Effects of Policy Changes to Universal Newborn Hearing Screening Follow-Up in a University Clinic

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Purpose: The purpose of this study was to evaluate the effects of policy changes on loss to follow-up rates and the ability to achieve the goals of the American Academy of Pediatrics Joint Committee on Infant Hearing Screening (2007) for diagnosis of hearing loss by 3 months, amplification within 1 month of diagnosis, and start of intervention by 6 months.

Method: From the files of 111 infants, data were extracted on the following: date of birth, birth hospital, hometown, parents' ages, ethnicity, nursery status, medical history, age at initial evaluation and diagnosis, results of evaluation(s), and age at hearing aid fitting and start of early intervention. Data were compared with previously published data from the clinic (Krishnan, 2009).

Results: Policy changes led to a decrease in loss to follow-up and a younger age at diagnosis of hearing loss. Infants identified with hearing loss were fit with amplification at younger ages but not within 1 month of diagnosis of hearing loss. Policy changes had positive outcomes on loss to follow-up and age of diagnosis and amplification. Conclusions: Challenges remain in meeting the goals of amplification within 1 month of diagnosis and documenting the start of early intervention. Improved communication between and education of all parties involved in the care of infants is needed.

Key Words: newborn hearing screening, Joint Committee on Infant Hearing goals, hearing loss

The past two decades have been a period of great growth in newborn hearing screening programs in the United States. The National Institutes of Health’s Consensus Development Conference on Early Identification of Hearing Loss first endorsed universal newborn hearing screening (UNHS) in 1993, and the American Academy of Pediatrics (AAP) Joint Committee on Infant Hearing (JCIH) followed in 1994. During these years, evidence also emerged regarding the prevalence of hearing loss, suggesting that it is one of the most common birth defects, with up to 6 out of 1,000 live births having hearing loss (Parving, 1993; Watkin, Baldwin, & McEnery, 1991; White & Behrens, 1993). It has also become clear that early diagnosis and intervention lead to improved language, academic, and social–emotional development for children with hearing loss (Calderon & Naidu, 1999; Moeller, 2000; Nelson, Bougatsos, & Nygren, 2008; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998).

Since 1994, the JCIH has released three position statements on UNHS implementation and follow-up, including the “1-3-6” Early Hearing Detection and Intervention (EJDI) goal, which states that infants should have access to hearing screening no later than 1 month of age, confirmation of hearing loss (if referred by the hearing screening) by 3 months of age, and early intervention by 6 months of age. Also included within this goal is the fitting of amplification if desired by the family within 1 month of confirmation of hearing loss (JCIH, 2007). The JCIH (2007) has also set the following benchmarks:

1. 95% of all infants should receive a hearing screening before 1 month of age;
2. 90% of infants who do not pass their second screening should receive audiologic and medical evaluations to confirm the presence of hearing loss by 3 months of age;
3. 95% of infants identified with permanent hearing loss should be fit with amplification (if desired by the family) within 1 month of diagnosis; and
4. 90% of infants identified with permanent hearing loss should be enrolled in early intervention services by 6 months of age.

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In addition to these JCIH goals and benchmarks, the Centers for Disease Control and Prevention (CDC) have identified responsibilities for EHDI systems. These include promoting the detection of hearing loss early in life, tracking infants and children who are identified with hearing loss, and providing and monitoring effective intervention systems (EHDI National Goals, 2013). In order to minimize loss to follow-up of infants identified with hearing loss, the CDC reiterates the “1-3-6 goals” previously described and recommends that families receive support with the early diagnosis and intervention process.

Although national guidelines and benchmarks exist for the provision of UNHS for the purposes of early diagnosis and treatment of hearing loss in infants, there is no uniform national policy. Currently, each state implements its own EHDI system, which means that not every state has legislation requiring UNHS, although all states do implement some method of screening infants for hearing loss (Krishnan, Messer, & Novak, 2013; National Center for Hearing Assessment and Management, http://www. infanthearing.org).

Screening programs across the United States are meeting the benchmark for newborn hearing screening: More than 97% of newborns had their hearing screened in 2011 (CDC, 2011). Despite the lack of a national policy, there has been a notable increase in the number of infants screened from 1999 (46.5%) to 2011 (97.9%).

However, in 2011, of the 1.8% of infants nationwide who did not pass the hearing screening, only 56.9% received their diagnosis (of either normal hearing or hearing impairment) by 3 months of age (CDC, 2011). This falls well short of the 90% benchmark set by the JCIH (2007). Of the remaining 43.1% of infants, 35.3% were considered lost to follow-up or documentation (CDC, 2011).

