

2020 LEGISLATIVE UPDATE: FIRST SOUND

South Carolina's Success in Newborn Hearing Screening



First Sound Program

First Sound is South Carolina's Early Hearing Detection and Intervention (EHDI) program mandated by legislation since 2001 for all hospitals with an annual average of 100 or more births. Currently all 39 birthing hospitals in South Carolina actively perform hearing screenings on newborns prior to discharge. First Sound uses the national 1-3-6 benchmarks to measure progress: Screen by 1 month, confirm by 3 months and early intervention by 6 months if applicable.

Early identification of hearing loss makes access to appropriate early intervention services during the critical window of a child's language development possible. Early intervention for deaf and hard of hearing children maximizes their potential for academic achievement and quality of life equal to their hearing peers. It also leads to long-term savings in special education expenses and public assistance in adulthood.

Highlights

- In 2021, First Sound will celebrate 20 years of the Universal Newborn Hearing Screening and Intervention Act (Section 44-37-40), passed by the South Carolina legislature in 2001.
- Birthing hospitals reported screening 51,787 infants for hearing loss prior to hospital discharge in SC in 2019. An additional 175 infants delivered outside of a hospital, i.e., free standing birthing centers, were screened for hearing loss.
- To date, 1,728 infants have been identified with hearing loss since the start of the program in 2001.
- First Sound surpasses the American Academy of Pediatrics (AAP) benchmark (95%) with an average of 97% of newborns screened annually.
- First Sound collaborated with family support organizations to organize the "2020 5th Annual Back to School Bash for Deaf and Hard of Hearing Students" using a virtual platform.

First Sound and COVID-19

- First Sound staff mobilized at the onset of the pandemic to develop and distribute revised protocols for hospitals and audiologists to maintain consistency in services and reporting.
- Hospitals maintained newborn hearing screening services with no interruption.
- First Sound staff also provided materials to parents to assist with navigation of services impacted by the pandemic.
- First Sound purchased a hearing screener for a large birthing center to use for onsite screening to avoid delayed screening and/or diagnostics due to limited availability of audiology appointments.
- Audiology providers remained open for limited services initially but resumed full services, including newborn hearing follow-up, within a few weeks of the onset of the pandemic.
- Preliminary data indicate minimal impact to timely screening and diagnostics.

Future Direction

- Strengthen the ability of the First Sound program to make direct referrals to early intervention and family support organizations to increase the number of infants identified with hearing loss and having received early intervention services.
- Identify and provide equipment to additional free-standing birthing centers to perform newborn hearing screenings on-site at time of birth.
- Expand diversity of family engagement in the early hearing detection and intervention systems through collaborative partnerships with deaf and hard of hearing family support organizations.

"On November 1 our precious boy arrived into the world. He was everything we dreamed of and we were so in love. We did however notice differences; underdeveloped ears, dents under the eyes, a small chin, a large nose, underdeveloped lower eyelids and more. Late that evening during Hunter's hearing test, we watched as the numbers did not meet their marker to pass. He did not pass a second attempt in the hospital and we were referred for follow-up. We went to the audiologist and ENT many times over the course of 2.5 months. The craniofacial team at MUSC confirmed that he has Treacher Collins Syndrome. However, if it wasn't for the hearing screen at the hospital [First Sound] Hunter's diagnosis could have been delayed for a long time, causing delays in learning or serious health concerns. He now has access to the resources he needs and we are actively seeking resources to help acquire a device to aid in Hunter's bilateral conductive hearing loss."

