

Likely Impact of the COVID-19 Pandemic on Newborn Hearing Screening and Follow-up Services in the United States in 2020

Kelly Dundon, AuD, MPH¹

Suhana Ema, MPH²

Xidong Deng, PhD²

Mia Morrison, MPH³

Treeby Brown, MA³

Karl White, PhD⁴

Linda Hazard, EdD⁵

Marcia Fort, AuD⁵

Kirsten Coverstone, AuD⁶

Craig A. Mason, PhD⁷

Marcus Gaffney, MPH²

¹GenTech Associates, Atlanta, GA

²U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Atlanta, GA;

³U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Rockville, MD;

⁴National Center for Hearing Assessment and Management, Utah State University Logan, UT;

⁵Directors of Speech and Hearing Programs in State Health and Welfare Agencies, Burlington, VT and Raleigh, NC

⁶Minnesota Department of Health, St. Paul, MN

⁷University of Maine, Orono, ME

Abstract

This perspective aims to highlight aspects of the Early Hearing Detection and Intervention (EHDI) newborn hearing screening and follow-up processes that were impacted by the COVID-19 pandemic and considers factors that likely impacted follow-up after failing newborn hearing screening among infants born in the United States during 2020. Efforts to minimize the potential impact of missed or delayed identification of hearing loss in infants and young children will also be discussed to help guide future program improvement activities.

Keywords: COVID-19, Newborn Hearing Screening

Acronyms: CDC = Centers for Disease Control and Prevention; DHH = deaf or hard of hearing; EHDI = Early Hearing Detection and Intervention; EHDI-IS = Early Hearing Detection and Intervention-Information System; HRSA = Health Resources and Services Administration; HSFS = Hearing Screening and Follow-up; LFU/LTD = lost to follow-up/lost to documentation

Disclosures: Jurisdictional EHDI data related work was supported under the current Centers for Disease Control and Prevention (CDC) Cooperative Agreement DD20-2006, “Improving Timely Documentation, Reporting and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems.” The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention or the Health Resources and Services Administration.

Acknowledgments: The authors would like to thank the jurisdictional EHDI Programs who continue to share information on the hearing status of infants and young children throughout the United States with the CDC and partners.

Correspondence concerning this article should be addressed to: Kelly Dundon, AuD, MPH, GenTech Associates. Phone: (678) 431-2096; Email: xlo2@cdc.gov

The Early Hearing Detection and Intervention (EHDI) Act (S. 652, PL 115-71) authorizes the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC) to support EHDI activities at state and territorial levels to help ensure infants receive recommended services according to established national benchmarks (i.e., hearing screening before one month of age, diagnosis before three months

of age, and enrollment in early intervention before six months of age (JCIH, 2019). Late identification of a child as deaf or hard of hearing (DHH) can adversely affect their ability to develop communication, language, cognitive, and social skills (Morton & Nance, 2006; Vohr, 2003). In March 2020, the United States declared a national emergency in response to the COVID-19 pandemic (Executive Office of the President, 2020).

Jurisdictional EHDI programs faced new challenges in helping families navigate the process of screening, diagnosis, and entry into intervention programs. Nationwide, performance in meeting EHDI benchmarks in 2020 declined compared to previous years, as indicated by the results from the CDC annual Hearing Screening and Follow-up Survey (HSFS; CDC, n.d.).

This perspective aims to highlight aspects of the EHDI system that were likely impacted by the COVID-19 pandemic and identify factors that likely impacted follow-up after failing newborn hearing screening for infants born in the United States during 2020. Efforts made by EHDI programs and federal partners to help mitigate the potential impact of missed or delayed identification of hearing loss will also be addressed.

EHDI Services During COVID-19

The percent of infants born in 2020 meeting the benchmark of being screened before one month of age remained high at 95% compared to the two previous years (range: 94%–96%; Figure 1). The high screening rate during the pandemic suggests that the in-hospital newborn screening remained a standard of newborn care. Among infants screened, the percent of infants who did not pass their most recent hearing screen increased from 1.6% for the 2018 birth cohort to 2.0% for the 2020 birth cohort (Table 1). An increase of 0.4% in the final refer rate translates into approximately 12,000 additional infants in need of a diagnostic evaluation by an audiologist. There was also an increase in the number of infants not receiving a hearing screen due to medical reasons in the 2020 birth cohort (approximately 3,300 in 2018 and 2019 to 4,500 in 2020; CDC, n.d.). This 36% increase likely reflects updated HSFS guidance that newborns who did

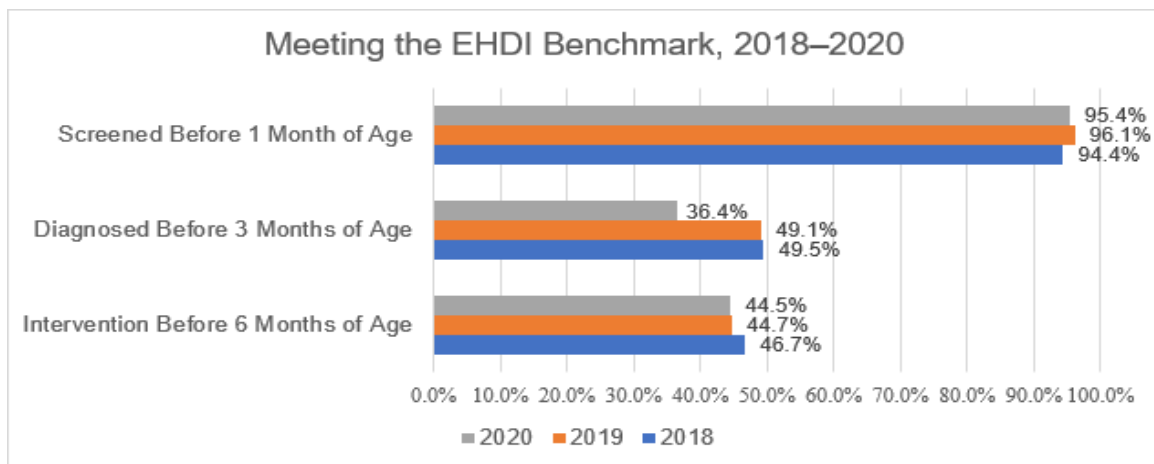
not receive a newborn hearing screening because the mother or child had COVID-19 should be reported as “not screened due to medical reasons.”

Among infants needing a diagnostic evaluation, a noticeable decrease in the percent meeting the benchmark of diagnosis before three months of age was documented. A little over one third (36.4%) of infants born in 2020, who failed their final hearing screen completed a diagnostic evaluation before three months of age. Whereas nearly half (2018: 49.5% and 2019: 49.1%) met this benchmark the previous years (Figure 1). Although there was no notable change in the average percent of families declining audiological diagnostic services, nationally the rate of lost to follow-up/lost to documentation (LFU/LTD) for diagnosis increased from 25.9% among 2018 births to 29.9% among 2020 births (Figure 2). The higher LFU/LTD rate, coupled with an increased number of referrals, means that more babies born during the first year of the pandemic who failed their newborn hearing screen were lost to the EHDI system and likely did not receive timely follow-up services.

Decreases in enrollment into intervention were also noted among 2020 births. Enrollment into intervention for infants with diagnosed hearing loss before the benchmark of 6 months of age declined from 46.7% among 2018 births to 44.5% among 2020 births (Figure 1). Refusal rates of intervention slightly increased from 9.2% (2018 and 2019) to 9.7% (2020; Table 1). Additionally, the LFU/LTD rate of intervention among infants with permanent hearing loss increased from 17.7% (2018) to 19.5% (2020; Figure 2). The nearly 2.0 percentage point difference represents 116 infants with permanent hearing loss not receiving, or not documented to be enrolled in, intervention services.

Figure 1

National Average of Early Hearing Detection and Intervention (EHDI) Benchmarks: 2018–2020



Note. Percent Screened Before 1 Month of Age = # Total screened before 1 month of age / # Total Births *100%; Diagnosed Before 3 Months of Age = # Total Diagnosed Before 3 Months of Age / # Total Not Pass *100%; Percent Intervention before 6 Months = # Total Enrolled in Intervention before 6 Months of Age (Part C and Non Part C) / # Total diagnosed with Permanent hearing Loss*100%.

Table 1

National Early Hearing Detection and Intervention (EHDI) Summary Data 2018–2020

	2018*	2019**	2020***
Total Births	3,744,815	3,604,761	3,576,050
Total Screened	3,681,776	3,545,388	3,510,821
Total/Percent ^a Not Pass Final Screen	60,258 (1.6%)	61,475 (1.7%)	69,989 (2.0%)
Total/Percent ^b Refused Diagnostic Service	1,878 (3.1%)	1,721 (2.8%)	2,138 (3.1%)
Total Permanent Hearing Loss	6,432	5,934	6,290
Total/Percent ^c Refused Intervention Service	590 (9.2%)	547 (9.2%)	612 (9.7%)

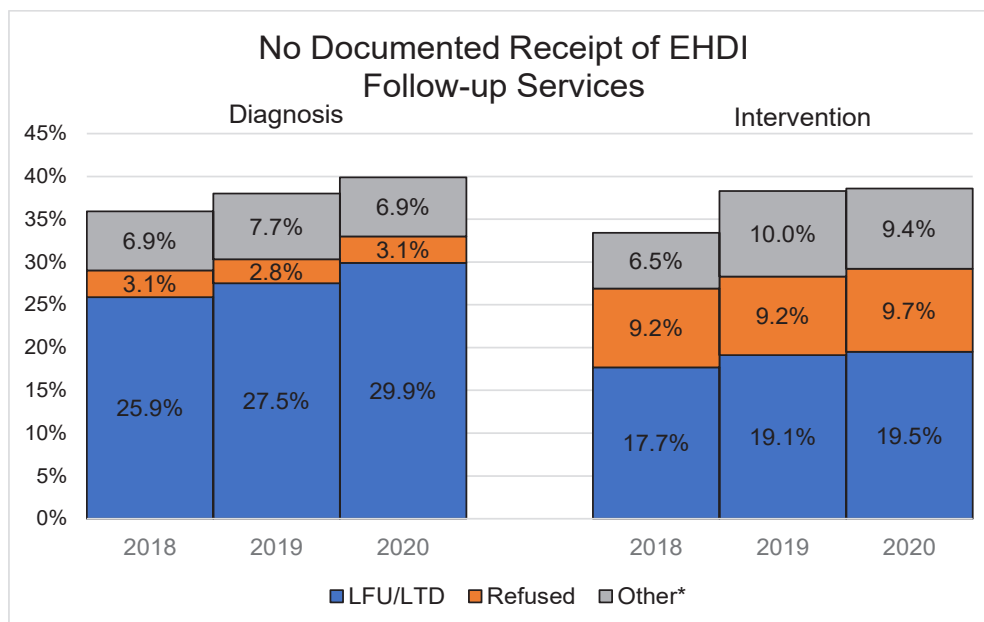
*57 Jurisdictions Reporting

**55 Jurisdictions Reporting

***56 Jurisdictions Reporting

^aPercent Not pass = #Total Not Pass /# Total Screened*100%^bPercent Refused Diagnostic Service = # Total Refused Diagnostic Service/Total Not Pass*100%^cPercent refused Early Intervention Service = #Total Refused Intervention Service/Total Permanent Hearing Loss*100%**Figure 2**

Percent of Infants Not Documented to Have Received Recommended Follow-up Early Hearing Detection and Intervention (EHDI) Services, 2018–2020



*The Other category includes no documented diagnosis or enrollment into intervention due to reasons other than family refusal or lost to follow-up/lost to documentation (LFU/LTD; e.g., not eligible for or not referred to service, infant deceased, moved out of jurisdiction, and medical reasons).

Factors Influencing EHDI

Plausible reasons for the reductions in follow-up diagnosis and access to services among infants who screened positive for possible hearing loss in 2020 can be found when considering both internal and external factors that impacted EHDI during COVID-19. In May 2020, HRSA convened a listening session co-hosted by the National Center for Hearing Assessment and Management (NCHAM) and the Association of Public Health Laboratories (APHL). The purpose of this meeting was to discuss

possible solutions to the challenges faced for newborn hearing and dried blood spot screening, and to understand families' experiences from screening through follow-up (APHL, n.d.). Barriers identified during the listening session included staffing shortages, facility closures, limited hours for out-patient procedures, families sick or quarantining, and parental hesitancy to return for follow-up services. As with many systems of care, the impact of COVID-19 touched every part of the EHDI system from screening to diagnosis and enrollment into intervention.

Typically, the newborn receives a first hearing screen between 18 and 24 hours after birth in the hospital and then a secondary screen before discharge, if the newborn did not pass the first screen. However, during the COVID-19 pandemic the duration of maternal/newborn stays in the hospital after delivery were often reduced (Greene et al., 2020). A shorter maternal/newborn stay may have impacted hospitals' ability to perform a second screen, which should be conducted at 6 hours after the first screen when necessary (JCIH, 2019). Staff at hospitals were also often diverted to assist with overflow of patients affected by COVID-19, potentially leaving less experienced or different staff to perform the hearing screens. Both short hospital stay and staffing issues combined could play a role in the observed higher refer rate (2.0%) during the pandemic, compared to the previous two years (Table 1). Lastly, some hospitals did not perform hearing screens on newborns of mothers who tested positive for COVID-19. This would increase the number of infants who required additional follow-up and tracking for hearing screening and/or evaluation services by EHDI programs.

As noted above, there was an increase in the number of infants who were LFU/LTD from screening to diagnosis in 2020. Underlying reasons for this increase in LFU/LTD and the resulting decline in the overall meeting of EHDI benchmarks include a reduction of services among pediatric diagnostic audiology facilities, inability of parents to locate childcare for siblings that could not attend appointments due to COVID-19 protocols, concerns of seeking healthcare due to COVID-19 exposure risk, and families having to quarantine due to exposure to COVID-19. Although healthcare was considered an essential service, some audiology facilities were required by the state or opted to cancel several weeks' worth of patient appointments when *stay at home* orders were initially put in place throughout the United States (Kornak, 2020). Limited availability of pediatric audiology services in some areas (e.g., rural) was already an issue pre-2020 and likely became more of a challenge during COVID-19. Although the expanded use of telehealth for audiology during the pandemic helped address the issue, families of infants needing diagnostic evaluation would still have had to travel to a location with the appropriate equipment so that an aide/technician could place the necessary electrodes for testing on the infant for the audiologist to remotely conduct the necessary test(s) from their office. Additionally, many audiology providers reduced the overall number of patients seen to allow for spacing of patients and increased disinfecting protocols (Kornak, 2020). Despite the additional measures providers were taking to reduce transmission of COVID-19 in healthcare facilities, many families still opted to delay healthcare (Czeisler et al., 2020). As of June 30, 2020, an estimated 41% of U.S. adults reported having delayed or avoided medical care during the pandemic due to concerns about COVID-19 (Czeisler et al., 2020).

Although the percentage of children enrolled in intervention programs did not decline dramatically during 2020 proportionately, the ability of intervention programs

to conduct assessments and services virtually may have helped minimize disruptions in services and any impact on benchmark performance compared to previous years. However, offering virtual only intervention may have negatively impacted communities (e.g., rural) that do not have access to high-speed internet even if it may have helped address the issue of limited transportation already present before the pandemic (Ekezue et al., 2021). Due to limitations of aggregated data reported through the HSFS, communities most impacted could not be determined.

EHDI programs generally operate within the jurisdiction's public health agency, which was usually the same agency that led the COVID-19 response. Many jurisdictions deployed EHDI staff to Public Health Emergency Teams, which led to less time for EHDI staff to provide care coordination for infants and families. Epidemiological support, necessary for EHDI programs to monitor and analyze performance, could also have been limited and delayed if epidemiologists were diverted to provide immediate and ongoing needs for COVID-19 surveillance activities. A fully functioning and up-to-date EHDI Information System (EHDI-IS) is essential to EHDI programs and their ability to perform tracking and surveillance. During the pandemic, building, enhancing, and maintaining a new module/database to support COVID-19 surveillance was often a top priority. Consequently, previously planned maintenance and enhancements for EHDI-IS were often deferred, causing further disruptions to EHDI program activities.

Implications for Practice, Policy, and Future Research

This article highlights disruptions to the provision of EHDI services nationwide during the first year of the COVID-19 pandemic. To help address these disruptions and ensure all infants and young children received recommended services, jurisdictional EHDI programs and providers initiated new strategies to adapt to the context of the pandemic to preserve the ability to serve children and families. Strategies included developing specific guidance for establishing newborn hearing screening and follow-up as an essential service not to be delayed due to COVID-19, increasing the use of telehealth to provide intervention services (Anckner & Frew, 2022), and upgrading their EHDI-IS to improve the timeliness of referrals and better support child find activities.

Moving forward, EHDI programs can consider reaching out to primary care physicians about the importance of knowing the status of newborn hearing screen results on infants born in 2020 and beyond. Primary care doctors can also encourage families to complete recommended diagnostic audiological examinations and seek evaluation for enrollment into intervention programs if concerns about hearing or other core areas of development are present. EHDI programs can continue and expand collaborations with other agencies and programs to engage families needing follow-up services. The use of existing EHDI-IS can support efforts to identify children in need of services. In addition, although the pandemic moved into a second year in 2021 and likely continued to impact the timely

provision and receipt of services, jurisdictional EHDI programs and healthcare providers have continued to actively support and work with families to navigate the EHDI process. CDC, along with other federal and national partners, recognize the unique challenges posed by COVID-19 pandemic for jurisdictional EHDI programs and healthcare providers. Although the COVID-19 pandemic impacted the receipt and timeliness of some EHDI services, over 6,000 infants with permanent hearing loss born in 2020 were nonetheless successfully identified early through newborn screening. The near universal hearing screening of newborns represents an important public health prevention program that is withstanding the many pressures of the COVID-19 pandemic. Families and professionals can continue to work together to ensure that all the infants and toddlers with signs of hearing loss receive the diagnostic and intervention services they need.

References

- Anckner, S., & Frew, B. (2022). AMCHP Cares Act awardees use telehealth to improve care during the pandemic and beyond—Highlights from three states. <https://amchp.org/amchp-cares-act-awardees-use-telehealth-to-improve-care-during-the-pandemic-and-beyond-highlights-from-three-states/>
- Association of Public Health Libraries. (n.d.). Newsteps: Newborn screening covid-19 challenges and response webinar. <https://www.newsteps.org/resources/webinars-events/newborn-screening-covid-19-challenges-and-response-webinar>
- Centers for Disease Control and Prevention. (n.d.). Annual Data: Early hearing detection and intervention (EHDI) program. <https://www.cdc.gov/ncbddd/hearingloss/ehdi-data.html>
- Czeisler, M., Marynak, K., Clarke, K., Salah, Z., Shakya, I., Thierry, J., Ali, N., McMillan, H., Wiley, J., Weaver, M., Czeisler, C., Rajaratnam, S., & Howard, M. (2020). Delay or avoidance of medical care because of COVID-19-related concerns—United States, June 2020. *MMWR: Morbidity and Mortality Weekly Report*, 69(36):1250–1257. <https://doi.org/10.15585/mmwr.mm6936a4>
- Ekezue, B. F., Bushelle-Edghill, J., Dong, S., & Taylor, Y. J. (2021). The effect of broadband access on electronic patient engagement activities: Assessment of urban-rural differences. *Journal of Rural Health*, 38(3), 472–481. <https://doi.org/10.1111/jrh.12598>
- Executive Office of the President. (2020). Declaring a national emergency concerning the novel coronavirus disease (COVID-19) outbreak. <https://www.federalregister.gov/documents/2020/03/18/2020-05794/declaring-a-national-emergency-concerning-the-novel-coronavirus-disease-covid-19-outbreak>
- Greene, N. H., Kilpatrick, S. J., Wong, M. S., Ozimek, J. A., & Naqvi, M. (2020). Impact of labor and delivery unit policy modifications on maternal and neonatal outcomes during the coronavirus disease 2019 pandemic. *American Journal of Obstetrics and Gynecology: Maternal Fetal Medicine*, 2(4), 100234. <https://doi.org/10.1016/j.ajogmf.2020.100234>
- Joint Committee on Infant Hearing. (2019). Year 2019 position statement: Principles and guidelines for early hearing detection and intervention programs. *Journal of Early Hearing Detection and Intervention*, 4(2), 1–44. <https://doi.org/10.15142/fptk-b748>
- Kornak, J. (2020). COVID-19 and audiology: Closed practices, empty campuses, halted research. *Leader Live*. <https://leader.pubs.asha.org/doi/10.1044/covid-19-and-audiology-closed-practices-empty-campuses-halted-research/full/>
- Morton, C. C., & Nance, W. E. (2006, May 18). Newborn hearing screening—A silent revolution. *New England Journal of Medicine*, 354(20), 2151–2164. <https://doi.org/10.1056/NEJMra050700>
- Vohr, B. (2003). Overview: Infants and children with hearing loss—part I. *Mental Retardation and Developmental Disabilities Research Reviews*, 9(2), 62–64. <https://doi.org/10.1002/mrdd.10070>

Assessing Impact of COVID-19 Pandemic on Receipt and Timeliness of Newborn Hearing Screening and Diagnostic Services Among Infants Born in Four States

Suhana Ema, MPH¹
 Sana Charania, MPH¹
 Xidong Deng, PhD¹
 Charles Rose, PhD¹
 Craig A. Mason, PhD²
 Marcus Gaffney, MPH¹
 Brandt Culpepper, PhD³
 Michael Lo, MSPH³
 Tri Tran, MD⁴
 Kirsten Coverstone, AuD⁵
 Marcia Fort, AuD⁶

¹National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA

²University of Maine, Orono, ME

³Georgia Early Hearing Detection and Intervention, Atlanta, GA

⁴Louisiana Early Hearing Detection and Intervention, New Orleans, LA

⁵Minnesota Early Hearing Detection and Intervention, St. Paul, MN

⁶North Carolina Early Hearing Detection and Intervention, Raleigh, NC

Abstract

The study compares receipt and timeliness of newborn hearing screening and follow-up diagnostic services between the pre-pandemic birth cohort and the pandemic birth cohort in four participating states. Findings from this study will help inform state Early Hearing Detection and Intervention (EHDI) programs in the future should a major public health event occur again.

Keywords: pandemic, hearing loss, newborn hearing screening, audiology, EHDI, diagnostic evaluation

Acronym: EHDI = Early Hearing Detection and Intervention

Disclosures: The findings and conclusions in this report are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention. The authors declare no conflicts of interest.

Acknowledgements: The data used in this study were provided by the following state EHDI programs: Georgia, Louisiana, Minnesota, and North Carolina. These programs are funded under the CDC-RFA-DD20-2006 cooperative agreement. CDC thanks the state EHDI programs for their input when drafting and reviewing the manuscript.

Correspondence concerning this article should be addressed to: Suhana Ema, MPH, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia. Email: sema@cdc.gov

On March 13, 2020, the United States declared a national emergency in response to the COVID-19 pandemic (Federal Emergency Management Agency, 2020). Across the nation, lockdowns and stay-at-home orders were issued to reduce the spread of COVID-19. This caused disruption to the U.S. health care system, specifically the delivery and receipt of health care services due to closures or reduced hours of facilities and, in at least some cases, families declining or delaying in-person appointments. One study published in May 2020 found the total diagnostic imaging volume significantly declined by 12.3% during the first 16 weeks of 2020 compared with 2019 (Naidich et al., 2020). A different study found that emergency

department visits declined by 42% during early months of the COVID-19 pandemic, compared to the same period in 2019 (Hartnett et al., 2020).

The purpose of this study was to assess the impact of the COVID-19 pandemic on Early Hearing Detection and Intervention (EHDI) services, specifically timeliness and receipt of newborn hearing screening and follow-up audiological diagnostic services among infants born in 2020. Findings from this study are intended to inform efforts at the state level as well as provide partners with a better understanding of how the COVID-19 pandemic impacted the EHDI process and to help guide future program improvement activities.

Method

Four states (Georgia, Louisiana, Minnesota, and North Carolina) were selected to participate in this study for their successful experience in reporting detailed child-level data to the Centers for Disease Control and Prevention (CDC). Child-level, de-identified datasets were extracted from the states' EHDI information systems and submitted to the CDC for analysis. Within each state, two cohorts of births were identified. The pre-pandemic birth cohort consists of 373,058 infants born between November 1, 2018 and October 31, 2019. The pandemic cohort consists of 364,530 infants born between November 1, 2019 and October 31, 2020. Although this predates the start of the pandemic, children with hearing loss born at the end of 2019 would have been impacted in early 2020 when many would typically be receiving diagnostic evaluations.

Analysis

We assessed the monthly percentage of (a) hearing screening by one month of age among newborns and (b) receipt of diagnostic evaluation by three months of age among infants who referred (e.g., failed) the hearing screen, before and during the pandemic. Screening and diagnostic evaluation by one and three months of age were examined because they represent key national benchmarks within the EHDI process (JCIH, 2007, 2019). We also examined the refer rate from the newborn hearing screen for each state, before and during the pandemic. Additionally, we generated Kaplan–Meier curves to assess receipt and timeliness to the start of the diagnostic evaluation process among infants who referred from the newborn hearing screening (see Appendix). If

the diagnostic evaluation date was available, the time to diagnostic evaluation was calculated as the number of days from the most recent referred hearing screen to the date of the first reported diagnostic evaluation. The time to event was set at 180 days (i.e., censored at 180 days). Although the recommended benchmark for infants to receive a diagnostic evaluation after referral from the hearing screen is by 90 days of age, we added an additional 90 days to allow for capturing infants who may have received an evaluation beyond the recommended 90 days of age. Infants who died ($n = 3,168$) or moved out of their birth state ($n = 736$) were excluded from the study because the date of when they died or moved was not available, hence it was not possible to censor them at appropriate times for the Kaplan–Meier analyses. The pre-pandemic and pandemic curves were constructed and compared using the log–rank test. P -values < 0.05 were considered statistically significant. Data analyses were performed using SAS version 9.4 software (SAS Institute Inc., Cary, NC, USA).

Results

As illustrated in Figure 1, the percentage of newborns screened by one month of age was largely unaffected by the pandemic, with rates of 95.1% to 96.7% pre-pandemic and 94.6% to 96.1% during the pandemic. However, while screening rates were minimally impacted by the pandemic, a significant increase in refer rates was observed ($z = 9.598$, $p < .0001$; see Table 1). Overall, prior to the pandemic 1.39% of screens in the participating states resulted in a referral. During the pandemic this grew to 1.66%, with increases in three of the four states.