Factors contributing to the low rates of timely diagnosis as well as loss to follow-up and documentation rates include parental noncompliance in scheduling, middle ear fluid, infants having other medical conditions, and distance from the testing facility (Munoz, Nelson, Goldgewicht, & Odell, 2011); information gaps between hospitals, parents, physicians, and audiologists as well as a limited number of audiologic testing facilities (Shulman et al., 2010); and co-occurring birth defects, which are present in nearly one third of infants identified with hearing loss (Chapman et al., 2011). Significant variability in wait times for scheduling the diagnostic testing across facilities has been identified as an additional challenge, as longer wait times impact the ability to obtain accurate test results during natural sleep (Munoz et al., 2011).

Data regarding the JCIH benchmark of fitting amplification (if desired by the family) within 1 month of diagnosis is scarce. Krishnan (2009) reported on a small sample size of five infants who were all identified with hearing loss by 3 months of age, yet did not receive their hearing aids until 9–14 months. The CDC (2011) did not report data on this benchmark.

In regards to starting early intervention services by the age of 6 months, the CDC (2011) report indicated that 86.2% of infants diagnosed with hearing loss were referred for early intervention services, but only 62.9% were enrolled in early intervention. Of these infants, 67.6% started early intervention before the age of 6 months. Thirty-five percent of infants with documented hearing loss received no early intervention services, with 26% considered lost to follow-up or documentation.

Following implementation of UNHS, more children with mild and moderate hearing loss are being identified and provided with amplification (Halpin, Smith, Widen, & Chertoff, 2010). However, children diagnosed with unilateral or mild hearing loss appear to be at the greatest risk of not receiving early intervention services (Liu, Farrell, MacNeil, Stone, & Barfield, 2008; Spivak, Sokol, Auerbach, & Gershkovich, 2009).

Despite these nationwide statistics, considerable variability exists across these data from different states. In Massachusetts, an 11% loss to follow-up and documentation rate was reported following a failed hearing screening. Clear communication and documentation were reported as strengths in the state, and infants at the highest risk for loss to follow-up and documentation were those whose mothers were non-White, covered by public insurance, smoked during pregnancy, or resided outside the Boston region (Liu et al., 2008). Higher levels of maternal education were associated with earlier confirmation of hearing loss and subsequent fitting of hearing aids (Holte et al., 2012). These studies seem to suggest that clear communication and documentation may be even more important to reduce loss to follow-up in rural communities with fewer resources and for families with public insurance and low maternal education.

Additional suggestions to reduce the rates of loss to follow-up and documentation in order to successfully meet national benchmarks include improving documentation and accuracy and detail in recording demographic data (Gaffney, Green, & Gaffney, 2010; Russ, Hanna, DesGeorges, & Forsman, 2010); involving the primary care provider prior to hospital discharge and using a consistent and specific “scripted” message when communicating with families about the initial screening results (Russ et al., 2010); using more culturally and linguistically appropriate communications (Deem, Diaz-Ordaz, & Shiner, 2012; Russ et al., 2010); and involving audiologists in working with EHDI programs to document services accurately (Mason, Gaffney, Green, & Grosse, 2008).

In a small-scale study at the Purdue University Audiology Clinic, Krishnan (2009) reported that 17% of infants evaluated were older than 3 months at the initial assessment and that 18% of infants who needed further evaluation were lost to follow-up. None of the five infants identified with hearing loss received amplification within 1 month of diagnosis or early intervention services by the age of 6 months.

Beginning in October 2010, the early intervention system in Indiana underwent significant changes brought on by financial restructuring and funding cuts to the Indiana Early Intervention (First Steps) program. In addition,
the Purdue University Audiology Clinic made internal policy changes in an attempt to reduce loss to follow-up rates subsequent to the Krishnan (2009) findings. Figure 1 is a flow chart of the referral and scheduling policies and procedures prior to October 2010 and the new policies implemented after that date. Prior to October 2010, the referral process for diagnostic audiologic assessment in Indiana included three steps: hospital referral to First Steps, First Steps referral to the clinic, and clinic call to the family to schedule the appointment for the assessment. This process included the First Steps intake process, which allowed the First Steps intake coordinator 2 business days from the date of referral to contact the family and set up a meeting to provide the family with information regarding available testing facilities (Central Indiana First Steps Early Intervention Program, http://www.cibaby.com/2011%20web%20updates/referral.htm). Beginning in October 2010, this process was streamlined to a single step, with hospitals making direct contact with audiology clinics to arrange the follow-up hearing testing appointment prior to the infant’s discharge. In addition, the pediatrician’s signature is on the hospital referral, and therefore physician involvement is a part of the process from the beginning. Although the onus to keep the appointment is still on the family, the Indiana EHDI program follows up every hospital referral via phone calls and letters to remind the family of the importance of keeping the diagnostic appointment (Indiana State Department of Health, Early Hearing Detection and Intervention Program, 2010).

