The Journal of Early Hearing Detection and Intervention
2017; 2(1): 40–47

# Evaluating Loss to Follow-Up in Newborn Hearing Screening in a Southern State

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**Abstract**
Objective: The aim of this study was to examine loss to follow-up (LTFU) for diagnostic or early intervention (EI) services for South Carolina infants screened or diagnosed with hearing loss, and the risk factors associated with LTFU.

Design: A cross sectional analysis of data from South Carolina was used to examine LTFU for the use of audiologic evaluation services after initial newborn hearing screening and receipt of EI services after confirmation of hearing loss.

Results: Three percent (3.1%) of newborns screened in the state of South Carolina did not pass their hearing screening in 2013. Nearly half (49.1%) of those children had a documented audiologic diagnostic evaluation within one month of their initial screen. Factors significant with documentation of a diagnostic evaluation include birth weight, mother's race, and mother's education. The degree of hearing loss was a significant determinant of documented EI services.

Conclusions: We found several characteristics that put children at risk for LTFU for both the initial diagnostic services and EI services in South Carolina. Interventions targeted at specific groups are needed to improve the delivery of both diagnostic evaluations and EI services, and prevent a public health shortfall.

**Key Words:** Early Hearing Detection and Intervention, Loss to Follow-Up, Early Intervention

**Acronyms:** AABR = Automated Auditory Brainstem Response, CDC = Centers for Disease Control and Prevention, EHDI = Early Hearing Detection and Intervention, EI = Early Intervention, LTFU = Loss to Follow-Up

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## Introduction

The estimated incidence of congenital hearing loss in the United States ranges from 1 to 3 out of 1,000 live births (Centers for Disease Control and Prevention [CDC], 2010; Finitzo, Albright, & O'Neal, 1998; Prieve & Stevens, 2000; Shulman et al. 2010; Vohr, 2003). Children whose hearing loss goes undetected often have significant language, speech, and social delays (Culbertson & Gilbert, 1986; Kusché & Greenberg, 1983). The timeliness of identification and intervention is crucial as children develop upwards of 80% of their language ability by 18 months of age (Rescorla, 1989). In 1999, the Newborn and Infant Hearing Screening and Intervention Act authorized newborn hearing screening programs across the United States. By the year 2000, with a federally funded maternal and child health grant, most states had newborn hearing screening programs in place (Mehl & Thomson, 2002). Before the implementation of universal newborn hearing screenings, many children with hearing loss were not diagnosed until two to three years of age (Shulman et al., 2010), when significant delays in development had already occurred.

The benefits of newborn hearing screening are well-documented (Porter, Neely, & Gorga, 2009), particularly in the development of language skills. Children whose hearing loss had been identified by 6 months of age were later found to have significantly higher language quotient scores than children identified after 6 months (Yoshinaga-Itano & Apuzzo, 1998).

While detection of hearing loss is important, intervention is essential. Timely intervention, defined as intervention successfully rendered by 6 months after birth, has been shown to significantly improve language, speech, and emotional development compared to children later identified with congenital hearing loss (Carney & Moeller, 1998; Kennedy et al., 2006; Moeller, 2000; Yoshinaga-Itano,

Sedey, Coulter, & Mehl, 1998). Early detection of hearing loss and subsequent intervention optimizes developmental outcomes for the child, family, and society as a whole (Moeller, 2000; Thompson et al., 2001; Yoshinaga-Itano, 2004).

Infants identified with hearing loss who do not receive early intervention services are at risk for development delays. Previous research has identified wide variations in language, emotional development, and educational achievement among children who do not receive early intervention services by six months of age (Sininger, Grimes, & Christensen, 2010; White, Forsman, Eichwald, & Munoz, 2010; Yoshinaga-Itano, Baca, & Sedey, 2010). Studies examining the effects of hearing loss on academic achievement have shown that children with hearing loss are at increased risk for grade failure and may need extra educational assistance, compared to children with normal hearing (Bess, Dodd-Murphy, & Parker, 1998; Keller & Bundy, 1980; Oyler, Oyler, & Matkin, 1988; Stein, Jabaley, Spitz, Stoakley, & McGee, 1990). A more recent study has shown that children with hearing loss were more likely to have an individualized education plan (Lieu, Tye-Murray, Karzon, & Piccirillo, 2010).

