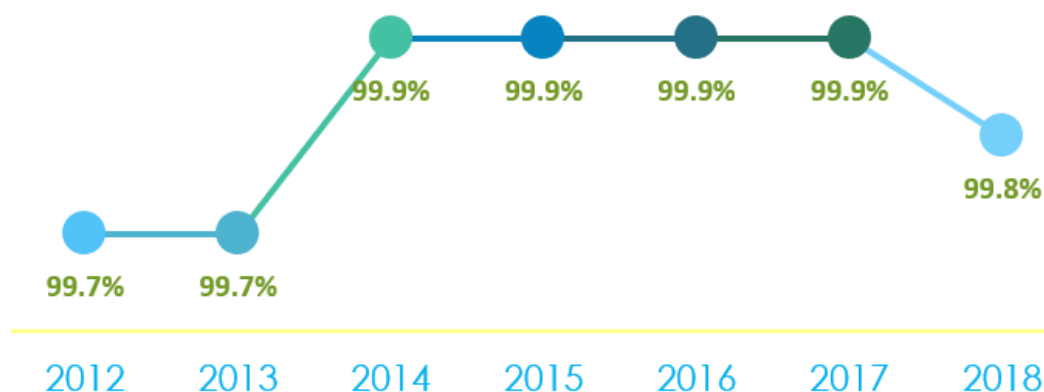
Quick Facts:

In 2018, there were 119,137 infants that passed their newborn hearing screening.

There were 869 infants born in 2018 who have no documented hearing screening.

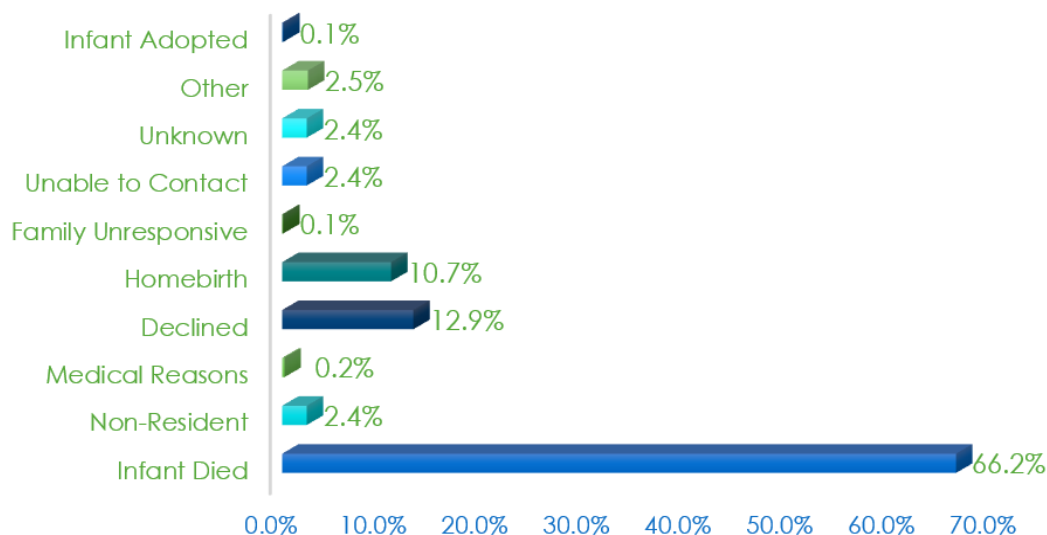


TOTAL PERCENT SCREENED BY YEAR



Reasons for the lack of a screening include infant death, family did not reside in NC, infant was unable to be screened due to medical reasons, parents declined screening, infant transferred and there is no documentation of screening, infant was adopted, infant born at home, parents/family unable to be contacted, unknown, or other.

Reasons for No Screening (2018 Data)





Newborn Hearing Screening in NC

North Carolina uses a 2-stage model for newborn hearing screening. Infants are screened at birth. If they do not pass this initial screening, they should be rescreened within 30 days of the date of birth (unless otherwise indicated due to risk factors).

Ideally this rescreening is performed at the birthing facility. In general, birthing facilities that complete outpatient rescreening have a lower loss to follow up rate than those that do not. If the infant does not pass the rescreen, they are referred for diagnostic testing at one of NC's infant diagnostic evaluation sites.