The Purdue University Audiology Clinic policy for rescheduling infants who needed additional assessment was also streamlined in 2010, with all infants needing additional assessment being scheduled for a return appointment before leaving the clinic, thereby shifting the responsibility for scheduling to the clinic rather than the family.

The primary aims of this study were to determine how these policy and procedure changes impacted the ability to meet the 1-3-6 goals recommended by the JCIH and whether they had an effect on the loss to follow-up rates at the clinic.

**Figure 1.** Flow chart showing the steps involved in the referral of infants who failed their hospital screening and scheduling procedures for infants for the initial and subsequent assessments prior to October 2010 and after the policy and procedure changes in October 2010. EHDI = Early Hearing Detection and Intervention; FS = First Steps; CHL = conductive hearing loss; SNHL = sensorineural hearing loss.
Method
This retrospective study examined data gathered from patient files of all infants evaluated at the Purdue University Audiology Clinic between January 2012 and March 2013. However, this sample did not include all referrals from the hospitals because parents are given a choice of follow-up diagnostic centers in the area. A total of 111 patient files were examined, and the data collected from each file included the following:

- demographic information, including the date of birth, birth hospital, area of residence, and family and physician information;
- medical history, including nursery placement (well baby or neonatal intensive care unit), medical diagnoses, and family history;
- timeline information, including time lapse between date of birth and date referral received at clinic, between date of referral and date of appointment for initial evaluation, and age at initial evaluation;
- outcomes of the assessments, including the results of the initial evaluation and any subsequent evaluations; and
- intervention information, including age at hearing aid fitting and referral to and start of early intervention when available.

Results
Demographic Information and Medical History
Data are reported from all infants evaluated at the Purdue University Audiology Clinic during the period from January 2011 to March 2012. Table 1 shows demographic information, including the birth hospital, area of residence, and family and physician information for the current subject sample, as well as the subject sample from Krishnan (2009) for comparison. Overall, the subject groups across the two studies were relatively similar. In both subject samples, about two thirds of the infants were born at one of the two local hospitals (St. Elizabeth or Home Hospital). Seventeen percent (19 infants) in the current sample were born at the other local hospital (IU Arnett Hospital), which opened after the 2009 study. The remaining 17% (19 infants; 30%, or 42 infants, in 2009) were born at other hospitals in surrounding communities or at home. Forty-four percent (49 infants; 58%, or 80 infants, in 2009) were from an urbanized area with population greater than 50,000, primarily from Lafayette, IN. Thirty-five percent (39 infants; 22%, or 31 infants, in 2009) were from urban clusters with population ranging from 2,500 to 50,000, and 21% (23 infants; 20%, or 28 infants, in 2009) were from rural areas with population less than 2,500.

Hispanic families made up 12% of the population in both studies. Of the non-Hispanic families, two infants were adopted (one infant in 2009) and one was in foster care (four infants in 2009). Although the Purdue University Audiology Clinic does not file health insurance, the infants were classified based on whether they had a private physician or went to the local community clinic that serves families who are uninsured or underinsured. The majority of infants had private physicians, including 77% (75 infants; 87% in 2009) of non-Hispanic families and 62% (8 infants; 53% in 2009) of Hispanic families. A slightly larger percentage of Hispanic infants (38%) compared with 25% of non-Hispanic infants (41% of Hispanic families compared with 11% of non-Hispanic families in 2009) received their primary care at the community clinic.

In both studies, approximately three fourths of the infants had no significant medical history. Of the remaining infants, 13% (6% in 2009) had a family history of childhood hearing loss, 7% (none in 2009) had a history of maternal herpès, and 6% (11% in 2009) were graduates from the Neonatal Intensive Care Unit (NICU). One infant had a cleft soft palate (four infants in 2009), one infant had a diagnosis of Pierre Robin Sequence (six infants had syndromes in 2009), and five infants were premature (10 in 2009). The 2009 sample also included two infants who had meningitis. Percentages may add up to more than 100% because some infants were included in more than one category of medical history.

