

## Factors Contributing to Late Identification of Deaf or Hard of Hearing Children in Louisiana

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### Abstract

It is imperative to identify children who are Deaf or Hard of Hearing (DHH) as early as possible to ensure they receive supports needed to reach their full potential. Early Hearing Detection and Intervention benchmarks stipulate children who are DHH be enrolled in early intervention no later than 6 months of age. A major barrier to early enrollment is late identification. We reviewed records of children identified as DHH in Louisiana after 6 months of age for 2015–2020 birth cohorts to determine factors contributing to the late identification. Cases were examined in-depth after it was determined that a diagnosis was attainable by 6 months of age. For each case, factors contributing to the late identification were evaluated and assigned to three sources: (a) family, (b) provider, or (c) hospital. Results of the analysis revealed that 46% of late identifications were due to families not completing recommended testing, while provider factors accounted for 25% of late identifications. Hospital factors accounted for 5% of late identifications and 24% of late identifications were attributable to more than one source. The analysis indicated that the percentage of late identifications due to families increased from 2015 to 2020, while the percentages due to provider and hospital factors decreased.

**Keywords:** deafness, hearing loss, newborn hearing screening, late identification

**Acronyms:** DHH = deaf or hard of hearing; EHDI = Early Hearing Detection and Intervention; EI = Early Intervention; NHS = Newborn Hearing Screening

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The prevalence of congenital hearing loss is two to three per 1,000 infants (NIDCD, 2021). Prior to the implementation of state Early Hearing Detection and Intervention (EHDI) programs, children with congenital deafness were typically not identified until two to three years of age, or later for milder hearing levels (Coplan, 1987; Naarden et al., 1999; Wake et al., 2016). Universal Newborn Hearing Screening (NHS) has elicited an increase in the number of children who are deaf or hard of hearing (DHH) being identified in infancy, which allows for early intervention (EI) services to be initiated sooner than what was possible in the past. There is now a large body of research demonstrating the benefits of early identification and intervention for children who are DHH (Ching et al., 2017; Ching & Leigh, 2020; Meinzen-Derr et al., 2011, 2020; Moeller, 2000; Vohr et al., 2011; Yoshinaga-Itano et al., 1998, 2017, 2020). The Joint Committee on Infant Hearing (JCIH) made recommendations surrounding early hearing detection and intervention, which are now known as the 1-3-6 EHDI benchmarks: screen hearing by 1 month of age, diagnose hearing loss by 3 months of age, and enroll in early intervention services by 6 months of age (2019).

In 2020, 97% of infants born in the United States were reported to have received a hearing screening by one month of age (CDC, 2022a). Despite this progress, approximately 30% of infants who do not pass their NHS become lost to follow-up before receiving a final diagnosis, and many children who do receive follow-up testing do not obtain a diagnosis by three months of age (CDC, 2022c, 2022d). Poor achievement of the 3-month diagnosis benchmark has downstream effects on the 6-month early intervention benchmark. If children are identified as DHH near or beyond six months of age, it will be difficult or impossible for the child to be enrolled in early intervention services by six months of age.

For children who are born DHH, risk of language delay is high (Stika et al., 2015; Vohr et al., 2008; Yoshinaga-Itano, 2003). Enrollment in early intervention services as early as possible, but no later than six months of age, mitigates this developmental risk (Yoshinaga-Itano, 2003; Yoshinaga-Itano et al., 2017). Yet, despite the ubiquitous presence of universal newborn hearing screening, only 45% of children identified as DHH enroll in early intervention services by six months of age (CDC, 2022b). This leaves

a large number of children at an unacceptably high risk of language delay. The reasons for these poor EI enrollment rates are varied, including perceived barriers to accessing services, lack of perceived benefits, and disconnects between family and provider culture (Woodruff-Gautherin & Cienkowski, 2023). However, another major barrier to early enrollment is that many children are not identified by six months of age, therefore precluding enrollment by six months of age.

Since diagnosis before six months of age is imperative to achieving timely early intervention enrollment for children identified as DHH, improving the rates of early diagnosis would provide more families with the opportunity for timely early intervention. It is essential to determine why so few children born DHH are receiving an early diagnosis, even though many state EHDI programs have been in existence for more than 20 years now. Parents of children identified as DHH have reported a variety of experiences with the diagnostic journey. Common barriers to timely diagnosis reported by parents include poor communication of hearing screening results by providers, limited access to hearing healthcare services, and the need for multiple outpatient visits to secure a diagnosis (Elpers et al., 2016; Reynolds et al., 2023; Robinson et al., 2023). However, population-level research into late diagnosis of congenital hearing loss is lacking. Studies in the United States investigating demographic factors found associations between late diagnosis and low maternal education, low socioeconomic status, and maternal race (Deng et al., 2022; Meyer et al., 2020; Zeitlin et al., 2021). A population-based study in Canada reported common reasons for late identification were medical issues, middle ear dysfunction, and family follow-up concerns (Fitzpatrick et al., 2017). Further population-level studies are needed to supplement the qualitative parent perspective studies and uncover potential approaches for amelioration. Strategies to improve rates of identification by three months of age may, in turn, yield an improvement in rates of early intervention enrollment by six months of age. The objective of this study was to investigate reasons for identification after six months of age for children born DHH in Louisiana.