North Carolina EHDl staff members continue to work to reduce the number of babies that do not receive an initial screening and to reduce the number of babies that do not receive a rescreen after failing the initial screening by doing the following:

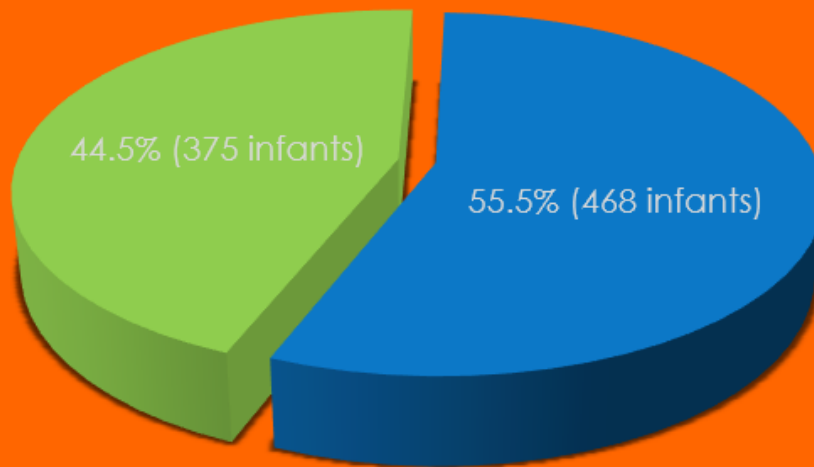
- Providing outreach to PCP offices to increase the knowledge of the importance of hearing screening and rescreening if necessary
- Working with midwives and staff at free-standing birthing centers to increase knowledge regarding hearing screening
- Making phone calls and sending letters (English/Spanish) to families of children with incomplete screening results
- Joining national pilot program (1 of 9 states) to report individualized EHDl data (excluding PII) in a standardized format
- Developing online training for hospitals and other providers to improve accuracy of data reported
- Contacting primary care providers and other community providers of children at-risk for loss to follow up
- Using quarterly hospital quality assurance reports to improve hospital screening programs
- Developing learning communities within counties that have been identified as at risk for increased loss to follow up

Diagnosis



The NC EHDI Program's goal is that all infants who refer on the newborn hearing screening receive a diagnostic evaluation by three months of age. In 2018, 843 of the 119,980 infants that were screened received a "refer" result. Of those 843 infants, 468 (55.5%) received a documented diagnostic evaluation that either found normal hearing or a hearing loss.

STATUS OF 843 INFANTS WHO REFERRED ON NBHS
(2018 DATA)



■ Complete Diagnosis (normal or hearing loss) ■ No Complete Diagnosis

Program Goal:

All infants referred from the screening process complete diagnostic audiological evaluation by **3 months of age.**

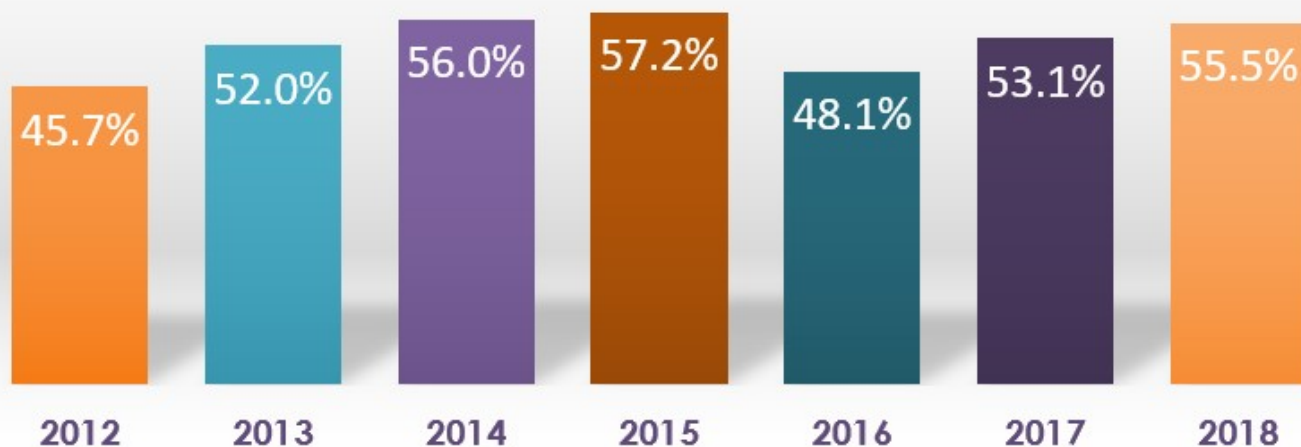


From 2012-2018, North Carolina worked to increase the percentage of babies that have a completed diagnostic (either of normal hearing or hearing loss) after failing newborn hearing screening.