Nationally, nearly a quarter (23.8%) of all children identified with hearing loss have no documented receipt of EI services (CDC, 2014). There are numerous potential determinants of loss to follow-up (LTFU) after the diagnostic evaluation. Maternal factors such as education, age, marital status, smoking and substance abuse, number of children, insurance status, and poverty level are all noted determinants (Folsom et al., 2000; Liu, Farrell, MacNeil, Stone, & Barfield, 2008; Oghalai, Chen, Brennan, Tonini, & Manolidis, 2002; Prince, Miyashiro, Weirather, & Heu, 2003). Parents with hearing loss may have a cultural preference for alternatives to amplification and traditional EI services (Prince et al., 2003). Child factors related to LTFU include birth weight, race, gender, and whether the child had a NICU stay (Davis & Wood, 1992; Folsom et al., 2000; Liu et al., 2008; Shoup et al., 2005; Stein et al., 1990; Stewart et al., 2000; Uus & Bamford, 2006). Residence has also shown to be a barrier to EI services. Audiologists and ear, nose, and throat physicians are often located in urban areas. Travel time and distance are major factors affecting timely follow-up and the scheduling of appointments (MacNeil, Liu, Stone, & Farrell, 2007). Few studies have examined the effect of residence on diagnosis and treatment of children with hearing loss in rural America, particularly in the South (Bush et al., 2015; Elpers, Lester, Shinn, & Bush, 2016).

Since July 2001, the South Carolina Department of Health and Environmental Control has run the First Sound Program, the state's early hearing detection and intervention (EHDI) program. The universal newborn hearing screening law in South Carolina requires that all South Carolina hospitals that birth an average of 100 or more babies per year screen each newborn baby for hearing loss. In South Carolina, all newborn hearing screening is performed using the Automated Auditory Brainstem Response (AABR) which records how the auditory nerve responds to sounds. For those infants who do not pass the initial newborn hearing screen, the First Sound program recommends a final screen before the age of one month. If the infant does not pass the final screen, they are referred to an audiologist for a diagnostic hearing evaluation, with the goal of diagnosis by three months of age. If an audiologist confirms hearing loss, the First Sound Program refers the child to BabyNet, South Carolina's interagency EI system for infants and toddlers under three years of age with developmental delays (Newborn Hearing, South Carolina Department of Health and Environmental Control).

Although there have been a number of studies completed in specific states and using national cohorts that describe many of the risk factors identified for untimely follow-up or LTFU for diagnosis or screening, much of this research has either been national in scope or conducted in areas with large urban centers (Dalzell et al., 2000, New York State; Gaffney, Green, & Gaffney, 2010, national; Harrison & Roush, 1996, national; Liu, Farrell, MacNeil, Stone, & Barfield, 2008, Massachusetts; Shulman et al., 2010, national). South Carolina differs demographically from previous studies and national means, with a much higher rate of African-American residents (27.9% vs. 12.6%, $p < 0.01$), a higher proportion of rural residents (33.7% vs. 19.3%, $p < 0.01$), and fewer residents with a bachelor's degree or higher (25.8% vs. 29.8%, $p < 0.01$) than national averages (U.S. Census Bureau, 2015). These characteristics are shared by many Southern states. The purpose of this study was to examine child and maternal factors related to timely follow-up for the diagnostic evaluation and timely intervention for infants identified with hearing loss in a Southern state.

## Method

A cross-sectional analysis examined data provided from the First Sound Program Manager. Data came from First Sound program records, birth certificate data, and BabyNet, South Carolina's interagency EI system. Two outcomes were examined: loss to follow-up for a diagnostic evaluation after initial newborn hearing screening and loss to follow-up for EI services after confirmation of hearing loss. To examine the first outcome, we used information from all children who did not pass their initial newborn hearing screening in 2013 ($N = 1,609$; $n = 100$ for confirmed hearing loss). For our second outcome, we examined whether, among children with confirmed hearing loss, intervention occurred either within the first six months of life or at any time. The sample for the second analysis was 408 children with confirmed hearing loss during 2009–2013. EI within the first six months of life was collapsed into two categories: those who had documented EI services within the first six months of life versus those who did not. EI at any time was collapsed into two categories: those with documented EI services at any time regardless of age versus those with no documented EI services.