## Method

### Institutional Review Board Statement

This study was considered exempt by the Louisiana Department of Health Institutional Review Board.

### Data Source and Study Population

A report was generated in the Louisiana Early Hearing Detection and Intervention Information System (LA EHDI-IS) for children born from 1/1/2015 to 12/31/2020 and identified as DHH. Children who were initially identified as DHH by six months of age (defined as at or before 180 days of age) were removed from the report. Of those cases remaining, further exclusions were conducted of children for whom obtaining a diagnosis by six months of age was not feasible. These late diagnoses occurred due to one of the following four reasons:

- 1) Child passed initial NHS.
- 2) Child passed outpatient follow-up testing (either rescreening or diagnostic evaluation) after not passing NHS.
- 3) Child was medically fragile or was still in the neonatal intensive care unit (NICU) at six months of age.
- 4) Child was born out of state and the birth record was not included in the LA EHDI-IS by six months of age.

### Record Evaluation

The remainder of cases were included in the report for in-depth analysis to determine why a diagnosis was not obtained by six months of age for children who did not pass NHS. Each record was examined in the LA EHDI-IS, and all available information in the record was reviewed. This information included:

- 1) NHS reports
- 2) Follow-up testing reports
- 3) Notations of scheduled appointments
- 4) Communications from pediatricians, audiologists, and other providers
- 5) Communications between parents and EHDI team members.

Identified reasons contributing to each late diagnosis were assigned to one of three sources: family, provider, or hospital. Late diagnoses attributed to families occurred when appointments were missed or canceled, families declined to complete all recommended testing, or families were unresponsive or could not be contacted. Late diagnoses were attributed to providers if families were following recommendations made to them, but the outpatient providers they saw were not following evidence-based practices to ensure a timely diagnosis. Examples included delay in referring a child to a diagnostic evaluation, and failure of the primary care provider to order the recommended test. Late diagnoses attributed to hospitals included reporting incorrect newborn screening results (reporting a *did not pass* result as *pass*), and failure to schedule outpatient follow-up appointments for families of children needing additional testing.

In addition, records of children identified as DHH who passed NHS were reviewed in an effort to identify cases whose NHS results were reported incorrectly. Any information in the record which indicated results may have been inaccurate led to contact of the birth hospital for verification. Those verified as passing NHS remained excluded from the report, while those determined not to have passed NHS were included.

## Results

### Late Identification of Early-Onset Hearing Loss

A total of 771 children from 2015–2020 birth cohorts have been reported to the LA EHDI-IS as being identified as

DHH (Table 1). Of these, 315 (40.9%) were identified after six months of age. There were 174 cases removed from the analysis because a diagnosis was not deemed attainable by six months of age, for reasons described above. In-depth records analyses were performed on the remaining 141 cases. Of the 141 participants, 51.8% were female vs. 48.2% male; 42.6% non-Hispanic White, 37.6% non-Hispanic Black, 6.4% non-Hispanic other, 12.8% Hispanic, and 0.7% race/ethnicity unknown. One-quarter of mothers did not finish high school (25.5%), 43.3% completed high school as the highest level of education, and 31.2% attained some level of education beyond high school.

### Source of Late Identification

Evaluation of the reasons children were late-identified revealed the most common source to be the family, which was the sole source in 46% of cases (Figure 1). Providers were the sole source in 25% of cases, while hospitals were the sole source in 5% of cases. In 24% of cases, two or more sources contributing to late identification were observed.