In 2018, 468 of the 843 babies (55.5%) who failed newborn hearing screening completed the diagnostic process, compared with 53.1% in 2017.



PERCENT OF INFANTS WITH A COMPLETE DIAGNOSIS
(EITHER NORMAL OR HEARING LOSS)



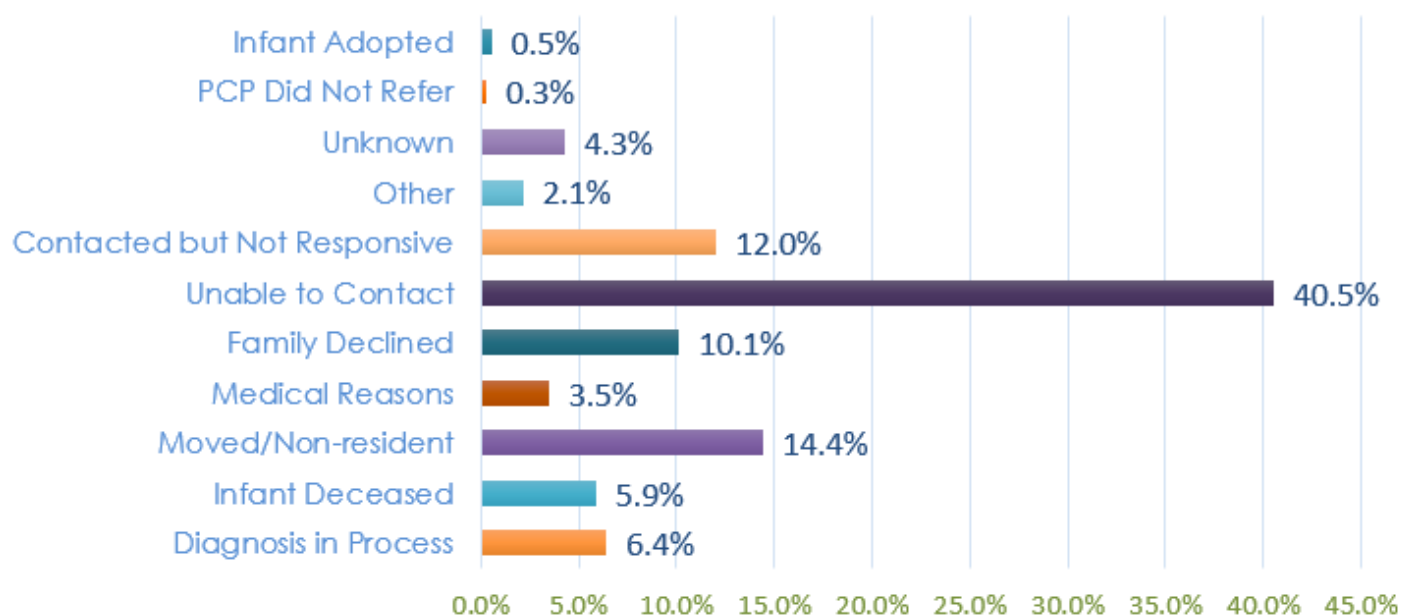
North Carolina EHDI staff members continue to work to reduce the number of babies that do not receive a complete diagnostic evaluation after failing newborn hearing screening by doing the following:

- Providing outreach to PCP and ENT offices to increase the knowledge of the importance of a timely diagnosis
- Providing family support by making phone calls and sending letters (English/ Spanish) to families of children that need diagnostic evaluation
- Contacting primary care providers of children in need of diagnostic follow-up to ensure they are aware of the need and the appropriate next steps

In 2018, 375 of the 843 babies who did not pass newborn hearing screening had no documented diagnosis. Reasons for no completed diagnosis include the following:

- Diagnosis in process (24)
- PCP/ENT did not refer infant for diagnostic testing (1)
- Infant deceased (22)
- Non-resident/Moved out of jurisdiction (54)
- Unable to receive diagnostic testing due to medical reasons (13)
- Parents/Family declined (38)
- Infant adopted (2)
- Parents contacted but not responsive (45)
- Unable to contact (152)
- Unknown (16)
- Other (8)

**Reasons for Not Completing the Diagnostic Process
(2018 Data)**



North Carolina's percentage of babies that are lost to follow-up/lost to documentation (LTFU) decreased steadily from 2012-2018.