Figure 1

Receipt of Hearing Screening by One Month of Age by Birth Month and Cohort

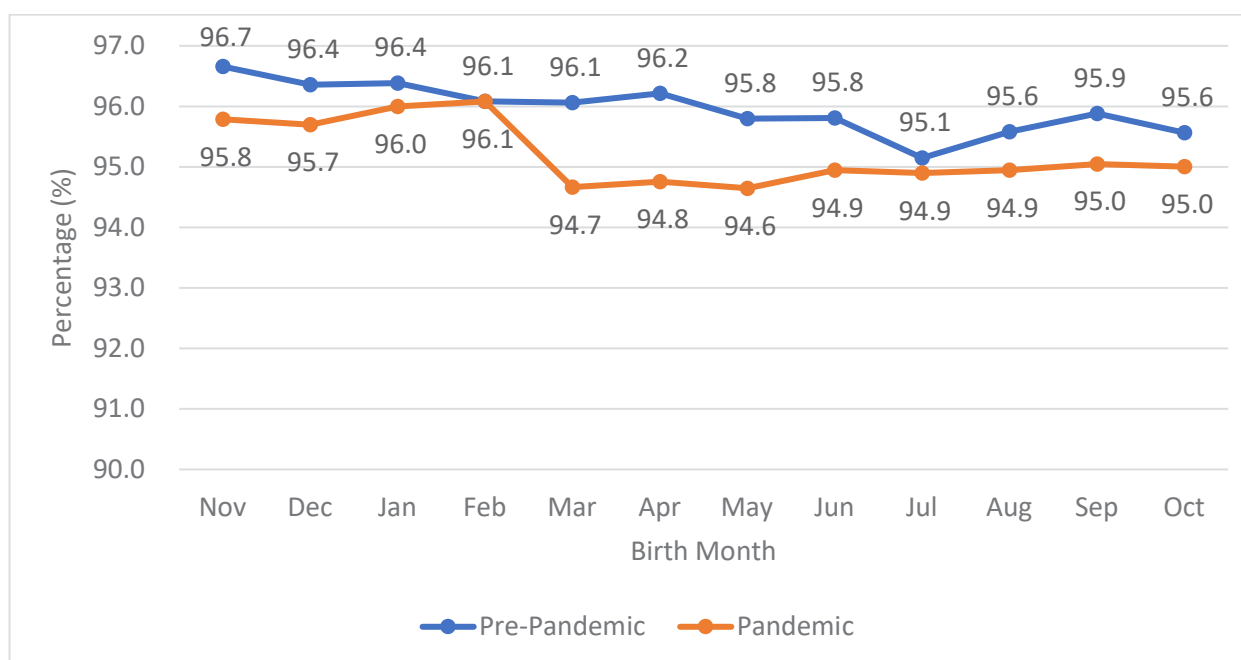


Table 1

Refer Rate from Newborn Hearing Screening by State and Cohort

	Pre-Pandemic				Pandemic			
	Total Births	Infants Screened	Infants Referred	Percent Infants Referred	Total Births	Infants Screened	Infants Referred	Percent Infants Referred
Georgia	128,945	123,681	2,106	1.7%	125,732	119,260	2,543	2.1%
Louisiana	58,545	58,292	1,140	2.0%	57,006	56,597	868	1.5%
Minnesota	65,469	64,825	834	1.3%	63,005	62,358	1,333	2.1%
N. Carolina	120,099	119,816	1,000	0.8%	118,787	118,387	1,184	1.0%

Note. Refer Rate (%) = (Infants Referred/Infants Screened) x 100.

As summarized in Table 2, this increase in referral rates was also associated with an increase in the time between referral and diagnostic evaluation for each of the four states (all p values < .05). For three of the states, the median time between referral and diagnostic evaluation increased by 11 to 31 days. In Georgia, less than half of referrals received a documented diagnostic evaluation making the median uninformative. Therefore, Table 2 reports time-to-evaluation in Georgia based on the 25th percentile—with the time more than doubling during the pandemic.

Figure 2 illustrates the percentage of newborns referred for diagnostic testing who received their diagnostic evaluation by the recommended three months of age. This is presented based on a child's birth month and cohort. For example, 35.9% of the children born in January 2020 who referred on their newborn hearing screen received their diagnostic evaluation by three months of age, while 46.2% of similar children in 2019 did so.

Finally, a Kaplan-Meier curve was generated showing the cumulative rate (percent) of diagnostic evaluation after referring from the most recent hearing screening for babies in the four states combined. Infants who received a diagnostic evaluation beyond 180 days of age, as well as those with no documented evaluation (i.e., either the baby never received an evaluation or they received an evaluation but it was not documented) were censored at 180 days. Separate curves are presented based on pre-pandemic/pandemic cohort.

As seen in Figure 3, pre-pandemic babies were evaluated sooner than babies impacted by the pandemic. Nearly half (49%) of the pre-pandemic infants compared to around 40% of the infants impacted by the pandemic were evaluated by three months of age ($p < 0.0001$).

Discussion

Figure 2 shows that overall, 15% more pre-pandemic infants who were referred from the hearing screen received a diagnostic evaluation by three months of age, compared to infants impacted by the pandemic. The

Table 2

Median time between Referred Hearing Screen and Diagnostic Evaluation Based on State and Cohort

Georgia		
	Pre-Pandemic ($n = 2,034$)	Pandemic ($n = 2,486$)
Median (days)	n/a	n/a
25th Percentile (days)	74	166
Number of events	635	632
Number censored	1,399	1,854
Louisiana		
	Pre-Pandemic ($n = 1,117$)	Pandemic ($n = 849$)
Median (days)	37	48
25th Percentile (days)	21	23
Number of events	796	575
Number censored	321	274
Minnesota		
	Pre-Pandemic ($n = 795$)	Pandemic ($n = 1,279$)
Median (days)	42	75
25th Percentile (days)	19	25
Number of events	533	709
Number censored	262	570
North Carolina		
	Pre-Pandemic ($n = 948$)	Pandemic ($n = 1,137$)
Median (days)	48	69
25th Percentile (days)	21	25
Number of events	677	694
Number censored	271	443

Figure 2

Receipt of Evaluation by Three Months of Age Among Referred Newborns, by Birth Month and Cohort

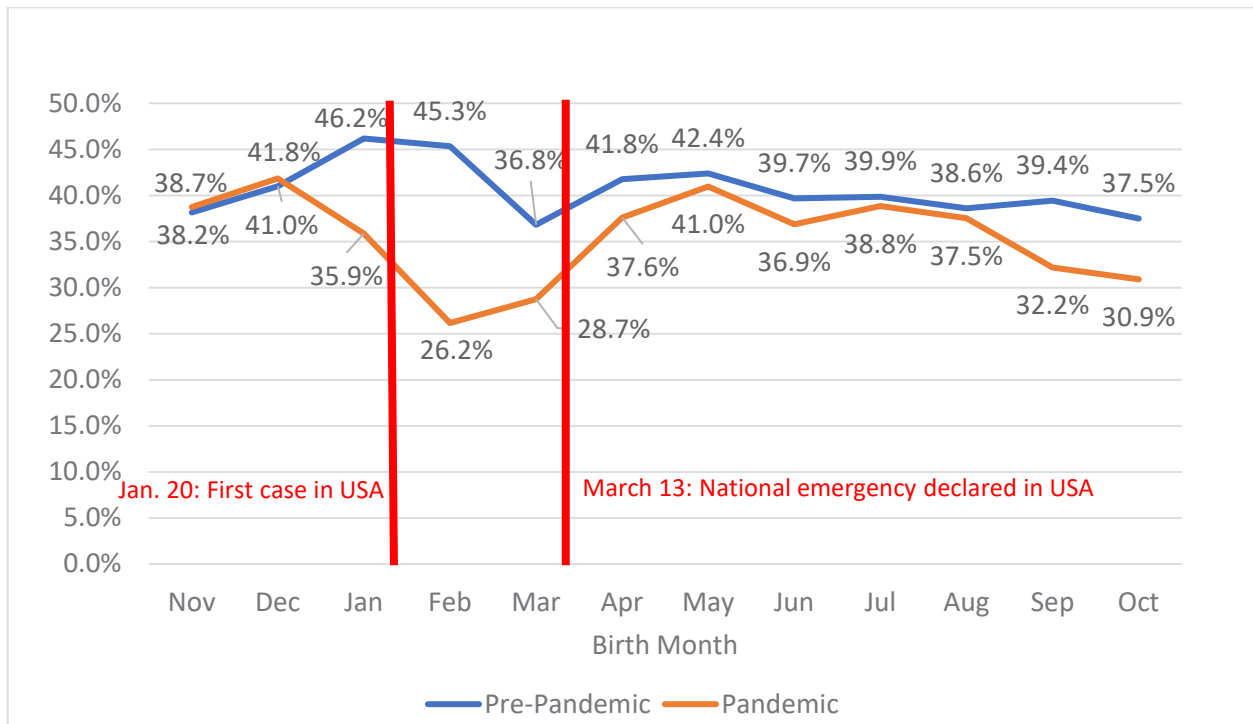
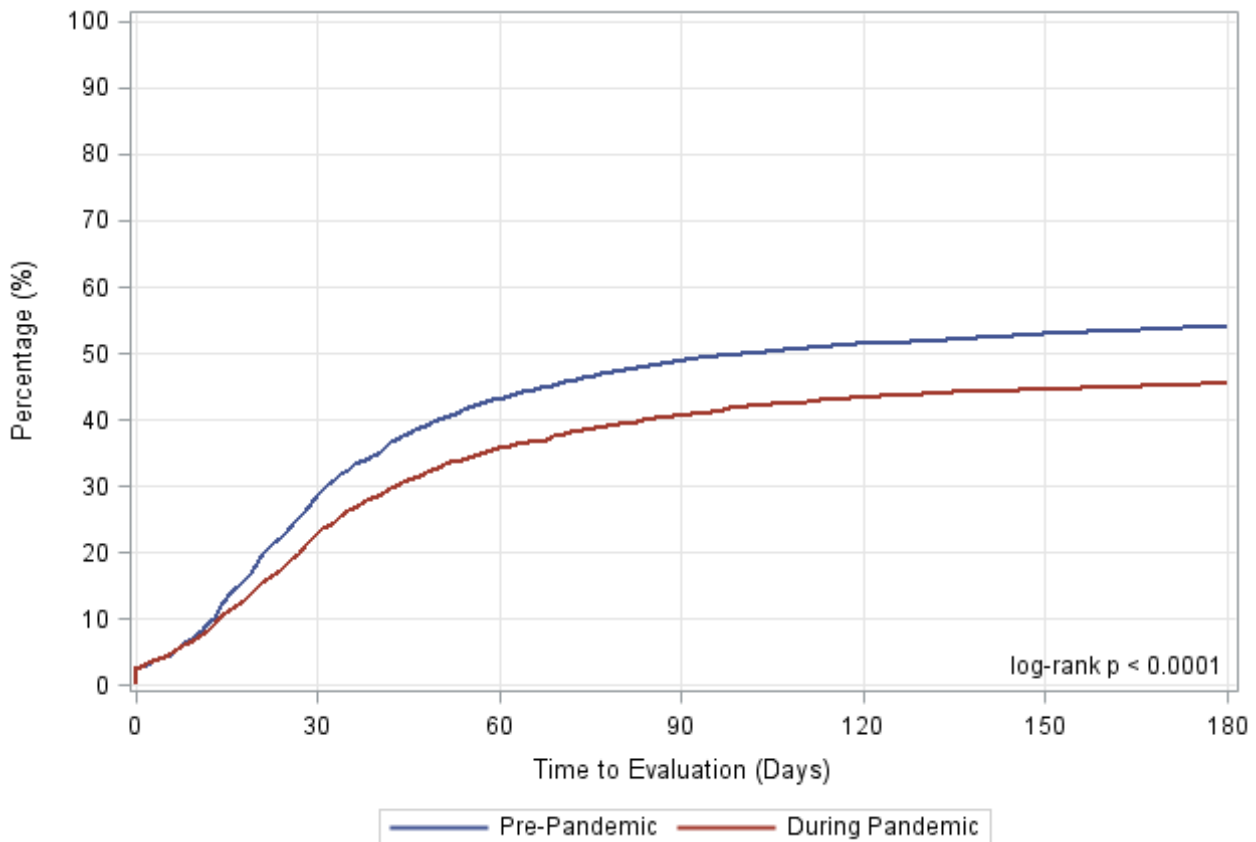


Figure 3

Four States Combined: Receipt and Timeliness of Diagnostic Evaluation After Referring from the Most Recent Hearing Screening



largest difference in the evaluated-by-three-months rates between the pre-pandemic and pandemic period was observed for February births. February was the birth month having the lowest reported receipt of evaluation by three months of age (26.2%) during the pandemic period, compared to 45.3% of pre-pandemic February births. This difference was likely due to audiology facilities being closed or operating at limited hours, which occurred across the nation during the pandemic. It may also reflect safety concerns among families about bringing infants for in-person appointments, especially during the first few months of the pandemic. The pandemic trend picks up relatively quickly for infants born after March 2020 and appears to stabilize for infants born between May and August 2020, possibly as states started to ease restrictions/lifted the stay-at-home orders. The trend fell off with September and October 2020 births, coinciding with large spike in COVID-19 cases at the end of the year.

Minnesota's refer rate increased noticeably during the pandemic period compared to before the pandemic (Table 1). According to a nationally representative study, short birth hospital stays (vaginal birth < 2 nights' stay; cesarean birth < 3 nights' stay) among new mothers and infants was 51% more common during the pandemic period than pre-pandemic (Handley et al., 2022). Short hospital stays can translate to a lower probability of infants who do not pass their initial screen receiving a rescreen before discharge. This could in part explain the high refer rate for Minnesota during the pandemic period. Staffing issues are another possible explanation. Hospitals across the country experienced staffing issues during the pandemic period. Staffing issues include staff being sick or having to quarantine due to exposure, staff calling out because of exhaustion, or reassignments. The aforementioned issues can potentially result in less experienced or different staff performing the newborn screens (Koracin et al., 2022), which could have played a role in the observed high refer rate during pandemic.

Figure 3 and Table 2 show increase in time to diagnostic evaluation after referring from the hearing screen. This could be due to state lockdown policies, diagnostic facilities being closed or operating at limited hours (especially early in the pandemic), and families' preference to delay in-person appointments due to exposure concerns.

Conclusion

All four participating states reported a decline in the receipt of infant audiological evaluation services and longer time to audiological evaluation after not passing the hearing screen during the first year of the COVID-19 pandemic. This information is of critical importance because there are long-term consequences for young children with unidentified or late identified permanent hearing loss, such as delayed language and cognitive development (JCIH, 2000). Should major public health events occur again in the future, state EHDI programs can work with partners to help minimize these consequences and expand follow-up efforts to ensure infants not passing the hearing screen

receive recommended services in a timely manner. These include developing specific guidance establishing that newborn hearing screening and follow-up should be considered an essential service and should not be delayed by the event, upgrading their EHDI information systems to improve the timeliness of referrals and better support child-find activities, and actively reaching out to primary care physicians about the importance of knowing the newborn hearing screen results on infants born during the event. Health care providers (e.g., physicians, hearing screeners) can continue to take the time to educate families about the importance of seeking recommended follow-up services as soon as possible when infants fail the hearing screening. In addition, use of tele-audiology services, where audiological evaluations are provided remotely, can be increased in the next public health event. However, use of tele-audiology needs improvement as it does not address families' concern about exposure during in-person appointments. The families of infants needing diagnostic evaluation would still have to travel to a location with the appropriate equipment so that a technician could place the necessary electrodes on the infant for the audiologist to be able to remotely conduct the necessary evaluation(s) from their office. This issue should be further explored because, if resolved, families may be comfortable in using tele-audiology services and we may see increase in use of these services should the next public health event occur. Finally, there are currently no similar published studies assessing timeliness from any type of newborn screening to follow-up care before and during the pandemic. To our knowledge, our study is the first of its kind. Consequently, these findings may inform other newborn programs beyond hearing screening.

Limitations

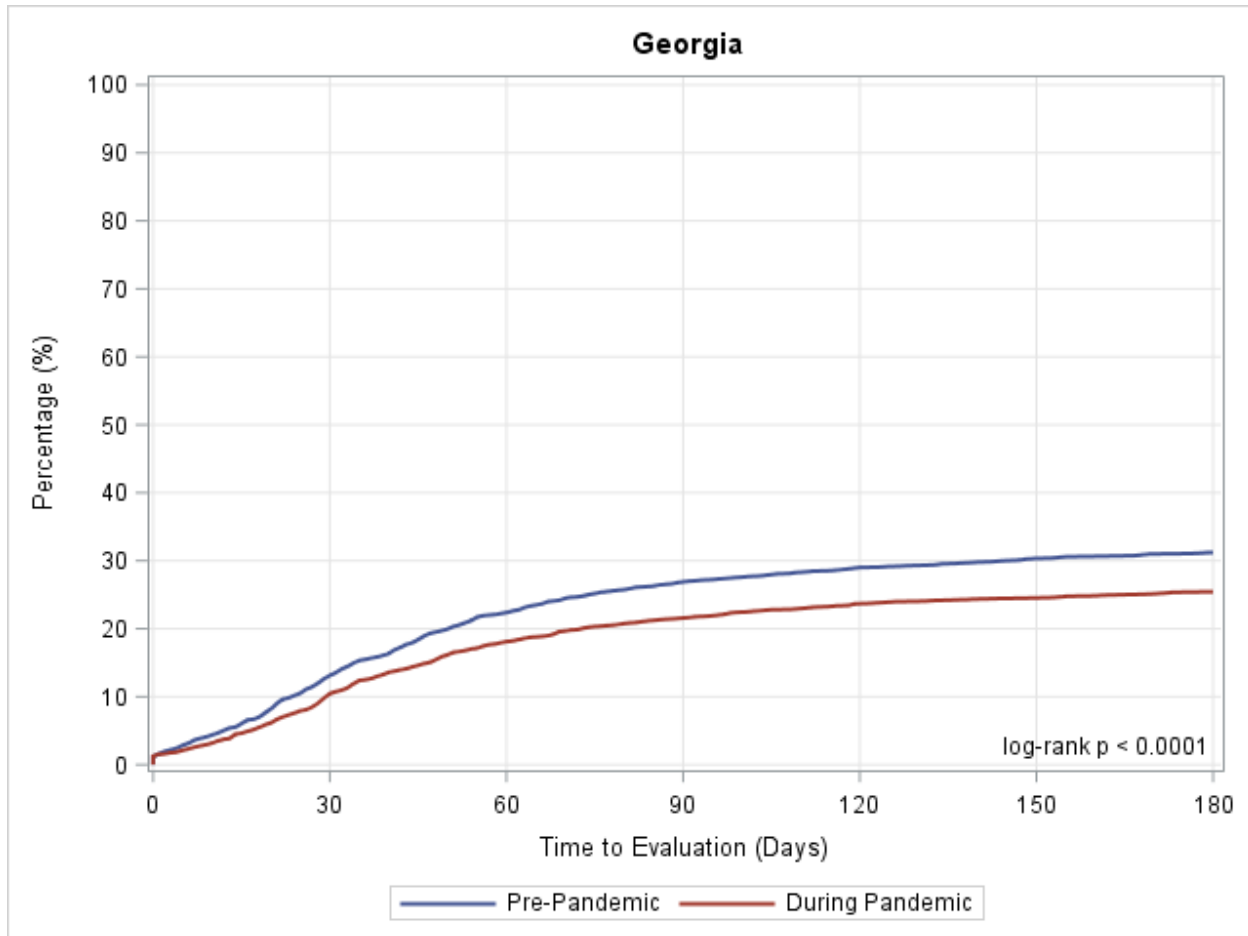
There are at least four limitations of this study. First, the study is not nationally representative as it reflects only data from four states. Future analyses including more states may be of interest. Second, the infants who died or moved out of the participating state were excluded from the study due to dates of death or when unavailable due to a family move. If this information were available, the affected infants would be censored at appropriate times in the Kaplan-Meier analysis and the curves may change (e.g., higher curve to reflect higher receipt of diagnostic evaluation). Third, there may be infants who did receive services, but it was not documented in the state EHDI information system (e.g., lost to documentation). Loss to documentation contributed to an unknown portion of missing data in diagnostic information. All missing diagnostic data were treated as negative responses (e.g., not evaluated) and therefore these findings report a lower-end estimate of the true diagnostic evaluation rate. And lastly, we were not able to assess the possible impact of COVID-19 pandemic on the receipt and timeliness of early intervention enrollment in the four participating states because complete early intervention information for infants born in 2020 were not yet available at the time of the study.

References

- Federal Emergency Management Agency. (2020). *Bringing resources to state, local, tribal & territorial governments*. United States Department of the Homeland Security, Federal Emergency Management Agency.
<https://www.fema.gov/coronavirus/governments>
- Handley, S. C., Gallagher, K., Breden, A., Lindgren, E., Lo, J. Y., Son, M., Murosko, D., Dysart, K., Lorch, S. A., Greenspan, J., Culhane, J. F., Burris, H. H. (2022). Birth hospital length of stay and rehospitalization during COVID-19. *Pediatrics*, *149*(1), e2021053498.
<https://doi.org/10.1542/peds.2021-053498>
- Hartnett, K. P., Kite-Powell, A., DeVies, J., Coletta, M. A., Boehmer, T. K., Adjemian, J., Gundlapalli, A. V., & National Syndromic Surveillance Program Community of Practice. (2020). Impact of the COVID-19 pandemic on emergency department visits—United States, January 1, 2019–May 30, 2020. *Morbidity and Mortality Weekly Report*, *69*, 699–704.
<http://doi.org/10.15585/mmwr.mm6923e1>
- Koracin, V., Loeber, J. G., Mlinaric, M., Battelino, T., Bonham, J. R., & Groselj, U. (2022). Global impact of COVID-19 on newborn screening programmes. *BMJ Global Health*, *7*, e007780.
<https://doi.org/10.1136/bmjgh-2021-007780>
- Joint Committee on Infant Hearing. (2000). Year 2000 position statement: Principles and guidelines for Early Hearing Detection and Intervention programs. *American Journal of Audiology*, *9*(1), 9–29.
[https://doi.org/10.1044/1059-0889\(2000/005\)](https://doi.org/10.1044/1059-0889(2000/005))
- Joint Committee on Infant Hearing. (2007). Year 2007 position statement: Principles and guidelines for Early Hearing Detection and Intervention programs. *Pediatrics*, *120*(4), 898–921.
- Joint Committee on Infant Hearing. (2019). Year 2019 position statement: Principles and guidelines for Early Hearing Detection and Intervention programs. *Journal of Early Hearing Detection and Intervention*, *4*(2), 1–44.
<https://doi.org/10.15142/fptk-b748>
- Naidich, J. J., Boltyenkov, A., Wang, J. J., Chusid, J., Hughes, D., & Sanelli, P. C. (2020). Impact of the Coronavirus Disease 2019 (COVID-19) pandemic on imaging case volumes. *Journal of the American College of Radiology*, *17*(7), 865–872.

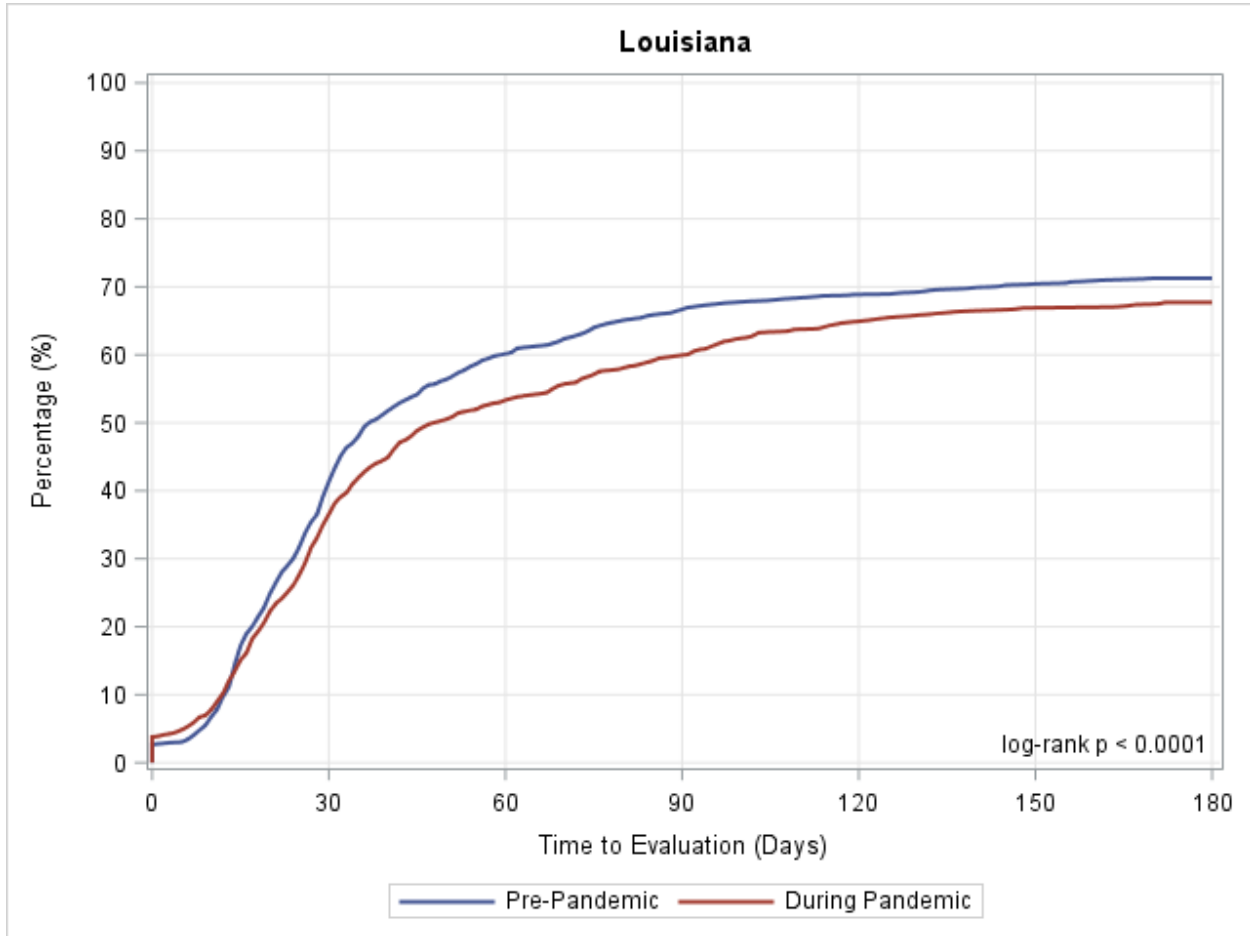
Appendix

Kaplan–Meier curves to assess receipt and timeliness to the start of the diagnostic evaluation process among infants who referred from the newborn hearing screening. Each state is represented by its own graph.