— Christiane Knighten, parent of Hunter — Charleston County

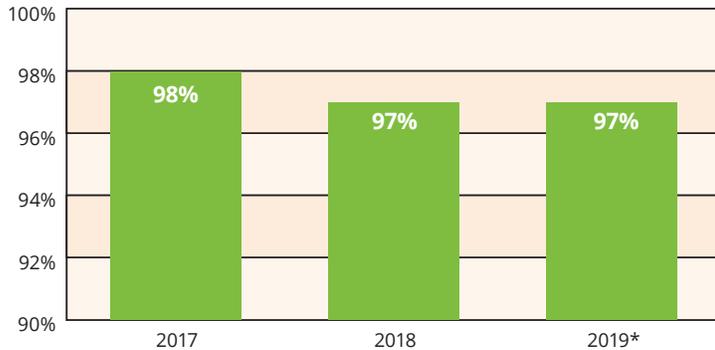


South Carolina by the Numbers

**It is important to note that the 2019 data are provisional and subject to change.*

SC Newborn Hearing Screening Rate

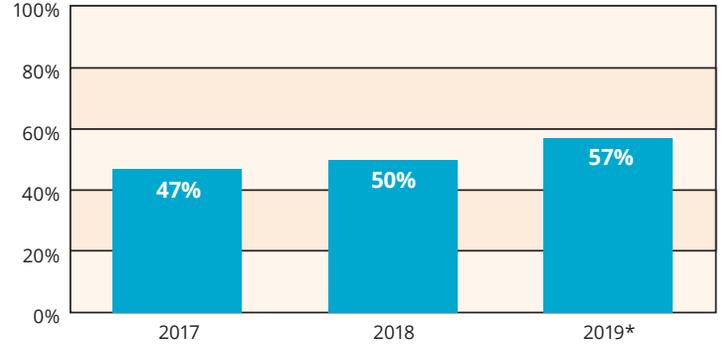
AAP Benchmark: 95% | 2018 National Average: 98%



The South Carolina newborn hearing screening rate among infants born in 2019 was 97%. The 2019 rate is above the American Academy of Pediatrics benchmark value of 95% and only slightly lower than the 2018 national average of 98%.

SC Infants with Hearing Loss Where Loss is Confirmed by 3 Months

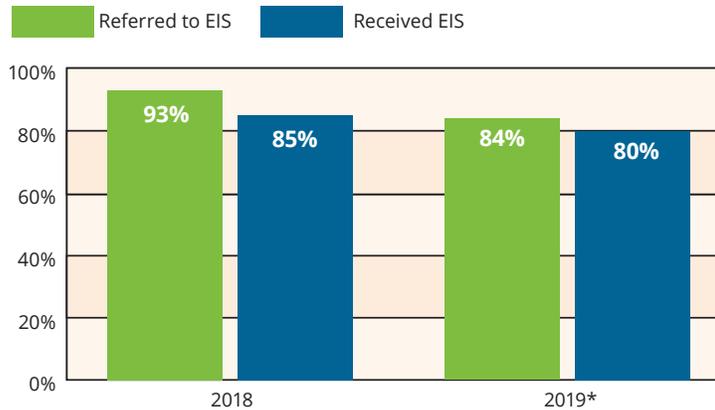
AAP Benchmark: 100% | 2018 National Average: 77%



The percentage of South Carolina infants with neonatal hearing loss whose loss was confirmed by 3 months of age has steadily increased over the past three years. In 2019, 57% of infants with confirmed hearing loss in South Carolina were diagnosed by 3 months. This is below the American Academy of Pediatrics standard of 100% and the 2018 national average of 77%.

Early Intervention for SC Infants with Permanent Hearing Loss

AAP Benchmark: 100% | 2018 National Average: 67%



The percentage of South Carolina infants who were identified with permanent hearing loss and referred for early intervention services (EIS) by 6 months of age, and the percentage receiving EIS services by 6 months of age have both decreased since 2018. In 2019, 84% of infants with confirmed hearing loss were referred to early intervention services with 80% having received early intervention services. South Carolina fell below the American Academy of Pediatrics standard of 100% but exceeded the 2018 national average of 67%.

Factors Contributing to Delayed Access to Early Intervention

2018 2019*



There are multiple factors that contribute to delayed access to early intervention services for infants with hearing loss. In 2019, parent withdrawal (18%) and unsuccessful contact with the family (16%) delayed access to early intervention services for infants who needed it.

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