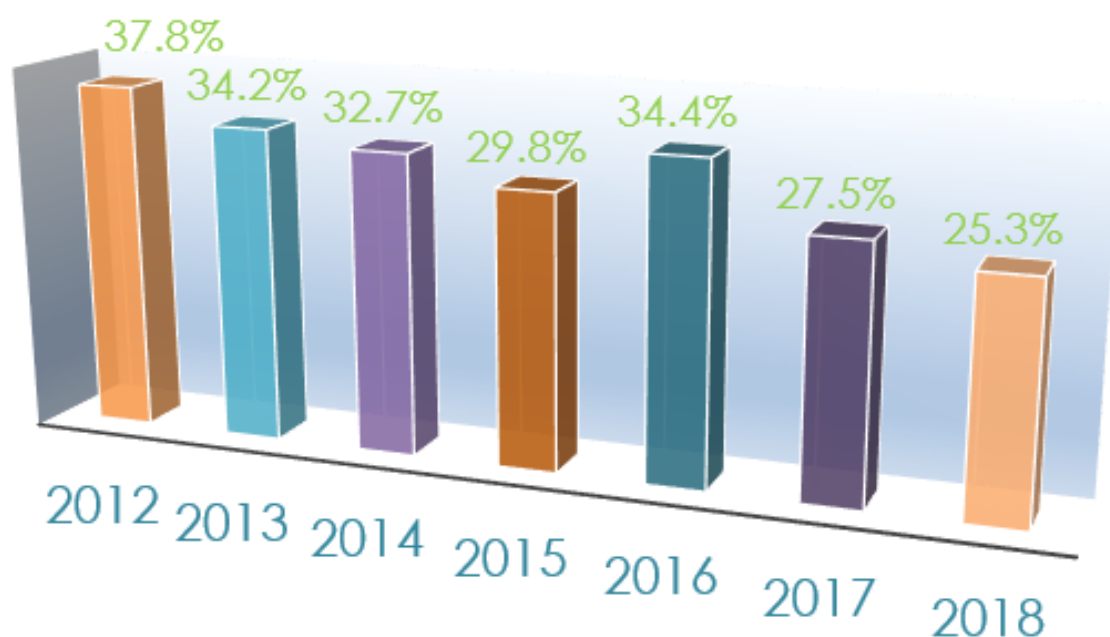
In 2018, LTFU reached an all-time low. 213 of the 843 infants (25.3%) who did not pass newborn hearing screening and had no documented diagnosis were considered Lost To Follow Up/Lost to Documentation in 2018.

The following categories for no diagnosis are used to calculate the LTFU rate:

- ♦ Parents/Family Contacted but Unresponsive (45)
- ♦ Unable to Contact (152)
- ♦ Unknown (16)



LTFU PERCENT AFTER REFERRING ON NBHS

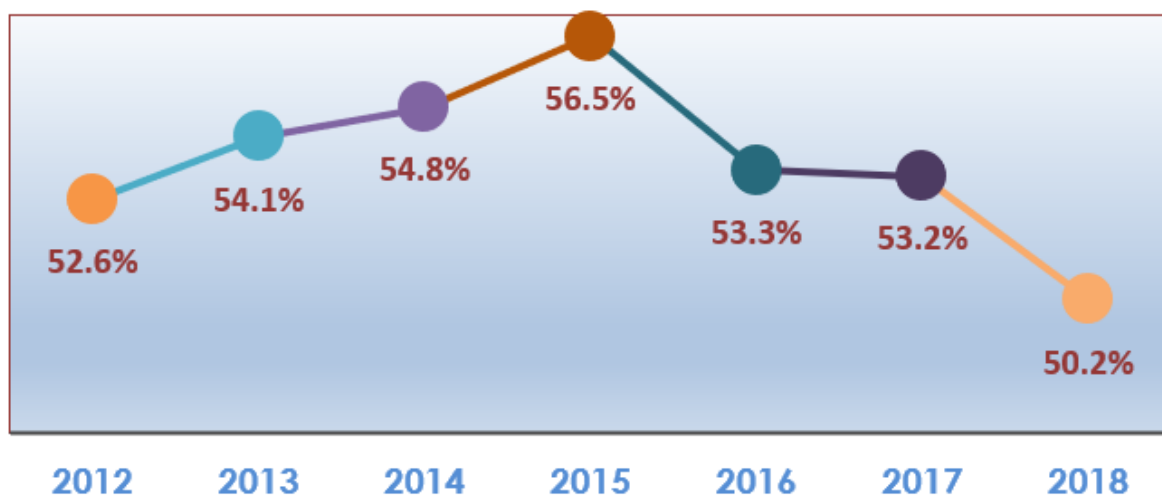


As part of our goal to promote quality improvement in meeting the national 1-3-6 timeline, the EHDI program began providing audiology facilities annual quality assurance reports beginning in 2016. Consultants meet annually with diagnostic sites to review these reports, which include site-specific data alongside statewide data, allowing facilities to see how they compare.