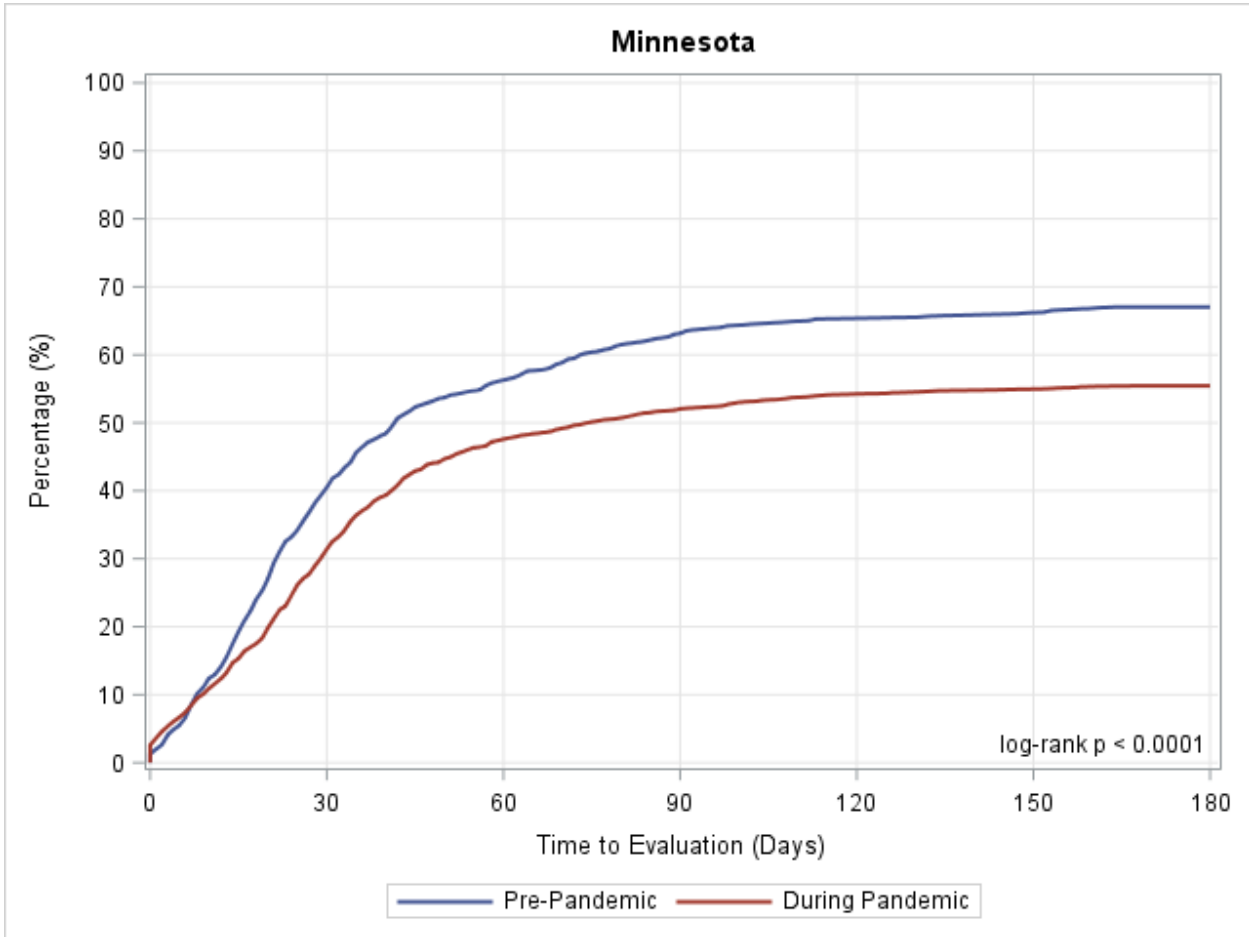
Georgia	Pre-Pandemic ($n = 2,034$)	Pandemic ($n = 2,486$)
Median (days)	n/a	n/a
25th Percentile (days)	74	166
Number of events	635	632
Number censored	1,399	1,854

Appendix (contd.)



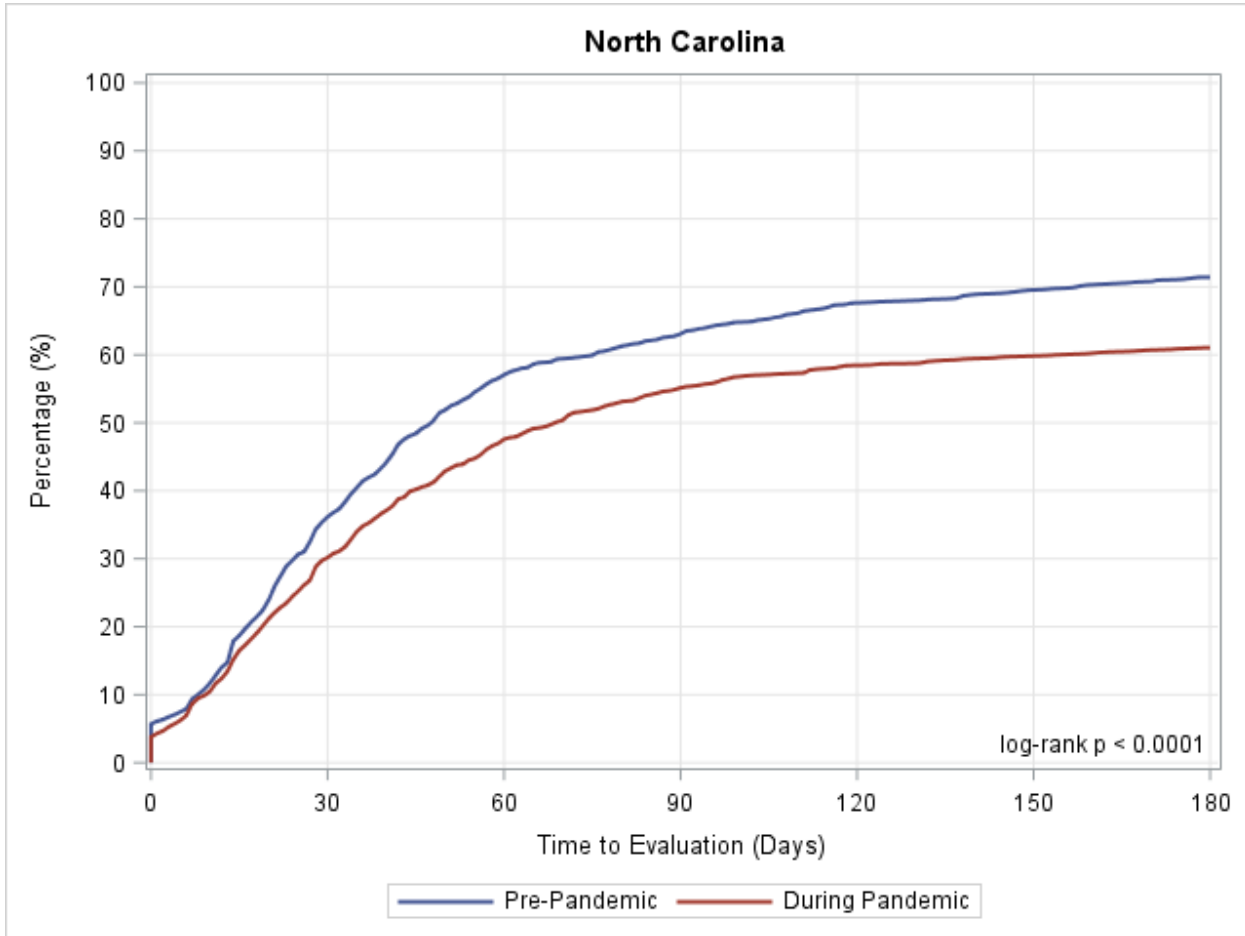
Louisiana	Pre-Pandemic ($n = 1,117$)	Pandemic ($n = 849$)
Median (days)	37	48
25th Percentile (days)	21	23
Number of events	796	575
Number censored	321	274

Appendix (contd.)



Minnesota	Pre-Pandemic ($n = 795$)	Pandemic ($n = 1,279$)
Median (days)	42	75
25th Percentile (days)	19	25
Number of events	533	709
Number censored	262	570

Appendix (contd.)



North Carolina	Pre-Pandemic ($n = 948$)	Pandemic ($n = 1,137$)
Median (days)	48	69
25th Percentile (days)	21	25
Number of events	677	694
Number censored	271	443

Impact of Social Determinants of Health on Early Hearing Detection and Intervention Screening/Diagnosis Outcomes

Nannette Nicholson, PhD¹

Ellen A. Rhoades, EdS²

Rachel E. Glade, PhD³

Laura Smith-Olinde, PhD⁴

¹Nova Southeastern University, Ft. Lauderdale, FL

²Private Practice, Plantation, FL

³University of Arkansas, Fayetteville, AR

⁴University of Arkansas for Medical Sciences, Little Rock, AR

Abstract

Purpose: We reviewed how Social Determinants of Health relate to health inequities and disparities for Early Hearing Detection and Intervention (EHDI) programs. Then, we examined links between specific sociodemographic factors (maternal age, maternal education, race/ethnicity) and hearing screening and diagnostic audiology follow-up for newborns in the United States and its territories.

Methods: Maternal demographic, hearing screening, and diagnostic data extracted from publicly available Centers for Disease Control and Prevention (CDC) records were reported to CDC by personnel responsible for EHDI programs. Data were subjected to statistical analysis using analysis of variance and multiple regression techniques.

Results: Results showed no significant differences in screening follow-up outcomes for maternal age, education, or race/ethnicity. There was a significant difference for maternal education and race/ethnicity for diagnostic follow-up outcomes, but not for maternal age.

Conclusion: Results of this study are consistent with the findings of previous studies regarding hearing screening follow-up and diagnostic audiology follow-up outcomes. Maternal education and race/ethnicity were linked to hearing diagnostic audiology follow-up for newborns in the United States and its territories. Suggestions for future research, policy, and practice to improve the effectiveness of EHDI efforts are provided.

Key Words: newborn hearing screening, diagnosis, Early Hearing Detection and Intervention, Social Determinants of Health, health disparities

Acronyms: CDC = Centers for Disease Control and Prevention; EHDI = Early Hearing Detection and Intervention; HSFS = Hearing Screening and Follow-Up Survey; IS = Information Systems; LTF/D = loss-to-follow-up/loss to documentation; SDoH = Social Determinants of Health

Acknowledgements: We have no conflicts of interest to disclose. No funding was received for this project.

Correspondence concerning this article should be addressed to: Nannette Nicholson, PhD, Department of Audiology, Ziff Building, 3200 S. University Drive, Ft. Lauderdale, FL 33328; Email: nnichols@nova.edu

The Early Hearing Detection and Intervention (EHDI) system, established to identify infants with hearing loss and to minimize long-term adverse effects that can result from unidentified congenital or early onset hearing loss, directly benefits American families across the 50 U.S. states and territories. EHDI's precise goals are screening for hearing loss by age 1 month/30 days, diagnosis by age 3 months/90 days for those not passing the screening, and enrollment in early intervention services by age 6 months/180 days for those identified with a hearing loss (Centers for Disease Control and Prevention [CDC], n.d.c; Joint Committee on Infant Hearing [JCIH], 2019). These

1-3-6 goals are known as the National EHDI Goals (CDC, 2003; CDC, n.d.a; National Center for Hearing Assessment and Management [NCHAM], n.d.).

The benchmark goal for newborn hearing screening was set as 95% by one-month chronological age, with a follow-up target of 70% (JCIH, 2000). With little data available from which to gauge a realistic benchmark, the JCIH set 100% as the goal for verification of hearing loss by three months of age. Each step of the process brings with it a transition of services between healthcare providers, agencies, and systems, presenting ample opportunities for

loss-to-follow-up/loss to documentation (LTF/D). Although the EHDI process is a national initiative, its programs are implemented and administered at state and territory levels, with each entity contributing aggregate data through the CDC's annual Hearing Screening and Follow-Up Survey (HSFS; Nicholson et al., 2022) which is used to help assess progress in EHDI. Laws and regulations related to the reporting of screening and diagnostic data vary by state/territory. The HSFS data is voluntarily reported public health data collected annually by the CDC and is available via a public website (CDC, n.d.c). Unique strengths and weaknesses within each jurisdiction influence reported outcomes for the EHDI program.

Social Determinants of Health (SDoH)

Social determinants of health (SDoH) are non-medical variables or environmental conditions influencing health outcomes (Matiz et al., 2022). The circumstances in which people are born, grow, live, play, work, and age constitute the SDoH (World Health Organization [WHO] and Commission on Social Determinants of Health, 2008). Having sufficient financial resources linked to economic stability, accessibility to quality education and healthcare, safe home and school environments, and accessibility to play areas within the social and community context are primary domains of SDoH (U.S. Department of Health and Human Services [DHHS], n.d.). Together, these factors influence the health and well-being of all individuals, influencing differences in sociodemographic variables as well as contributing to health disparities and inequities. (e.g., Erikson et al., 2022).

Health Inequities and Health Disparities

It is important to understand the difference between health inequities and health disparities; ambiguity might lead to misdirection of resources (Braveman, 2014). Health **inequities** refers to *inequalities* or differences in treatment due to being marginalized or minoritized (e.g., those who are resource-constrained or not identified as white or residing in rural communities). On the other hand, health **disparities** refer to outcome differences largely due to the impact that SDoH have on specific populations, irrespective of service provider treatment (e.g., Florentine et al., 2022; Schuh & Bush, 2021).

Hearing health disparities among children contribute to poorer outcomes. Children with hearing loss from certain ethnic or impoverished backgrounds or from specific geographic regions have been significantly delayed in diagnosis and intervention (Barr et al., 2019; Boss et al., 2011; Bush et al., 2013; Bush, Bianchi, et al., 2014; Bush, Osetinsky, et al., 2014; 2017; Parker et al., 2020). Children with hearing loss are more likely to live in poverty and not take advantage of hearing health services (Boss et al., 2011; Emmett & Francis, 2014; Linton et al., 2019). Hearing health services seem either less likely to be sufficient or not provided at all to some children with hearing loss from marginalized or non-white groups (e.g., Bush et al., 2017; Ely & Driscoll, 2019; Linton et

al., 2019; Liu et al., 2020; Nieman, Marrone, et al., 2016; Nieman, Tunkel, et al., 2016; Okolie et al., 2020; Qian et al., 2021; Tolani et al., 2017; Zhang et al., 2019). The first two decades of this century often placed non-white American children at distinct disadvantages (Cooc & Kiru, 2018; Love & Beneke, 2021; McManus et al., 2010; Morgan et al., 2017; Park et al., 2021; Parker et al., 2020; Thorne et al., 2019). Hearing health disparities are linked to identification/diagnosis of hearing loss, use of hearing devices, and medical treatment of hearing-related issues that include cochlear implantation (e.g., Liu et al., 2020; Okolie et al., 2020; Peltz et al., 2021; Zhang et al., 2021).

Sociodemographic Factors

Sociodemographic data are the classifiable characteristics of a given population (e.g., age, gender, race, ethnicity), commonly used in public health surveys and reports. Sociodemographic characteristics may impact outcomes among young children with hearing loss by influencing a primary caregiver's ability to: (a) acquire knowledge about the value of early identification of hearing loss, (b) communicate effectively with hearing healthcare providers, and (c) obtain effective social support for securing audiological diagnosis. Researchers often consider sociodemographic factors as predictors or independent variables used in regression analyses (Salkind, 2010).

Sociodemographic Variables

A *sociodemographic variable* is any variable that relates to or involves a combination of social and demographic factors which can significantly influence mental and physical health or intervention outcomes. For example, research having to do with child development often associates child health, educational, or intervention outcomes with such variables as maternal age, child sex/gender identification, parental educational attainment, marital status, family composition/living arrangements, religious affiliation/practices, caregivers' ethnic background, maternal/child skin color, level of household income, parental employment status, geographic area of residence, neighborhood characteristics, language/s spoken at home, household routines, abuse or complex needs of family members, and/or availability of neighborhood/family resources (e.g., Behforouz et al., 2014; Crutchfield et al., 2022; Davis-Strauss et al., 2021). It is important to recognize that one of these variables can exacerbate the effects of another variable (e.g., poverty can unduly influence the effects of being marginalized due to skin color). Likewise, poverty can negatively influence household routines, neighborhood characteristics, and so on. As a variable, low-income level is particularly insidious.

Publicly reported EHDI hearing screening and follow-up outcomes collected from voluntary state and territory HSFS reports to the CDC are published on the CDC EHDI website. The sociodemographic variables collected and reported include maternal age, education, race, and ethnicity. These data provide a limited window into sociodemographic factors or variables that may impact outcomes.

Age. Maternal age, a significant sociodemographic variable influencing child diagnostic and developmental outcomes is considered a high-risk factor with teen pregnancies under 17 years and geriatric pregnancies over 35 years (Shanker et al., 2019). Although such high-risk maternal age groups involve more birth complications (Cavazos-Rehg et al., 2015), geriatric pregnancies are at lower risk for problematic child developmental outcomes (Duncan et al., 2018; Falster et al., 2018).

Education. Maternal education, one of the sociodemographic variables reported as EHDI outcomes by the CDC, is linked to language outcomes for both typically hearing children (Bruce et al., 2022; Hoff et al., 2018; Justice et al., 2020) and children using hearing technology (Ching et al., 2018; Tomblin et al., 2015; Yoshinaga-Itano et al., 2018). Maternal education is also linked to EHDI outcomes (Nicholson et al., 2022; Zeitlin et al., 2021).

Race. Race is a fluid social construct based primarily on perception of skin color (Monk, 2021). Skin color is a visual attribute assigned to African-Americans as well as non-white Latino-Americans, Asian-Americans, Pacific Islanders, and indigenous groups such as Native Americans/Hawaiians/Alaskans (Braveman et al., 2022). Race, linked with EHDI outcomes, warrants further analysis (Cunningham et al., 2018; Deng et al., 2022).

Ethnicity. Ethnicity is a social construct distinct from race/skin color (Breathett et al., 2021; Flanagin et al., 2021). Regardless of skin color or other visual attributes, people within many ethnic groups self-identify more so with their ethnic backgrounds (e.g., Vietnamese, Ethiopian, Hmong, Guatemalans, Filipinos, Haitians, Nigerians, Pakistani, Osceola, Inuit, Moroccan, Samoan; see, e.g., Holland & Palaniappan, 2012). Previously reported research demonstrated no relationship between Hispanic and non-Hispanic ethnicities and EHDI outcomes (Nicholson et al., 2022).

Purpose

The purpose of this study was to investigate differences in CDC EHDI HSFS reported data for maternal age, education, and race/ethnicity from 2016 to 2018. Specifically, we hypothesized significant differences: (a) in the percentage of states and territories reporting screening and diagnostic rates for 2016, 2017, and 2018 by maternal age, education, and race/ethnicity; (b) between the type of reason for LTF (documented reasons for lack of follow-up) or LTD (undocumented reasons for lack of follow-up or no report in screening and diagnostic testing during 2016, 2017, and 2018); and (c) by maternal sociodemographic and socioeconomic variables (age, education, and race/ethnicity) on screening, diagnostic, and LTF/D rates for 2016, 2017, and 2018. For this study, we refer to these variables as maternal demographic variables to maintain consistency with the CDC EHDI HSFS data reporting.

Method

Protocol #2022-132 was approved by the Nova Southeastern University Institutional Review Board. The

data included in this study was reported to the CDC on the EHDI HSFS by participating state and territory jurisdictions and is publicly available on the CDC EHDI website (n.d.b).

Study Population

The participant cohort for this study was comprised of 11,382,997 infants who were born January 1, 2016 through December 31, 2018, as documented in the CDC EHDI HSFS annual report. At the time of this study, data through 2018 was available for analysis.

Data Collection

The CDC reported data by jurisdictions for screening, diagnostic, and intervention related variables from Part 1 of the HSFS while maternal demographic data was reported in the aggregate for all jurisdictions that provided these data. The jurisdictional de-identified data for LTF/D for screening and for diagnosis were exported into an excel spreadsheet for birth years 2016, 2017, and 2018 (CDC, n.d.b). The reasons for lack of follow-up data were coded as documented and undocumented for the purposes of further analysis. Aggregate maternal demographic data for age, education, and race/ethnicity were extracted from the CDC website for birth years 2016, 2017, and 2018 (CDC, n.d.b).

Measures

Number of Jurisdictions Reporting Demographic Data

The CDC listed the number of jurisdictions who reported maternal demographic data on the HSFS for each year. Jurisdictions reporting greater than 20% of the total demographics in the *unknown* category were excluded from the CDC analysis and demographic summary (CDC, n.d.b). The aggregate maternal demographic data available from the CDC consisted of those jurisdictions reporting less than or equal to 20% for each demographic variable which were included in the dataset for maternal demographics. To calculate the percentage of states and territories reporting for each service (i.e., screening or diagnosis) for each demographic variable (i.e., age, education, ethnicity, race/ethnicity) for each year (i.e., 2016, 2017, and 2018) served as the numerator. The total number of jurisdictions reporting demographic data and included in the data set served as the denominator. Percentages were calculated for each maternal demographic for each condition, demographic, and year.

LTF/D for Screening

The definitions for screening LTF/D were those standard HSFS definitions used by the CDC. The total number and percentage of infants, for whom maternal demographic data was reported, who did not complete the follow-up hearing screening after failing the initial screen for 2016, 2017, and 2018 were extracted from the CDC website. Infants considered LTF were those with reasons for lack of follow-up documented by the hospital (e.g., in an electronic medical record). Infants considered LTD were those who may have received services, but data were not reported, and the parents could not be contacted by the state EHDI follow-up team following the hearing screening.

Documented reasons listed on the HSFS for not receiving services included: infant died, moved out of jurisdiction, medical reason, parents declined, transferred, adopted, homebirth. Undocumented reasons listed on the HSFS for not receiving services included: parents unresponsive, unable to contact, unknown, and other. Numbers were recorded and percentages were calculated for each reason for each year in each category.

LTF/D for Diagnostics

The total number and percentage of infants who did not complete the follow-up diagnostic after failing the screening process for whom maternal demographic data were reported were extracted and recorded. Infants who had a documented status were considered as LTF. Infants who did not have a documented status and could not be contacted were considered LTD. Documented reasons included diagnostic in process, primary care physician (PCP) did not refer, non-resident or moved, medical reason, parents declined, transferred, or adopted. Undocumented reasons included parents unresponsive, unable to contact, and other.

Maternal Demographic Variables

Maternal Age. The percent of infants born to mothers by year (2016, 2017, 2018), condition (screening or diagnostic), and age group (< 15, 15–19, 20–24, 25–34, 35–50, and 50+ years) for whom maternal demographic data were extracted and plotted.

Maternal Education. The percentage of infants born to mothers by year (2016, 2017, 2018), condition (screening or diagnostic), and education level (less than high school, high school/GED, some college/associate degree, and college graduate+) were extracted and plotted.

Maternal Race/Ethnicity. The percent of infants born to mothers by year (2016, 2017, 2018), condition (screening or diagnostic), and race/ethnicity (white Non-Hispanic, white Hispanic, black Non-Hispanic, black Hispanic, Asian, Native Hawaiian or Pacific Islander, American Indian or Alaskan Native, or Other) were extracted and plotted.

Data Analysis

Data were combined across 56 jurisdictions for 2016 and 2017 and 57 jurisdictions for 2018 for analysis. Screening and diagnostic evaluation processes based on birth cohort for number of jurisdictions reporting, LTF/D, and demographic variables (maternal age, education, ethnicity, and race/ethnicity) were analyzed. Descriptive statistics consisted of group frequencies and/or percentages. Inferential analysis consisted of the univariate analysis of variance (ANOVA) to test hypotheses with follow-up post hoc multiple pairwise comparisons as needed.

Results

The purpose of this study was to (a) investigate jurisdictional reporting patterns in CDC EHDI HSFS data by year, condition, and maternal demographic variable,

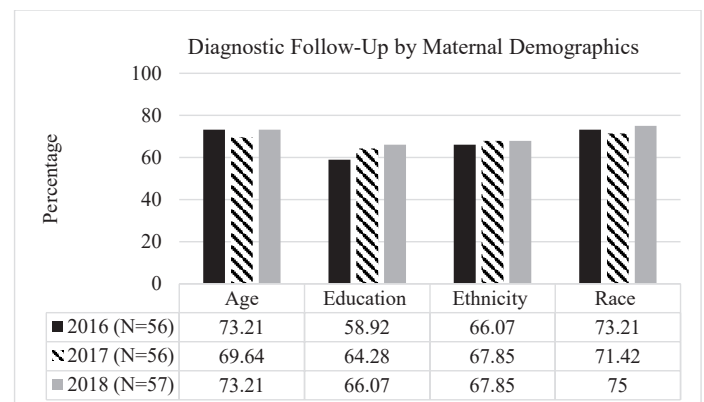
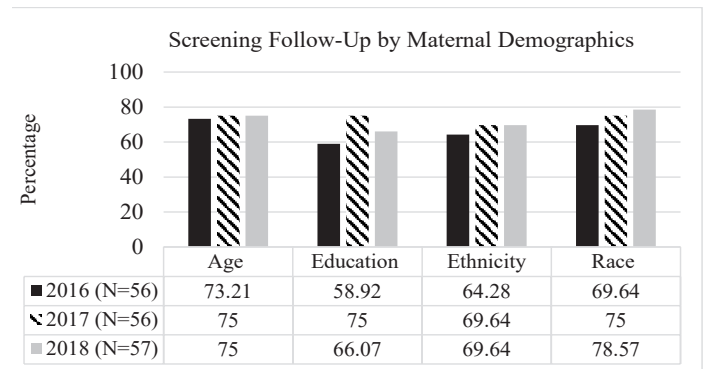
(b) explore type of LTF/D by year, specific reason, and condition, and (c) examine differences in screening and diagnostic completion rates by year and maternal sociodemographic factor.

Number of Jurisdictions Reporting Demographic Data

The first research question: Was there a significant difference in jurisdictional reporting patterns in CDC EHDI HSFS data by year for condition or for maternal sociodemographic variable? An Analysis of Variance (ANOVA) revealed no significant differences between screening and diagnostic reporting by year or with interaction of year and maternal demographic. There was a significant effect on reporting by maternal demographic [$F(2, 9) = 14.55, p = .002$]. The number of jurisdictions reporting maternal age and race/ethnicity were significantly higher than those reporting education ($p < .05$). See Figure 1.

Figure 1

Number and Percent of Jurisdictions Reporting Maternal Demographics for Screening and Diagnostic Follow-Up Outcomes 2016–2018



Note. The number and percentage of jurisdictions reporting to the Centers for Disease Control and Prevention (CDC) on the Early Hearing Detection and Intervention (EHDI) Hearing Screening and Follow-Up Survey (HSFS) is shown for screening follow-up outcomes (top panel) and diagnostic follow-up outcomes (bottom panel). Fifty-six jurisdictions responded to the survey in 2016 and 2017; 57 responded in 2018. See <https://www.cdc.gov/ncbddd/hearingloss/ehdi-data.html> by year for more information.

