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Access to Pediatric Audiological Evaluation Facilities for Infants and Young Children in the United States: Results from the EHDI-PALS System

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Abstract

Early Hearing Detection and Intervention–Pediatric Audiology Links to Services (EHDI-PALS) is a web-based national directory of pediatric audiology facilities in the United States, launched in October 2012. It was created by a committee of national experts to improve diagnostic audiology follow-up for infants and young children who failed the newborn hearing screening or were suspected of having hearing loss. In this study, data from 1,232 audiology facilities registered in EHDI-PALS were analyzed to identify the location of facilities, types of diagnostic hearing tests offered, and the number of children under five years of age who were diagnosed with hearing loss. Some states had almost 15 times as many registered facilities as other states, suggesting that access to quality diagnostic hearing testing for infants and young children is still a major public health problem in many states. Approximately 90% of registered facilities have equipment necessary for diagnosing hearing loss in children over seven months of age. However, less than 70% of facilities had appropriate auditory brainstem response (ABR) equipment required for effectively evaluating hearing status for infants six months of age or younger. The data suggest that steps need to be taken to increase the number of pediatric audiology facilities registered in EHDI-PALS in each state to efficiently deal with the large number of infants and young children being referred from newborn hearing screening programs.

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Acronyms: AAA = American Academy of Audiology; ABR = auditory brainstem response; ASHA = American Speech, Language and Hearing Association; CPA = conditioned play audiometry; ASSR = auditory steady state responses; DHH = deaf or hard of hearing; DPOAE = distortion-product otoacoustic emissions; EHDI = Early Hearing Detection and Intervention; EHDI-PALS = Early Hearing Detection and Intervention–Pediatric Audiology Links to Services; HL = hearing loss; OAE = otoacoustic emissions; TEOAE = transient evoked otoacoustic emissions; VRA = Visual Reinforcement Audiometry

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Every state has established an Early Hearing Detection and Intervention (EHDI) program (White, 2014). One of the goals of these state-based EHDI programs is to ensure early identification of all children born with permanent hearing loss. According to the Centers for Disease Control (CDC, 2010), 2 to 3 out of every 1,000 children born in the United States have some degree of permanent hearing loss in one or both ears. Identification of permanent hearing loss before the age of three months and intervention service provision before six months of age leads to significant gains in the speech and language development of children who are deaf or hard of hearing (DHH; Downs & Yoshinaga-Itano, 1999; Pimperton et al., 2016). Identifying and treating hearing loss at a very early age is crucial because children who are DHH often lag not only in their speech and language development, but also in their cognitive and social development (Kral, 2013; Kral, Kronenberger, Pisoni, & O'Donoghue, 2016). Substantial evidence from developmental neuroscience demonstrates the remarkable ability of the child's brain to change as a result of experience (Kuhl, 2010). To benefit from the critical window of neuroplasticity, early identification and management of hearing loss is crucial (Benasich, Choudhury, Realpe-Bonilla, & Roesler, 2014; Kral, Dorman, & Wilson, 2019). To maximize the potential of better outcomes for children who are DHH, all infants who fail newborn hearing screening should have access to comprehensive audiological evaluation by 2 months of age with initiation of intervention no later than three months of age (Jount Committee of Infant Hearing [JCIH], 2019).

The goal of the Early Hearing Detection and Intervention-Pediatric Audiology Links to Services (EHDI-PALS) was to create a free, online database where parents or interested parties can search for pediatric audiology service facilities for young children (birth to 5 years of age) with or suspected of being DHH. This was done by creating an easy-to-use and searchable website (http://www.ehdi-pals. org) with information about pediatric audiology facilities that meet best practices based on the EHDI-PALS facility survey (Chung et al., 2017). Pediatric audiology facilities can enroll in the EHDI-PALS system by completing an in-depth survey that describes the equipment they use and the services they provide. The survey, based on the best practice standards set forth by American Speech. Language and Hearing Association (ASHA), the American Academy of Audiology (AAA), and the Joint Committee on Infant Hearing (JCIH) contains a built-in algorithm with integrated diagnostic practice templates for children birth to 6 months, 7 months to 3 years, and 3 to 5 years. If a facility's reported practices match standards outlined in the template, the facility is listed in the EHDI-PALS directory.