The reports also highlight the 1-3-6 standards with data showing the percentage of patients receiving a timely audiologic rescreen, percentage of confirmed hearing loss cases diagnosed by three months, and time from diagnosis to connection with early intervention services and hearing aid fitting. It is our hope that these reports will lead to improvement in increasing the number of infants that are diagnosed before 3 months of age in the future.



PERCENT DIAGNOSED BY 3 MONTHS OF AGE (INCLUDES NORMAL HEARING AND HEARING LOSS)



Quick Facts:

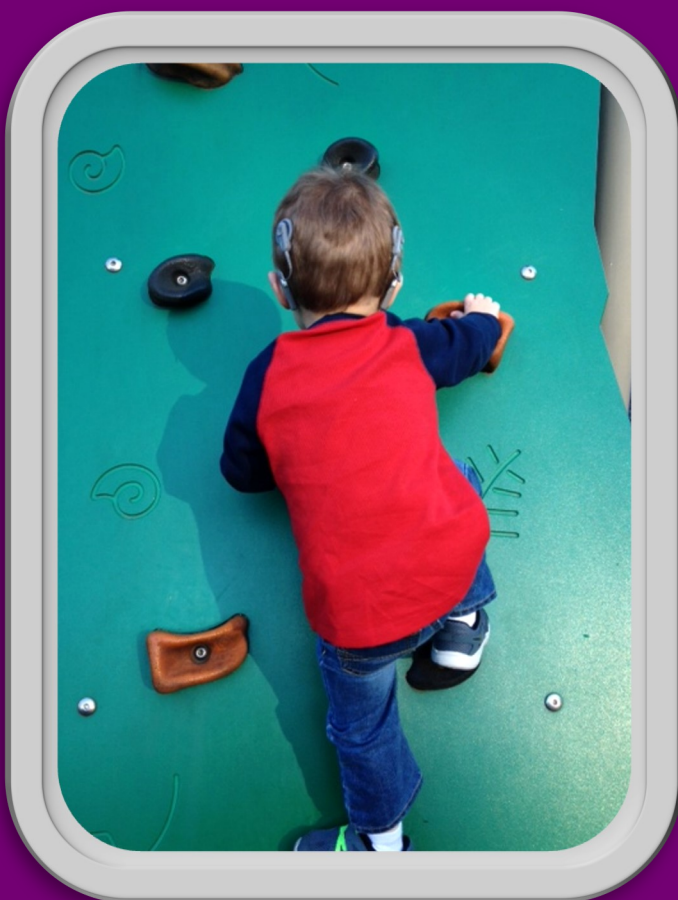
Early diagnosis of a hearing loss is crucial for acquiring language. In 2018, 235 out of the 468 babies (50.2%) that received a diagnosis (of either hearing loss or normal hearing) were diagnosed by age 3 months. This is a slight decrease compared with 53.2% in 2017.