LTF/D for Screening and Diagnosis

The second research question posed: Was there a significant difference for LTF/D outcomes by year or classification of reason (documented vs. undocumented)? Screening results are presented separately from diagnostic results. Table 1 shows screening data by year, classification of documented versus undocumented, and specific reason for LTF/D. The three highest documented reasons for loss to screening follow up consistent across years were “infant dies”, “parents declined”, and “homebirth”, each receiving approximately 25–33% of responses. The largest undocumented category was “unknown” at about 75%. Similar data for diagnostics is visible in Table 2, although the list of specific reasons is slightly different. For the documented reasons, “parents declined” and “non-resident or moved” have response levels between 25–35%. A third documented reason, “in process” (i.e., the jurisdiction is working to finalize and

submit the data), shows a 10% downward trend, 27% to 17%, across the three years, suggesting that processes and/or reporting improved in many jurisdictions. Multiple regression analyses on the screening and diagnostic data indicated that year and documented/undocumented type predicted 90.3% (screening) and 98.7% (diagnostics) of the variances. Results show that documented vs. undocumented was significant in predicting the outcomes (screening: $\beta = -.91$, $p = .007$; diagnostic: $\beta = .99$, $p < .001$), but year was not.

Maternal Demographics

The third research question: Was there a significant difference in reported procedure completion rates by condition (screening versus diagnostic) or for each maternal demographic (age, education, race/ethnicity)? To assess this question, screening and diagnostic data were analyzed separately, and a univariate ANOVA was conducted for each demographic variable. Data are shown for maternal age, education, ethnicity, and race on Figures 2–3.

Table 1

Number and Percentage of Infants Not Completing Screening Process for Birth Years 2016, 2017, and 2018 by Reason (CDC EHDI HSFS Data)

	Reason	2016	2017	2018	
Loss to Follow-Up (LTF)	Infant dies	11,988 (28%)	11,708 (29%)	12,222 (31%)	
	Moved out of Jurisdiction	988 (2%)	948 (2%)	1,204 (3%)	
	Documented Reasons for LTF	Medical Reason	2,284 (5%)	2,769 (7%)	3,304 (8%)
		Parents declined	9,955 (24%)	10,878 (27%)	9,793 (25%)
		Transferred	4,691 (11%)	1,396 (3%)	1,702 (4%)
		Infant Adopted	20 (<1%)	7 (<1%)	203 (<1%)
		Homebirth	12,185 (29%)	12,962 (31%)	11,263 (28%)
Subtotal # LTF		42,111	40,668	39,691	
Subtotal Percent LTF		56%	63%	63%	
Loss to Documentation (LTD)	Unresponsive	1,489 (4%)	1,169 (5%)	1,023 (4%)	
	Unable to contact	1,051 (3%)	1,035 (4%)	2,484 (11%)	
	Undocumented re: follow-up	Unknown	26,067 (71%)	18,820 (77%)	16,145 (69%)
		Other	4,005 (11%)	3,356 (15%)	3,696 (16%)
Subtotal # LTD		32,612	24,380	23,348	
Subtotal Percent LTD		44%	37%	37%	
Total # LTF/D		74,742	65,048	63,039	
Total # Births		3,830,526	3,807,656	3,744,815	
Total Percentage LTF/D		2%	2%	2%	

Note. Total Percent LFU / LTD: ((# Contacted but Unresponsive + # Unable to Contact + # Unknown) / # Total Occurrent Births) * 100. LTF/D = Loss-To-Follow-up/Documentation. The number of jurisdictions reporting to the Centers for Disease Control and Prevention (CDC) on the Early Hearing Detection and Intervention (EHDI) Hearing Screening and Follow-Up Survey (HSFS) was 56 for 2016 and 2017; however, 57 reported for 2018.

Table 2

Number and Percentage of Infants Not Completing Diagnostic Process for Birth Years 2016, 2017, and 2018 by Reason (CDC EHDI HSFS Data)

Reason/Birth Year		2016	2017	2018
Documented	In process	1,607 (27%)	1,201 (21%)	898 (17%)
(LTF)	PCP did not refer	67 (1%)	61 (1%)	104 (2%)
	Infant died	403 (7%)	410 (7%)	437 (8%)
	Non-resident or moved	1,676 (28%)	1,758 (31%)	1,755 (33%)
	Medical Reason	418 (7%)	211 (4%)	256 (5%)
	Parents declined	1,666 (28%)	2,051 (36%)	1,878 (35%)
	Infant Adopted	106 (2%)	18 (<1%)	35 (1%)
Subtotal # LTF		5,943	5,710	5,363
Subtotal Percent LTF		24%	26%	25%
Undocumented	Unresponsive	4,708 (26%)	5,778 (36%)	5,229 (32%)
(LTD)	Unable to contact	2,675 (15%)	2,714 (17%)	3,828 (24%)
	Unknown	9,139 (50%)	6,957 (43%)	6,524 (40%)
	Other	1,856 (10%)	713 (04%)	680 (4%)
Subtotal # LTF		18,378	16,162	16,261
Subtotal Percent LTD		76%	74%	75%
Total # LTF/D		24,321 (37%)	21,872 (35%)	21,624 (36%)
Total # Failed Screening		65,157	62,859	60,258

Note. Total Percent LFU / LTD: ((# Contacted but Unresponsive + # Unable to Contact + # Unknown) / # Total Occurrent Births) * 100. LTF/D = Loss-To-Follow-up/Documentation. The number of jurisdictions reporting to the Centers for Disease Control and Prevention (CDC) on the Early Hearing Detection and Intervention (EHDI) Hearing Screening and Follow-Up Survey (HSFS) was 56 for 2016 and 2017; however, 57 reported for 2018.

Maternal Age

Categories for maternal age in years were (a) less than 15, (b) 15 to 19, (c) 20 to 24, (d) 25 to 34, (e) 35 to 50, (f) 51 and above (see Figure 2). The ANOVA showed no significant difference by year for screening or diagnostics. Analysis for all three years revealed a significant difference by maternal age for diagnostics [$F(5,12) = 5.31, p = .008$] but none for screening. Figure 2 shows that the reporting pattern for age is similar for the youngest and oldest groups, low-high-low for 2016–2018. By contrast the remaining age groups all had a similar pattern of age reporting, with a decreasing trend across the three years. An additional ANOVA of the maternal age diagnostic data collapsed across the three years was completed, which indicated no differences among any age groups [$F(5,12) = 1.81, p = .184$]. This finding suggests that the individual group differences reported for the < 15 and > 50 age groups are likely due to anomalous reporting in one or more years.

Maternal Education

Categories for maternal education were (a) less than high school, (b) high school/GED, (c) some college, and (d) college graduate (see Figure 3, top panel). Although results of the univariate ANOVA showed a significant difference for education level in screening condition by

year [$F(2,11) = 4.32, p = .048$], the Bonferroni post hoc analysis indicated no significant differences between any pairs of years, and the data were collapsed. Subsequent analysis of screening data yielded no significant differences by maternal education.

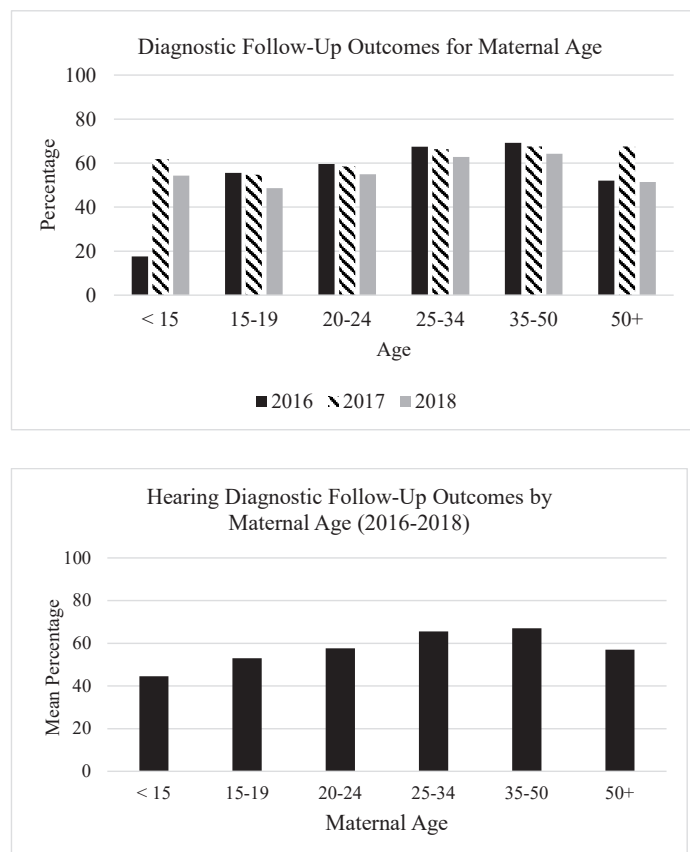
ANOVA results showed a significant effect for diagnostics collapsed across years [$F(3,8) = 116.98, p < .001$]. Bonferroni post hoc pairwise comparisons indicated significant differences for all comparisons. See Table 3 for mean differences, level of significance, and confidence intervals. Figure 3 indicates that, in general, the higher the level of maternal education, the higher percentage of reported diagnostics results. That trend appears to be roughly 10% higher for each category of education level. Across individual years there is a trend, albeit small, for a lower level of reporting for all categories except less than high school.

Maternal Race/Ethnicity

Categories for race/ethnicity used in this study were (a) white Non-Hispanic, (b) white Hispanic, (c) black Non-Hispanic, (d) black Hispanic, (e) Asian, (f) Native Hawaiian or Pacific Islander, (g) American Indian or Alaskan Native, or (h) Other. No significant difference was found by year for screening. There were statistical differences between and among the race/ethnicity categories for

Figure 2

Hearing Screening and Diagnostic Follow-Up Outcomes for Maternal Age for 2016–2018



Note. Hearing diagnostic follow-up outcomes for maternal age by year are shown in the top panel and mean percentage of hearing diagnostic follow-up outcomes for maternal age (2016–2018 averaged) are shown in the lower panel. Data represents maternal demographic variables reported by the Centers for Diseases Control and Prevention (CDC) for the Early Hearing Detection and Intervention (EHDI) Hearing Screening and Follow-Up Survey (HSFS) for 2016, 2017, and 2018. See <https://www.cdc.gov/ncbddd/hearingloss/ehdi-data.html> by year for more information.

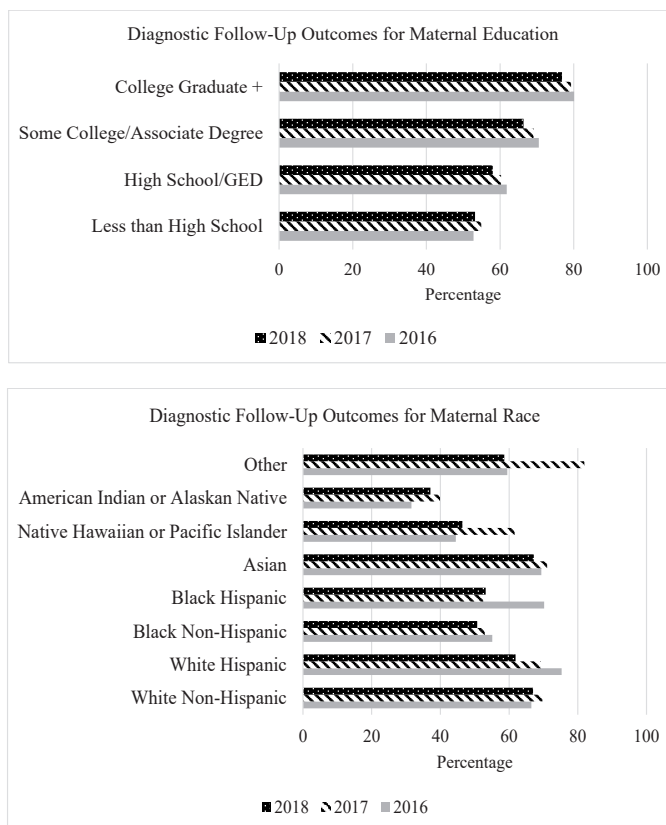
screening across years. However, we suggest they are not meaningful, given the quite similar values across categories shown in Figure 3 (lower panel) and we do not report those here.

The across-year ANOVA on maternal race/ethnicity showed significant differences for diagnostics [$F(7,16) = 7.533, p < .001$]. The subsequent post hoc pairwise comparisons using Dunnett T3 [Levene = 4.523, $p = .006$] indicated significantly lower follow-up rates for black Non-Hispanics compared to (a) white Non-Hispanics and (b) Asians, and significantly lower follow-up rates between American Indians or Alaskan Natives and (a) white Non-Hispanics, (b) white Hispanics, (c) black Non-Hispanics, and (d) Asians (see Table 4 for the mean differences and significant results matrix). All other pairs were statistically similar.

Our results suggest that the number of jurisdictions reporting demographic data has remained stable over the

Figure 3

Hearing Diagnostic Follow-Up Outcomes for Maternal Education (top panel) and Maternal Race/Ethnicity (lower panel) for Years 2016–2018



Note. Hearing diagnostic follow-up outcomes for maternal education are shown by year in the top panel. Hearing diagnostic follow-up outcomes are shown by race/ethnicity by year in the lower panel. Data represents maternal demographic variables reported by the Centers for Diseases Control and Prevention (CDC) for the Early Hearing Detection and Intervention (EHDI) Hearing Screening and Follow-Up Survey (HSFS) for 2016, 2017, and 2018. See <https://www.cdc.gov/ncbddd/hearingloss/ehdi-data.html> by year for more information.

past three years. Year did not predict LTF/D screening or diagnostic outcomes. To tease out variables related to SDoH, we categorized LTF/D variables by those that have valid documented reasons why screening and/or diagnostics could not be completed and those that did not have valid documented reasons. We found that documented versus undocumented categories of reasons for LTF/D did not predict LTF/D outcomes for screening or diagnostics. We then evaluated the impact of maternal demographics on completion rates for screening and diagnostic processes and found that there are no significant differences for age; however, education and race/ethnicity play a significant role.

Discussion

The goal of this study was to explore how SDoH is related to hearing health disparities. Specifically, we sought to examine CDC EHDI HSFS screening and diagnostic outcomes, maternal demographic variables, and LTF/D for years 2016, 2017, and 2018; at the time of the analysis, this was the available data. For newborn hearing

Table 3

Mean Differences for Education Level, Standard Error, Level of Significance, 95% Confidence Intervals (Lower Bound and Upper Bound) for Bonferroni Post Hoc Pairwise Comparisons for Diagnostics

Education Level	Comparison	Mean Difference	Significance	95% Confidence Interval	
				Lower Bound	Upper Bound
Less than High School	HS/GED	-.063	.012	-.127	.000
	AA/AS/Some	-.150	< .001	-.220	-.079
	Coll Grad	-.250	< .001	-.307	-.193
High School Diploma/GED	< HS	.063	.012	-.000	.127
	AA/AS/Some	-.086	.002	-.158	-.015
	Coll Grad	-.187	< .001	-.252	-.122
AA/AS/Some College	< HS	.150	< .001	.079	.221
	HS/GED	.086	.002	.015	.157
	Coll Grad	-.100	< .001	-.170	-.031
College Graduate	< HS	.250	< .001	.194	.307
	HS/GED	.187	< .001	.121	.252
	AA/AS/Some	-.100	< .001	.031	.170

Note. < HS = Less than high school; HS/GED = High School degree or Graduate equivalent degree; AA/AS/Some = Associate of Arts, Associate of Science, Some college; Coll Grad = College Graduate. *The mean difference is significant at the .05 level.

Table 4

Mean Difference and Significant Results Matrix for Diagnostics—Dunnett T3 Post Hoc Pairwise Comparisons for Race/Ethnicity

	White Non-Hispanic	White Hispanic	Black Non-Hispanic	Black Hispanic	Asian	Native Hawaiian or Pacific Islander	American Indian or Alaskan Native	Other
White Non-Hispanic	.000	-.011	.148*	.091	-.015	.169	.315*	.011
White Hispanic			.159	.102	-.004	.180	.326*	.022
Black Non-Hispanic				-.057	*.163	.021	.167	-.138
Black Hispanic					-.106	.078	.224	-.080
Asian						.184	.330*	.026
Native Hawaiian or Pacific Islander							.146	-.158
American Indian or Alaskan Native								.304
Other								.000

Note. Matrix for Dunnett's T3 post hoc analysis for race/ethnicity for the diagnostic condition. Mean differences are shown. *indicates significance at the .05 level.

screening, there was no significant difference by year; however, the number of jurisdictions reporting maternal age and race/ethnicity variables was significantly higher than those reporting maternal education.

Screening Outcomes

Year did not predict LTF/D hearing screening outcomes; however, reasons reported by the CDC accounted for 90.3% of the variation in screening follow-up outcomes. Reasons categorized as LTF (documented in the electronic health record) accounted for a higher predictive value than reasons categorized as LTD (could not reach parents for follow-up). Results showed no significant difference in follow-up outcomes for maternal age, education, or race/ethnicity for screening.

Diagnostic Outcomes

For diagnostic follow-up outcomes, when years were collapsed there was a significant difference for education, and race/ethnicity. For education, the higher the level of educational attainment, the higher the likelihood of follow-up. In general, diagnostic follow-up outcomes were significantly lower for infants of mothers of color (black Non-Hispanics, American Indian or Alaskan Natives) than for other race/ethnicity categories.

CDC EHDI HSFS Data Quality for Demographic Variables

Recent studies have brought attention to or identified issues regarding the quality in CDC EHDI HSFS data for demographic variables (Alam et al., 2016; Alam et al., 2018; Gaffney et al., 2014; Sanchez-Gomez et al., 2019). Salvidar (2012) suggests that U.S. government surveys such as the CDC EHDI HSFS are expected to have a response rate of at least 75%. Response rates (number and percentages) for jurisdictions are shown in Figure 1. These response rates fall slightly below the expected 75% response rate for government surveys; therefore, we suggest that data for maternal demographics be interpreted with appropriate caution.

LTF/D Rates by Year, Condition, and Classification

Regression analysis results showed there was no significant effect for year on screening or diagnostic follow-up outcomes; however, there was a significant effect for classification for type of reasons (LTF documented versus LTD undocumented) for both screening and diagnostics. Some suggest several additional family variables that may influence LTF/D (Holte et al., 2012; Zeitlin et al., 2021) such as parental decision-making or cultural factors/biases (Chung et al., 2017; Gaffney et al., 2014; Gonzalez et al., 2017; Kenna, 2021; Landon et al., 2021; Linton et al., 2019). Other variables identified include (a) transportation issues, (b) health insurance coverage, (c) language differences, (d) health literacy issues, and (e) communication skills (Shulman et al., 2010). The reasons used to classify LTF/D provide insight into the social and cultural variables that may influence outcomes (e.g., parents declined, infant in the foster care system

or adopted, homebirths, parents unresponsive to contact attempts, unable to contact).

Impact of SDoH on Screening LTF/D Rates

Although there was no significant difference by year for screening follow-up outcomes, there was a significant difference in categories for LTF/D (see Table 1). Of infants categorized as LTF/D, 61% had an identifiable cause. Of these, approximately 29% were due to infant deaths; however, about 29% were due to home births, and about 25% were due to parent denials. In each of these cases, an educational intervention could be designed and implemented to mitigate loss to follow-up. For the cases categorized as LTD (39%), we do not know the *why* for unresponsiveness, lack of accurate contact information, or the other unknowns. Importantly, the overall LTF/D rate for newborn hearing screening is very small for the total population (2%).

Impact of SDoH on Diagnostic LTF/D Rates

Previously reported data suggested a decreased likelihood of diagnostic follow-up for: (a) mothers with less than a high school education (Crouch et al., 2017); (b) in rural areas with limited access to services (Bush, Osetinsky, et al., 2014; Crouch et al., 2017); and (c) for those on public insurance versus private insurance (Crouch et al., 2017; Deng et al., 2022). Child variables that increase the likelihood of delayed diagnostic testing include low birthweight (Tran et al., 2016) and multiple audiology appointments (Shanker et al., 2019; Tran et al., 2017). Our data shown in Table 2 indicates that, on average, 33% of the time LTF is due to decline to follow-up by the parents, 31% of the time it is due to the family moving or being a nonresident of the state, and 22% of the time, the diagnostic is still in process. The Action Kit for Audiologists developed by the National Institute for Children's Health Quality (NICHQ) provides suggestions to facilitate follow-up. Several identified system challenges may also contribute to a decrease in LTF/D for diagnostic evaluations (NICHQ, 2016; Williams et al., 2015). These data indicate the possibility that additional SDoH, and other cultural variables played a significant role in LTF/D. Our results are consistent with previously reported data except for the impact of maternal age on diagnostic follow-up outcomes.

Impact of Maternal Demographics

Sociodemographic data are the classifiable characteristics of a given population and are commonly used in public health reports. SDoH are the conditions in the environment in which people are born, live, learn, and play that predict quality of life outcomes and risks (National Center for Health Statistics, 2001). Two of the maternal demographics reported by the CDC fall into the category of sociodemographic variables (i.e., age and race/ethnicity) whereas others are considered SDoH (i.e., education). The EHDI maternal demographic data are readily available from the CDC HSFS annual report and are important factors when assessing disparities in health services. Our data show no significant difference in maternal age, education, or race/ethnicity for screening follow-up outcomes, but a significant difference for education and race/ethnicity for diagnostic follow-up outcomes. Follow-up

rates for screening and diagnostics are integrally related to LTF/D rates, representing the inverse. Some research on maternal demographics uses follow-up outcome rates whereas other research uses the inverse, presenting LTF/D outcome data. This is something to be aware of when examining and interpreting the data.

Maternal Age

Teen mothers tend to be over-represented by low socioeconomic status or low maternal education (Hunter, 2012) or come from families with similar backgrounds (e.g., a cycle of intergenerational hardship referred to as a *culture of despair*; Basch, 2011; DeBacker & Routon, 2021). Restated, social context plays a role in teenage pregnancy and childbearing (Hunter, 2012). The incidence of birth complications is much more significant among non-white women, largely due to environmental stressors and health care disparities (Anifantaki et al., 2021; Braveman et al., 2021; Petersen et al., 2019).

Given that children of teen mothers are at greatest risk for a host of health, social, and economic issues (Agnafors et al., 2019), one might expect a relationship between maternal age, hearing screening, and follow-up outcomes (Deng et al., 2022; Shanker et al., 2019). Meyer and colleagues (2020) reported a higher risk of delayed diagnosis in infants of mothers younger than 25 years of age for 2012 to 2016 in Minnesota. Our data, however, does not support this finding. Differences could be attributed to several variables such as population source and number, age categories, choice of statistical analyses, and/or data quality. Meyer et al. (2020) reported a significant difference for maternal age less than 25 years, and our lowest age category was less than 15 years.

Maternal Education

Historically, research-based evidence typically includes at least one of three key variables that constitute *socioeconomic status* (SES), sometimes referred to as *social class*: (a) parental educational attainment, (b) parental occupational status/job prestige/subjective perceptions of social class; (c) household or family income/financial security. These three factors, designated to establish an individual's social standing, are intended to encompass quality of life attributes as well as opportunities and privileges afforded people within society (Darin-Mattsson et al., 2017). Although some consider SES to be a reliable predictor of physical and mental health across the life span, others question the validity of what it measures (e.g., Navarro-Carrillo et al., 2020; Zang & Bardo, 2019). Questions have been raised about the quality of such data, the narrowness of the measures, and the lack of a composite SES measure (Cowan et al., 2012; Dickinson & Adelson, 2014). Maternal education continues to be used as a substitute for SES when data on income and occupation is not available. Such is the case with the CDC HSFS EHDI data.

Education/SES Indicator. Maternal education is the only one of the three SES indicators reported by the CDC on the EHDI HSFS. Limitations in using a level of formal education attained by a parent have been reported.

For example, a parent may or may not have attained a secondary/high school diploma yet have attained considerable distance and technology-based informal learning (Latchem, 2014). Informal education may be insufficiently represented in the sociodemographic variable of maternal education; the quality of this sociodemographic variable has long been called into question (Alderman & Headey, 2017; Harding et al., 2015). Rather than formal education, the executive functioning or cognitive capacities of parents may sometimes be a better proxy for SES (Cuevas et al., 2014; Walhovd et al., 2022). Although this is true, cognitive capacity or measures of executive function are not easily accessible or included in publicly reported data.

Villalba (2014) cautions against the use of maternal education as the sole or primary determinant of SES, suggesting it to be meaningless and statistically invalid. SES is really a much larger issue than that of education alone; it is typically based on several variables such as occupation, number of years of education, income, and place of living (Aarø et al., 2009). Deng and colleagues (2022) used an approach to improve the validity of the SES component by coupling maternal education with family participation in the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). They found the rate of diagnostic follow-up to be lower among infants enrolled in the WIC program than those not enrolled and occurring at an increased rate with higher maternal education. This finding has potential intervention implications for EHDI programs.

Our results concur with previously reported findings demonstrating significantly higher follow-up rates with higher maternal education. The relationship between education and SES is noteworthy as maternal education may be a confounding factor when considering resource constrained families. Regardless of maternal education, resource constrained families are in desperate need of immediate social supports and diagnostic follow-up, identification has the potential to connect families with a holistic approach to intervention (Rendall et al., 2022).

Occupation. Although economic resources matter, income can fluctuate and does not necessarily equal wealth (e.g., work-related benefits may be excluded; Thompson & Dahling, 2019). Moreover, income can vary dramatically as in the case of well-educated students who are unemployed. Similarly, using occupation as a data collection point can exclude a good part of a population, such as retirees, students, or temporarily unemployed parents who may be transitioning to other occupations. Occupations are not necessarily indicative of social class (Svedberg et al. 2016). Income, education, and occupation are not interchangeable SES characteristics; efforts to equate these variables can result in validity issues (e.g., Darin-Mattsson et al., 2017; Galobardes et al., 2006). Our data did not include consideration of occupation; however, it is included here as one of the *big three* SES indicators.

Income. It is well known that insufficient or unstable household income/economic resources can have

deleterious effects on child development (e.g., Beech et al., 2021). Nearly one in six children under the age of six in the United States lives in poverty; these children reside in food-insecure homes and are the poorest age group in America (Children's Defense Fund, 2021; Wight et al., 2014). Poverty disproportionately affects children of color; indeed, more than 70% of America's impoverished children are from marginalized non-white groups (Children's Defense Fund, 2021; Haider, 2021). The effects of childhood poverty are pervasive, including its lifetime link to injuries, chronic illness, hearing health, and mental health difficulties (e.g., Gupta et al., 2007; Schmidt et al., 2021).

More importantly, research that considers just the three SES variables of education, occupation, and income is often deemed insufficient in the use of statistical controls (Dickinson & Adelson, 2014; Williams & Mohammed, 2013). How data are collected for measuring these three variables is often not consistent across research studies (Cowan et al., 2012). It is now widely understood that many more factors affect intervention outcomes (e.g., Adams & Beeble, 2019; Park et al., 2021; Rollè et al., 2019). It is important to know if all the subgroups in any target audience are fairly represented and which factors might be associated with specific outcomes (Deaton & Cartwright, 2018). Simply stated, poverty exacerbates the effects of race and age and education.