Infant covariates included birthweight (< 2500 g and ≥ 2500 g), laterality of hearing loss (bilateral vs. unilateral), and degree of hearing loss (severe/profound vs. mild/moderate). Maternal covariates included age (< 26 years vs. ≥ 26 years), race (Non-Hispanic White vs. Nonwhite), educational attainment (< high school graduate/GED vs. high school graduate or above), insurance (private, public, uninsured), and residence (rural vs. urban). Although it would be desirable to examine the experience of specific race/ethnicity populations, the number of infants with confirmed hearing loss was too few for accurate estimation.

We used standard statistical analysis procedures to estimate frequencies and proportions for categorical variables. Analyses were carried out to detect statistical significance between variables using chi-square tests with $\alpha = 0.05$. Logistic regression models were used to examine the impact of infant and maternal characteristics on intervention and follow-up status. All analyses were conducted with statistical software (SAS, version 9.3; SAS Institute Inc.). The data were de-identified for analysis and the study was approved by the university's institutional review board as exempt.

## Results

### Loss to Follow-Up for Audiologic Evaluation Services

Three percent (3.1%, $n = 1,609$) of all children screened in the state of South Carolina did not pass their newborn hearing screen in 2013. The majority of these children were normal birthweight (83.7%), with a mother who had completed high school (72.5%), lived in an urban area (68.7%), were publicly insured (67.7%), and were nonwhite (53.4%).

Nearly half (49.1%) of those children had a documented audiologic diagnostic evaluation within one month of their initial screen (Table 1). Within 2 or 3 months, two-thirds (60.0%) of all infants who did not pass their initial newborn hearing screening had received a follow-up diagnostic evaluation. More than a quarter (29.4%) of children were never documented as having received a diagnostic evaluation.

**Table 1**

***Receipt of Follow-Up Diagnostic Evaluation Services Among Newborns Who Failed Newborn Hearing Screening, by Time of Follow Up and Infant and Maternal Characteristics: South Carolina 2013***

| | | | Diagnostic Evaluation Activites | | | |
|---|---|---|---|---|---|---|
| | | Population | Seen by 1 month | Seen by 2-3 months | Seen at all | Never Seen |
| **Total** | | 1,609 | *N* = 790 (49.1%) | *N* = 965 (60%) | *N* = 1,136 (70.6%) | *N* = 473 (29.4%) |
| **Infant Factors** | | | | | | |
| **Birth Weight** | | | | | | |
| | **≥ 2500 g** | 83.7% | 52.3%† | 63.3%† | 71.9%† | 28.1% |
| | **< 2500 g** | 12.4% | 31.2%† | 43.7%† | 67.8%† | 32.2% |
| | **Unknown** | 4.0% | 37.5%† | 2.7%† | 51.6%† | 48.4% |
| **Maternal Factors** | | | | | | |
| **Age** | | | | | | |
| | **≥ 26 years** | 46.9% | 50.2% | 62.1%† | 72.7%† | 27.3% |
| | **< 26 years** | 49.1% | 49.0% | 59.5%† | 70.1%† | 29.9% |
| | **Unknown** | 4.0% | 3.0% | 40.6%† | 51.6%† | 48.4% |
| **Race or Ethnicity** | | | | | | |
| | **White** | 41.9% | 54.6%† | 64.4%† | 74.0%† | 26.0% |
| | **Nonwhite** | 58.1% | 45.1%† | 57.0%† | 68.1%† | 31.9% |
| **Education** | | | | | | |
| | **High School education or more** | 72.5% | 53.7%† | 63.4%† | 74.5%† | 25.5% |
| | **Less than a high school education** | 20.4% | 38.4%† | 50.0%† | 62.2%† | 37.8% |
| | **Unknown** | 7.1% | 32.5%† | 44.7%† | 55.3%† | 44.7% |
| **Source of Delivery Payment*** | | | | | | |
| | **Private Insurance** | 28.1% | 53.1% | 65.0%† | 76.8%† | 23.2% |
| | **Public Insurance** | 67.7% | 47.5% | 58.0%† | 68.2%† | 31.8% |
| **Residence** | | | | | | |
| | **Urban** | 68.7% | 48.7% | 60.1%† | 72.0%† | 28.0% |
| | **Rural** | 27.3% | 51.8% | 62.5%† | 70.0%† | 30.0% |
| | **Unknown** | 4.0% | 37.5% | 40.6%† | 51.6%† | 48.4% |