Current best practice guidelines (see AAA, 2012, 2013; ASHA, 2004; and JCIH, 2019) for audiological diagnostic testing for children are different based on the child's age. Hearing assessment for infants under the age of 6 months is recommended to be conducted using:

- Auditory brainstem responses (ABR) using wide-band stimuli such as clicks and frequency-specific stimuli such as tone-bursts (Gorga et al., 2006; McCreery et al., 2015) to obtain frequency specific hearing threshold information.
- Otoacoustic emissions (OAE) testing to assess cochlear function using either Distortion-Product OAE (DPOAE) or Transient-Evoked OAE (TEOAE; Gorga et al., 1997; Hussain, Gorga, Neely, Keefe, & Peters, 1998).
- High frequency (1000 Hz) immittance testing to evaluate middle ear status (Hunter, Prieve, Kei, & Sanford, 2013; Margolis, Bass-Ringdahl, Hanks, Holte, & Zapala, 2003).
- High frequency (1000 Hz) acoustic reflex testing to test middle ear functioning and the integrity of the brainstem auditory pathway (de Lyra-Silva, Sanches, Neves-Lobo, Ibidi, & Carvallo, 2015; Kei, 2012).

For young children from 7 months of age up to 3 years, it is recommended that ear-specific and frequency-specific hearing threshold testing be conducted using visual reinforcement audiometry (VRA) and/or conditioned play audiometry (CPA). In addition, middle ear and cochlear function needs to be assessed using standard (226 Hz) immittance testing including acoustic reflex and OAE (DPOAE or TEOAE) testing respectively. Anytime an audiologist questions the reliability of behavioral test results in young children, electrophysiological tests such as frequency specific ABR or auditory steady state responses (ASSR) need to be used to cross-check the behavioral test results.

Diagnostic testing for children between 3 to 5 years is focused on obtaining reliable ear specific and frequency specific hearing thresholds using conditioned play audiometry. Testing should also include OAE and immittance testing. In addition, inclusion of speech recognition tests in guiet and noise is recommended.

In this study, we analyzed the information provided by each facility registered in the EHDI-PALS system as of September 18, 2019 to identify the number of diagnostic facilities registered in each state that can provide recommended diagnostic hearing evaluations for young children. Results provide valuable information about the services offered by facilities to assist parents and healthcare professionals in selecting an appropriate facility for their needs as well as providing guidance about the status of pediatric audiology services in the United States.

Method

The EHDI-PALS system became available in October 2012 and can be accessed at <u>http://www.ehdipals.org</u>. As of September 18, 2019, 1,390 facilities from all over the United States had completed the survey and registered in the EHDI-PALS system. The EHDI-PALS Facility Survey consists of 68-questions developed by an advisory committee of pediatric audiology experts. The process of developing the survey and using the results of the survey to display facilities in the EHDI-PALS system is described by Chung et al. (2017). The following survey data related to diagnostic testing and reporting categories were analyzed in this study.

- 1. Number and type of registered facilities (e.g., hospital, public school, privately-owned, etc.).
- 2. Types of diagnostic services offered by the facility.
- 3. Number of children under 5 years of age diagnosed in the past year.

Facilities registered in EHDI-PALS are asked to update their information each year, but this is not always done. Data used in these analyses were based on the latest available information for 1,232 facilities after excluding data from 158 facilities because they were no longer active or a profile was created, but the survey was never completed.