Maternal Race/Ethnicity

Deng and colleagues (2022) assessed the impact of race/ethnicity on follow-up outcomes and found non-Hispanic black mothers with the lowest rate of follow-up for screening and non-Hispanic black and American Indian/Alaska Natives with the lowest rates of diagnostic outcomes. We found no significant difference for screening outcomes; however, our diagnostic outcomes support the results of Deng et al. (2022). The CDC EHDI HSFS guidance documents do not specifically address the reasons why information about race/ethnicity is so important. Providing respondents (e.g., hearing screeners and oversight personnel) with more specific information about the importance of demographic variables may facilitate better data collection procedures and outcomes (Avvisati, 2020; Williams-Roberts et al., 2018). Our findings indicate that maternal race predicts diagnostic follow-up outcomes. Specifically, Asian diagnostic follow-up outcomes are the highest for maternal race/ethnicity while American Indian and Alaskan Native, followed by Native Hawaiian and Pacific Islander, and then Black Hispanic and Black Non-Hispanic are notably lower than white. These results suggest that race or skin color plays a role in diagnostic follow-up outcomes. Additional research is needed to further delineate.

Reporting Sociodemographic Variables

The CDC identified one maternal demographic category as race/ethnicity, which may cause some confusion. The separation of these categories, and inclusion of more ethnic categories than Hispanic versus non-Hispanic may

provide relevant data. The CDC practice of collecting race and ethnicity as combined variables should be reconsidered. It may also be important to note whether race was self-identified by the mother or by the data collector. Deng and colleagues (2018) suggest that many states apparently do not consider these data essential for appropriate and timely EHDI care, thus they apparently are not considered critical from a reporter perspective. This lack of data impedes research regarding the influence of SDoH on EHDI outcomes (Deng et al., 2018). Deng and colleagues (2018) concluded that the paucity of race/ethnicity data reported for the three states they studied necessitates an increased awareness and emphasis on the importance of reporting demographic variables.

Despite clinical and research advances in hearing health, there is mounting evidence of long-standing hearing health disparities across the United States and its territories. Disparities persist by skin color, ethnicity, household income, and other sociodemographic variables among young American children with hearing loss (e.g., Juarez et al., 2020; Kingsbury et al., 2022; Lantos et al., 2020; Mohapatra & Mohan, 2021). Therefore, race/skin color and ethnicity should be considered as two distinct variables to be disaggregated. These two variables should be included with other sociodemographic variables collected and analyzed in EHDI research. Identification of such critical factors enables segmentation of subjects and improved accuracy in interpretation of results that, in turn, can facilitate improvement in the timely delivery of intervention services (Orkin et al., 2021).

It is widely recognized that ethno-racial data collection is both challenging and wanting in research studies within the United States (Chaiya-chati et al., 2022; Davis & Jones, 2022; Kader et al., 2022; National Research Council, 2013; Rees et al., 2022). Federal research and regulatory authorities as well as medical journals seek to increase the number of people from underrepresented ethno-racial populations in clinical research and to disaggregate that ethno-racial data (Blumenthal & James, 2022; Chaiya-chati et al., 2022; Davis & Jones, 2022). Even with the recognition that many barriers exist, more agencies and funding sources are necessitating an increase in the inclusion of marginalized people as pertains to data collection (Blumenthal & James, 2022). It behooves all those involved with EHDI to develop consistent protocol for equalizing the identification of ethno-racial demographics.

The United States has undergone enormous changes since the advent of the 20th century, particularly those marked by size and diversity (Cohn & Caumont, 2016). Some sociodemographic variables, particularly those having to do with race and ethnicity, are referred to as real world data and considered predictors of a vast array of outcomes in such Westernized democracies as the United States (Concato et al., 2020; Tarver, 2021). Indeed, whether self-identified or other-identified, race and ethnic background should always be considered when analyzing intervention outcomes to produce real-world evidence (e.g., Chodankar, 2021; National Research Council, 2013;

Valdez & Langellier, 2015). Although race and ethnicity are often used interchangeably, it is critical that these two social constructs be (a) disentangled and (b) included in outcome findings (Kauh et al., 2021; Tarver, 2021). It is also important that ethno-racial data be accurate and complete; such detail can identify the nature and extent of disparities in health care, target quality improvement efforts, and monitor progress (Concato & Corrigan-Curay, 2022; National Research Council, 2013). This is vital if we are to improve hearing health care for families and their children with hearing loss.

Limitations

There are several limitations inherent in this study. First, the original source of data used in this study was provided via jurisdictional EHDI Information Systems (IS) in the form of responses to the CDC HSFS questions. Some of the EHDI IS are more sophisticated and robust than other systems; however, the details regarding the characteristics of various EHDI IS are not publicly available. All analyses were conducted on the entire data sets available for 2016, 2017, and 2018 as reported by individual jurisdictions and are thus subject to a wide variety of different tracking, reporting, and other surveillance methodology and may have different population characteristics and conventions. The data is incomplete in that not all states participated in data collection. The reliability and validity and completeness of the parental ethno-racial identities are unknown, subject to response-bias, and may differ between hospitals as well as jurisdictions. Furthermore, some non-respondent demographic characteristics were unavailable, potentially introducing sampling variance. We previously described the limitations of the CDC data in terms of quality, incomplete data, and risk for participation and nonresponse bias.

Implications for Future Research, Policy, and Practice

The results of this study are consistent with the findings of previous studies regarding hearing screening follow-up and diagnostic audiologic follow-up outcomes. Depending on the sociodemographic profile of pregnant mothers, researchers can better understand one sociodemographic factor with respect to another, thus improving the effectiveness of EHDI efforts. Further exploratory research examining LTF/D variables may provide additional insight into SDoH variables contributing to difference in screening and diagnostic follow-up outcomes. Suggestions to improve the effectiveness of EHDI efforts include the following:

- Developing more specific data collection protocol/procedures and guidelines for the CDC EHDI HSFS that will be consistently implemented across all 50 of the United States and American territories.
- Implementing a nationwide training program pertaining to the need for consistent and standardized reporting of sociodemographic variables; this training program will include EHDI coordinators, pediatric audiologists, hearing

screeners, and hospital employees involved with data collection.

- Broadening the data collection protocol so that service providers attain an improved understanding of each family's social landscape (e.g., number of children in the household, additional medical/developmental problems within the family, or transportation issues).
- Development of specific sociodemographic profiles could permit some mothers and their newborns to be red-flagged for more intensive follow-up or personalized attention.
- Linking child level data to disaggregated sociodemographic variables in future research to allow for better analysis and interpretation (e.g., exploring the LTF/D reasons relative to race/ethnicity to improve the identification of at-risk groups.
- Implementing an intervention protocol that is holistic in nature, targeting at-risk groups to further minimize LTF/D.

References

- Aarø, L. E., Flisher, A. J., Kaaya, S., Onya, H., Namisi, F. S., & Wubs, A. (2009). Parental education as an indicator of socioeconomic status: Improving quality of data by requiring consistency across measurement occasions. *Scandinavian Journal of Public Health, 37*(Suppl 2), 16–27. <https://doi.org/10.1177/1403494808086917>
- Adams, A. E., & Beeble, M. L. (2019). Intimate partner violence and psychological well-being: Examining the effect of economic abuse on women's quality of life. *Psychology of Violence, 9*(5), 517–525. <https://doi.org/10.1037/vio0000174>
- Agnafors, S., Bladh, M., Svedin, C. G., & Sydsjo, G. (2019). Mental health in young mothers, single mothers and their children. *BMC Psychiatry, 19*, 112. <https://doi.org/10.1186/s12888-019-2082-y>
- Alam, S., O'Hollearn, T., Beavers, J., Rex, A. K., Cunningham, R. F., Chung, W., Deng, X., & Do, T. N. (2018). Restructuring data reported from state Early Hearing Detection and Intervention (EHDI) programs: A pilot study. *Journal of Early Hearing Detection and Intervention, 3*(1), 57–66. <https://doi.org/10.26077/ggr8-kn56>
- Alam, S., Satterfield, A., Mason, C. A., & Deng X. (2016). Progress in standardization of reporting and analysis of data from Early Hearing Detection and Intervention (EHDI) programs. *Journal of Early Hearing Detection and Intervention 1*(2), 2–7. <https://doi.org/10.15142/T3JG6D>

- Alderman, H., & Headey, D. D. (2017). How important is parental education for child nutrition? *World Development*, *94*, 448–464.
<https://doi.org/10.1016/j.worlddev.2017.02.007>
- American Speech-Language-Hearing Association. (2008). *Loss to follow-up in Early Hearing Detection and Intervention* [Technical Report]. Available from www.asha.org/policy
- Anifantaki, F., Pervanidou, P., Lambrinou, I., Panoulis, K., Vlahos, N., & Eleftheriades, M. (2021). Maternal prenatal stress, thyroid function, and neurodevelopment of the offspring: A mini review of the literature. *Frontiers in Neuroscience*, *15*, Art 692446.
<https://doi.org/10.3389/fnins.2021.692446>
- Avvisati, F. (2020). The measure of socio-economic status in PISA: A review and some suggested improvements. *Large-scale Assessments in Education*, *8*(8).
<https://doi.org/10.1186/s40536-020-00086-x>
- Barr, M., Dally, K., & Duncan, J. (2019). Service accessibility for children with hearing loss in rural areas of the United States and Canada. *International Journal of Pediatric Otorhinolaryngology*, *123*, 15–21.
<https://doi.org/10.1016/j.ijporl.2019.04.028>
- Basch, C. E. (2011). Teen pregnancy and the achievement gap among minority youth. *Journal of School Health*, *81*, 614–618.
<https://doi.org/10.1111/j.1746-1561.2011.00635.x>
- Beech, B. M., Ford, C., Thorpe, R. J., Bruce, M. A., & Norris, K. C. (2021). Poverty, racism, and the public health crisis in America. *Frontiers in Public Health*, *9*, Art 699049.
<https://doi.org/10.3389/fpubh.2021.699049>
- Behforouz, H. L., Drain, P. K., & Rhatigan, J. J. (2014). Rethinking the social history. *New England Journal of Medicine*, *371*, 1277–1279.
<https://doi.org/10.1056/nejmp1404846>
- Blumenthal, D., & James, C. V. (2022). A data infrastructure for clinical trial diversity. *New England Journal of Medicine*, *220*1433.
<https://doi.org/10.1056/nejmp2201433>
- Boss, E. F., Niparko, J. K., Gaskin, D. J., & Levinson, K. L. (2011). Socioeconomic disparities for hearing-impaired children in the United States. *Laryngoscope*, *121*, 860–866.
<https://doi.org/10.1002/lary.21460>
- Braveman, P. A. (2014). What are health disparities and health equity? We need to be clear. *Public Health Reports*, *129*(Suppl 2), 5–8.
<https://doi.org/10.1177/00333549141291S203>
- Braveman, P. A., Arkin, E., Proctor, D., Kauh, T., & Holm, N. (2022). Systemic and structural racism: Definitions, examples, health damages, and approaches to dismantling. *Health Affairs*, *41*(2), 171–178.
<https://doi.org/10.1377/hlthaff.2021.01394>
- Braveman, P., Dominguez, T. P., Burke, W., Dolan, S. M., Stevenson, D. K., Jackson, F. M., Collins, J. W., Jr., Discoll, D. A., Haley, T., Acker, J., Shaw, G. M., McCabe, E. R. B., Hay, W. W., Jr., Thornburg, K., Acevedo-Garcia, D., Cordero, J. F., Wise, P. H., Legaz, G., Rashied-Henry, K., Frost, J., Verbiest, S., & Waddell, L. (2021). Explaining the black-white disparity in preterm birth: A consensus statement from a multi-disciplinary scientific work group convened by the March of Dimes. *Frontiers in Reproductive Health*, *3*, Art 684207.
<https://doi.org/10.3389/frph.2021.684207>
- Breathett, K. K., Spatz, E. S., & Nallamothu, B. K. (2021). Reporting of race and ethnicity in medical and scientific journals. *Journal of the American Medical Association*, *326*, 673.
<https://doi.org/10.1001/jama.2021.9271>
- Bruce, M., Miyazaki, Y., & Bell, M. A. (2022). Infant attention and maternal education are associated with childhood receptive vocabulary development. *Developmental Psychology*, *58*(7), 1207–1220.
<https://doi.org/10.1037/dev0001365>
- Bush, M. L., Bianchi, K., Lester, C., Shinn, J. B., Gal, T. J., Fardo, D. W., & Schoenberg, N. (2014). Delays in diagnosis of congenital hearing loss in rural children. *Journal of Pediatrics* *164*(2), 393–397.
<https://doi.org/10.1016/j.jpeds.2013.09.047>
- Bush, M. L., Burton, M., Loan, A., & Shinn, J. B. (2013). Timing discrepancies of early intervention hearing services in urban and rural cochlear implant recipients. *Otology & Neurotology*, *34*(9), 1630–1635.
<https://doi.org/10.1097/MAO.0b013e31829e83ad>
- Bush, M. L., Kaufman, M. R., & McNulty, B. N. (2017). Disparities in access to pediatric hearing health care. *Current Opinion in Otolaryngology & Head & Neck Surgery*, *25*, 359–364.
<https://doi.org/10.1097/MOO.0000000000000388>
- Bush, M. L., Osetinsky, M., Shinn, J. B., Gal, T. J., Ding, X., Fardo, D. W., & Schoenberg, N. (2014). Assessment of Appalachian region pediatric hearing healthcare disparities and delays. *The Laryngoscope*, *124*(7), 1713–1717.
<https://doi.org/10.1002/lary.24588>
- Cavazos-Rehg, P. A., Krauss, M. J., Spitznagel, E. L., Bommarito, K., Madden, T., Olsen, M. A., Subramaniam, H., Peipert, J. F., & Bierut, L. J. (2015). Maternal age and risk of labor and delivery complications. *Maternal Child Health*, *19*, 1201–1211.
<https://doi.org/10.1007/s10995-014-1624-7>
- Centers for Disease Control and Prevention (n.d.a). *2018 CDC EHDI Hearing Screening and Follow-up Survey (HSFS): Explanations*. Centers for Disease Control and Prevention. Author.
<https://www.cdc.gov/ncbddd/hearingloss/2018-data/documents/2018-HSFS-Explanations.pdf>

- Centers for Disease Control and Prevention (n.d.b). *Annual data early hearing detection and intervention (EHDI) program*. <https://www.cdc.gov/ncbddd/hearingloss/ehdi-data2017.html>
- Centers for Disease Control and Prevention (n.d.c). *National goals, program objectives, and performance measures for the early hearing detection and intervention (EHDI) tracking and surveillance system*. <https://www.cdc.gov/ncbddd/hearingloss/documents/goals.pdf>
- Centers for Disease Control and Prevention (2003). *Early hearing detection and intervention program guidance manual*. <https://www.cdc.gov/ncbddd/hearingloss/guidancemanual/index.html>
- Chaiya-chati, B. H., Peña, M.-M., & Montoya-Williams, D. (2022). The complicated inadequacy of race and ethnicity data. *JAMA Pediatrics*. <https://doi.org/10.1001/jamapediatrics.2022.0525>
- Children's Defense Fund. (2021). *The state of America's children: Child poverty*. <https://www.childrensdefense.org/state-of-americas-children/soac-2021-child-poverty/>
- Ching, T. Y. C., Dillon, H., Leigh, G., & Cupples, L. (2018). Learning from the Longitudinal Outcomes of Children with Hearing Impairment (LOCHI) study: Summary of 5-year findings and implications. *International Journal of Audiology*, 57 (Supp. 2), S105–S111. <https://doi.org/10.1080/14992027.2017.1385865>
- Chodankar, D. (2021). Introduction to real-world evidence studies. *Perspectives in Clinical Research*, 12, 171–174. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8323556/>
- Chung, W., Beauchaine, K. L., Grimes, A., O'Hollearn, T., Mason, C., & Ringwalt, S. (2017). Reporting newborn audiologic results to state EHDI programs. *Ear and Hearing*, 38(5), 638–642. <https://doi.org/10.1097/AUD.0000000000000443>
- Cohn, D., & Caumont, A. (2016). *10 demographic trends shaping the U.S. and the world in 2016*. Pew Research Center. <https://www.pewresearch.org/fact-tank/2016/03/31/10-demographic-trends-that-are-shaping-the-u-s-and-the-world/>
- Concato, J., & Corrigan-Curay, J. (2022). Real-World Evidence—Where are we now? *The New England Journal of Medicine*, 386(18), 1680–1682. <https://doi.org/10.1056/NEJMp2200089>
- Concato, J., Stein, P., Dal Pan, G. J., Ball, R., & Corrigan-Curry, J. (2020). Randomized, observational, interventional, and real-world: What's in a name? *Pharmacoepidemiology Drug Safety*, 29, 1514–1517. <https://doi.org/10.1002/pds.5123>
- Cooc, N., & Kiru, E. W. (2018). Disproportionality in special education: A synthesis of international research and trends. *The Journal of Special Education*, 52, 163–173. <https://doi.org/10.1177/0022466918772300>
- Cowan, C. D., Hauser, R. M., Kominski, R. A., Levin, H. M., Lucas, S. R., Morgan, S. L., Beale Spencer, M., & Chapman, C. (2012). *Improving the measurement of socioeconomic status for the National Assessment of Educational Progress: A theoretical foundation*. https://nces.ed.gov/nationsreportcard/pdf/researchcenter/Socioeconomic_Factors.pdf
- Crouch, E. L., Probst, J., Bennett, K. J., & Carroll, T. (2017). Evaluating loss to follow-up in newborn hearing screening in a southern state. *Journal of Early Hearing Detection and Intervention*, 2(1), 40–47. <https://doi.org/10.15142/T3T33Z>
- Crutchfield, J., Keyes, L., Williams, M., & Eugene, D. R. (2022). A scoping review of colorism in schools: Academic, social, and emotional experiences of students of color. *Social Sciences*, 11, 15. <https://doi.org/10.3390/socsci11010015>
- Cuevas, K., Deater-Deckard, K., Kim-Spoon, J., Watson, A. J., Morasch, K. C., & Bell, M. A. (2014). What's mom got to do with it? Contributions of maternal executive function and caregiving to the development of executive function across early childhood. *Developmental Science*, 17(2), 224–238. <https://doi.org/10.1111/desc.12073>
- Cunningham, M., Thomson, V., Mckiever, E., Dickinson, L. M., Furniss, A., & Allison, M. A. (2018). Infant, maternal, and hospital factors' role in loss to follow-up after failed newborn hearing screening. *Academic Pediatrics*, 18(2), 188–195. <https://doi.org/10.1016/j.acap.2017.05.005>
- Darin-Mattsson, A., Fors, S., & Kåreholt, I. (2017). Different indicators of socioeconomic status and their relative importance as determinants of health in old age. *International Journal for Equity in Health*, 16(1), 173. <https://doi.org/10.1186/s12939-017-0670-3>
- Davis, C. M., & Jones, B. L. (2022). Increasing meaningful representation of children in clinical trials to inform science and achieve health equity. *JAMA Pediatrics*, 176(5), e220139. <https://doi.org/10.1001/jamapediatrics.2022.0139>
- Davis-Strauss, S. L., Johnson, E., & Lubbe, W. (2021). Information and support needs of parents with premature infants: An integrative review. *Journal of Early Intervention*, 43, 199–220. <https://doi.org/10.1177/1053815120957734>
- Deaton, A., & Cartwright, N. (2018). Understanding and misunderstanding randomized controlled trials. *Social Science Medicine*, 210, 2–21. <https://doi.org/10.1016/j.socscimed.2017.12.005>
- DeBacker, J. M., & Routon, P. W. (2021). A culture of despair? Inequality and expectations of educational

- success. *Contemporary Economic Policy*, 39(3), 573–588.
<https://doi.org/10.1111/coep.12528>
- Deng, X., Ema, S., Mason, C., Nash, A., Carbone, E., & Gaffney, M. (2022). Receipt and timeliness of newborn hearing screening and diagnostic services among babies born in 2017 in 9 states. *Journal of Public Health Management and Practice*, 28(1), E100–E108.
<https://doi.org/10.1097/PHH.0000000000001232>
- Deng, X., Finitzo, T., & Aryal, S. (2018). Measuring Early Hearing Detection and Intervention (EHDI) quality across the continuum of care. *The Journal for Electronic Health Data and Methods*, 6(1), 18.
<https://doi.org/10.5334/egems.239>
- Dickinson, E. R., & Adelson, J. (2014). Exploring the limitations of measures of students' socioeconomic status (SES). *Practical Assessment, Research, and Evaluation*, 19, Art 1.
<https://doi.org/10.7275/mkna-d373>
- Duncan, G. J., Lee, K. T. H., Rosales-Rueda, M., & Kalil, A. (2018). Maternal age and child development. *Demography*, 55, 2229–2255.
<https://doi.org/10.1007/s13524-018-0730-3>
- Ely, D. M., & Driscoll, A. K. (2019). Infant mortality in the United States: Data from the period linked birth/infant death file. *National Vital Statistics Reports*, 68(10).
https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68_10-508.pdf
- Emmett, S. D., & Francis, H. W. (2014). The socioeconomic impact of hearing loss in U. S. adults. *Otology & Neurotology*, 36, 545–550.
<https://doi.org/10.1097/MAO.0000000000000562>
- Erikson, C. E., Dent, R. B., Park, Y. H., & Luo, Q. (2022). Historic redlining and contemporary behavioral health workforce disparities. *JAMA Network Open*, 5(4), e229494.
<https://doi.org/10.1001/jamanetworkopen.2022.9494>
- Falster, K., Hanly, M., Banks, E., Lynch, J., Chambers, G., Brownell, M., Eades, S., & Jorm, L. (2018). Maternal age and offspring developmental vulnerability at age five: A population-based cohort study of Australian children. *PLOS Medicine*, 15(4), e1002558.
<https://doi.org/10.1371/journal.pmed.1002558>
- Flanagin, A., Frey, T., & Christiansen, S. L. (2021). Updated guidance on the reporting of race and ethnicity in medical and science journals. *Journal of the American Medical Association*, 326, 621–627.
<https://doi.org/10.1001/jama.2021.13304>
- Florentine, M. M., Rouse, S. L., Stephans, J., Conrad, D., Czechowicz, J., Matthews, I. R., Meyer, A. K., Nadaraja, G. S., Parikh, R., Virbalas, J., Weinstein, J. E., & Chan, D. K. (2022). Racial and ethnic disparities in diagnostic efficacy of comprehensive genetic testing for sensorineural hearing loss. *Human Genetics*, 141, 495–504.
<https://doi.org/10.1007/s00439-021-02338-4>
- Gaffney, M., Eichwald, J., Gaffney, C., Alam, S., & Centers for Disease Control and Prevention. (2014). Early hearing detection and intervention among infants: Hearing screening and follow-up survey, United States, 2005–2006 and 2009–2010. *Morbidity and Mortality Weekly Report Supplements*, 63(2), 20–26.
<https://www.cdc.gov/mmwr/preview/mmwrhtml/su6302a4.htm>
- Galobardes, B., Shaw, M., Lawlor, D. A., Lynch, J. W., & Smith, G. D. (2006). Indicators of socioeconomic position (Part I). *Journal of Epidemiology & Community Health*, 60(1), 7–12.
<https://doi.org/10.1136/jech.2004.023531>
- Gonzalez, M., Iarossi, L., Wu, Y., Huang, Y., & Siegenthaler, K. (2017). Using data to improve services for infants with hearing loss: Linking newborn hearing screening records with early intervention records. *Journal of Early Hearing Detection and Intervention*, 2(2), 2–9.
<https://doi.org/10.15142/T3934P>
- Gupta, R. P., de Wit, M. L., & McKeown, D. (2007). The impact of poverty on the current and future health status of children. *Paediatrics Child Health*, 12, 667–672.
<https://doi.org/10.1093/pch/12.8.667>
- Haider, A. (2021). The basic facts about children in poverty. *Center for American Progress*.
https://americanprogress.org/wp-content/uploads/2021/01/ChildPovertyPrimer-report1.pdf?_ga=2.133266766.1139010294.1646945917-1802301635.1646945917
- Harding, S., Read, U. M., Molaodi, O. R., Cassidy, A., Maynard, M. J., Lenguerrand, E., Astell-Burt, T., Teyhan, A., Whitrow, M., & Enayat, Z. E. (2015). The determinants of young adult social well-being and health (DASH) study: Diversity, psychosocial determinants, and health. *Social Psychiatry and Psychiatric Epidemiology*, 50, 1173–1188.
<https://doi.org/10.1007/s00127-015-1047-9>
- Hoff, E., Burrige, A., Ribot, K. M., & Giguere, D. (2018). Language specificity in the relation of maternal education to bilingual children's vocabulary growth. *Developmental Psychology*, 54(6), 1011–1019.
<https://doi.org/10.1037/dev0000492>
- Holland, A. T., & Palaniappan, L. P. (2012). Problems with the collection and interpretation of Asian-American health data: Omission, aggregation, and extrapolation. *Annals of Epidemiology*, 22(6), 397–405.
<https://doi.org/10.1016/j.annepidem.2012.04.001>
- Holte, L., Walker, E., Oleson, J., Spratford, M., Moeller, M. P., Roush, P., Ou, H., & Tomblin, J. B. (2012). Factors influencing follow-up to newborn hearing screening for infants who are hard of hearing. *American Journal*