Diagnosis by Age 3 Months
Hospital screening and referral. Two thirds of the infants failed the hospital screening in either the right ear or the left ear (33% for each ear), compared with 42% who failed in the left ear and 20% who failed in the right ear in 2009. Twenty-eight percent (27% in 2009) failed the screening in both ears. The remaining 5% (6% in 2009) passed the screening in both ears but were referred because of a risk factor for hearing loss (two infants with a history of...
maternal herpes, three infants with a family history of hearing loss, and one infant by physician request).

About half of the infants (54) referred for diagnostic assessment received their hospital screening at age 2 days. Of the remaining infants, 27 (24%) were screened at age 1 day, five infants were screened at age 3 days, and two infants were screened the day they were born. The mean age at hospital screening was 1.7 days, excluding NICU graduates. The date of screening was not available for 16% (18) of infants, two of whom were NICU graduates. Five infants who were in the NICU were screened at 7, 48, 49, 70, and 81 days. Although the exact date of discharge from the hospital is not known, per parental report regarding the length of the NICU stay (7–79 days), these five infants were all screened close to their discharge date.

With the new referral procedure directly from the hospital to the clinic, most referrals were obtained via fax from the birth hospital. Over three fourths (78%) of the faxed referrals were received 0–3 days after the infant received the hospital screening, with the majority (53%) being received the same day that the infant received the hospital screening. Of the remaining referrals, four infants were referred 4–7 days after the screening, three were referred 10–12 days after the screening, and four were referred 15–19 days after the screening; there were 14 infants for whom we did not receive paperwork regarding the exact screening date. The mean time lapse from hospital screening to the referral being received at the clinic was 1.68 days.

Age at initial assessment. The age range of the infant at the initial diagnostic assessment ranged from less than 1 week to 16 weeks, with the majority of infants (80%) evaluated at the age of 4 or 5 weeks, and a mean age at initial assessment of 5.1 weeks. Of the five infants who were more than 10 weeks old at the initial assessment, four were NICU graduates and one had hernia surgery after discharge from the hospital, delaying the appointment for the assessment. Overall, more than 90% of the infants had their initial assessment well before the age of 3 months, meeting the benchmark set by the JCIH.

Comparison of age at initial assessment: Current and previous (2009) data. Figure 2 shows a comparison of the age of the infant at the initial diagnostic assessment in the current study and previous data from this clinic (Krishnan, 2009). This figure demonstrates an improvement in the age at initial assessment, with the majority of infants currently being assessed at the age of 4–5 weeks. The mean age at initial assessment decreased from 7.9 weeks in 2009 to 5.1 weeks in the current study. Excluding the four infants who had extended stays in the NICU, the age at the initial assessment was further decreased to a mean of 4.78 weeks.

Results of initial assessment. The results of the initial assessment revealed that of the 111 infants evaluated, 84 (76%) had normal hearing in both ears. Of the remaining infants, five (5%) were identified with sensorineural hearing loss. There were 14 infants (13%) who likely had conductive hearing loss, seven infants (6%) who had normal hearing via auditory brain response (ABR) thresholds but with a conductive component as measured by flat tympanograms, and one infant who had inconclusive results. Thus, there were a total of 22 infants who needed further assessment and follow-up to determine the nature of the hearing loss pending medical consultation regarding the conductive component.

Follow-up assessment outcomes. The 22 infants who needed additional assessment were scheduled for follow-up appointments until such time as a normal tympanogram was obtained in each ear and an accurate estimation of hearing sensitivity was obtained. The number of follow-up appointments kept by these infants ranged from zero to four appointments. Five infants did not return for any follow-up, while three more infants kept one to two appointments but did not return for a diagnosis to be confirmed.

The follow-up assessment outcomes of these 22 infants were as follows: half of the infants (11) had normal hearing at a subsequent appointment for reassessment. Two infants went to another facility for follow-up, and no further documentation of the outcomes was received. One infant was found to have sensorineural hearing loss and was fit with hearing aids. Eight infants of the total of 111 evaluated (7%) were lost to follow-up.

Comparison of loss to follow-up: Current and previous (2009) data. Figure 3 shows a comparison of the outcomes of infants who needed additional assessment in the current study and in the Krishnan (2009) study. A similar number of infants had normal hearing, went to another facility, or were identified with hearing loss and fit with hearing aids. However, the number of infants who were lost to follow-up was reduced substantially from 18% (25 of 139 infants in 2009) to 7% (8 of 111 infants) in the current study.