### Age at Identification

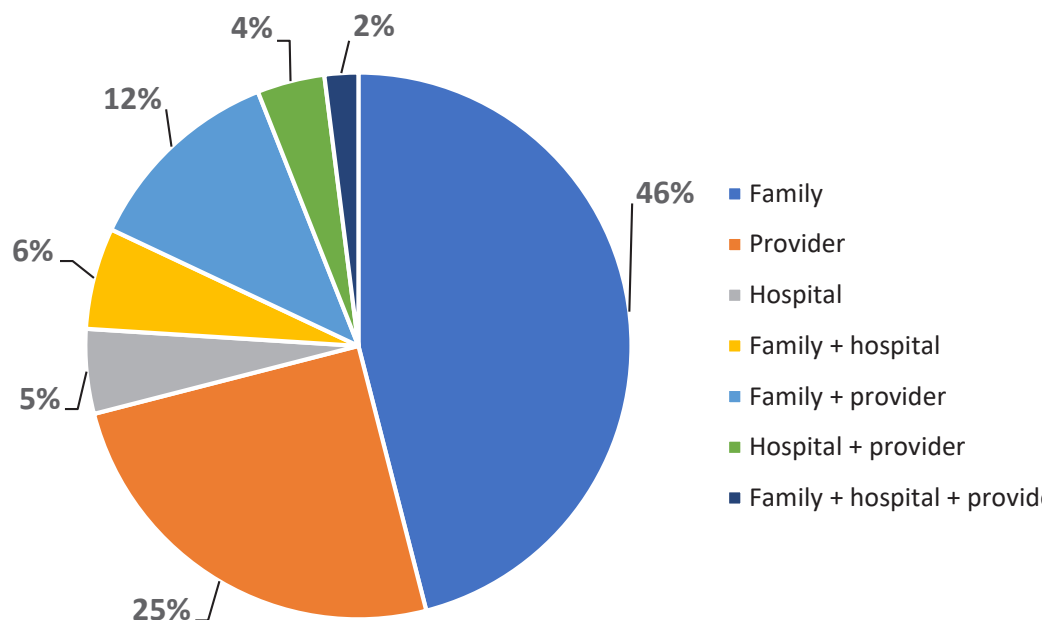
Over 70% of late-identified children were diagnosed before turning two years of age (Figure 2). Forty children (28%) received their initial diagnosis after turning two years of age, with the eldest reported at six years, 11 months of age.

### Source of Late Identification by Birth Year

Sources of late identification were evaluated by birth cohort to visualize trends occurring over time (Figure 3). An analysis was performed to enable observation of the contributions of each source (family, provider, and hospital) to the total number of late identifications. For example, if a child was late-identified due to both the family and a provider, the source of the late identification was assigned as 50% family and 50% provider. Analysis by birth cohort

**Figure 1**

*Source of Late Identification Among Children Identified as DHH Receiving a Late Diagnosis (Greater Than 6 Months of Age; n = 141)*



**Table 1**

*Children Born in Louisiana in 2015–2020 and Identified as Deaf or Hard of Hearing (DHH)*

Total DHH	771
Total late-identified DHH (> 6 months of age)	315
Cases removed from analysis	174
Passed Newborn Hearing Screening	90 (51.7%)
Passed outpatient follow-up testing	29 (16.7%)
Medically fragile	30 (17.2%)
Born out of state	25 (14.4%)
Cases included in analysis	141

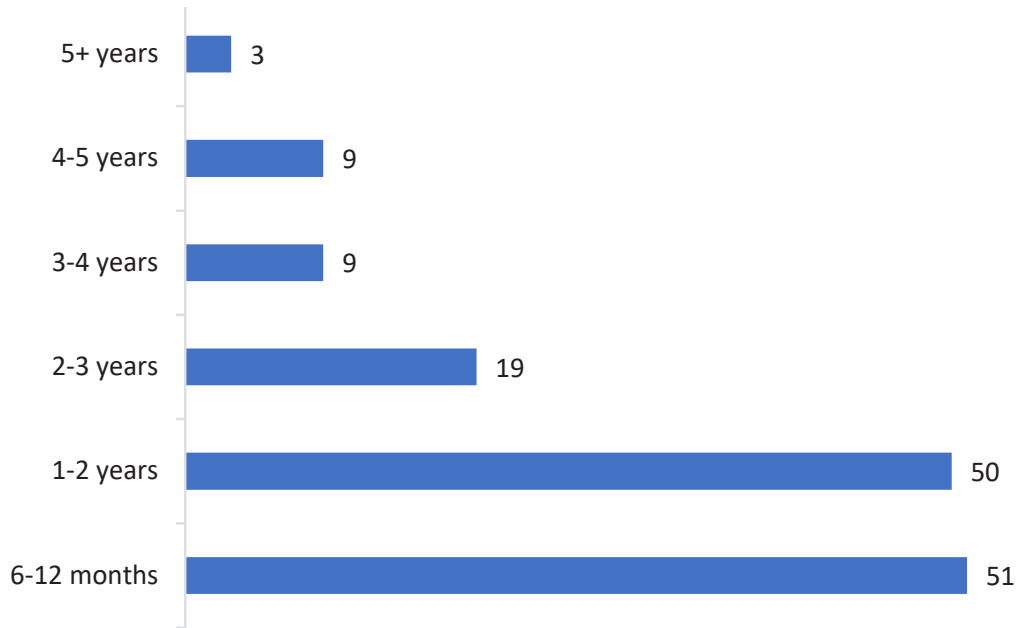
over time demonstrated an increase in the percentage of late identifications attributable to families, and a decrease in the proportion of late identifications attributable to hospitals and providers.