- of *Audiology*, 21(2), 163–174.
[https://doi.org/10.1044/1059-0889\(2012/12-0016\)](https://doi.org/10.1044/1059-0889(2012/12-0016))
- Hunter, L. M. (2012). *U.S. teen birth rate correlated with state income inequality*. Washington DC: Population Reference Bureau.
<https://www.prb.org/resources/u-s-teen-birth-rate-correlates-with-state-income-inequality/>
- Joint Committee on Infant Hearing (2000). Year 2000 position statement: Principles and guidelines for Early Hearing Detection and Intervention programs.
<http://www.jcih.org/posstatements.htm>
- Joint Committee on Infant Hearing (2019). Year 2019 position statement: Principles and guidelines for Early Hearing Detection and Intervention programs. *Journal for Early Hearing Detection and Intervention*, 4(2), 1–44.
<https://doi.org/10.15142/fptk-b748>
- Juarez, J. M., Shaffer, A. D., & Chi, D. H. (2020). Follow-up after failed newborn hearing screening: Parental and primary care provider awareness. *American Journal of Otolaryngology*, 41(6), 102614.
<https://doi.org/10.1016/j.amjoto.2020.102614>
- Justice, L. M., Jiang, H., Bates, R., & Koury, A. (2020). Language disparities related to maternal education emerge by two years in a low-income sample. *Maternal and Child Health Journal*, 24(11), 1419–1427.
<https://doi.org/10.1007/s10995-020-02973-9>
- Kader, F., Doan, L. N., Lee, M., Chin, M. K., Kwon, S. C. & Yi, S. S. (2022). Disaggregating race/ethnicity data categories: Criticisms, dangers, and opposing viewpoints. *Health Affairs Forefront*.
<https://www.healthaffairs.org/doi/10.1377/forefront.20220323.555023/full/>
- Kauh, T. J., Read, J. G., & Scheitler, A. J. (2021). The critical role of racial/ethnic data disaggregation for health equity. *Population Research and Policy Review*, 40(1), 1–7.
<https://doi.org/10.1007/s11113-020-09631-6>
- Kenna, M. A. (2021). Just do it—Everyone should follow the guidelines. *JAMA Otolaryngology–Head & Neck Surgery*, 147, 261–262. <https://doi.org/10.1001/jamaoto.2020.5077>
- Kingsbury, S., Khvalabov, N., Stim, J., Held, C., Fleckenstein, S. M., Hendrickson, K. & Walker, E. A. (2022). Barriers to equity in pediatric hearing health care: A review of the evidence. *Perspectives of the ASHA SIG*, 9, 1–12.
https://doi.org/10.1044/2021_PERSP-21-00188
- Landon, B. E., Onnela, J-P., Meneades, L., O'Malley, J., & Keating, N. L. (2021). Assessment of racial disparities in primary care physician specialty referrals. *Journal of the American Medical Association Network Open*, 4, e2029238.
<https://doi.org/10.1001/jamanetworkopen.2020.29238>
- Lantos, P. M., Maradiaga-Panayotti, G., Barber, X., Raynor, E., Tucci, D., Hoffman, K., Permar, S., Jackson, P., Hughes, B. L., Kind, A., & Swamy, G. K. (2020). Geographic and racial disparities in infant hearing loss. *Otolaryngology Head & Neck Surgery*, 159, 1051–1057.
<https://doi.org/10.1177/0194599818803305>
- Latchem, C. (2014). Informal learning and non-formal education for development. *Journal of Learning for Development*, 1(1).
<https://files.eric.ed.gov/fulltext/EJ1106082.pdf>
- Linton, J. M., Green, A., & Council on Community Pediatrics. (2019). Providing care for children in immigrant families. *Pediatrics*, 144(3), e20192077.
<https://doi.org/10.1542/peds.2019-2077>
- Liu, X., Rosa-Lugo, L. I., Cosby, J. L., & Pritchett, C. V. (2020). Racial and insurance inequalities in access to early pediatric cochlear implantation. *Otolaryngology-Head and Neck Surgery*, 164, 667–674.
<https://doi.org/10.1177/0194599820953381>
- Love, H. R., & Beneke, M. R. (2021). Pursuing justice-driven inclusive education research: Disability critical race theory (DisCrit) in early childhood. *Topics in Early Childhood Special Education*, 41(1), 31–44.
<https://doi.org/10.1177/0271121421990833>
- Matiz, L. A., Leong, S., Peretz, P. J., Kuhlmeier, M., Bernstein, S. A., Oliver, M. A., Medina, K., & Lalwani, A. K. (2022). Integrating community health workers into a community hearing health collaborative to understand the social determinants of health in children with hearing loss. *Disability and Health Journal*, 15(1), 101181.
<https://doi.org/10.1016/j.dhjo.2021.101181>
- McManus, M. A., Levitov, R., White, K. R., Forsman, I., Foust, T., & Thompson, M. (2010). Medicaid reimbursement of hearing services for infants and young children. *Pediatrics*, 126, S34–S42. <https://doi.org/10.1542/peds.2010-0354H>
- Meyer, A. C., Marsolie, M., Brown, N., & Coverstone, K. (2020). Delayed identification of infants who are deaf or hard of hearing—Minnesota, 2012–2016. *Morbidity and Mortality Weekly Report*, 69(11), 303–306.
<https://www.cdc.gov/mmwr/volumes/69/wr/pdfs/mm6911a6-H.pdf>
- Mohapatra, B., & Mohan, R. (2021). A proposed framework for increasing racial and ethnic diversity in Communication Sciences and Disorders academic programs: The REAP model. *Perspectives*, 6(4), 755–767.
https://doi.org/10.1044/2021_PERSP-20-00285
- Monk, E. P. (2021). The unceasing significance of colorism: Skin tone stratification in the United States. *Dædalus*, 150, 76–90.
https://doi.org/10.1162/daed_a_01847

- Morgan, P. L., Farkas, G., Hillemeier, M. M., Li, H., Pun, W. H. & Cook, M. (2017). Cross-cohort evidence of disparities in service receipt for speech or language impairments. *Exceptional Children, 84*, 27–41. <https://doi.org/10.1177/0014402917718341>
- National Center for Health Statistics (2001). *Healthy People 2000 Final Review*. Public Health Service. <https://www.cdc.gov/nchs/data/hp2000/hp2k01.pdf>
- National Center for Hearing Assessment and Management. (n.d.). *National goals and program objectives for the EHDI tracking and surveillance system*. <https://www.infanthearing.org/programevaluation/standards.html>
- National Institute for Children's Health Quality. (2016). *Improving follow-up after newborn hearing screening: An action kit for audiologists*. Boston, MA. <https://www.nichq.org/resource/improving-follow-after-newborn-hearing-screening>
- National Panel on DHHS Collection of Race and Ethnicity Data. (2004). *Eliminating health disparities: Measurement and data needs*. National Academies Press.
- National Research Council. (2013). *Nonresponse in social science surveys: A research agenda*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/18293>
- Navarro-Carrillo, G., Alonso-Ferres, M., Moya, M., & Valor-Segura, I. (2020). Socioeconomic status and psychological well-being: Revisiting the role of subjective socioeconomic status. *Frontiers in Psychology, 11*, Art 1303. <https://doi.org/10.3389/fpsyg.2020.01303>
- Nicholson, N., Rhoades, E. A., & Glade, R. (2022). Analysis of health disparities in the screening and diagnosis of hearing loss: Early Hearing Detection and Intervention Hearing Screening Follow-up Survey. *American Journal of Audiology, 31*(3), 1–25. https://doi.org/10.1044/2022_AJA-21-00014
- Nieman, C. L., Marrone, N., Szanton, S. L., Thorpe, R. J., & Lin, F. R. (2016). Racial/ethnic and socioeconomic disparities in hearing health care among older Americans. *Journal of Aging and Health, 28*, 68–94. <https://doi.org/10.1177/0898264315585505>
- Nieman, C. L., Tunkel, D. E., & Boss, E. F. (2016). Do race/ethnicity or socioeconomic status affect why we place ear tubes in children? *International Journal of Pediatric Otorhinolaryngology, 88*, 98–103. <https://doi.org/10.1016/j.ijporl.2016.06.029>
- Okolie, F., South-Paul, J. E., & Watchko, J. F. (2020). Combating the hidden health disparity of kernicterus in black infants. *Journal of the American Medical Association: Pediatrics, 174*, 1199–1205. <https://doi.org/10.1001/jamapediatrics.2020.1767>
- Orkin, A. M., Nicoll, G., Persaud, N., & Pinto, A. D. (2021). Reporting of sociodemographic variables in randomized clinical trials, 2014–2020. *Journal of the American Medical Association Network Open, 4*, e2110700. <https://doi.org/10.1001/jamanetworkopen.2021.10700>
- Park, J., Saha, S., Chee, B., Taylor, J., & Beach, M. C. (2021). Physician use of stigmatizing language in patient medical records. *Journal of the American Medical Association Network Open, 4*(7), e2117052. <https://doi.org/10.1001/jamanetworkopen.2021.17052>
- Parker, M. G., Garg, A., & McConnell, M. S. (2020). Addressing childhood poverty in pediatric clinical settings: The Neonatal Intensive Care Unit is a missed opportunity. *Journal of the American Medical Association: Pediatrics, 174*, 1135–1136. <https://doi.org/10.1001/jamapediatrics.2020.2875>
- Peltz, A., Kan, K., Garg, A., Pomerantz, A., Bilaver, L. A., & Davis, M. M. (2021). Racial and ethnic differences in managed care enrollment among US children. *JAMA Network Open, 4*, e214162. <https://doi.org/10.1001/jamanetworkopen.2021.4162>
- Petersen, E. E., Davis, N. L., Goodman, D., Cox, S., Syverson, C., Seed, K., Shapiro-Mendoza, C., Callahan, W. M., & Barfield, W. (2019). Racial/ethnic disparities in pregnancy-related deaths—United States, 2007–2016. *Morbidity and Mortality Weekly Report, 68*, 762–765. <http://dx.doi.org/10.15585/mmwr.mm6835a3>
- Qian, Z. J., Chang, K. W., Ahmad, I. N., Tribble, M. S., & Cheng, A. G. (2021). Use of diagnostic testing and intervention for sensorineural hearing loss in US children from 2008 to 2018. *JAMA Otolaryngology–Head & Neck Surgery, 147*, 253–260. <https://doi.org/10.1001/jamaoto.2020.5030>
- Rees, C. A., Stewart, A. M., Mehta, S., Avakame, E., Jackson, J., McKay, J., & Fleegler, E. W. (2022). Reporting of participant race and ethnicity in published US pediatric clinical trials from 2011 to 2020. *JAMA Pediatrics, 176*(5), e220124. <https://doi.org/10.1001/jamapediatrics.2022.0142>
- Rendall, M. S., Weden, M. M., & Brown, J. (2022). Family and household sources of poverty for Black, Hispanic, and White newborns. *Journal of Marriage and Family, 84*(1), 330–346. <https://doi.org/10.1111/jomf.12781>
- Rollè, L., Gullotta, G., Trombetta, T., Curti, L., Gerino, E., Brustia, P., & Calderera, A. M. (2019). Father involvement and cognitive development in early and middle childhood: A systematic review. *Frontiers in Psychology, 10*, Art 2405. <https://doi.org/10.3389/fpsyg.2019.02405>
- Salkind, N. J. (2010). *Encyclopedia of Research Design*. Sage.
- Salvidar, M. G. (2012). A primer on survey response rates.

Learning Systems Institute, Florida State University.
https://mgsaldivar.weebly.com/uploads/8/5/1/8/8518205/saldivar_primer_on_survey_response.pdf

Sanchez-Gomez, M. C., Dundon, K., & Deng, X. (2019). Evaluating data quality of newborn hearing screening. *Journal of Early Hearing Detection and Intervention*, 4(3), 26–32. <https://doi.org/10.26077/fz0y-v617>

Schmidt, K. L., Merrill, S. M., Gill, R., Miller, G. E., Gadermann, A. M., & Kobor, M. S. (2021). Society to cell: How child poverty gets “under the skin” to influence child development and lifelong health. *Developmental Review*, 61, 100983. <https://doi.org/10.1016/j.dr.2021.100983>

Schuh, M., & Bush, M. L. (2021). Defining disparities in cochlear implantation through the Social Determinants of Health. *Seminars in Hearing*, 42, 321–330. <https://doi.org/10.1055/s-0041-1739282>

Shanker, A., Rojas-Ramirez, M. V., Jacobs, J. A., Shinn, B. J., Lester, C., Westgate, P. M., Bush, M. L. (2019). Assessment of factors involved in non-adherence to infant hearing diagnostic testing. *Journal of Early Hearing Detection and Intervention*, 4(3), 1–8. <https://doi.org/10.26077/93y1-x227>

Shulman, S., Besculides, M., Saltzman, A., Ireys, H., White, K. R., & Forsman, I. (2010). Evaluation of the universal newborn hearing screening and intervention program. *Pediatrics*, 126(Supp. 1), S19–S27. <https://doi.org/10.1542/peds.2010-0354F>

Svedberg, P., Nygren, J. M., Staland-Nyman, C., & Nyholm, M. (2016). The validity of socioeconomic status measures among adolescents based on self-reported information about parents' occupations, FAS and perceived SES: Implication for health-related quality of life studies. *BMC Medical Research Methodology*, 16(1), Article 48. <https://doi.org/10.1186/s12874-016-0148-9>

Tarver, M. E. (2021). Race and ethnicity in real-world data sources: Considerations for medical device regulatory efforts. *Journal of Primary Care & Community Health*, 12, 1–4. <https://doi.org/10.1177/2150132721994040>

Thompson, M. N., & Dahling, J. J. (2019). Employment and poverty: Why work matters in understanding poverty. *The American Psychologist*, 74(6), 673–684. <https://doi.org/10.1037/amp0000468>

Thorne, N., Witcomb, G. L., Nieder, T., Nixon, E., Yip, A., & Arcelus, J. (2019). A comparison of mental health symptomatology and levels of social support in young treatment seeking transgender individuals who identify as binary and non-binary. *International Journal of Transgenderism*, 20(2-3), 241–250. <https://doi.org/10.1080/15532739.2018.1452660>

Tolan, M., Serpas, A., McElroy, K., Craun, P., Williams, C., Reilly, B. K., & Preciado, D. (2017). Delays in sound recognition and imitation in underinsured children receiving cochlear implantation. *JAMA Otolaryngology–Head Neck Surgery*, 143, 60–64. <http://dx.doi.org/10.1001/jamaoto.2016.2730>

Tomblin, J. B., Harrison, M., Ambrose, S. E., Walker, E. A., Oleson, J. J., & Moeller, M. P. (2015). Language outcomes in young children with mild to severe hearing loss. *Ear & Hearing*, 36(Supp. 1), 76S–91S. <https://doi.org/10.1097/aud.0000000000000219>

Tran, T., Ng, I., Choojitarom, T., Webb, J., Jumonville, W., Smith, M., Ibieta, T., Peat, M., & Berry, S. (2016). Late newborn hearing screening, late follow-up, and multiple follow-ups increase the risk of incomplete audiologic diagnosis evaluation. *Journal of Early Hearing Detection and Intervention*, 1(2), 49–55. <https://doi.org/10.15142/T36880>

Tran, T., Schindelar, L., Ibieta, T., Webb, J., Jumonville, W., Peat, M., & Berry, S. (2017). Scheduling hearing appointments prior to hospital discharge improves follow-up after failed newborn screening. *Journal of Early Hearing Detection and Intervention*, 2(2), 24–29. <https://doi.org/10.15142/T3WS70>

U.S. Department of Health and Human Services (n.d.). *Healthy people 2030: Social determinants of health*. <https://health.gov/healthypeople/priority-areas/social-determinants-health>

Valdez, L. A., & Langellier, B. A. (2015). Racial/ethnic and socioeconomic disparities in mental health in Arizona. *Frontiers in Public Health*, 3, 170. <https://doi.org/10.3389/fpubh.2015.00170>

Villalba, C. M. H. (2014). Socioeconomic status. In A. C. Michalos (Ed.), *Encyclopedia of Quality of Life and Well-Being Research*. Springer, Dordrecht. https://doi.org/10.1007/978-94-007-0753-5_2805

Walhovd, K. B., Fjell, A. M., Wang, Y., Amlien, I. K., Mowinckel, A. M., Lindenberger, U., Düzel, S., Bartrés-Faz, D., Ebmeier, K., Devon, C. A., Baaré, W. F. C., Ghisletta, P., Johansen, L. B., Kievit, R. A., Henson, R. N., Madsen, K. S., Nyberg, L., Harris, J. R., Sole-Padullés, C., ... Brandmaier, A. M. (2022). Education and income show heterogeneous relationships to lifespan brain and cognitive differences across European and US cohorts. *Cerebral Cortex*, 32, 839–854. <https://doi.org/10.1093/cercor/bhab248>

Wight, V., Kaushal, N., Waldfogel, J., & Garfinkel, I. (2014). Understanding the link between poverty and food insecurity among children: Does the definition of poverty matter? *Journal of Children & Poverty*, 20(1), 1–20. <https://doi.org/10.1080/10796126.2014.891973>

Williams, D. R., & Mohammed, S. A. (2013). Racism and health I: Pathways and scientific evidence. *American*

Behavioral Scientist, 57(8), 1152–1173. <https://doi.org/10.1177/0002764213487340>

Williams, T. R., Alam, S., & Gaffney, M. (2015). Progress in identifying infants with hearing loss—United States, 2006–2012. *Morbidity and Mortality Weekly Report*, 64, 351–356. <http://www.cdc.gov/ncbddd/hearingloss/ehdi-data.html>

Williams-Roberts, H., Neudorf, C., Abonyi, S., Cushon, J., & Muhajarine, N. (2018). Facilitators and barriers of sociodemographic data collection in Canadian health care settings: A multisite case study evaluation. *International Journal for Equity in Health*, 17(1), 186. <https://doi.org/10.1186/s12939-018-0903-0>

World Health Organization and Commission on Social Determinants of Health. (2008). *Closing the gap in a generation: Health equity through action on the social determinants of health*. World Health Organization. <https://www.who.int/publications/i/item/WHO-IER-CSDH-08.1>

Yoshinaga-Itano, C., Sedey, A. L., Wiggin, M., & Mason, C. A. (2018). Language outcomes improved through early hearing detection and earlier cochlear implantation. *Otology & Neurotology*, 39(10), 1256–1263. <https://doi.org/10.1097/MAO.0000000000001976>

Zang, E., & Bardo, A. R. (2019). Objective and subjective socioeconomic status, their discrepancy, and health: Evidence from East Asia. *Social Indicators Research*, 143, 765–794. <https://doi.org/10.1007/s11205-018-1991-3>

Zeitlin, W., McInerney, M., Aveni, K., Scheperle, R., & Chontow, K. (2021). Better late than never? Maternal biopsychosocial predictors of late follow-up from New Jersey's early hearing detection and intervention program. *International Journal of Pediatric Otorhinolaryngology*, 145, 110708. <https://doi.org/10.1016/j.ijporl.2021.110708>

Zhang, G., Xu, L.-C., Zhang, M.-F., Zou, Y., He, L.-M., Cheng, Y.-F., Zhang, D.-S., Zhao, W.-B., Want, X.-Y., Want, P.-C., & Zhang, G.-Y. (2021). Changes of the brain causal connectivity networks in patients with long-term bilateral hearing loss. *Frontiers in Neuroscience*, 15, Art 628866. <https://doi.org/10.3389/fnins.2021.628866>

Zhang, L., Links, A. R., Boss, E. F., White, A., & Walsh, J. (2019). Identification of potential barriers to timely access to pediatric hearing aids. *JAMA Otolaryngology–Head & Neck Surgery*, 146(1), 13–19. <https://doi.org/10.1001/jamaoto.2019.2877>

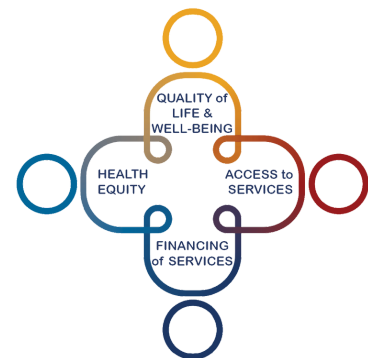
EHDInfo

HRSA MCHB: *Blueprint for Change*

We are proud to announce that the journal *Pediatrics* released a special supplement: [*Blueprint for Change: A National Framework for a System of Services for Children and Youth with Special Health Care Needs \(CYSHCN\)*](#)

The *Blueprint for Change* serves as national framework to improve the lives of the nearly 1 in 5 children (about 14 million children) who experience a special health care need.

We are calling on our families, our states, and our fellow federal agencies to work alongside us to transform our health care system into one where all CYSHCN thrive and can reach their fullest potential. [Learn more and find out what you can do](#)



Learn more about HRSA MCHB at mchb.hrsa.gov

Nurses' Perceptions of the Universal Newborn Hearing Screening Program

Aaron M. Roman, AuD¹

Michelle O'Connor Kensey, DNP²

¹Salus University, Elkins Park, PA

²West Chester University of Pennsylvania, PA

Abstract

This study explores the knowledge and perceptions of the newborn hearing screening (NBHS) program from the perspective of nurses and nursing support staff. Registered nurses and nursing support staff ($N = 84$) completed a digitally administered survey that queried their understanding of JCIH guidelines, perceptions around NBHS administration, and parental anxiety. The results demonstrated that while most respondents felt comfortable and confident about NBHS administration, there was a significant difference in their understanding of appropriate screening milestones compared to JCIH recommendations. Participants further demonstrated an interest in additional learning opportunities related to the NBHS.

Keywords: newborn hearing screening, nursing, newborn screening

Acronyms: AABR = automated auditory brainstem response; NBHS = newborn hearing screen; NCHAM = National Center for Hearing Assessment and Management; OAE = otoacoustic emissions

Correspondence concerning this article should be addressed to: Aaron M. Roman, AuD, Osborne College of Audiology, Salus University, 8360 Old York Road, Elkins Park, PA 19027. Email: aroman2@salus.edu

For more than twenty years, screening newborns for permanent hearing loss has become a standard of practice in perinatal care in the United States. In 1999, the Centers for Disease Control and Prevention estimated that 45% of newborns were screened for hearing loss (Centers for Disease Control and Prevention [CDC], 2010). As of 2019, 97.9% of newborns were screened before hospital discharge (CDC, 2021). Currently, at least 45 states, including Puerto Rico and the District of Columbia require all hospitals and birthing centers to screen infants for hearing loss prior to discharge (National Conference of State Legislatures [NCSL], 2021). Most states either mandate insurance providers to cover the cost of the screenings or use state funding to provide the necessary monies to identify newborns at risk for developmental speech, language, and cognitive issues (NCSL, 2021). Although screening rates have grown substantially in the two decades since the 1999 position statement from the American Academy of Pediatrics (AAP), a strong screening program is reliant on consistent administration and access to follow-up resources for those in need.

The responsibility of administering the initial newborn hearing screen (NBHS) is not allocated to a singular professional. Across the United States, technicians, audiologists, perinatal nurses, and unlicensed nursing support staff often shoulder the responsibility to administer the screening tests, as well as informing the parents of the

results. In many settings, the responsibility of screening for hearing loss falls into the scope of practice and practice purview of perinatal nurses and nursing support staff (Ravi et al., 2018). However, birthing hospitals and other neonatal institutions may not provide any formal training or education on how to perform the tests, proper techniques, or explanation of results. This can lead to high rates of inter-rater error among those personnel performing the screening. Furthermore, it is often the responsibility of the nurse or nursing support staff (including nursing students) to provide the parents with the results of the screen.

To date, there are few studies that assess the knowledge of and sentiment toward NBHS programs from a screener's perspective. Ravi et al. (2018) conducted a systematic review analyzing knowledge and attitudes toward NBHS programs worldwide and found that, in most studies, there was a lack of understanding around NBHS by healthcare providers, though it was not directed exclusively at screening providers. There was a lack of understanding regarding etiology of permanent hearing losses, state regulations, and current practices in executing the screening. Ravi et al. further note that between 43% to 78% of healthcare providers feel as if they require additional training on NBHS.

Despite nurses being one of the primary providers of the NBHS in birthing hospitals and centers, there is little evidence assessing the perception of NBHS programs

among them. Roberts and Jones (2017) conducted a survey of 15 nursing professionals to evaluate their perceptions of the NBHS program prior to completing a training provided by the National Center for Hearing Assessment and Management (NCHAM). The pre-training survey responses suggest that participants felt as though their initial training did not adequately prepare them to complete NBHS procedures using the most up-to-date practices. The study noted discomfort surrounding testing equipment and documenting the results of the screening. Importantly, this study found that the NCHAM training improved the participants' survey responses, indicating a perceived improvement in comfort around the NBHS. Jones et al. (2018) expanded upon these concerns by assessing whether NBHS training in nursing school would increase comfort among nurses. The study found that following training, perceived comfort around the NBHS significantly increased. However, after five months, this perceived comfort decreased significantly, indicating the need for continued education around the NBHS program.

The survey designed by Roberts and Jones (2017) was modified to design the survey used for this study. The specific goals of this study were to (a) evaluate maternal newborn/perinatal nurses' and support staff knowledge related to NBHS programs, (b) understand the attitudes and perceptions of those who deliver NBHS services, and (c) determine areas of further education for this population.

Method

This study targets the knowledge and perceptions of nurses and nursing support staff members who administer newborn hearing screenings. To accomplish this, an invitation to participate in a 20-item survey was circulated to those who provide newborn hearing screening services via email request to perinatal clinical educators at a large five-institution health system and to members of Association of Women's Health, Obstetrics and Neonatal Nurses (AWHONN). The AWHONN was selected due to its potential ability to reach a wide variety of professionals who provide newborn hearing screening services. The health systems was used due to its affiliations with the university, thereby producing a higher likelihood of responses. To qualify for this study, participants must have self-identified as a nurse or nurse support staff who directly administers a newborn hearing screening at a birthing center. The survey was administered using Qualtrics Survey software. Those who accepted the invitation to participate were required to provide their consent prior to initiating the survey. This study was supported by the Institutional Review Board (IRB). No incentive was provided for completing this survey.

Survey Development

The survey for this study was developed through a modification of the survey administered to nurses by Roberts and Jones (2017) and to nursing students by Jones et al. (2018). Specifically, the survey from Roberts and Jones was modified to add questions that reflect on the participants' sentiments toward the newborn hearing

screening (e.g., "In your opinion, how important is it to screen all children for hearing loss?"), perceptions on the impact of the screening on parental anxiety (e.g., "Do you believe that newborn hearing screenings cause excessive anxiety and/or concern for parents?"), and general knowledge (e.g., "Does your state have a newborn hearing screening program?"). Questions reflecting on participants' perceptions were assessed using a five-point Likert scale. Additionally, general knowledge questions were scored using forced-choice responses. A full copy of the survey can be found in Appendix A.

Analysis

All survey data were analyzed using R statistical software (R Core Team, 2021). Descriptive statistics were used to calculate means and standard deviations for all Likert-scale data. Questions regarding participants' knowledge related to the JCIH (2019) 1-3-6 guidelines were measured using one-sample *t*-tests with each *mu* value set to a JCIH recommended timeframe. For example, when analyzing at what age participants believe a newborn should receive a formal diagnosis, the *mu* value was set to 3 to reflect the JCIH recommendation of receiving a formal diagnosis by three months of age. Further *t*-tests were used to assess whether participants experience a difference in comfort between screening instrumentation (automated auditory brainstem response measurement [AABR] vs. otoacoustic emission [OAE] screening) and documenting passing vs. referring outcomes.

Sullivan and Artino (2013) and de Winter and Dodou (2010) provided a rationale for the use of *t* tests for pairwise comparisons of Likert-scale data. Reasons supporting the use of *t* tests included that parametric tests such as *t* tests are generally more robust than non-parametric tests even when statistical assumptions (e.g., a normal distribution of data) are violated. Parametric tests are also robust enough to yield unbiased answers when analyzing Likert-scale responses or ordinal data (Sullivan & Artino, 2013). For five-point Likert items, the *t* tests (i.e., parametric test) and Mann-Whitney-Wilcoxon (i.e., non-parametric test) have equivalent power for pairwise comparisons (de Winter & Dodou, 2010). Moreover, using non-parametric methods can result in a loss of information when Likert-scale responses with high response rates are analyzed (Mircioiu & Atkinson, 2017).

Results

A total of 84 participants (81 licensed nurses and 3 nursing support staff) participated in this survey. However, not all participants responded to every question. The number of responses are indicated with each analysis. Table 1 highlights the demographic distribution of the study population. Most respondents were female-identifying licensed nurses between the ages of 35 and 44 who have been practicing for ten years or greater.