Amplification Within 1 Month of Diagnosis

Amplification. A total of six of the 111 infants (5.4%) were identified with sensorineural hearing loss compared with five of 139 (3.6%) in 2009. Table 2 shows the outcomes for these six infants. None of the infants had a severe–profound hearing loss, with all six infants having hearing thresholds ranging from slight to moderate hearing loss. These outcomes differ from the 2009 sample, which included initial ABR thresholds indicating that there were three infants with bilateral moderate hearing loss, one with bilateral profound hearing loss, and one with auditory neuropathy. Although it has been noted that current hearing screening protocols are likely to miss unilateral and mild bilateral hearing losses (Ross et al., 2008), three of the six infants identified with hearing loss (Infants 1, 3, and 4) fell in this category. Infant 1 had a mild–moderate unilateral hearing loss and despite recommendation for a hearing aid fitting was counseled by the otolaryngologist that he did not need a hearing aid because he had normal hearing in one ear. He continues to return for regular reassessments to monitor his hearing. Infants 3 and 4 had slight high-frequency hearing loss, and hearing aids were not recommended. Regular follow-up to monitor hearing continues to be recommended. Infant 2 was lost to follow-up.
despite multiple attempts to contact the family to continue services. Infants 5 and 6 were fit with hearing aids; however, neither received hearing aids within 1 month of diagnosis. Both of these infants had their diagnosis confirmed by the age of 9 weeks. However, medical clearance for amplification was not received until the age of 4 and 6 months, respectively. Both infants did receive their hearing aids within 1 month of receiving medical clearance for amplification at the age of 5 and 7 months, respectively.

Comparison of age at identification, confirmation, and amplification: Current and previous (2009) data. Six infants were identified with sensorineural hearing loss in the current study compared with five infants in the previous study (Krishnan, 2009). A total of five infants were fit with hearing aids across the two studies: two infants in the current study and three infants in the previous study. However, despite the small sample size and the milder hearing losses identified in the current sample, the comparison in Table 3 shows that the mean age at identification decreased from 7 weeks to 4.8 weeks (excluding Infant 2 in the current study, who was identified at age 15 weeks because he was in the NICU for 79 days). The mean age at confirmation of the hearing loss also decreased from 18.7 weeks in the previous study to 7 weeks in the current study. Finally, the age at hearing aid fitting was 5 and 7 months in the current study, compared with 9, 10, and 14 months in the previous study.

Intervention by the Age of 6 Months

Complete data are not available regarding the start date of early intervention services or the type of services each infant received, as this information is not always received by the clinic. Table 2 shows the limited data that are available. Four of the six infants (Infants 1, 3, 4, and 6) were referred to the Indiana Early Intervention Program (First Steps) within 1 week of the diagnosis of hearing loss. Infant 5 was enrolled in First Steps at birth because of a seizure disorder and services for hearing loss were requested upon diagnosis. Infant 2, who was lost to follow-up, did
have an individualized family service plan (IFSP) written at the age of 7 months, but it is not known whether this was for other developmental delays or subsequent to a diagnosis of hearing loss. Data regarding early intervention also were limited in the previous study (Krishnan, 2009). The date of referral to First Steps was not known, but three of the five infants with hearing loss did start receiving services at 13–15 months of age.

Table 4 shows a comparison of the information regarding early intervention services for the infants identified with hearing loss in the current study and the previous study (Krishnan, 2009). Although limited data were available, two observations can be made. The first observation is that the age at which early intervention services were started has decreased from 13–15 months in 2009 to 3–7 months in the current study. The second is that additional details are available for some infants in the current data set regarding when referrals were made and date of the IFSP.

### Discussion

The primary aims of this study were to determine whether policy and procedure changes in the state of Indiana and at the Purdue University Audiology Clinic impacted the ability to meet the goals and benchmarks recommended by the JCIH and whether they had an effect on the loss to follow-up rates at the clinic. A direct comparison was made between findings of the current study and a previous study (Krishnan, 2009) to evaluate changes to outcomes as a result of the policy and procedure changes.

### Table 2. Initial assessment results, age at diagnosis, hearing aid fitting, start of early intervention services, and current status for the infants identified with hearing loss.