† Differences significant, compared to those not seen by the time period, $p < 0.05$
* A small number of children (68, 4.2%) had no recorded insurance

In bivariate analyses (see Table 1), infants were less likely to receive a diagnostic evaluation by one month if they were born low birth weight (31.2%) compared to infants of normal birth weight (52.3%). Similarly, those born to non-white mothers (45.1%) versus white mothers (54.6%), and those born to mothers with less than a high school education (38.4%) compared to mothers with a high school education (53.7%) were less likely to receive a diagnostic evaluation by one month. As reported in Table 2, when these predictors were examined simultaneously in a logistic regression to adjust for confounding effects, infants born with low birth weight were less likely to receive a diagnostic evaluation by one month compared to infants of normal birth weight (OR 0.44; 95% CI, 0.31–0.60). Infants with non-white mothers were also less likely to receive a diagnostic evaluation by one month compared to infants with white mothers (OR 0.77; 95% CI, 0.62–0.96). Infants with mothers having less than a high school education were also less likely to receive a diagnostic evaluation by one month than those whose mothers had at least a high school education (OR 0.55; 95% CI, 0.42–0.72).

Infants were less likely to have any documented diagnostic evaluation—regardless of the time frame—if they were born with low birth weight (32.2%) versus normal birth weight (28.1%, see final column in Table 1). This was also true if they were born to non-white mothers (31.9%) versus white mothers (26.0%), and if their mothers had less than a high school education (37.8%) versus mothers with at least a high school education (25.5%). Additionally, infants with public insurance were less likely to have any documented diagnostic testing regardless of age than infants with private insurance (31.8% vs. 23.2%, $p < 0.05$), as were rural infants (30.0%) compared to infants residing in urban areas (28.0%).

**Table 2**
***Maternal and Infant Factors Associated with Diagnostic Service Follow-Up within One Month Post Failed Newborn Hearing Screening***

| | Adjusted odds ratio (95% CI) |
|---|---|
| | seen by 1 Month[a] |
| **Infant factors** | |
| Birthweight | |
| ≥ 2500g | 1 [Reference] |
| < 2500g | **0.44 (0.32-0.60)** |
| **Maternal factors** | |
| Age | |
| ≥ 26 years | 1 [Reference] |
| < 26 years | 1.04 (0.83-1.30) |
| Race | |
| Non-hispanic white | 1 [Reference] |
| Non-white | **0.77 (0.62-0.96)** |
| Educational attainment | |
| High school education or greater | 1 [Reference] |
| Less than a high school education | **0.55 (0.42-0.72)** |
| Source of delivery payment | |
| Private insurance | 1 [Reference] |
| Public insurance | 0.98 (0.77-1.25) |
| Residence | |
| Urban | 1 [Reference] |
| Rural | 1.25 (0.99-1.58) |

[a]Received diagnostic services within one month of failed newborn hearing screening.

**Loss to Follow-Up for Early Intervention Referrals**

From 2009 to 2013, there were 408 cases of confirmed hearing loss (Table 3). The majority of children with confirmed hearing loss were of normal weight, had bilateral hearing loss, and lived in an urban county. Nearly one-third (32.1%) had documented EI services, with 14.2% receiving those services within the first six months of life (Table 4). Nearly 70% had no documented EI services, regardless of age. In bivariate analyses, children were more likely to receive EI within six months if they had severe or profound hearing loss (23.4) versus mild or moderate hearing loss (10.2%), and if their mothers were 26 years or older (20.1%) versus younger than 26 years of age (8.4%). Children were more likely to receive EI within any time frame if they were born low birth weight (41.6%) versus normal birth weight (29.1%), if they had severe or profound hearing loss (43.2%) versus mild or moderate hearing loss (25.7%), and if their mothers were 26 years or older (37.3%) versus younger than 26 years of age (26.7%).