Sentiment Toward NBHS

Of the 82 respondents who completed questions relative to the sentiment toward NBHS, 11% (9/82) had completed

Table 1
Demographic Characteristics of Participants

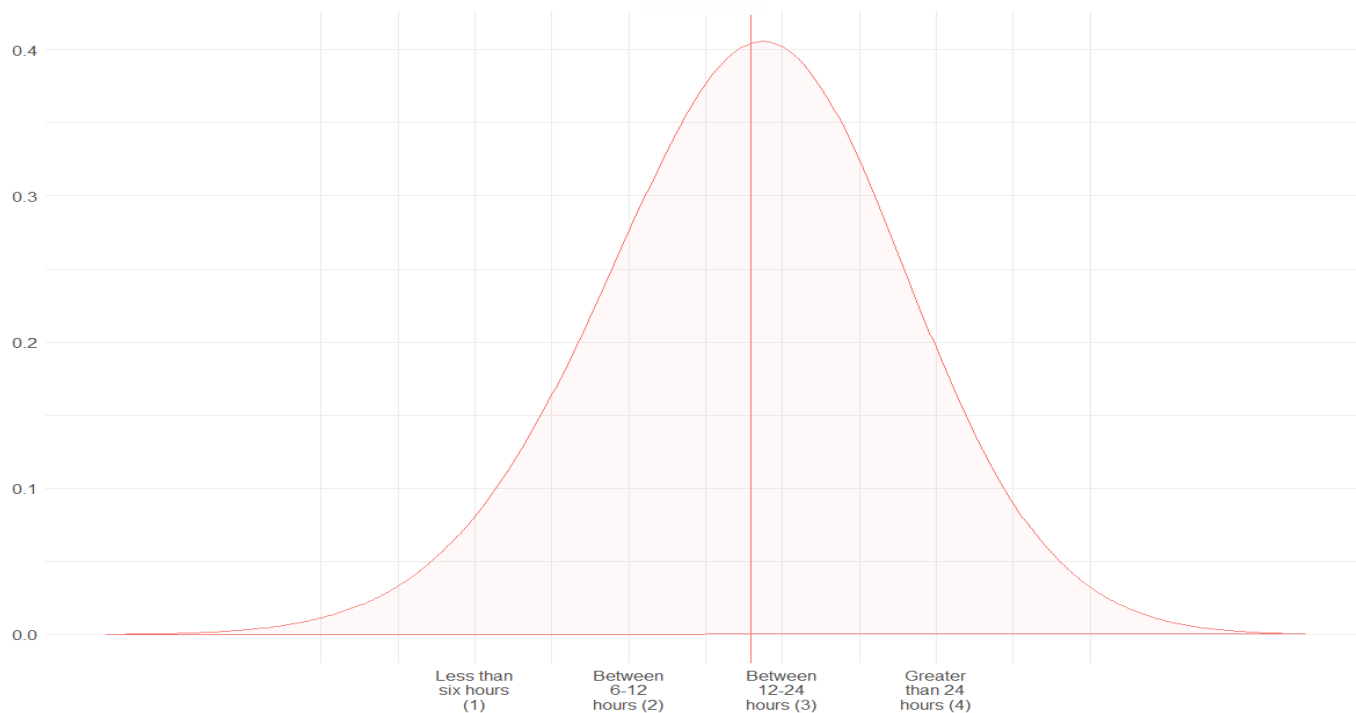
	Characteristic	Frequency	Percentage
Age	18–24	5	6.0%
	25–34	18	21.4%
	35–44	22	26.2%
	45–54	20	23.8%
	55–64	17	20.2%
	65–75	2	2.4%
Gender	Female/Woman	83	98.8%
	Male/Man	1	1.2%
Licensure	Licensed Nurse	81	96.43%
	Nursing Aid/ Support Staff	3	3.57%
Employment Status	Employed Full Time	57	67.86%
	Employed Part Time	27	32.14%
Employment Length	1–3 years	7	8.33%
	4–7 years	9	10.71%
	8–10 years	6	7.14%
	> 10 years	62	73.81%

the NCHAM NBHS Training Program, while 89% (73/82) had not. Over 86% of participants (71/82) viewed the importance of the NBHS program as either *very* or *extremely* important. When queried if they knew whether their state mandated newborn hearing screening, 85% (70/82) stated that yes, their state mandated hearing screenings for newborns, with 15% (12/82) stating that they were unsure. Additionally, sentiment among respondents suggested that they perceived the NBHS to be a relatively low-stress procedure for parents. Nearly three quarters (74.4% [61/82]) of respondents felt that the NBHS did not cause stress/anxiety to parents of newborns. Additionally, 77.6% (59/76) reported being either *somewhat* or *extremely* comfortable communicating the results of the newborn hearing screening to parents.

Knowledge of JCIH 1-3-6 Guidelines

When queried on the optimal time to wait to rescreen a newborn that fails the initial NBHS, 69% of respondents believe that the ideal wait time is between 12 and 24 hours. Figure 1 illustrates the density of responses to this question. Participants were asked at what age (in months) was an appropriate time to rescreen in the event of a failed NBHS at the birthplace. 64.4% of participants indicated that 1 month was the appropriate age, 15.8% of participants indicated three months was an appropriate age, 10.5% stated that two months was the appropriate time, and the remaining 5.25% said four months or later was an appropriate age. When asked by what age would it be appropriate to diagnose a hearing loss, only 26.3% of participants reported that three months of age (the recommended age by the JCIH) would

Figure 1
Density of Participant Responses When Asked the Optimal Time to Rescreen a Newborn who Fails Their Initial Hearing Screen



be an appropriate age. Almost 60% of participants (59.7%) stated an age higher than three months and 14.3% believed the age to be lower.

Participants appeared to vary in their responses when queried about the appropriate timeline for intervention. When asked about their perception of the appropriate time to fit a child with hearing aids, 31.6% of participants (18/57) answered six months, which aligns with the JCIH recommendations. This answer was the most concentrated of the responses, though the highest percentage of respondents (38.6% [22/57]) believed that newborns should be fit with hearing aids earlier than six months. When queried regarding the recommended age to enroll in early intervention (EI) services, 31.6% of participants (18/57) again indicated that the recommended age was enrollment by six months of age. As with hearing aids, this response had the highest concentration of respondents, but the majority of respondents (47.4%) believed that the recommended age of EI enrollment is before six months.

One-sample *t*-tests were used to compare the knowledge of the study group to the JCIH's recommendations of screening by one month, diagnosing by three months, and treating by six months. The mean estimated age of rescreening after referring from the birth center by

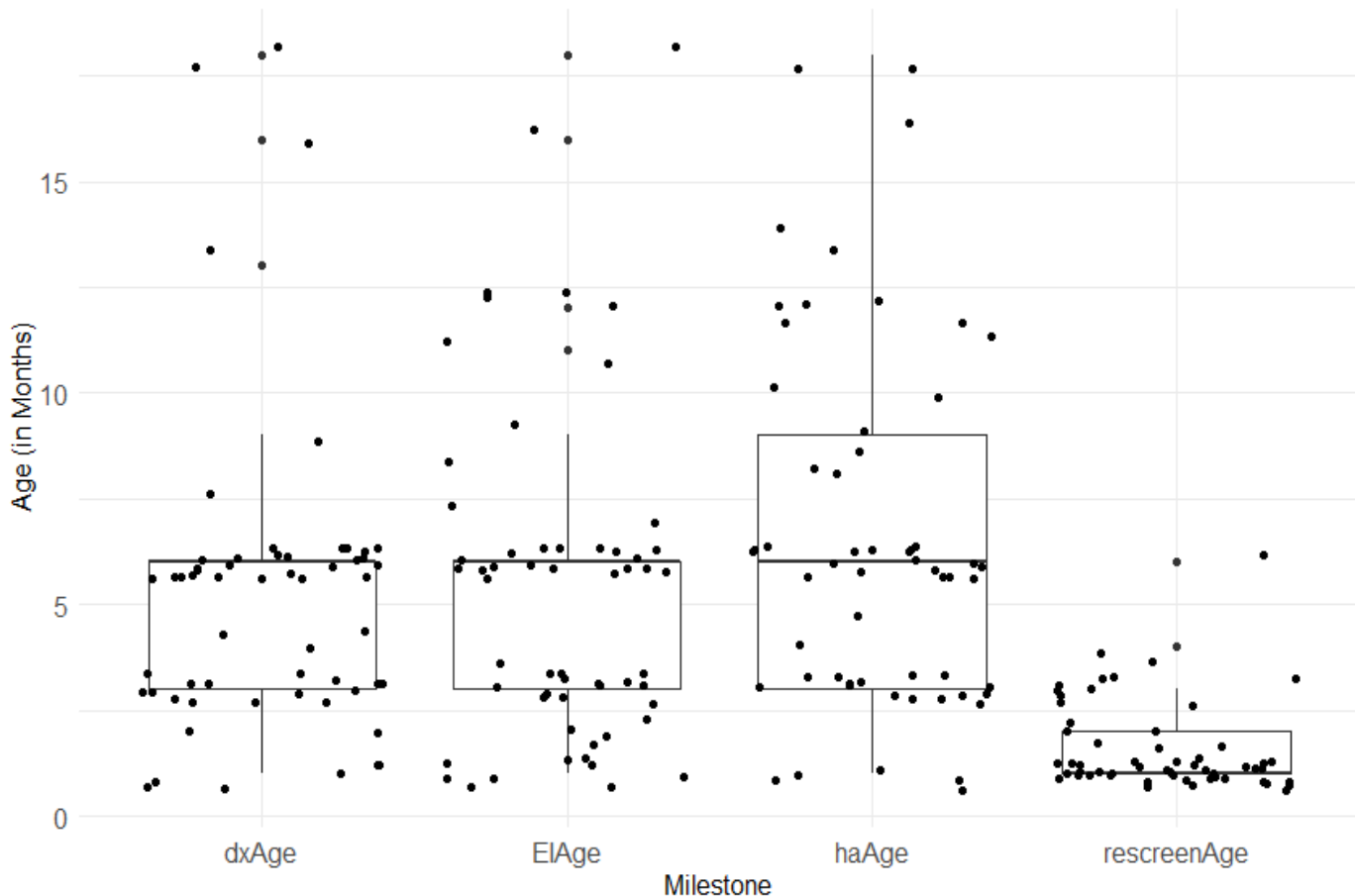
respondents was 1.69 months, significantly higher than the recommended one month ($t(61) = 5.408, p < .005$). Respondents estimated that the recommended age for diagnosis of hearing loss was 5.49 months, significantly higher than the recommended three months ($t(69) = 5.701, p < .001$). Estimates for treatment were divided into estimated age for early intervention enrollment ($M = 5.44$ months) and hearing aid fitting ($M = 6.33$), neither of which were significantly different from the JCIH's recommendation of treatment by six months of age. Individual responses are visualized on Figure 2.

Education Preparation

Respondents' opinions were divided as to whether their educational training prepared them to conduct newborn hearing screenings. Thirty-four percent (26/76) indicated that their educational training prepared them either *very* or *extremely well*, while 30% (23/76) felt that their training prepared them only *slightly well* or *not well at all*. Respondents largely felt that their education training helped prepare them to use the equipment for administering NBHS, with 67% (51/76) reporting that they felt adequately trained to use the equipment. Despite their comfort, 78% (59/76) expressed interest in future trainings related to NBHS procedures.

Figure 2

Participant Responses When Asked for the Optimal Age (in Months) to Rescreen, Diagnose (dx), Treat with Hearing Aids (ha), and Enroll in Intervention (EI)



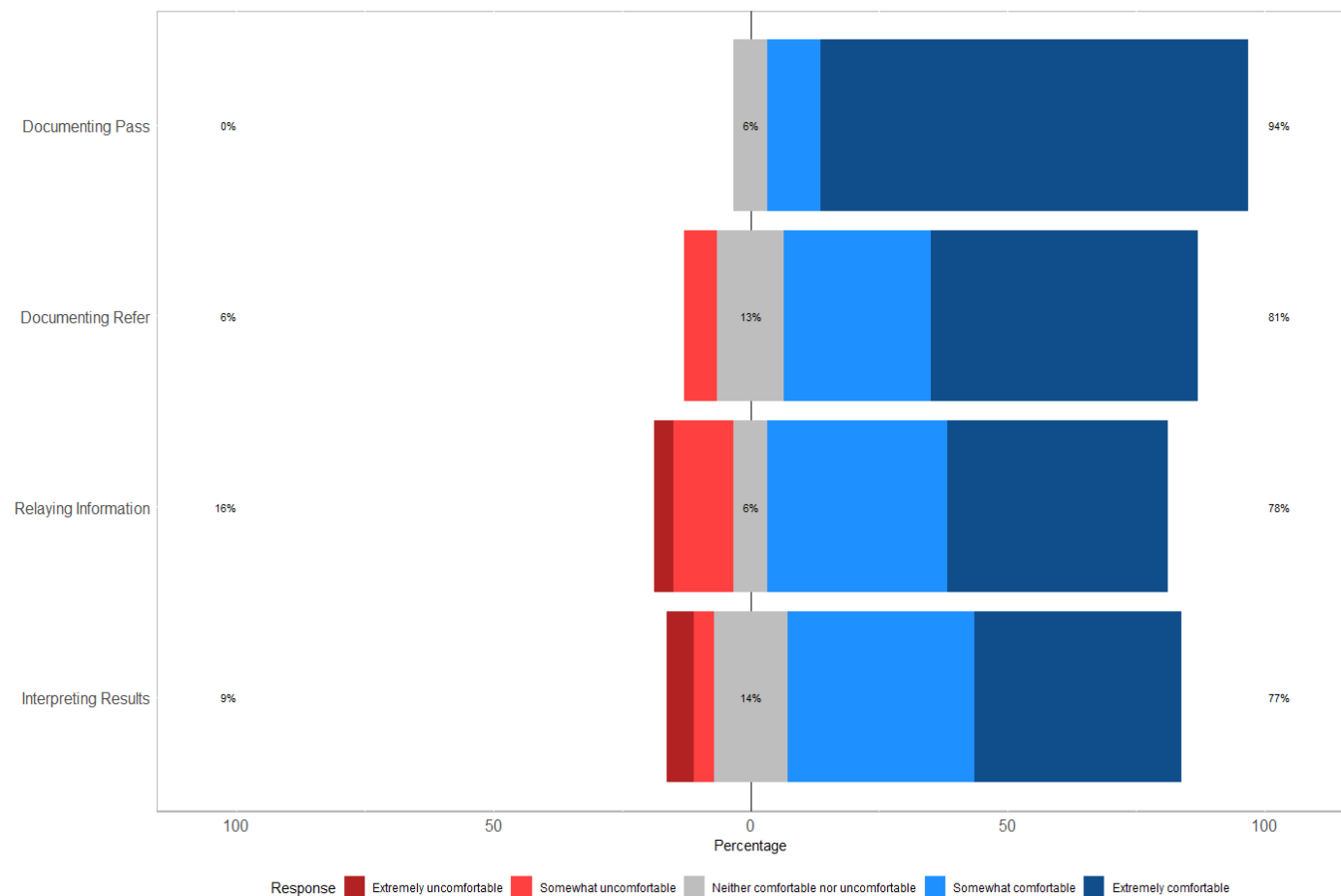
Administration Comfort

Figure 3 illustrates the perceived comfort levels related to administering the newborn hearing screening, including interpreting the results, documenting both pass and referrals, and informing parents of the results of the screening. Overall, 78% (60/77) of respondents classified their comfort level administering the newborn hearing screening as either *somewhat* or *extremely comfortable*. Seventy-seven percent (59/77) of respondents were either *somewhat* or *extremely*

comfortable interpreting the results of the screening once administered, and 78% (60/77) of respondents were either *somewhat* or *extremely comfortable* relaying the results to parents. Informing parents of the results of the screening appeared to be the area of highest discomfort, with 16% (12/77) noting that they were either *somewhat* or *extremely uncomfortable*. Respondents perceived the NBHS to have little impact on the stress of parents, with 75% (62/83) indicating that they do not believe that the NBHS creates anxiety to parents of newborns.

Figure 3

Likert Responses Highlighting Participants' Comfort Levels Regarding (a) The NBHS Administration in General, (b) Informing Parents of Screening Results, and (c) Interpreting the Results of the Screen



Perceptions of Documentation

When asked about their comfort documenting results of a passing NBHS, 93% of respondents stated that they felt either *somewhat* or *extremely comfortable* completing the necessary documentation. In contrast, 80% of participants were *somewhat* or *extremely comfortable* documenting the results of a NBHS in which the individual referred. This difference is statistically significant ($t(125.18) = 4.12, p < .001$).

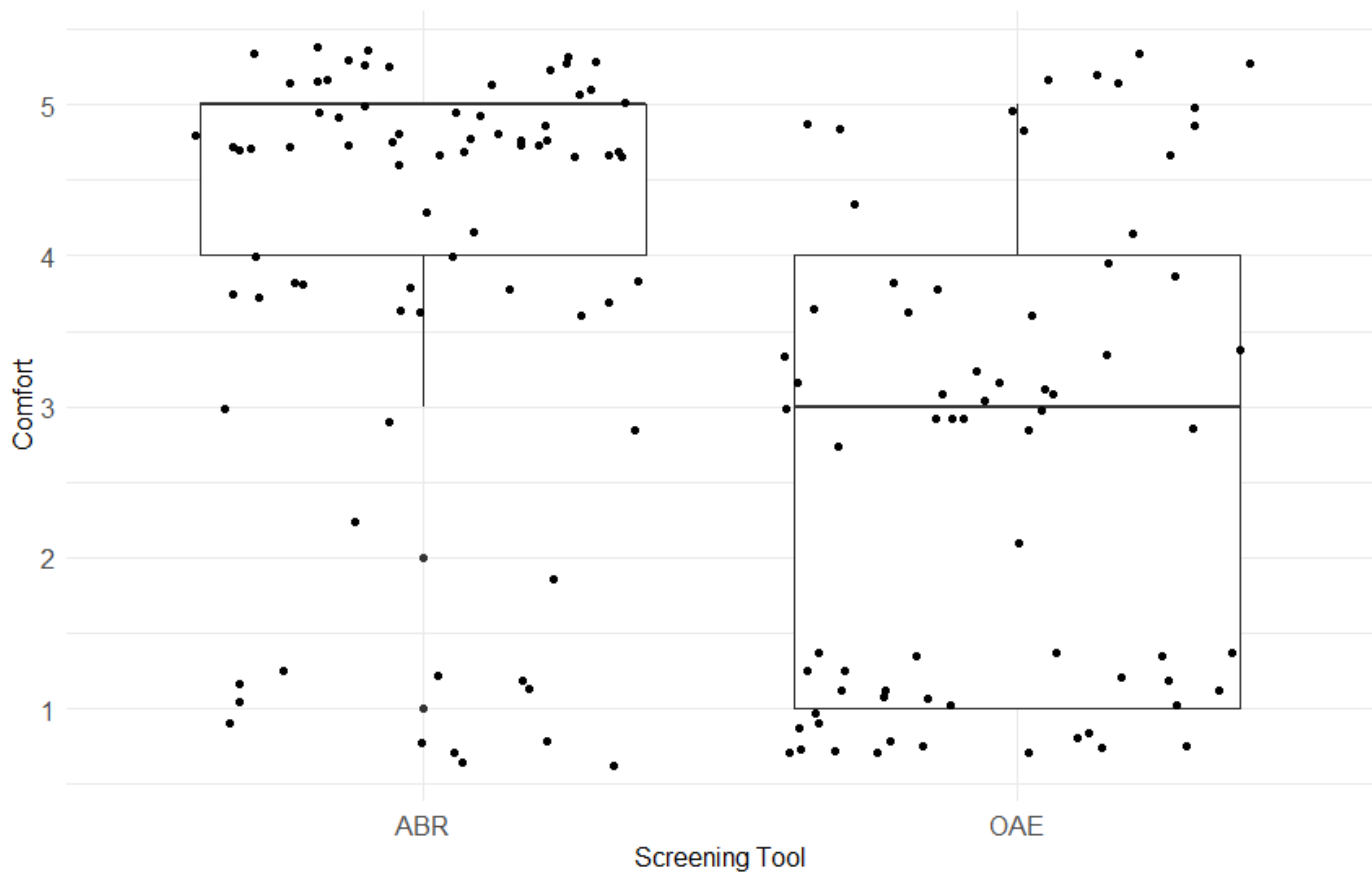
Instrumentation Comfort

Participants were asked to rank their comfort using an automated auditory brainstem response (AABR) screening device and otoacoustic emissions (OAE) screening

device on a scale of 1 (*Not at All Comfortable*) to 5 (*Very Comfortable*). More than three quarters of respondents (77.6%; 59/76) indicated that they were either *somewhat* or *extremely comfortable* using an AABR system compared to the 30% (21/70) of respondents who felt similarly about the OAE system. Only 18.4% (14/76) felt uncomfortable using an AABR to conduct screenings, while 44.3% were uncomfortable using an OAE machine to conduct screenings. Overall, participants perceived themselves as significantly more comfortable using AABRs to conduct NBHS procedures compared to OAE devices ($t(141.39) = 5.624, p < .001$). The distribution of responses can be found in Figure 4.

Figure 4

Perceived Comfort Between Use of Automated Auditory Brainstem Response (AABR) and Otoacoustic Emissions (OAE) to Screen for Hearing Loss



Discussion

The goal of this study was to gain greater insight into the perception of the newborn hearing screening program directly from those who administer the screening. To achieve this goal, this study assessed (a) the general knowledge of those who administer newborn hearing screening, (b) the perceptions around the NBHS procedures, and (c) whether there is interest in further education around NBHS in the population that administers these screenings.

NBHS Knowledge

The findings from this study suggest that participants, while generally comfortable with newborn hearing screening techniques, may benefit from education around the policies and procedures that guide NBHS programs in the United States. Fifteen percent of participants surveyed were unsure if their state mandated a NBHS screening. This finding is not entirely new, as Ravi et al. (2017) cite state regulations as a gap in knowledge among healthcare providers in their systematic review. However, the study that Ravi et al. cited assessed physician sentiment toward NBHS prior to the 1999 recommendation from the AAP (Wall et al., 2006). Since that time, providers seem to be more cognizant of state-level mandates around NBHS, with 85% of this study's population accurately indicating that their state (Pennsylvania) mandates the screening.

Presently, 43 of the 50 states in the United States have either statutes or regulations that mandate a NBHS (NCHAM, 2021).

The participants' knowledge regarding the JCIH's 1-3-6 guidelines in this study is somewhat similar to previously documented studies. Ravi et al. (2017) found that roughly 67% of pediatricians were aware of the 1-3-6 guidelines from the JCIH, though the pediatricians surveyed were based in India. Danhauer et al. (2009) surveyed America-based pediatricians and found that they demonstrated a fair to moderate amount of familiarity with the 1-3-6 guidelines, with the most respondents (86.7%) familiar with the one-month screening guidance. Interestingly, this study found statistically significant differences in the participants' responses from the JCIH recommended ages for rescreening and age of diagnosis, but not age of interventions. This differs from Danhauer et al., who found that the fewest number of respondents (63.6%) were able to correctly identify the age of intervention at six months.

Attitude and Perceptions of NBHS

Our study finds that 86% of respondents found the NBHS program to be an important aspect of the newborn screening process. This finding aligns with findings by Moeller et al. (2006), who surveyed primary care physicians' attitudes toward the NBHS program and found

that 81% of physicians supported the program. Although Moeller et al. surveyed physicians, there is little evidence regarding the perception of the NBHS program among those who carry out the screening services. To that end, our study adds to the literature, indicating that sentiment toward the program among nurses and nurse-support staff is similar, if not higher, than primary care providers.

In terms of administration and documentation comfort and their relationship to educational training, this study found that many nurses surveyed felt well-educated on the use of the NBHS instrumentation used by their institution. Although most of the study participants reported high comfort levels performing the newborn screening tests and reporting the results to the parents, many perinatal nurses and nursing support staff remain below optimal comfort levels with performing the screening tests and reporting the results to parents. This further supports the need for nursing and nurse-support staff education on reporting findings to parents.

Of particular significance is the low percentage of those surveyed who perceived that their formal education was useful in conducting NBHS procedures. This finding aligns with the findings by Roberts and Jones (2017), who also found that nurses felt that they were not adequately trained on NBHS procedures. In addition to lack of education about the procedures in general, Roberts and Jones found that nurses felt that they were not trained to use the most up-to-date equipment. Interestingly, our study negates this finding, instead finding that most participants felt well-trained to use the most up-to-date equipment. When asked about the specific tools used to screen, there was a statistically significant difference between equipment comfort, with more respondents comfortable using AABR as a screening tool compared to an OAE machine.

The results of this survey suggest the need for perinatal nurses and support staff continuing education about screening procedures, test validity, and reporting results to parents. According to Moeller et al. (2006), there is considerable evidence that newborn hearing screening tests are accurate and that most experts and physicians believe in the value of such screening. Beliefs about the importance of newborn hearing screening may be linked to nurses' clear understanding of the consequences for newborns with hearing loss on speech development, language acquisition, and learning. A clear understanding that even minimal hearing loss has consequences for the development of speech and language will put nurses in a better position to guide families in providing effective counseling relative to screenings. Specifically, nurses and other newborn hearing screening administrators should be effectively educated on the importance of counseling parents and caregivers on the implications and limitations of screening, while providing beneficial referral information in the event of a referral.

Interest in Future Education

Respondents overwhelmingly indicated that they would largely be interested in future educational opportunities

related to newborn hearing screening practices and guidelines. Designing such programs must be considered carefully to optimize practical learning for these individuals. For example, Moeller et al. (2006) found that though 51.7% of physicians reported using the Internet to access medical information, very few indicated that they used Internet-based resources to research topics related to newborn hearing screening. The authors postulate that the physicians surveyed may not have been knowledgeable about these resources, but resource accessibility may not be the only barrier. Continuing education presented in the form of print documents tends to only have a slight effect on medical decision-making (Giguère et al., 2020). Therefore, it may be prudent for future research to design interactive educational opportunities for newborn hearing screening providers to optimize learning opportunities.

Limitations and Future Directions

Attitudes, not just knowledge, are paramount to promote changes in health care practices. Perceptions regarding comfort level in administration and documentation, as well as educational preparation were important aspects of this study to elucidate the need for further research and education on NBHS, though there are several limitations that should be noted in interpreting results. In this study, nursing personnel and support staff felt much more comfortable using the AABR machine versus the OAE machine. However, the primary tool to conduct newborn hearing screens in the area surveyed is AABR. Participants may have felt significantly less comfortable with OAEs because they simply use AABR machines more often for newborn screenings. Additionally, as reported in Moeller et al. (2006), participants may have become aware of areas that they lack knowledge in as they completed this survey. This awareness may have biased their later responses.

Although this study adds to the existing literature by further exploring perceptions and attitudes of nurses who administer newborn hearing screenings, future research is essential for this group. Moving forward, research may wish to direct a lens toward nursing education, including the incorporation of undergraduate nursing student knowledge, comfort, and perceptions of NBHS. According to Jones et al. (2018), nursing students who completed the NCHAM NBHS Training Program showed significantly higher comfort and knowledge levels performing the screenings and documenting and reporting the results. Their study further found that regular follow-up training was required to be comfortable with NBHS policies and procedures, akin to the recommended guidelines for CPR training.