<table>
<thead>
<tr>
<th>Infant</th>
<th>Initial results</th>
<th>Identified</th>
<th>Confirmed</th>
<th>HA fitting</th>
<th>Update</th>
<th>EI services</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>RE: normal LE: mild-moderate SNHL</td>
<td>4 weeks</td>
<td>6 weeks</td>
<td>None</td>
<td>ENT counseled that HA not necessary for unilateral loss. At 18 months, continuing to test hearing every 6 months and monitor language development</td>
<td>Referral made at age 7 weeks; enrolled at age 6 months</td>
</tr>
<tr>
<td>2</td>
<td>Likely bilateral mild-moderate SNHL</td>
<td>15 weeks</td>
<td>Not confirmed</td>
<td>None</td>
<td>One follow-up at age 1 year, after multiple contacts to family and state EHDI program. Then lost to follow-up</td>
<td>IFSP at age 7 months</td>
</tr>
<tr>
<td>3</td>
<td>Likely bilateral mild SNHL</td>
<td>5 weeks</td>
<td>6 weeks</td>
<td>None</td>
<td>Four VRA appointments; hearing near normal post-tubes</td>
<td>Referral made at age 7 weeks; no further update</td>
</tr>
<tr>
<td>4</td>
<td>Likely bilateral mild SNHL</td>
<td>4 weeks</td>
<td>5 weeks</td>
<td>None</td>
<td>Second ABR: slight HF SNHL; VRA: near normal; hearing monitored every 3 months</td>
<td>Referral made at age 6 months; enrolled at age 3 months</td>
</tr>
<tr>
<td>5</td>
<td>RE: inconclusive LE: likely moderate SNHL</td>
<td>5 weeks</td>
<td>9 weeks</td>
<td>5 months</td>
<td>Medical clearance received at age 4 months</td>
<td>Enrolled at birth for seizure disorder; speech monitoring added upon confirmation of HL</td>
</tr>
<tr>
<td>6</td>
<td>Likely bilateral mild conductive HL</td>
<td>6 weeks</td>
<td>9 weeks (SNHL)</td>
<td>7 months</td>
<td>ENT recommended sedated ABR and tubes; medical clearance received at age 6 months</td>
<td>Referral made at age 9 weeks; enrolled: age unknown</td>
</tr>
</tbody>
</table>

Note. EI = early intervention; RE = right ear; LE = left ear; SNHL = sensorineural hearing loss; ENT = ear, nose, and throat physician; HA = hearing aid; EHDI = Early Hearing Detection and Intervention; IFSP = individualized family service plan; HF = high frequency; VRA = Visual Reinforcement Audiometry; ABR = auditory brainstem response testing; HL = hearing loss.

### Table 3. Comparison of age at identification of hearing loss, confirmation of hearing loss, and hearing aid fitting in the current study to previously published data from this clinic.

<table>
<thead>
<tr>
<th>Infant</th>
<th>Identified</th>
<th>Confirmed</th>
<th>HA fitting</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Previous</td>
<td>Current</td>
<td>Previous</td>
</tr>
<tr>
<td>1</td>
<td>8 weeks</td>
<td>4 weeks</td>
<td>12 weeks</td>
</tr>
<tr>
<td>2</td>
<td>7 weeks</td>
<td>15 weeks</td>
<td>8 weeks</td>
</tr>
<tr>
<td>3</td>
<td>9 weeks</td>
<td>5 weeks</td>
<td>Unknown</td>
</tr>
<tr>
<td>4</td>
<td>5 weeks</td>
<td>4 weeks</td>
<td>9 months</td>
</tr>
<tr>
<td>5</td>
<td>6 weeks</td>
<td>5 weeks</td>
<td>Unknown</td>
</tr>
<tr>
<td>6</td>
<td>—</td>
<td>6 weeks</td>
<td>—</td>
</tr>
<tr>
<td>M</td>
<td>7 weeks</td>
<td>4.8 weeks</td>
<td>18.7 weeks</td>
</tr>
</tbody>
</table>

Note. Previous data are from Krishnan (2009).

*Neonatal Intensive Care Unit (NICU) graduate.*
Although screening programs nationwide and in Indiana are meeting the benchmark for newborn hearing screening, with more than 97% of newborns receiving a hearing screening in 2011 (CDC, 2011), the statistics for follow-up of infants who need additional assessment remain below the JCIH (2007) benchmarks.