### Family Component to Late Identification

For children whose late identifications were attributed at least in part to the family, we reviewed what occurred after not passing NHS (Figure 4). In nearly half of these cases, the child was lost to follow-up after NHS. An additional 29% received one or more outpatient screenings, but did not complete a diagnostic evaluation by six months of age. In another 22% of cases ( $n = 20$ ), diagnostic evaluations were completed prior to six months of age, but the findings indicated either transient conductive hearing loss ( $n = 7$ ), or hearing loss of undetermined type ( $n = 13$ ). These families did not complete all recommended follow-up testing, and subsequently became lost to follow-up.

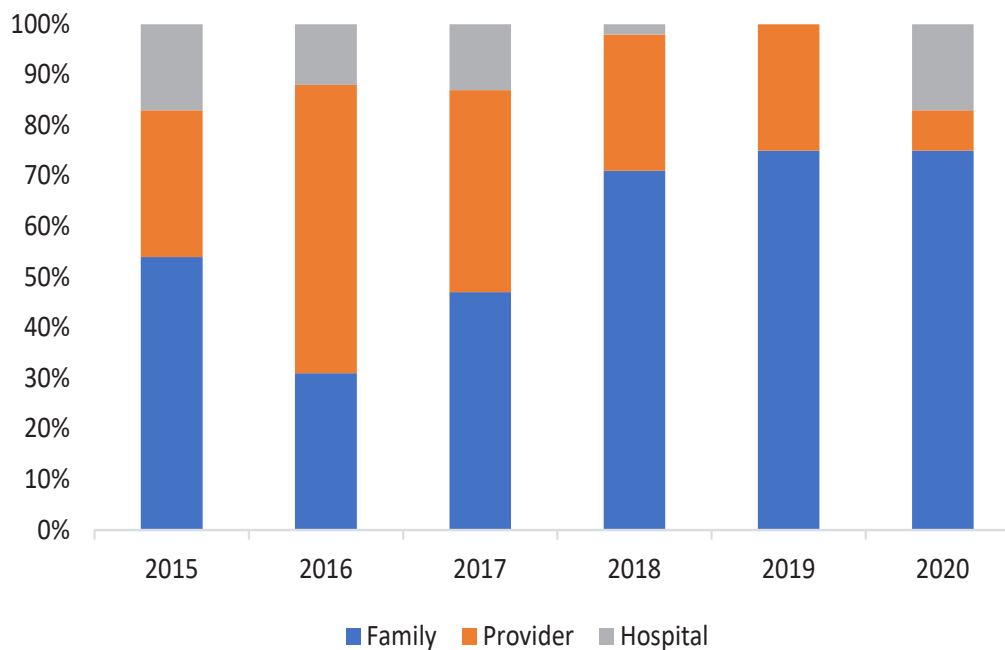
**Figure 2**

Number of Children Newly Identified as Deaf or Hard of Hearing (DHH) by Age Group



**Figure 3**

Sources of Late Identification by Birth Year



*Note.* The figure shows the contributions of each source to late identification (family, provider, and hospital) by each birth year cohort. Cases with more than one contributing factor were given equal weighting (i.e., two sources were each weighted as 50% contributors). A trend is seen over time with families being the most common contributing factor in the more recent birth cohorts.

### Provider Component to Late Identification

Provider contributions for late identifications were also evaluated (Figure 5). The most common provider issues were performing excessive rescreens prior to referring for diagnostic evaluation, and waiting too long to schedule a diagnostic evaluation (excessive scheduling gap between appointments). An excessive scheduling gap was defined