Results

Facilities per 1,000 births and Reported Data on Diagnostic Testing

The number of registered facilities in EHDI-PALS from each state was compared with birth statistics to obtain a ratio of registered facilities per 1,000 births in each state as shown in Figure 1. Birth data for these calculations were taken from CDC National Vital Statistics Reports (2018, <u>https://www.cdc.gov/nchs/fastats/births.htm</u>). As

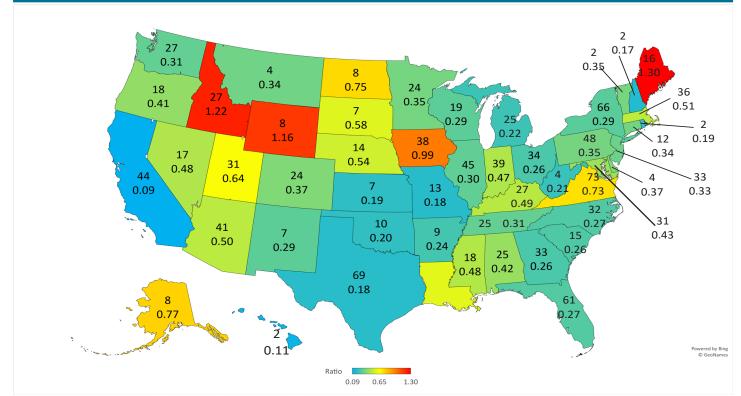


Figure 1. Ratio of number of registered Early Hearing Detection and Intervention–Pediatric Audiology Links to Services (EHDI-PALS) facilities in the United States per 1,000 births. State labels show the number of registered facilities in each state (top number) and the ratio of facilities per 1,000 births (bottom number).

can be seen in Figure 1, the number of facilities per 1,000 births registered in EHDI-PALS is dramatically different from state to state, ranging from a low in California of 0.09 per 1,000 to a high in Maine of 1.30 per 1,000—almost a 15-fold difference.

Survey questions that reflected different types of clinical settings were used to group facilities into categories of hospital, medical office, private practice, public school, university, non-profit center, military, Indian health service clinic, state affiliated clinic, or other. The survey allowed for the selection of multiple categories. For the results reported in this article, facilities that marked more than one type of facility were classified into a single category based on results from an internet search of the specific facility. Six distinct facility types were identified based on our search results: University, Private Practice, Medical Office, Public School, Hospital, and Others. Facilities that fell under non-profit center, military, Indian health service clinic, and state affiliated clinic were included under Others. Number of registered facilities by type are shown in Figure 2.

When registering or updating their data for EHDI-PALS, facility contacts were asked to report the annual number of diagnostic evaluations and the annual number of children with confirmed permanent hearing loss at their facility in one of five categories: 0, 1–10, 11–25, 26–50, and 50+. The number of diagnostic evaluations performed and the number of children annually diagnosed with permanent hearing loss was reported for four age ranges: 0 to 1 month, 1 to 3 months, 4 to 24 months, and 25 to 60 months. To meaningfully display these data by accounting for the range of values in the estimation, we totaled the number of facilities by state in each of the five categories

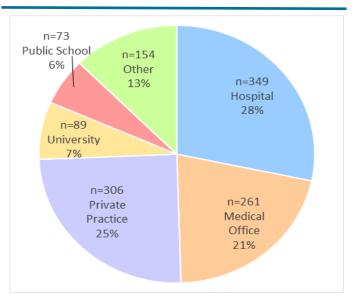


Figure 2. Percentage of registered facilities in each of the six categories of facilities registered with Early Hearing Detection and Intervention–Pediatric Audiology Links to Services (EHDI-PALS).

and multiplied them by the middle value in the range (i.e., 0, 5, 18, 38, and 65) respectively. For the category of 50+, we multiplied the category total by 65 because there was no upper value. This resulted in a calculated value of the approximate average number of children tested and diagnosed in a 12-month period prior to registration or most recent updating by each facility for each state.