**Diagnosis by Age 3 Months**

The JCIH (2007) benchmark for diagnosis states that 90% of infants who need additional assessment following a failed hearing screening should receive a diagnostic evaluation to confirm the hearing loss by 3 months of age. Although more than 90% of infants in this study had their diagnostic assessment well before the age of 3 months, a closer look at whether infants received a diagnosis (whether of normal hearing or hearing loss) by the age of 3 months (Figure 2) reveals that 87% of the population in this study met this criterion. The remaining 13% did not meet the criterion because they needed additional assessment due to a conductive component. Overall, these data are better than state and nationwide statistics, which indicate that 74.1% of infants diagnosed in Indiana received their diagnosis by the age of 3 months (CDC, 2011). Nationwide, 70.8% of the 56.9% of infants who received a diagnosis did so by 3 months of age (CDC, 2011). Caution must be used in generalizing the data from this study because of the small sample size and possibly the demographics of the sample. Although income information was not available, it is known that about one quarter of the infants received their primary care at the local community clinic for uninsured or underinsured families. More than half the sample (56%) did not live in an urbanized area (21% in rural and 35% in urban clusters); this is in comparison to data from the United States Census Bureau (2013) that shows that 19% of the population lives in rural areas and 9.5% in urban clusters.

An important factor in the goal of diagnosis by the age of 3 months is the age at which the referral is made for the diagnostic assessment, which in turn affects the age of the infant at the initial assessment. In this study, referrals from the hospital were received between 0 and 19 days from the date of hospital screening \( (M = 1.68 \text{ days}) \) and the age of the infants at the initial assessment ranged from less than 1 week to 16 weeks \( (M = 5.1 \text{ weeks}) \). Comparing these data with previous data (Figure 2) from the same clinic (Krishnan, 2009) reveals that referrals were previously received between 1 and 23 weeks after birth \( (M = 4 \text{ weeks}) \), with the age at initial assessment ranging from 1 to more than 13 weeks \( (M = 7.9 \text{ weeks}) \). The streamlining of the referral process, whereby referrals were sent directly from the hospital to the clinic, reduced the time lapse from date of birth to date of referral to the clinic (and therefore to age at initial assessment) substantially. States where hospitals are responsible for scheduling the diagnostic assessment have lower loss to follow-up rates (Krishnan et al., 2013), and the data from this study additionally indicate that this direct referral process also leads to lower age at diagnosis, well below the age of 3 months in most cases.

**Amplification Within 1 Month of Diagnosis**

The JCIH (2007) statement recommends that all infants diagnosed with hearing loss should receive amplification (if the family desires) within 1 month of diagnosis. Further, the committee set the benchmark for this goal at 95%. Literature regarding this goal is scarce, and the CDC (2011) statistics do not report data on this. Of note in the data presented here (Table 2) is that all six infants identified with hearing loss had slight to moderate hearing loss, with one infant having a mild–moderate unilateral hearing loss and two infants having slight high-frequency hearing loss. Of the two infants who received hearing aids, both were diagnosed by the age of 9 weeks, but neither met the criterion of amplification within 1 month of diagnosis.

Although screening programs nationwide and in Indiana are meeting the benchmark for newborn hearing screening, with more than 97% of newborns receiving a hearing screening in 2011 (CDC, 2011), the statistics for follow-up of infants who need additional assessment remain below the JCIH (2007) benchmarks.
amplification. Given the constraints at this clinic and the lack of medical personnel on site, the goal of amplification within 1 month of diagnosis may not be feasible. Improving communication between audiologists and otologists may help the clinic get closer to achieving the goal, and a policy to have the audiologist make personal contact with the otologist may be one way to improve communication. However, a more reasonable and achievable goal may be to fit amplification within 1 month of receiving medical clearance for amplification.

Comparison of the current data with previous data (Krishnan, 2009) is encouraging, despite the small sample size in both studies (Table 3). In addition to achieving earlier diagnosis, the age at fitting of amplification of both infants in this study was substantially lower (5 and 7 months, respectively) than in the previous study (9, 10, and 14 months, respectively) despite the milder hearing losses of the infants in this study. The authors’ current clinical experiences are that this is continuing to improve, and both authors now have several infants on their caseload that they have fit with amplification on or about the age of 3–4 months.

**Intervention by Age 6 Months**

The JCIH (2007) benchmark regarding early intervention is that 90% of infants identified with hearing loss should be enrolled in early intervention services by the age of 6 months. At this clinic, obtaining early intervention records consistently continues to be a major challenge. Despite referring infants identified with hearing loss to First Steps, being part of the early intervention team for the infants identified with hearing loss, and receiving approval for ongoing audiology services from First Steps, progress reports and IFSPs are not consistently sent to the audiologists. Improved communication between First Steps personnel, other early intervention service providers, and audiologists will facilitate improvement in data collection in this area.