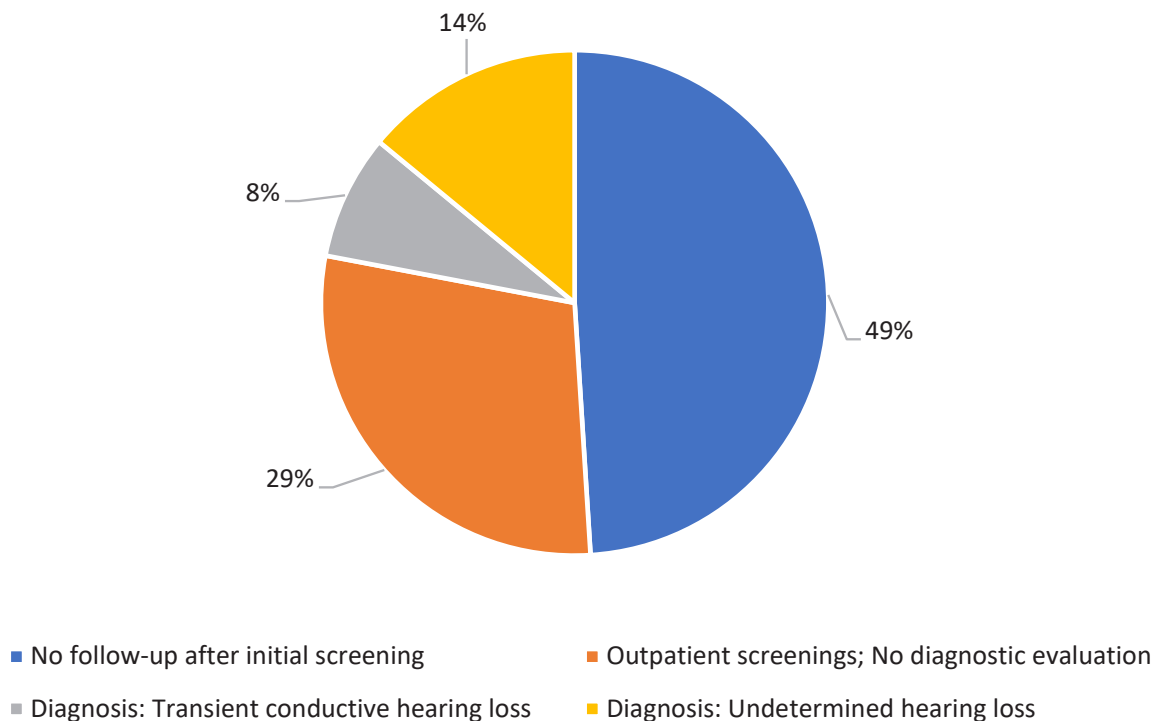
as more than one month between appointments.

### Hearing Levels of Children Late-Identified

Hearing laterality and levels of children late-identified were compared to the whole group of children identified as DHH from these cohorts (Figure 6). This indicated similar distributions in hearing levels between the two groups. The only hearing levels exhibiting between-group differences

**Figure 4**

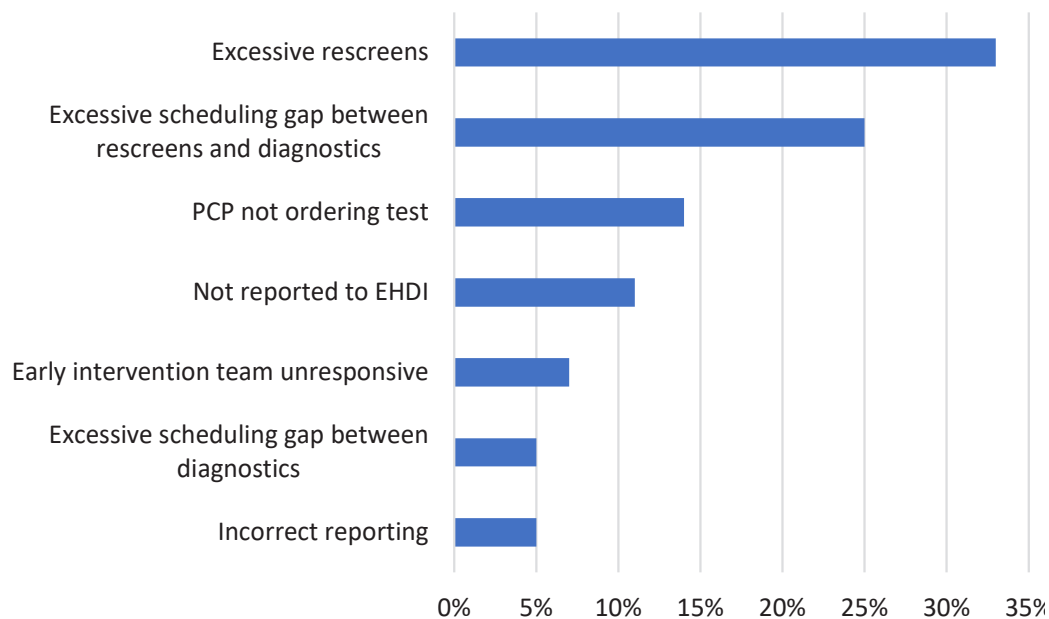
*Follow-up Outcomes for Children Late-Identified as Deaf or Hard of Hearing due to Family Factors*



*Note.* The graph displays outpatient follow-up outcomes for children who were late-identified as deaf or hard of hearing due to the family as a contributing source. Nearly half of these children received no outpatient testing in the newborn period after not passing newborn hearing screening.