Figures 3 and 4 show the estimated average number of children tested and diagnosed with permanent hearing loss per 1,000 births, respectively.

Registered diagnostic facilities in each state

To identify the percentage of registered facilities in each state that offered best practice diagnostic audiologic evaluations for infants and young children, the number of facilities with objective physiological hearing tests and behavioral hearing tests were tabulated. Figure 5 shows box plots of the percentage of facilities in each state that offer various types of diagnostic hearing tests. Physiological tests included are auditory evoked potential testing (ABR using click, tone burst, and bone conduction; and ASSR), Distortion Product and Transient evoked OAE, and Immittance testing (226 Hz Tympanometry, High-Frequency Tympanometry and Acoustic Reflex testing).

Behavioral tests included free-field VRA, ear and frequency specific VRA, conditional play audiometry, and conventional pure-tone audiometry. Planned pairwise analyses between the diagnostic tests using Wilcoxon signed rank test found that the number of facilities with ASSR testing was significantly smaller compared to tone evoked ABR testing (Mean Difference = 42.23, *W*

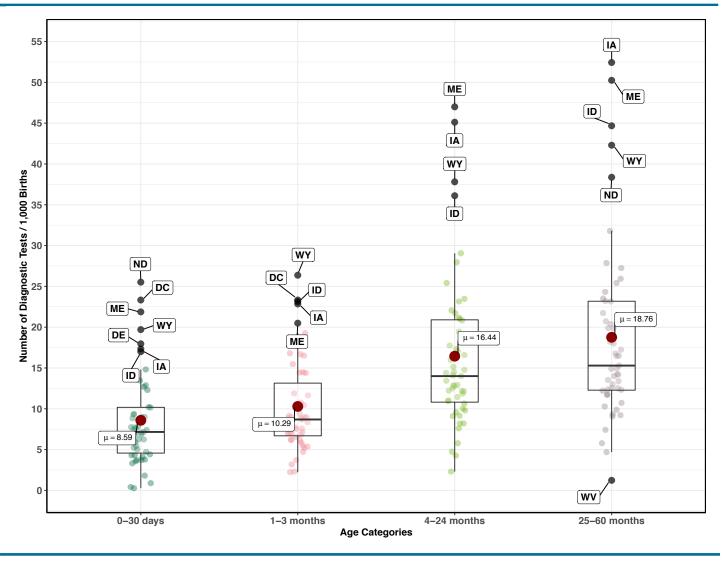


Figure 3. Estimated average number of children reported as having diagnostic testing per 1,000 births in each state. Extreme data points in boxplots are labeled by state ID if they are greater than $q_3 + w \times (q_3 - q_1)$ or less than $q_1 - w \times (q_3 - q_1)$, where w = 1, q_1 and q_3 are the 25th and 75th percentiles of the sample data, respectively.

statistic = -6.15, p < 0.001). Percentage of facilities with DPOAE testing were significantly higher than TEOAE (Mean Difference = 43.14, *W* statistic = -6.03, p < 0.001). Facilities reported to have 1000 Hz high-frequency tympanometry were also less than facilities with 226 Hz tympanometry (Mean Difference = 7.77%, *W* statistic = -4.86, p < 0.001).

Analyses were done using *ggstatsplot* package in R (Patil, 2019) to determine if there were statistically

significant differences in the percentage of facilities with recommended diagnostic tests for infants under the age of six. Nonparametric Friedman test of differences for diagnostic tests (ABR Click, ABR TONE, DPOAE, 1000 Hz tympanometry, and acoustic reflex) was conducted and the Chi-squared value [χ 2 = 162.2 (df = 4), p < .001, n = 51] was statistically significant. Pairwise comparisons for differences between the diagnostic tests were conducted using the Durbin-Conover test with Bonferroni adjustment.