All six infants identified with hearing loss were referred to First Steps, and five of the six infants did enroll in early intervention services between the ages of 3 and 7 months (Table 2). This appears to be better than the nationwide statistics that indicate that 62.9% of infants diagnosed with hearing loss received early intervention and, of those, that 67.6% started services by the age of 6 months (CDC, 2011). These data also seem better than the state of Indiana statistics, which are slightly lower than the nationwide statistics, with 59.4% of infants enrolled in early intervention services and only 34.7% before the age of 6 months (CDC, 2011). However, caution should be exercised in interpreting these data because of the very small sample size and patient demographics that may not be representative of the national population.

There is also insufficient documentation regarding the nature and types of services the infants are receiving. The availability of qualified personnel in the area to provide early intervention services remains a challenge, although in the authors’ recent experiences, this is being addressed somewhat in Indiana by making available the online therapy program ihear by the St. Joseph Institute for the Deaf (http://ihearlearning.org). Infant 6 did start the ihear program and continues to receive services.

In addition, as shown in Table 4, comparison with previous data (Krishnan, 2009) does reveal a decrease in the age at which early intervention services started, as well as improvement in documentation regarding early intervention services, although much still needs to be done in this area.

**Loss to Follow-Up Rates**

Loss to follow-up can occur at several steps in the process of UNHS and subsequent follow-up: between screening and outpatient rescreening, between the final screening and diagnostic, and between the diagnostic and start of intervention. Nationwide, 12.1% of infants are lost to follow-up between the inpatient and outpatient rescreening (CDC, 2011). However, in Indiana, this loss to follow-up is eliminated because although two screenings are performed, both are prior to discharge from the hospital. Overall loss to follow-up rates nationwide have decreased from 64% in 2005 to 39.3% in 2010 (Gaffney, 2013) and are at 35.3% for infants receiving no diagnosis and 26% for intervention (CDC, 2011). Loss to follow-up rates in Indiana are substantially lower at 9.9% for infants receiving no diagnosis. However, 30% of infants in Indiana are lost to follow-up for intervention (CDC, 2011).

One of the aims of this study was to make a direct comparison between previous data (Krishnan, 2009) and current data regarding loss to follow-up rates for the clinic to determine whether changes in state policies and clinic procedures implemented in 2010 had an impact on clinical loss to follow-up rates. Figure 3, which summarizes the loss to follow-up rate comparison, shows that the changes in policy and procedures had a positive impact on clinical loss to follow-up rates. The loss to follow-up rate decreased substantially from 18% (25 of 139 infants evaluated) to 7% (8 of 111 infants evaluated). Considering only infants who needed additional assessment subsequent to the initial diagnostic, the change in clinic policy to schedule infants for repeated follow-ups until such time as the conductive component was resolved and an accurate estimation of hearing sensitivity could be obtained also had a significant positive impact on clinical loss to follow-up rates. Krishnan (2009) reported that 25 of 41 (61%) infants who needed additional assessment were lost to follow-up, whereas in the current cohort, 8 of 22 (36.4%) infants who needed additional assessment were lost to follow-up.

**Conclusions and Future Directions**

The results of this small-scale study conducted at a university clinic show two main findings with implications to improve UNHS follow-up in terms of improving the goal of diagnosis by the age of 3 months and reducing loss
to follow-up rates from the clinic. First, direct referral from the hospital to the clinic with the onus of scheduling the appointment placed on the hospital rather than on First Steps or the parents substantially reduced delays in receiving referrals for diagnostic assessment as well as the age of the infant at the initial assessment, thereby facilitating testing during natural sleep. Second, clinic loss to follow-up rate was substantially reduced by placing the responsibility of scheduling repeated follow-up appointments on the clinic rather than on the parents.

Some improvements were noted in providing timely amplification, and despite the small sample size, it may be appropriate to consider revising the benchmark of fitting amplification within 1 month of diagnosis to fitting amplification within 1 month of receiving medical clearance but no later than 3 months after diagnosis. Improvements were also noted in providing and documenting appropriate intervention services, but challenges remain in terms of meeting these goals. Future efforts at the clinic should include trying to obtain accurate and comprehensive documentation regarding early intervention services for all infants diagnosed with hearing loss. Continuing to work on educating all parties involved about the benefits of early diagnosis and intervention, including for infants with mild and unilateral hearing losses, as well as improving communication between audiologists, physicians, First Steps, and EHDI programs is required to meet these JCIH benchmarks and provide the best care for infants with hearing loss and their families.

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