**Figure 5**

*Follow-up Outcomes for Children Late-Identified as Deaf or Hard of Hearing due to Providers*

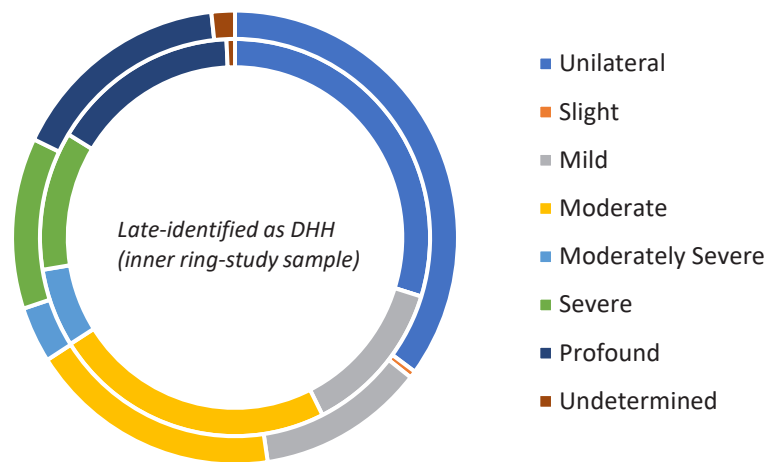


*Note.* The graph displays outpatient follow-up outcomes for children who were late-identified as DHH due to the provider as a contributing source. The most common problems attributed to providers were performing excessive rescreens before scheduling a diagnostic evaluation and failing to schedule a diagnostic evaluation in a timely fashion (excessive scheduling gap between appointments). PCP = primary care provider; EHDI = Early Hearing Detection and Intervention.

**Figure 6**

*Hearing Levels of Children Late-Identified as DHH vs. Remainder of DHH*

*Remainder of children identified as DHH  
(outer ring-excluded from study)*



*Note.* The graph shows the proportion of children late-identified as deaf or hard of hearing (DHH) with each hearing level (inner ring,  $n = 141$ ), as compared to children identified as DHH who were excluded from the report (outer ring,  $n = 630$ ). All hearing levels listed are bilateral hearing losses. The unilateral groups include unilateral hearing losses at all levels. The distribution of hearing levels was not substantially different between groups.

were unilateral hearing losses (greater proportion observed in the whole DHH group) and bilateral moderate hearing levels (greater proportion observed in the late-identified group). Percentages of other hearing levels were similar between groups.

### Discussion

Of children born in Louisiana from 2015 to 2020 and identified as DHH, 41% received their initial diagnosis after six months of age (315/771). Of these 315 children identified after 6 months of age, 141 were included in our analysis because they did not pass newborn hearing screening and did not appear to have any medical barriers to obtaining a timely diagnosis. Factors attributed to families were observed more than any other source among children with late diagnoses, accounting for 46% of late diagnoses as the sole reason for late identification, and an additional 20% of cases as a contributing source. Thus, families were a contributing factor in a full 2/3 of cases in which children were late-identified. When evaluating late-identified children with only a family component, the most common scenario identified was no outpatient follow-up testing after not passing NHS (49%, Figure 4). In an additional 29% of cases with a family component to late identification, the child received one or more outpatient screenings in the first few months after hospital discharge, but the family did not follow through with a diagnostic evaluation. The remaining children with family components received a diagnostic evaluation by three months of age and were identified with hearing loss not deemed permanent (transient conductive or type undetermined). The families did not complete recommended follow-up to receive a timely final diagnosis. It is particularly concerning that half of the cases with a family component to the late diagnosis received outpatient testing indicating a hearing

loss was present, or was likely present, even if this hearing loss was transient. In some of these cases, providers further contributed to the delayed diagnosis by not scheduling or recommending appropriate follow-up testing to rule out a permanent hearing loss.

There were a variety of ways outpatient providers were found to contribute to a late diagnosis (Figure 5). Providers were the sole source of late identification in 25% of cases, and were a contributing source in an additional 18% of cases. The most common provider issue was performing excessive rescreens before referring for a diagnostic evaluation, which was seen in a third of late identifications with a provider component. Per Joint Committee on Infant Hearing (JCIH) recommendations, no more than one outpatient rescreen following a referred initial hearing screening should be performed before sending an infant for a full diagnostic audiological evaluation (JCIH, 2019). When evaluating our birth cohorts, we found that the number of children who received excessive outpatient rescreens peaked in 2016, and has been declining since. Our program works to educate providers on the JCIH guidelines and to lend support in remediation. This has resulted in a reduction of children undergoing excessive rescreens since 2017, which is in large part responsible for the reduced contributions of providers to late identifications (Figure 3).