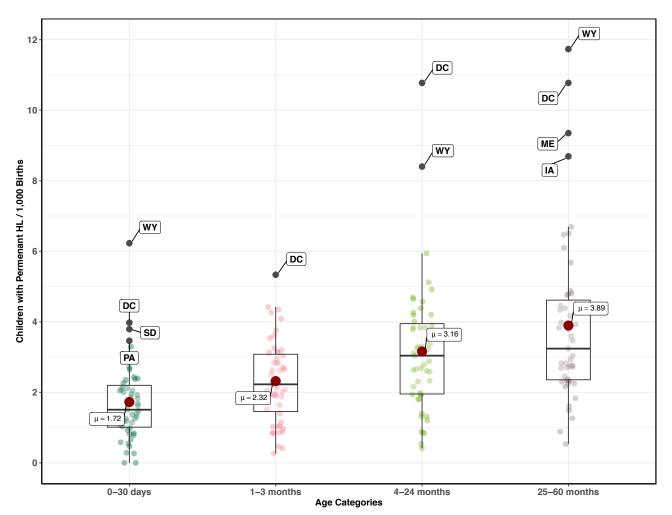


Figure 4. Estimated average number of children diagnosed as having permanent hearing loss per 1,000 births in each state. Extreme data points in boxplots are labeled by state ID if they are greater than $q_3 + w \times (q_3 - q_1)$ or less than $q_1 - w \times (q_3 - q_1)$, where w = 1, q_1 and q_3 are the 25th and 75th percentiles of the sample data, respectively. HL = hearing loss.

Figure 6 shows the multiple paired comparison test results between ABR (Click and tone burst), DPOAE, high frequency tympanometry, and acoustic reflex texting. In general, facilities with access to click evoked ABR and frequency specific tone burst ABR are significantly less compared to other recommended tests for children under 6 months of age. Percentage of diagnostic facilities reported to have access to natural sleep ABR, sedated ABR, and ABR testing under anesthesia are plotted in Figure 7.

Discussion

Data about the types of diagnostic services offered and the number of children diagnosed with permanent hearing loss were analyzed from 1,232 pediatric audiology facilities from throughout the United States that are registered in the EHDI-PALS system. Most children are evaluated in hospital, medical office, or private practice settings. Based on the recommended practices by ASHA (2004) and JCIH (2019), it is an encouraging and significant finding that ~90% of the facilities across the nation have the recommended diagnostic tests (DPOAE, immittance testing, and behavioral audiometry) for children from 7–60 months of age (see Figure 5).

However, as shown in Figure 1, the number of pediatric audiology facilities per 1,000 births varies dramatically from state to state ranging from a low in California of 0.09 per 1,000 to a high of 1.16, 1.22, and 1.30 per 1,000 in Wyoming, Idaho, and Maine, respectively. In other words, parents in Wyoming, Idaho, and Maine have 12–14 times as many options as parents in California when they are using the EHDI-PALS system to search for pediatric audiological evaluation services. Although some of this variation is likely due to differences in percentage of facilities in that state that are registered with EHDI-PALS, it is also likely that there are more acute shortages of pediatric audiologists in those parts of the country where rates per 1,000 are significantly lower.

As shown in Figure 1, of the 50 states, only seven states have a ratio of facilities per 1,000 births that is greater than 0.7. This suggests that access to quality diagnostic hearing testing for children is still a major public health problem