Early Intervention

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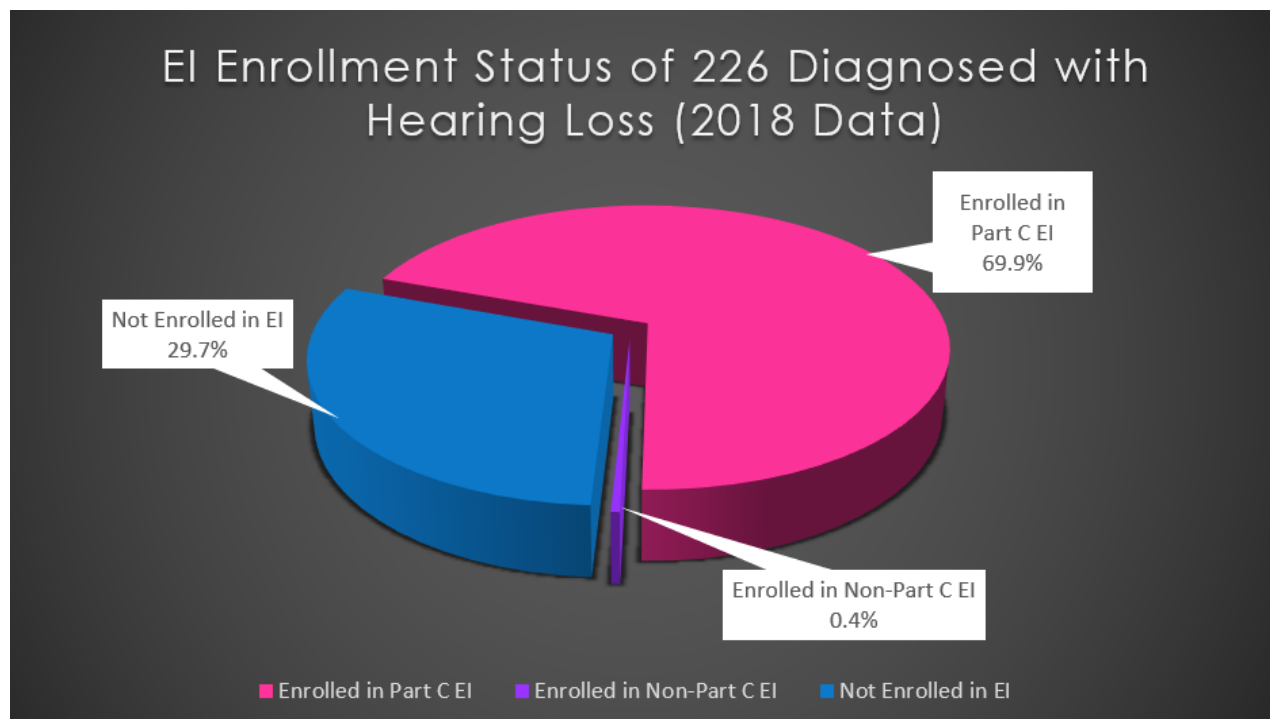
For children who are Deaf and Hard of Hearing (D/HH) to reach their full potential, it is critical that they and their families are connected to comprehensive family support and quality early intervention programs as soon as possible after diagnosis. EHDI staff play an important role in ensuring babies diagnosed with hearing loss are enrolled with early intervention as quickly as possible through use of a standardized referral form. EHDI staff help facilitate ongoing communication between families of infants diagnosed as D/HH, diagnosing audiologists, and early intervention providers.



Program Goal:

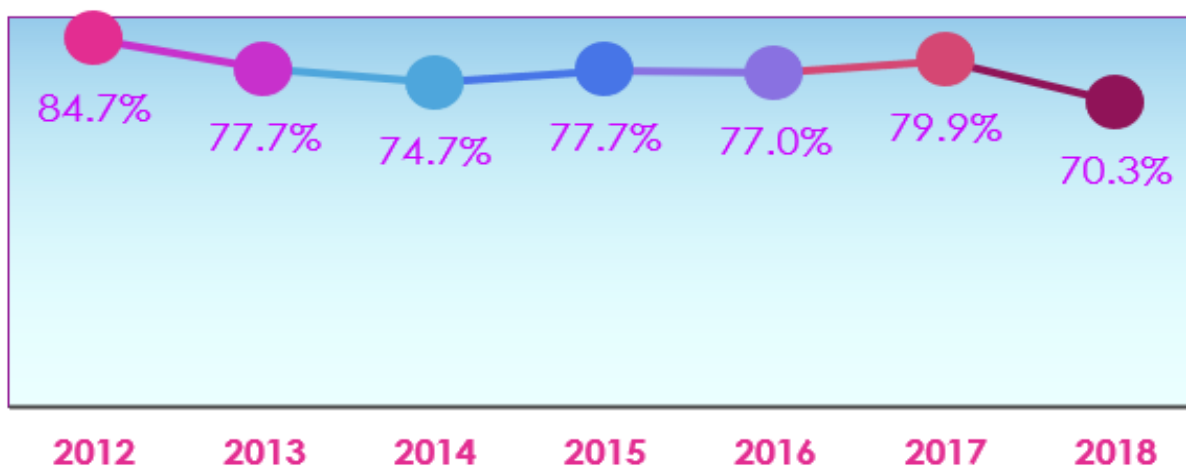
All infants diagnosed with hearing loss will receive appropriate interventions **by 6 months of age**, including amplification selection (if appropriate) and early intervention.

EHDI's goal is that all infants with confirmed hearing loss enroll in early intervention (EI) by 6 months of age. In 2018, 226 babies were diagnosed with permanent hearing loss in North Carolina. Of those 226, 159 (70.3%) were enrolled in either Part C or Non-Part C early intervention. Enrollment in EI has decreased overall since 2012.