Another substantial issue discovered with providers was an excessive scheduling gap between visits, which was seen in a total of 30% of cases found to have a provider component. In the majority of these cases (18), the gap was seen between the rescreen and diagnostic evaluation appointments, but a smaller portion (four) exhibited gaps between two diagnostic appointments when the first evaluation did not yield a conclusive result. Time is of the essence in EHD systems, so follow-up appointments

should be made as soon as possible if a firm diagnosis has not been obtained. If an immediate appointment is not available, the facility should provide a referral to another facility who can accommodate the family. We defined a scheduling gap as excessive if the facility scheduled the family's next appointment at greater than one month away from the previous appointment. However, in nearly all of these cases, the next appointment was far beyond this, with three to six months being common. Again, this issue was seen more frequently in birth cohorts prior to 2017, with one facility being responsible for most of the scheduling gaps. Remediation discussions with this facility successfully addressed this issue moving forward.

We found reporting errors by providers to account for a smaller, but significant, number (12; 16%) of provider component cases, including a lack of reporting into the EHDI-IS system and the reporting of incorrect results. We believe the numbers found in this study to be an underestimation, as we could only attribute a reporting error if documentation was available in our system to support that an error was made. In most of these cases, an outpatient follow-up report was not submitted to the EHDI program. Though this action may not be directly responsible for a late diagnosis, we consider it a contributing factor because our program contacts families and primary care providers to alert them of the need for further testing, and assist when they have challenges to obtaining an appointment. These actions may have resulted in timelier diagnoses for some of these cases. In addition, in four cases (5%), a diagnostic report was obtained indicating a diagnosis of hearing loss, yet the provider reported the child passed in the EHDI-IS system, which prevented our program from providing any further assistance. An additional 10 cases (14%) of provider late identifications were due to the primary care provider (PCP) failing or refusing to order a diagnostic evaluation, a problem that our program has virtually eliminated in recent years by communicating directly with the PCP office. We also found five children whose Part C early intervention family support coordinators were alerted by our program of the need to complete hearing follow-up testing, to no avail. Three of the children aged out of Part C before they were identified as DHH.

Issues arising from the hospitals who perform inpatient screenings represented a smaller portion of errors. Hospitals accounted for five percent of late-identified cases, and were contributing factors in an additional 11% of cases. Of the 23 cases with a hospital component to the late identification, 52% did not schedule a follow-up appointment for the family prior to hospital discharge, and 48% reported an incorrect NHS result (reported *pass* instead of *did not pass/further testing needed*; data not shown). Similar to provider issues, the bulk of hospital errors were found in the earlier birth cohorts, with only three errors found in birth cohorts 2018 to 2020 combined. This suggests that accurate entry of NHS results has improved at the hospital level, although it is more likely due to increased surveillance by our program. Louisiana EHDI has reviewed records of recent birth cohorts with greater vigilance, and we work with hospitals to make corrections when probable errors

are found. This work has improved the accuracy of NHS data at the hospital level. We have also seen a greater number of outpatient appointments scheduled for families prior to hospital discharge, which has been demonstrated to improve compliance with follow-up (Tran et al., 2017).

Of the children who were late-identified, 36% were identified between six to 12 months of age, and 35% were identified between one to two years of age (Figure 2). A total of 15% of our study cohort were identified after turning three years of age, at which time they were no longer eligible for Part C early intervention services. We believe these numbers to be an underrepresentation, as reporting to EHDI programs tends to decline as children get older. This decline is exacerbated for children three years of age and older, who may see an audiologist who does not specialize in pediatrics, and therefore is not accustomed to reporting to their state EHDI program.

We reviewed the laterality and hearing levels to determine if there were differences in hearing levels between children who were late-identified as DHH, relative to the remainder of children identified as DHH (Figure 6). Since the latter group was composed largely of children identified by six months of age, we hypothesized that the group of late-identified children may consist more heavily of unilateral hearing losses and mild hearing levels, which may have caused less concern to parents and providers. However, the proportion of children with each hearing level was nearly identical between groups, and the only exceptions to this went in the opposite direction expected. Children with bilateral moderate hearing levels were more heavily represented in the late-identified group, while children with unilateral hearing loss were more common in the remainder of children, though the difference was only about five percent for each. All other hearing levels were nearly identical between groups.