**Table 3**

***Number of Children Screened by the First Sound Program (2009-2013)***

| Year | Number of children screened | Cases of confirmed hearing loss |
|---|---|---|
| 2009 | 55,937 | 65 |
| 2010 | 53,682 | 71 |
| 2011 | 53,017 | 78 |
| 2012 | 52,400 | 94 |
| 2013 | 52,097 | 100 |

**Table 4**

***Characteristics of Study Population: South Carolina 2009–2013 Confirmed Hearing Loss Cases (Unknowns Included), by Intervention within the First Six Months***

| | | Intervention within 6 months | | Intervention at any date (includes previous) | | No intervention in record | |
|---|---|---|---|---|---|---|---|
| | | *N* | % | *N* | % | *N* | % |
| Total | | 58 | 14.2% | 58 | 14.2% | 58 | 14.2% |
| **Infant Characteristics** | | | | | | | |
| Laterality of hearing loss | | | | | | | |
| | Bilateral | 40 | 14.8% | 88 | 32.5% | 183 | 67.5% |
| | Unilateral | 13 | 11.6% | 31 | 27.7% | 81 | 72.3% |
| | Unknown | 5 | 20.0% | 12 | 48.0% | 13 | 52.0% |
| Degree of hearing loss | | | | | | | |
| | Severe or profound | 26 | 23.4%† | 48 | 43.2%† | 63 | 56.8% |
| | Mild or moderate | 25 | 10.2%† | 63 | 25.7%† | 182 | 74.3% |
| | Unknown | 7 | 13.5%† | 20 | 38.5%† | 32 | 61.5% |
| Birth weight | | | | | | | |
| | ≥ 2500g | 42 | 14.0% | 87 | 29.1%† | 212 | 70.9% |
| | < 2500g | 16 | 15.8% | 42 | 41.6%† | 59 | 58.4% |
| | Unknown | 0 | 0.0% | 2 | 25.0%† | 6 | 75.0% |
| **Maternal Characteristics** | | | | | | | |
| Age | | | | | | | |
| | ≥ 26 years | 42 | 20.1% | 78 | 37.3%† | 131 | 62.7% |
| | < 26 years | 16 | 8.4% | 51 | 26.7%† | 140 | 73.3% |
| | Unknown | 0 | 0.0% | 2 | 25.0%† | 6 | 75.0% |
| Race or ethnicity | | | | | | | |
| | White | 34 | 16.0% | 68 | 32.1% | 144 | 67.9% |
| | Nonwhite | 24 | 12.2% | 63 | 32.1% | 133 | 67.9% |
| Education | | | | | | | |
| | At least high school | 45 | 15.1% | 99 | 33.2% | 199 | 66.8% |
| | Hgh school graduate or greater | 10 | 12.7% | 23 | 29.1% | 56 | 70.9% |
| | Unknown | 3 | 9.7% | 9 | 29.0% | 22 | 71.0% |
| Source of delivery payment | | | | | | | |
| | Private insurance | 25 | 17.5% | 48 | 33.6% | 95 | 66.4% |
| | Public insurance | 28 | 12.9% | 71 | 32.7% | 146 | 67.3% |
| | No insurance | 5 | 10.4% | 12 | 25.0% | 36 | 75.0% |
| Residence | | | | | | | |
| | Urban | 46 | 13.1% | 106 | 30.2% | 245 | 69.8% |
| | Rural | 12 | 24.5% | 23 | 49.6% | 26 | 53.1% |
| | Unknown | 0 | 0.0% | 2 | 25.0% | 6 | 75.0% |

Given the small proportion of children with documented EI services within six months of age, a logistic regression focused on whether a child had documented EI services at any point in time. Controlling for all other covariates, the only significant predictor was the degree of hearing loss, with children with mild or moderate hearing loss less likely to have documented EI services compared to children with severe or profound hearing loss (OR 0.48; 95% CI, 0.29–0.80, Table 5).