EHDI staff are now meeting regularly with EI Providers to trouble-shoot the cause(s) of this continued decrease. NC EHDI has also developed an informational sheet regarding EI services that audiologists provide to families at diagnosis in an effort to better explain the benefits of EI services for children with hearing loss.

EI ENROLLMENT BY YEAR (PART C AND NON-PART C)

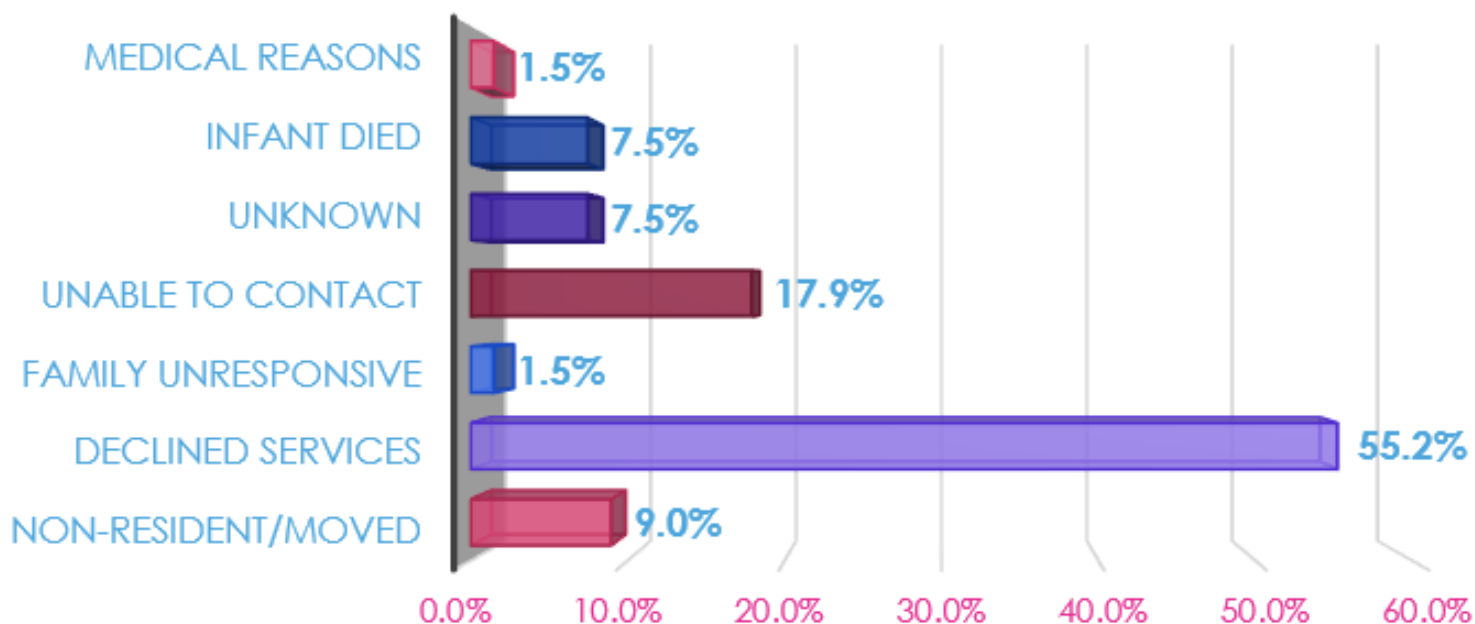


In 2018, 67 babies out of the 226 (29.7%) diagnosed with a permanent hearing loss were not enrolled in early intervention.

The reasons for non-enrollment are as follows:

- Infant deceased (5)
- Non-resident/Moved out of jurisdiction (6)
- Parents/Family declined services (37)
- Medical reasons (1)
- Parents/Family contacted but unresponsive (1)
- Unable to contact (12)
- Unknown (5)