### Strengths and Limitations

The strengths of this study lie in the detailed analysis of late identification of congenital hearing loss. This analysis was possible due to the LA EHDI-IS, a robust statewide database with widespread adoption by providers. The profiles of many children in this study contained detailed records, including test reports, comments by providers, and actions by EHDI staff members. Date stamps for each entry allowed for historical tracking of actions taken. To our knowledge, there are no population-based studies in the United States investigating the diagnostic process from screening to identification for late diagnoses for children who are DHH. However, as approximately 30% of children who do not pass newborn hearing screening do not complete a diagnostic evaluation (CDC, 2022d), understanding the reasons testing is not completed can aid in targeting areas for improvement.

An additional strength of this study was that, for many children, the analysis enabled differentiation of late-onset hearing loss from congenital hearing loss that was late-identified. Of the 315 children identified after six months of age, 90 were reported as passing their newborn hearing screenings (28.6%) and 29 passed outpatient follow-up

testing (9.2%). The remaining 196 (62.2%) did not pass their newborn hearing screenings, and are therefore presumed to have congenital hearing loss. If all 119 children who passed their newborn hearing screenings or outpatient follow-up testing are presumed to have late-onset childhood hearing loss, the total percentage of DHH children from this birth cohort with late-onset hearing loss is 15.4% (119/771). However, records of many of these children included diagnoses of mild hearing loss, frequency-specific hearing loss, and auditory neuropathy spectrum disorder after a newborn screening via otoacoustic emissions. These hearing losses are all frequently missed by newborn hearing screening, suggesting the incidence of true late-onset childhood hearing loss in our cohort is relatively low, although we acknowledge that these cases may be underreported or underidentified.

There are several limitations of this study. First, we were limited to the information that was available in the child's initial and follow-up hearing screening records reported to the LA EHDI database. This means that relevant information was likely missing in some of our cases. This may be particularly pertinent to the birth hospitals, as we have no way of ascertaining what materials were provided to parents at the time of the screening in the hospital. Previous studies indicate that many parents do not follow up after NHS because the results were downplayed or were not clearly communicated to them (Elpers et al., 2016; Reynolds et al., 2023; Robinson et al., 2023). It is possible that poor communication from hospitals to parents contributed to some of the late identifications that were attributed to families. Although there were no parents of late-identified children who relayed this to us, we cannot rule this out as a factor. Second, reporting of children newly identified as DHH to EHDI programs is less consistent for older children than for children under three years of age. Though our program has worked hard to improve reporting, there may be children identified as DHH that are not known to us. Finally, data for the younger birth cohorts may be incomplete. At the time of data collection, the 2020 birth cohort was still relatively young, so there may be children who are DHH that were yet to be identified. The apparent improvement in provider and hospital errors over time may prove to be misleading as more children are identified as DHH, and previously unseen errors are revealed. It should be noted that this study defined a late diagnosis as being obtained after six months of age. This timeline was chosen because an identification by six months of age would still allow for enrollment into early intervention services by six months of age, per the JCIH goal (JCIH, 2019). However, if we had chosen the JCIH diagnostic goal of three months of age, 58% of our cohort of 771 children would be considered late-identified. If we additionally excluded the 119 children presumed to have late-onset hearing loss, 51% would be considered late-identified, which is only a slight improvement.

### Conclusion

We reviewed records of 141 children born in Louisiana from 2015 to 2020 who were identified as DHH after

six months of age, despite not passing their NHS. Our evaluation of reasons for each late diagnosis revealed that families not following up after NHS were a factor in 2/3 of cases, being the sole factor in nearly half of cases. Outpatient providers were responsible for another 1/4 of cases, with hospital errors accounting for a smaller proportion of cases. Our year-by-year analysis indicated that the percentage of cases late-identified due to families has been increasing over time, while the percentage due to hospitals and providers has been decreasing. This is likely due, in large part, to improvement strategies deployed by Louisiana EHDI to correct errors and mismanagement of cases by hospitals and outpatient providers. Change strategies targeting families have also been put into place, but the impact of these strategies has been smaller. Follow-up outcomes for children not passing NHS have steadily improved, but much progress is still needed. Future efforts must be geared toward connecting with families and communicating information clearly and effectively. This will be key to improving timely diagnosis and early intervention rates for children who are DHH.

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## EHDInfo



# World Health Organization



## World Hearing Day

3 March is World Hearing Day. For more information, [click here](#).

World Hearing Day is held on 3 March each year to raise awareness on how to prevent deafness and hearing loss and promote ear and hearing care across the world. Each year, WHO decides the theme and develops evidence-based advocacy materials such as brochures, flyers, posters, banners, infographics and presentations, among others. These materials are shared with partners in government and civil society around the world as well as WHO regional and country offices. At its headquarters in Geneva, WHO organizes an annual World Hearing Day event. In recent years, an increasing number of Member States and other partner agencies have joined World Hearing Day by hosting a range of activities and events in their countries. WHO invites all stakeholders to join this global initiative.