**Table 5**
***Maternal and Infant Factors Associated with Intervention Services Received after Confirmed Hearing Loss***

| | Adjusted odds ratio (95% CI) |
|---|---|
| | Intervention ever received[a] |
| **Infant factors** | |
| Birthweight | |
| ≥ 2500g | 1 [Reference] |
| < 2500g | 1.71 (0.98-2.97) |
| **Laterality of hearing loss** | |
| Bilateral | 1 [Reference] |
| Unilateral | 0.87 (0.50-1.49) |
| **Degree of hearing loss** | |
| Severe or profound | 1 [Reference] |
| Mild or moderate | **0.48 (0.29-0.80)** |
| **Maternal factors** | |
| Age | |
| ≥ 26 years | 1 [Reference] |
| < 26 years | 0.84 (0.50-1.42) |
| Race | |
| Non-hispanic white | 1 [Reference] |
| Non-white | 1.07 (0.64-1.78) |
| Educational attainment | |
| ≥ High school | 1 [Reference] |
| > High school | 0.69 (0.35-1.34) |
| Source of delivery payment | |
| Private insurance | 1 [Reference] |
| Public insurance | 0.69 (0.40-1.19) |
| Residence | |
| Urban | 1 [Reference] |
| Rural | 2.30 (1.16-4.57) |

[a]Received diagnostic services within one month of failed newborn hearing screening.

## Discussion

The purpose of this study was to examine how selected social determinants of health impact timely follow-up for infants who do not pass their newborn hearing screen in South Carolina. The results indicate that despite programs and investment in this process, many gaps remain in achieving a higher rate of timely intervention.

Of particular concern is the LTFU rate, which we found to be nearly 30% between screening and diagnosis, and nearly 70% between diagnosis and EI. The LTFU rate for audiologic diagnostic evaluation in South Carolina is similar to findings in New York, which showed a 72% follow-up rate during the program year (Prieve & Stevens, 2000). Loss to follow-up for diagnostic services was more common among the highest risk children: children born to younger mothers, non-white mothers, mothers with less than high school education, and mothers insured by Medicaid.

The previous state-level studies were in Northeastern states. In Massachusetts, parents in the sample were 38% non-white and 32% publicly insured (Liu et al., 2008), versus 58.1% non-white and 67.2% with public insurance in our sample. Similarly, New York parents were largely urban, leading the authors to note that their findings had limited applicability to rural areas (Prieve & Stevens, 2000). In contrast, over a quarter (27.3%) of the South Carolina sample were from rural areas. Yet, many of our findings are the same, with younger and less-educated mothers, as

well as those insured by public insurance, more likely to be lost to follow-up. This suggests that targeting efforts can be similar, even across populations with apparently disparate characteristics. Additional effort is needed to reduce educational and health disparities for these children.

Two-thirds of children in South Carolina with confirmed hearing loss had no documented record of EI services. In a similar study examining EI among infants and children in Massachusetts, 75% of children received early intervention services (Carney & Moeller, 1998). One possible explanation for this may be the data source for EI services in South Carolina. The data only included children who were enrolled in BabyNet to receive EI services. Early intervention data does not account for children who may have received amplification and speech therapy through services outside of BabyNet.

Assistance is needed to increase early diagnostic evaluation and EI services for children in South Carolina, and indeed in many or most states. It is evident that the highest risk children are lost to follow-up for both the initial diagnostic evaluation and EI services. The developmental delays and subsequent costs associated with LTFU for diagnostic evaluation or late intervention are long-term for these children. These costs include societal costs such as an increased need for special education, health, and social services, as well as estimated lifetime costs of more than $1 million per individual (Honeycutt et al., 2003; Johnson et al., 1993; Mohr et al., 2000; Schroeder et al., 2006). The benefits of early intervention for language skills and subsequent educational achievement are significant (Bess & Tharpe, 1984; Kelly & Gaustad, 2007; Lieu 2004; Moeller, 2000). Interventions targeted at specific groups are needed to improve the delivery of hearing care services and prevent a public health shortfall.

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