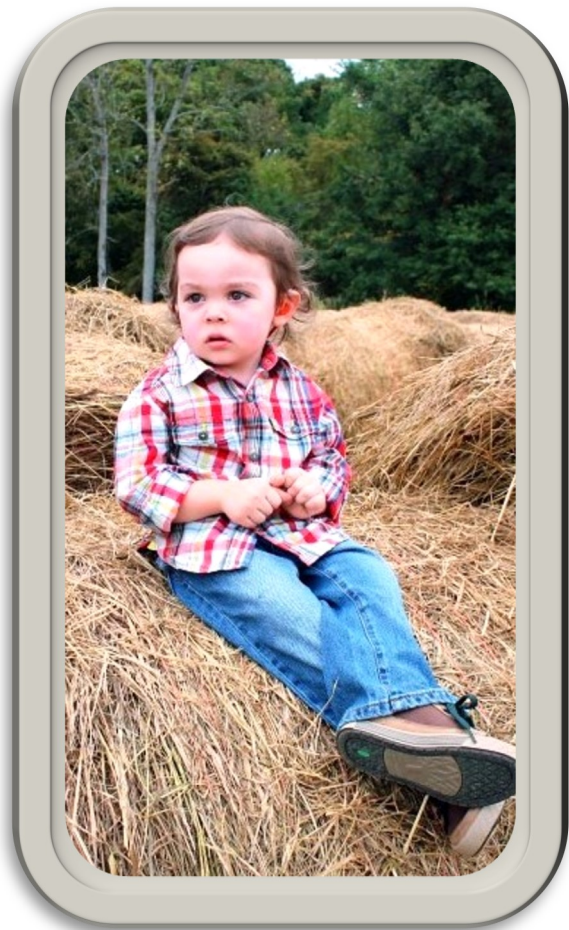
REASON FOR NO EI ENROLLMENT (2018)



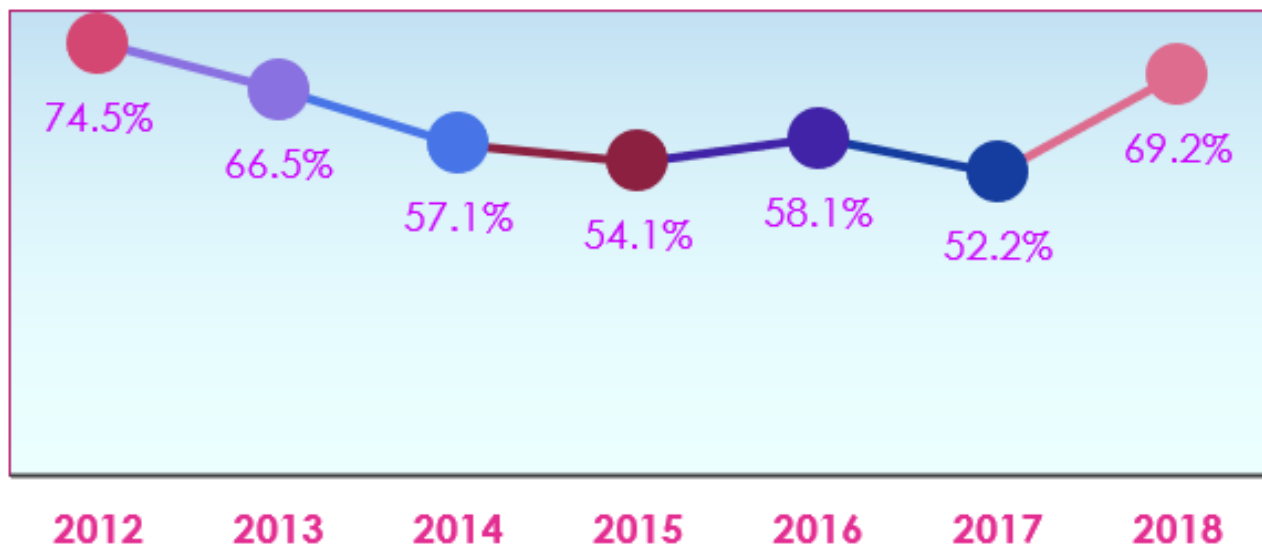
In 2018, 226 infants born in North Carolina were identified with hearing loss. Of these, 159 (70.3%) were enrolled in early intervention. Of those enrolled, 110 received early intervention services by 6 months of age (69.2%).

This is a large improvement from 52.2% enrolled in EI by 6 months of age in 2017. The NC EHDI team hopes to continue improving in this area through increased collaboration with Part C and Non-Part C early intervention providers.

Increasing the number of infants that enroll in early intervention and also increasing the percentage that enroll by 6 months of age will continue to be a major area of focus for the NC EHDI Program.



PERCENT RECEIVED EI SERVICES BEFORE 6 MONTHS OF AGE



Conclusion

Our goal is to ensure that all North Carolina infants who are deaf or hard of hearing (D/HH) are identified early and receive appropriate and timely intervention services.

We continue to partner with EHDI stakeholders, engage in quality improvement projects, and strive to improve outcomes for children in North Carolina who are D/HH.



Thank You!

We would like to thank all the partners and stakeholders whose work helps improve North Carolina's EHDI system.

This system is made up of many dedicated people and programs all working to improve the lives of North Carolina's children.

The NC EHDI Program is just one part of this important system.



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