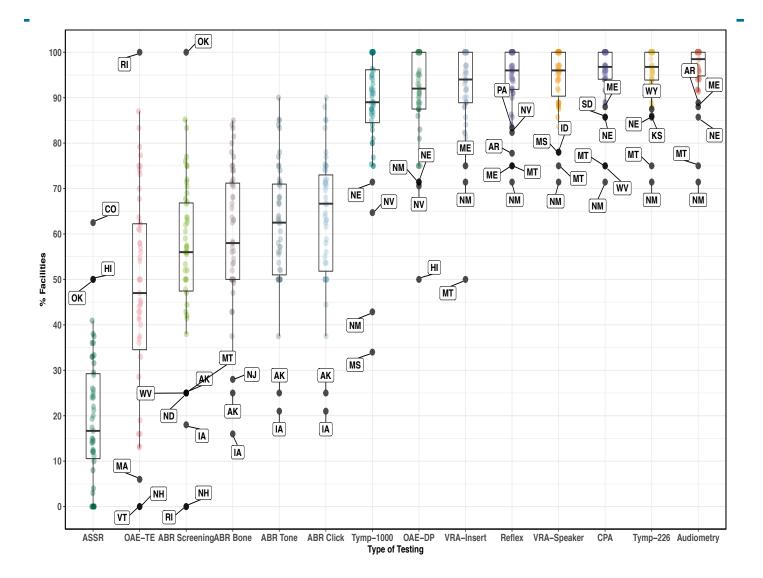
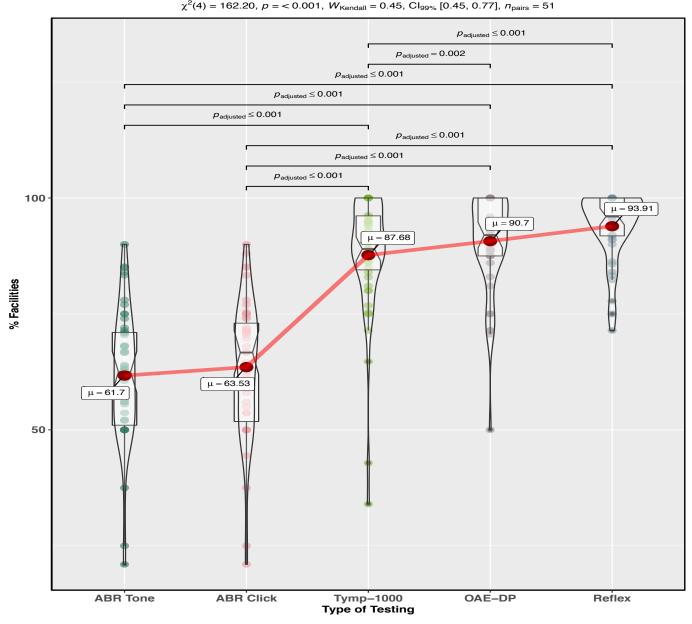


Figure 5. Percentage of facilities in each state or jurisdiction reported to have the following diagnostic tests: Auditory evoked potential testing (auditory brainstem response [ABR] screening, click evoked [ABR Click], bone conduction ABR [ABR bone], tone burst ABR [ABR Tone], auditory steady state responses [ASSR]), otoacoustic emission testing (distortion product [OAE-DP] and transient evoked [OAE-TE]), immittance testing (226 Hz tympanometry [Tymp-226], high frequency tympanometry [Tymp-HF], acoustic reflex testing [Reflex]), and behavioral testing (field-free visual reinforcement audiometry [VRA-Speaker], ear and frequency specific VRA using insert or headphone [VRA-Insert], condition play audiometry], and conventional pure tone audiometry [Audiometry]). Extreme data points in boxplots are labeled by state ID if they are greater than q3 + w × (q3 – q1) or less than q1 – w × (q3 – q1), where w = 1, q1 and q3 are the 25th and 75th percentiles of the sample data, respectively.

in most states. Pediatric hearing assessment requires specialized competency and knowledge. Currently, there is a shortage of pediatric audiologists in the nation (McCreery, 2014; JCIH, 2019). Assessing infants and young children requires specialized equipment, an assistant, more time, and multiple follow-up appointments for proper diagnosis and to counsel parents. These factors make it expensive for most facilities to provide high-quality services for children—especially children under 7 months of age. Not having enough facilities within each state places an undue burden on parents. This is a greater challenge for families who live in remote/rural areas. Lack of immediate access to quality pediatric hearing health care facilities invariably leads to delayed intervention for children who are DHH.

Of course, there are many variables that affect access to services that are not addressed in these analyses. For example, it is interesting that the three states with the highest ratio of audiology facilities registered in EHDI-PALS to number of annual births are Maine, Idaho, and Wyoming—all states with a relatively low number of annual births and low population densities. The analyses reported here are a beginning point for EHDI programs to evaluate accessibility of services, but much more work is needed to understand how accessibility is affected by issues such as how far families have to travel to a pediatric audiology



Tests: < Six Months Old

Pairwise comparisons: Durbin-Conover test; Adjustment (p-value): Bonferroni

Figure 6. Statistical test details comparing differences in percentage of Early Hearing Detection and Intervention– Pediatric Audiology Links to Services (EHDI-PALS) facilities with diagnostic tests crucial for testing children under 6 months of age.

facility, the adequacy of insurance coverage in different states, and what diagnostic services are available.

To ensure that all infants with hearing loss are diagnosed at less than 2 months of age and followed up for intervention by 3 months of age, it is crucial that steps are taken in most states to increase the number of facilities that can do pediatric audiological testing. One option that should be considered is to enhance resources toward diagnostic tele-audiology for infants under 6 months of age. EHDI programs that have successfully implemented remote diagnostic audiological evaluations with infants can serve as models for other sites. For example, synchronous immittance testing and remote cochlear implant mapping has been demonstrated in several previous studies (e.g., Hughes et al., 2012; Lancaster, Krumm, Ribera, & Klich, 2008; Wesarg et al., 2010). Recently, Canada's British Columbia Early Hearing Program successfully implemented remote ABR testing for infants (Hatton, Rowlandson, Beers, & Small, 2019). Another potential solution to overcome the lack of diagnostic facilities within a state is to improve access to facilities in bordering states that have appropriate facilities. Physical visits to the facilities across the state border should be supported and follow-up visits could be made available through teleaudiology practice. Potential barriers such as insurance restrictions and state licensure restrictions for tele-practice

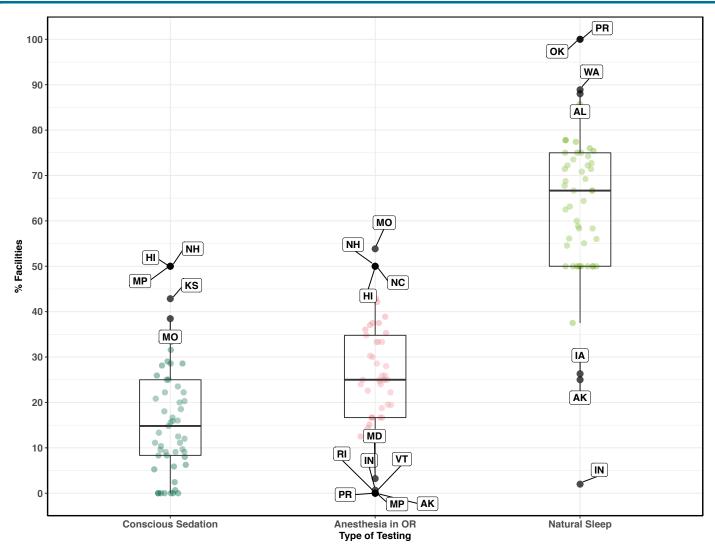


Figure 7. Percentage of Early Hearing Detection and Intervention–Pediatric Audiology Links to Services (EHDI-PALS) facilities with infrastructure for automated brainstem response testing under anesthesia, conscious sedation, and natural sleep. Extreme data points in boxplots are labeled by state ID if they are greater than $q3 + w \times (q3 - q1)$ or less than $q1 - w \times (q3 - q1)$, where w = 1, q1 and q3 are the 25th and 75th percentiles of the sample data, respectively. OR = operating room.

must be addressed. Joint programs across state borders that pool available resources may be considered to provide effective diagnostic evaluations to infants and young children who fail newborn hearing screenings.

The analyses reported in this article revealed that only about 62% of the facilities registered in EHDI-PALS are equipped with diagnostic ABR test equipment (Figure 6). The lack of availability of ABR testing across facilities must be addressed urgently because ABR is an essential diagnostic tool for hearing assessment in infants under the age of six months. ABR along with OAE is one of the goldstandard diagnostic tests for obtaining hearing thresholds in infants. The full diagnostic ABR testing must include not just click evoked ABR, but also frequency specific tone burst and bone conduction ABR evaluations. These evaluations are crucial for obtaining type, degree, and configuration of hearing loss (JCIH, 2019).

A relatively small number of facilities (~25%) reported having sedated ABR capability (Figure 7). The clinical

implications of this shortcoming are significant because ABR testing under sedation is often needed for successful completion of hearing evaluation, especially in older infants. Sedation ABR can also reduce the burden of follow-up visits. For younger infants (e.g., those younger than three months of age), testing during natural sleep is often possible because very young babies typically sleep naturally for longer durations.

There is a need to evaluate why ABR availability is not as widespread as OAEs given the significance of ABR testing in diagnosing hearing loss in children under six months of age. One possibility could be the longer time involved in obtaining ear and frequency specific tone burst ABR thresholds. Second, interpretation of ABR is more subjective than OAE and requires significant experience in pediatric ABR testing (Norrix & Velenovsky, 2018). Third, diagnostic ABR systems are at least twice as expensive as OAE systems. These factors may be potential barriers to its use and may be a focus area as part of academic

training, research, and continuing professional education. Finally, perhaps the facilities' lack of access/collaboration with physicians and other medical professionals who can administer and monitor sedation for young children may be a barrier to providing ABR testing. These multiple factors related to ABR testing clearly need improvement for early diagnosis and intervention of children with hearing loss and have the potential for improving services significantly. Recent advances in automated ABR and ASSR testing using click evoked-chirp stimuli have provided objective interpretation of results and helped to obtain faster and accurate estimates of hearing threshold in infants and young children (Sininger, Hunter, Hayes, Roush, & Uhler, 2018). The number of evaluations in younger infants was lower in comparison to older infants. The potential reason for this may be the limited availability of facilities with the capability to complete infant diagnostic testing (e.g., ABR) which in turn leads to missed opportunities at early identification and intervention.

We noted that high frequency tympanometry is available about as often as OAE and VRA. This finding was encouraging given the contribution of high frequency tympanometry in increasing diagnostic accuracy of middle ear conditions in neonates and infants up to 9 months of age (Hoffmann et al., 2013). However, the availability of 1,000 Hz tympanometry was lower than 226 Hz tympanometry. There were also fewer facilities with ear and frequency specific VRA than other behavioral tests. This is another area that has room for improvement given that obtaining ear and frequency specific hearing thresholds is crucial for selection and verification of amplification devices. Verification of audibility and selection of prescriptive hearing aid targets in young children necessitates ear and frequency specific hearing thresholds (McCreery, Bentler, & Roush, 2013).

Conclusions

The EHDI-PALS system is a valuable resource to help parents and professionals find appropriate pediatric diagnostic services. Analyses of data from 1,232 facilities registered in EHDI-PALS revealed that most facilities are well equipped to provide diagnostic audiology services to 7- to 60-month-old children. However, a significant number of facilities are not equipped to provide diagnostic audiology services to children in the birth to 6-month age range because of not having access to ABR procedures. The results also highlight the need for a greater number of facilities in many states and the need to ensure that all pediatric audiology facilities are registered with EHDI-PALS and have updated profiles.

The present study results must be interpreted within the limitation that not all facilities in a state may be registered with EHDI-PALS and some that are registered may not have updated their information. The continued efforts of EHDI coordinators and program administrators are needed to increase the effectiveness of this system.

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