Conclusions

The purpose of this study was to evaluate the knowledge and perceptions of the newborn hearing screening program from those who directly administer the screening, specifically nurses and nursing support staff. The study found that perceptions from this sample population are generally very favorable around the NBHS program,

and that those who administer the screening perceive themselves as quite proficient in the knowledge and skills required to execute the screening. Participants also find the screening as a low-stress procedure for both screeners and parents of newborns. Areas of further development in this population include training on documentation, particularly when a newborn does not pass their initial screen, as well as further training on the JCIH 1-3-6 guidelines around the timing of screenings and subsequent follow-ups.

References

- Centers for Disease Control and Prevention. (2010). Overview and summary of 1999–2004 DSHPSHWA Data. https://www.cdc.gov/ncbddd/hearingloss/documents/1999-2004_dshpshwa-summary.pdf
- Centers for Disease Control and Prevention. (2021). 2019 Summary of hearing screening among total occurrent births. <https://www.cdc.gov/ncbddd/hearingloss/2019-data/02-screen.html>
- Danhauer, J. L., David, K. B., Johnson, C. E., & Meyer, D. H. (2009). Survey of pediatricians and early hearing detection and identification programs at a precise local level: An academic medical center. *Seminars in Hearing, 30*(3), 165–183.
- de Winter, J. C. F., & Dodou, D. (2010). Five-point Likert items: *T* test versus Mann-Whitney-Wilcoxon (addendum added October 2012). *Practical Assessment, Research & Evaluation, 15*(Article 11). <https://doi.org/10.7275/bj1p-ts64>
- Giguère, A., Zomahoun, H. T. V., Carmichael, P. H., Uwizeye, C. B., Légaré, F., Grimshaw, J. M., Gagnon, M-P., Auguste, D. U., & Massougbojji, J. (2020). Printed educational materials: Effects on professional practice and healthcare outcomes. *Cochrane Database of Systematic Reviews, 8*(8), CD004398.
- Joint Committee on Infant Hearing. (2019). Year 2019 position statement: Principles and guidelines for early hearing detection and intervention programs. *Journal of Early Hearing Detection and Intervention, 4*(2), 1–44. <https://doi.org/10.15142/fptk-b748>
- Jones, A. L., Lambert, A. W., & Barnett, M. (2018). Nursing students: Training and maintaining universal newborn hearing screening knowledge. *Nurse Education in Practice, 32*, 72–77. <http://doi.org/10.1016/j.nepr.2018.07.011>
- Mircioiu, C., & Atkinson, J. (2017). A comparison of parametric and non-parametric methods applied to a Likert scale. *Pharmacy (Basel, Switzerland), 5*(2), 26. <https://doi.org/10.3390/pharmacy5020026>
- Moeller, M. P., Eiten, L., White, K., & Shisler, L. (2006). Primary care physicians' knowledge, attitudes, and practices related to newborn hearing screening. *Pediatrics, 118*(4), 1357–1370. <http://dx.doi.org/10.1542/peds.2006-1008>
- National Center for Hearing Assessment and Management. (2021). State EHDI/UNHS mandates: Summaries by provision: Requires screening. <https://www.infanthearing.org/legislative/provisions/requires.html>
- National Conference of State Legislatures. (2021). Newborn hearing screening state laws. <https://www.ncsl.org/research/health/newborn-hearing-screening-state-laws.aspx>
- R Core Team. (2021). R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. <https://www.R-project.org/>
- Ravi, R., Gunjawate, D. R., Yerraguntla, K., & Rajashekhar, B. (2018). Systematic review of knowledge of, attitudes towards, and practices for newborn hearing screening among healthcare professionals. *International Journal of Pediatric Otorhinolaryngology, 10*, 138–144. <https://doi.org/10.1016/j.ijporl.2017.11.004>
- Roberts, C. P., & Jones, A. L. (2017). Measuring nurses' knowledge and understanding of universal newborn hearing screenings. *The Journal of Early Hearing Detection and Intervention, 2*(2), 38–47. <https://digitalcommons.usu.edu/jehdi/vol2/iss2/8/>
- Sullivan, G. M., & Artino, A. R., Jr. (2013). Analyzing and interpreting data from Likert-type scales. *Journal of Graduate Medical Education, 5*(4), 541–542. <https://doi.org/10.4300/JGME-5-4-18>
- Wall, T. C., Senicz, E., Evans, H. H., Woolley, A., & Hardin, J. M. (2006). Hearing screening practices among a national sample of primary care pediatricians. *Clinical Pediatrics, 45*(6), 559–566.

Appendix A

Newborn Hearing Screening Survey

Please select the age range that aligns to your age.

- | | |
|--------------------------------|-----------------------------------|
| <input type="radio"/> Under 18 | <input type="radio"/> 55–64 |
| <input type="radio"/> 18–24 | <input type="radio"/> 65–74 |
| <input type="radio"/> 25–34 | <input type="radio"/> 75–84 |
| <input type="radio"/> 35–44 | <input type="radio"/> 85 or older |
| <input type="radio"/> 45–54 | |

Which of these best applies to you

- | | |
|---|--------------------------------------|
| <input type="radio"/> I am a licensed nurse | <input type="radio"/> I am a student |
| <input type="radio"/> I am a nursing aid or support staff | |

Which of the following best describes your employment status?

- | | |
|---|---|
| <input type="radio"/> Employed full time | <input type="radio"/> Unemployed not looking for work |
| <input type="radio"/> Employed part time | <input type="radio"/> Retired |
| <input type="radio"/> Unemployed looking for work | <input type="radio"/> Student |

Please select the gender that you identify, or most closely identify, as:

- | | |
|------------------------------|----------------------------------|
| <input type="radio"/> Male | <input type="radio"/> Non-binary |
| <input type="radio"/> Female | <input type="radio"/> Other |

How many years have you been a practicing clinician?

- | | |
|---------------------------------|--|
| <input type="radio"/> 0–1 years | <input type="radio"/> 8–10 years |
| <input type="radio"/> 1–3 years | <input type="radio"/> 10 + years |
| <input type="radio"/> 4–7 years | <input type="radio"/> I am currently a student |

In which unit do you most commonly work?

Have you completed the Newborn Hearing Screening Training Curriculum from the National Center for Hearing Assessment and Management (NCHAM)?

- | |
|---|
| <input type="radio"/> Yes - I have completed the NCHAM Newborn Hearing Screening Training Curriculum |
| <input type="radio"/> No - I have not completed the NCHAM Newborn Hearing Screening Training Curriculum |
-

Appendix A (contd.)

Does your state have a newborn hearing screening program?

- Yes
 No
 Unsure

Do you believe that newborn hearing screenings cause excessive anxiety and/or concern for parents?

- Yes
 No
 Unsure

Do you think your training has prepared you to complete the newborn hearing screening using the most up to date equipment?

- Yes
 No

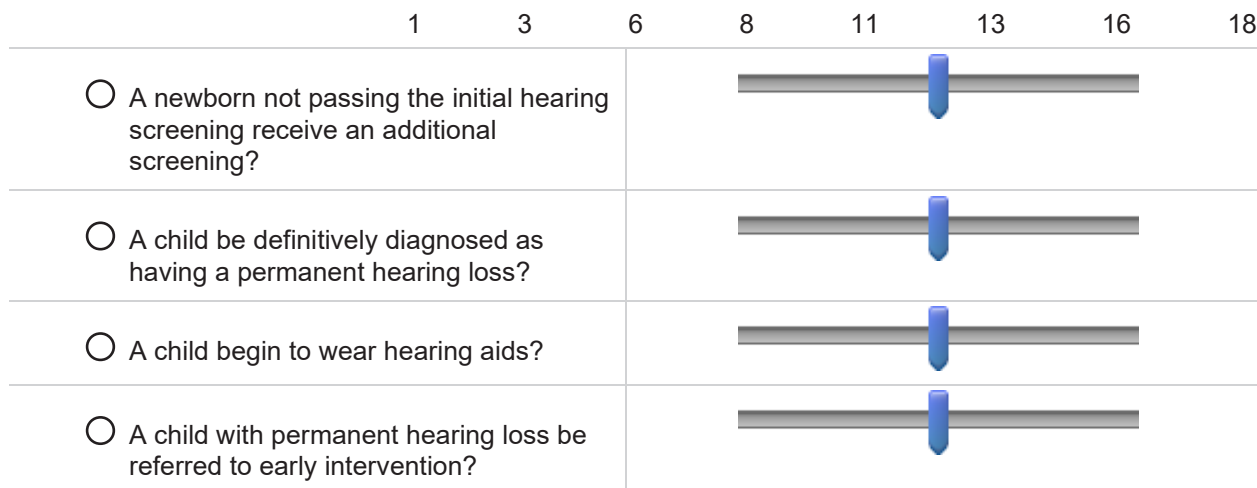
How well do you feel that your educational training prepared you concerning the newborn hearing screening?

- Extremely well
 Very well
 Moderately well
 Slightly well
 Not well at all

In your opinion, how important is it to screen all children for hearing loss?

- Extremely important
 Very important
 Moderately important
 Slightly important
 Not at all important

In your opinion, at what age (in months) should...



Appendix A (contd.)

Please rate your overall comfort with administering a newborn hearing screen

- Extremely comfortable Slightly comfortable
 Very comfortable Not at all comfortable
 Moderately comfortable

Please rate your comfort level using the following screening equipment

	Extremely comfortable	Somewhat comfortable	Neither comfortable nor uncomfortable	Somewhat uncomfortable	Extremely uncomfortable
(A)ABR - (Automated) Auditory Brainstem Response Equipment					
OAE - Otoacoustic Emission Testing Equipment					

How comfortable are you in interpreting the results of the newborn hearing screening?

- Extremely comfortable Somewhat uncomfortable
 Somewhat comfortable Extremely uncomfortable
 Neither comfortable nor uncomfortable

If your newborn refers on their initial screening, how comfortable do you feel documenting the result?

- Extremely comfortable Somewhat uncomfortable
 Somewhat comfortable Extremely uncomfortable
 Neither comfortable nor uncomfortable

If your newborn refers on their initial screening, how long should you wait to re-screen?

- Less than six hours Between 12–24 hours
 Between 6–12 hours Greater than 24 hours

Appendix A (contd.)

If your newborn has a passing result, how comfortable do you feel documenting the result?

- Extremely comfortable
- Somewhat comfortable
- Neither comfortable nor uncomfortable
- Somewhat uncomfortable
- Extremely uncomfortable

How comfortable are you in relaying information to parents who have questions about their child's newborn hearing screening results?

- Extremely comfortable
- Somewhat comfortable
- Neither comfortable nor uncomfortable
- Somewhat uncomfortable
- Extremely uncomfortable

Would you be interested in further information and/or training related to newborn hearing screenings?

- Yes
 - No
-

A Systematic Review of the Effects of LENA-Based Feedback on Parent-Child Language Interactions in Families with Young Children

Beula M. Magimairaj, PhD¹

Naveen K. Nagaraj, PhD¹

Ana Caballero, AuD²

Karen F. Muñoz, EdD¹

Karl R. White, PhD¹

¹Utah State University, Logan, UT

²Centro de Audición y Balance & Clínica Audiológica
Pediátrica, San Salvador, El Salvador

Abstract

Enhancing parent language interactions with children beginning in infancy is important because it results in better language abilities, social skills, and academic outcomes in children. A number of researchers have suggested that parent language interactions with children could be enhanced by giving parents feedback about their language interactions using the Language ENvironment Analysis (LENA) system. The LENA system records communication exchanges between a child and the adult caregiver and provides an automated analysis of adult word count, child vocalization count, and conversational turn count. We did a systematic review of the studies that investigated the use of LENA-based feedback to enhance parent language interactions with children. Although most previous studies have concluded that LENA-based feedback improves parental language interactions with children, methodological factors and confounding of treatment components in almost all of these studies make it impossible to know whether quantitative feedback from interactions recorded by the LENA system enhances parent language interactions with children. The designs and results of previous studies are discussed to suggest how future research can better address this important issue.

Keywords: LENA-based feedback; systematic review; early intervention; children; deaf or hard of hearing

Acronyms: AWC = adult word count; CTC = conversational turn counts; CVC = Child Vocalization Count; DHH = deaf or hard of hearing; NPC = non-parental caregiver; SES = socioeconomic status

Correspondence concerning this article should be addressed to: Beula M. Magimairaj, PhD, Early Childhood Education and Research Center, Utah State University, 2610 Old Main Hill, Logan, UT 84322. Email: beula.m@usu.edu

Parents¹ are almost always their children's first language teachers and play an important role during early childhood, a critical period for speech and language development. A large body of literature supports the significant role of parent-child interactions in the development of spoken language and social communication abilities in children. Roberts and Kaiser (2011) suggested four aspects of parent-child communication interactions that are important for language development in children: (a) the amount of parent-child interaction (e.g., conversations, joint attention activities); (b) responsiveness to child communication (e.g., parents' verbal and nonverbal responses to the child's communication attempts, eye contact, and play); (c) quality of language input (e.g., the diversity of words and complexity of linguistic structures that parents use when talking to their child); and (d) the use of language stimulation strategies (e.g., imitation, expanding and

recasting children's communicative attempts, listening and spoken language strategies). Other researchers have shown a strong positive relationship between children's vocabulary size and the amount and quality of their exposure to parentese (Conway et al., 2018; Guralnick et al., 2008; Hirsh-Pasek et al., 2015; Rowe, 2012; Weisleder & Fernald, 2013; Zimmerman et al., 2009). For example, Hirsh-Pasek et al. (2015) found that children's expressive language was positively correlated ($r = .34$) with maternal words per minute and quality of maternal input predicted 27% of the variance in children's expressive language. Conway et al. (2018) found that intrusive or directive maternal behaviors (in contrast to responsive expansion) were associated with poorer receptive and expressive language outcomes at 36 months and 48 months. For example, each unsuccessful directive was associated with an estimated 0.37 *SD* lower receptive language score at 36 months (95% CI = $-0.69, -0.04$) and 0.66 *SD* lower score at 48 months of age (95% CI = $-0.99, -0.33$).

¹The word *parent* will be used to include all adult caregivers of the child in the home environment.

The early language environment of a child's life not only shapes their language development but also predicts academic success, cognitive outcomes, and social skills (Huttenlocher et al., 1991, 2007, 2010; Leffel & Suskind, 2013; Pan et al., 2005; Tamis-Lemonda et al., 1998; Tomblin et al., 2020). For example, Pan et al. (2005) showed that at 24 and 36 months of age, a child whose mother scored at the 90th percentile on the language and literacy composite produced about 15 more word-types than a child whose mother scored at the 10th percentile. According to Tomblin et al. (2020), children's oral language ability at 5 years predicted 35% to 47% of the variance in reading outcomes at 8 years of age in children with typical hearing.

Children with developmental or intellectual disabilities, those who are deaf or hard of hearing (DHH), and children from families with lower socioeconomic status (SES) are at an increased risk for delays in language development (Campbell et al., 2003; DesJardin & Eisenberg, 2007; Fernald et al., 2013; Leffel & Suskind, 2013; Pace et al., 2017; Suskind et al., 2016). For example, Campbell and colleagues reported that with low maternal education as a risk factor, the odds-ratio of having a speech delay in 3-year-old children was 2.58. Fernald et al. (2013) demonstrated that by 24 months of age, children from higher SES backgrounds produced an average of 150 more words compared to children from lower SES families and this difference in expressive vocabulary was statistically significant as early as 18 months of age. Furthermore, reduced quantity and quality of parental linguistic input can be a reciprocal result of children's poor communication ability (Suskind et al., 2013). For example, as reported by VanDam et al. (2012), language ability in children who were DHH, was positively correlated with the number of conversational turns between parents and children ($r = .62, p < .01$) whereas both adult word count (AWC) and conversational turn counts (CTC) was associated with children's pure tone thresholds ($r_{AWC} = -.54, p < .01$; $r_{CTC} = -.47, p < .03$) and Speech Intelligibility Index or speech audibility ($r_{AWC} = .56, p < .01$; $r_{CTC} = .66, p < .01$). Additionally, Rufsvold et al. (2018) reported that while the degree of hearing loss did not significantly influence the quantity of adult input, the latter was associated with demographic variables such as the child's age ($r = .38, p = .025$) and father education [$F(6, 22) = 3.99, p = .008$].

Researchers have shown that children who are DHH, especially those who enroll for intervention after 2 years of age, are typically delayed by 1.0 to 1.5 standard deviations in language scores compared to their peers with typical hearing (Moeller, 2000; Nott et al., 2009; Tomblin et al., 2015; Yoshinaga-Itano, 2003), and mothers of children who are DHH tend to talk less to their children (DesJardin & Eisenberg, 2007; Suskind et al., 2013). Even children that were DHH who were enrolled earlier in intervention programs, performed in the low-average range relative to peers with typical hearing. Therefore, it is not surprising that most people agree that young children who are DHH and are learning spoken language, need access to a language-rich environment to support their development (e.g., Glanemann et al., 2013; VanDam et al., 2012).

Parents are in the best position to create and maintain a rich language environment during the critical language learning period beginning in infancy. Evidence from neuroscience research has also shown that language stimulation in infancy results in significantly better language outcomes and desirable neurophysiological changes in the child's brain, with these relationships being reciprocal (Kuhl, 2010; Ramírez-Esparza et al., 2017a, 2017b; White et al., 2013). Therefore, enrichment of the home language environment is a crucial component of achieving successful language outcomes for children who are DHH.

One method that has been suggested as a way of helping parents improve the language environment for young children is to provide the parents with feedback about the frequency and quality of their language, using data from the Language ENvironment Analysis (LENA) system (Greenwood et al., 2018; Wang et al., 2017). The LENA is a specialized audio-recording system worn by the child in a vest. It captures and automatically analyzes audio recordings on the number of words children use or are exposed to, and the number of language interactions the child engages in with adult caregivers. After a systematic search, nine studies were found that included an examination of whether providing LENA-based feedback to parents about language interactions increases the quantity and quality of their language input (Beecher & Van Pay, 2019, 2020; Elmquist et al., 2020; Gilkerson et al., 2017; Pae et al., 2016; Sacks et al., 2014; Suskind et al., 2013, 2015, 2016; Zhang et al., 2015). Two other studies (Hoffman et al., 2020; Ramírez et al., 2020) were not included because the primary focus of these studies was parent coaching/language intervention and LENA recordings in these studies were made only 4 times over a period of 18 months (Ramírez et al., 2020) and 12 months (Hoffman et al., 2020).

Our long-term research goal is to determine whether LENA-quantitative feedback enhances the quality and quantity of parent-child language interaction in families of children who are DHH. In this article, we first summarize research on language outcomes in children who are DHH to highlight the relevance of the measures generated by the LENA system. Next, we present a systematic review of existing research on the use of the LENA system to provide feedback to parents about their verbal interactions with their children as a way of increasing the frequency and quality of those interactions. We discuss the results, strengths, and limitations of existing studies on this topic in families of young children with and without hearing loss. In conclusion, we offer an evidence-based framework for future studies to investigate the efficacy of using LENA data to provide feedback about the language environment to parents of children who are DHH.

Summary of Language Outcomes in Children who are DHH and the Role of Parent Input

Even though children who are DHH are being identified and provided with intervention earlier and earlier (White, 2014), recent research has shown that most of these children continue to exhibit delays in language

development compared to their peers with typical hearing. For example, a series of population-based studies from three states of Australia investigated the longitudinal outcomes of children who were DHH (Ching et al., 2010, 2013, 2018; Ching & Dillon, 2013). These researchers found that children who were DHH (even those with mild hearing loss) lagged behind their peers by an average of at least 1.0 *SD* and had difficulty learning new words. Tomblin et al. (2015) examined the language outcomes of 2-year-old children with mild to severe hearing loss and found that on average, when fit with hearing devices later than 12 months of age, these children had spoken language scores approximately 1.0 *SD* lower than their chronological age and SES matched peers with typical hearing. Even those children who were fit with hearing devices before 12 months of age averaged about .5 *SD* lower than their peers with typical hearing on language outcomes.

Substantial empirical evidence supports that children who are DHH need increased exposure to language and parental talk compared to their normal hearing peers to reach developmentally appropriate linguistic outcomes (Ambrose et al., 2014; Aragon & Yoshinaga-Itano, 2012; Caskey & Vohr, 2013; Charrón et al., 2016; Tomblin et al., 2020; Wiggin et al., 2012). Using LENA technology, Ambrose et al. (2014) examined how adult word count, adult-child conversational turn count, and electronic media exposure at 6 months of age predicted communication outcomes in children who were DHH. Communication outcomes were measured using the *Mullen Scales of Early Learning* (Mullen, 1995) at 2 years and the *Comprehensive Assessment of Spoken Language* (Carrow-Woolfolk, 1999) at 3 years of age. Positive correlations were found between conversational turn count and children's receptive and expressive language outcomes at 2 years ($r = .61, p < .01$ and $r = .45, p < .05$, respectively) and composite language at 3 years of age ($r = .45, p < .05$). Moeller and Tomblin (2015) concluded there were three primary factors that influenced children's access to linguistic input: (a) access to sound through the use of hearing technology; (b) duration and consistent use of hearing devices; and, (c) the quantity and quality of caregiver talk.

Research on parent-child interaction has shown that parents of children who are DHH tend to talk less to their children (e.g., use fewer utterances, fewer words, and fewer variety of words) compared to parents of children with typical hearing (Ambrose et al., 2015; Cross et al., 1980; Nienhuys et al., 1985). Even when quantitative differences were not observed in the communication used by parents of children with and without hearing loss, qualitative differences were evident in communication ability. For example, in a large sample study of 156 children who were DHH and 59 children with typical hearing, Ambrose et al. (2015) found that parents of 3 year old children who were DHH used significantly fewer different words (Standardized Mean Difference Effect Sizes [*SMD*ES] = .59, $p = .002$), shorter utterances (*SMD*ES = .67, $p < .001$), and greater proportions of directing utterances (*SMD*ES = -.55, $p = .002$), compared to parents of children with typical hearing. No significant

differences between the groups were observed in the number of total utterances (*SMD*ES = .02, $p = .90$) used by parents. The authors concluded that it was the quality of language input at 18 months, not quantity, that predicted 28.3% variance in children's composite language scores at 3 years of age ($p < .05$).

Nienhuys et al. (1985) compared the communication interactions between hearing mothers and their hearing children (ages 2 years or 5 years) with eight hearing mothers and their children who were DHH (age-matched or linguistically matched with the control children). Results revealed that mothers of children who were DHH used language that was simpler in meaning and linguistic structure than mothers of typically hearing children. These findings suggest that parents may benefit from additional support to provide an enriched language environment to children who are DHH. Given the importance of a rich auditory-verbal learning environment for children who are DHH and developing spoken language, the LENA system may be able to provide important information related to children's language environment that could promote positive change in parental language behavior.

Language ENvironment Analysis (LENA) System Overview

In response to research demonstrating the benefits of early language enrichment, the LENA system was developed to measure the spoken language and listening environment (television, electronic sounds, noise, and silence) of infants and young children (Ganek & Eriks-Brophy, 2018). The LENA system consists of a digital language processor and speech recognition software. It functions as a *talk pedometer*. The small wearable recording device uses low-power processors similar to hearing aids. The device records for up to 16 hours and an automated speech recognition cloud-based software is used to process the data and provide information on three primary variables: (a) Adult Word Count (AWC), words spoken to or near the child by an adult; (b) Child Vocalization Count (CVC), such as words, babbling, and single sounds; and (c) Conversational Turn Count (CTC), adult-child alternations when either the adult or child responds to each other within 5 seconds. In addition, the LENA system differentiates and selects audio segments between meaningful speech and non-speech or distant speech. To obtain these measures the cloud processing system uses complex algorithms trained to identify and differentiate adult versus child speech, and tv/electronic noise. The algorithms can also distinguish the (LENA user) child's speech from other children's speech and from non-speech sounds (e.g., cries). The software uses speech sound frequencies and the gaps between sounds and not the actual words spoken to generate data reflecting the quantity of talk in the child's environment. The use of the LENA system has been validated in five languages (www.lena.org).

The majority of published studies about the LENA system have used it to quantify the language environment of young children and to study associations between LENA data and other factors such as SES and children's

language outcomes (reviewed in Greenwood et al., 2018 and Wang et al., 2020). Although such studies are valuable, the current article focuses on a different issue. Specifically, those studies that have used LENA data to provide feedback to parents with the aim of increasing parental language quantity and quality. More recently, studies have also evaluated the reliability and validity of LENA generated classifications of speaker tags, non-speech or distant speech, in comparison to classifications generated from manual transcriptions (Bulgarelli & Bergelson, 2019; Busch et al., 2018; Cristia et al., 2020; Lehet et al., 2021). We do not review these studies here given the scope of the present study which was limited to those studies that used LENA data to provide parents feedback about their child's language environment.

Studies Using LENA-Based Feedback to Improve Children's Home Language Environment

To be included in this systematic review, articles needed to address the efficacy of using LENA data to provide feedback to parents of young children. Articles were limited to populations of children with normal hearing or children who were DHH. Articles were included in the study if they were in peer-reviewed journals, written in English, and published between January 1, 2010 (start year was selected based on the earliest LENA publications in clinical populations as reported in www.lena.org) and December 31, 2021.

Five databases were used to identify relevant articles (APA Psychinfo, Pubmed, Medline, Cinhal complete, and academic search ultimate via EBSCO host). The following keywords were used: Language Environment Analysis, LENA, LENA feedback, parent feedback, LENA-based feedback, children. The database search was performed by the first author. Article titles and abstracts were reviewed and then authors discussed and resolved any discrepancies in selected articles. Following article and abstract review, a full text review was completed by the first author followed by discussion to finalize article selection. Included articles were analyzed to identify general characteristics, methods, participants, and outcomes.

We found nine published studies (Table 1) that used the LENA system to measure and give feedback to adult caregivers as a significant part or all of efforts aimed at improving the child's language environment (Beecher & Van Pay, 2019, 2020; Elmquist et al., 2020; Gilkerson et al., 2017; Pae et al., 2016; Sacks et al., 2014; Suskind et al., 2013, 2015, 2016; Zhang et al., 2015). Results of these studies are discussed below. Importantly, only two of these studies were done in families with children who were DHH (Sacks et al., 2014; Suskind et al., 2016), with the remaining conducted with families of children with normal hearing. We have included a reference to the Beecher and Van Pay (2020) quasi-experimental study which is from the same project as Beecher and Van Pay (2019).

A stated goal of all studies was to investigate the effect on the quality and quantity of parent-child language interactions of LENA-based quantitative feedback. Some of the studies explicitly recognized that LENA feedback

was being given in conjunction with additional parent coaching activities by design (Beecher & Van Pay, 2020; Elmquist et al., 2020; Gilkerson et al., 2017; Sacks et al., 2014; Suskind et al., 2015, 2016), while others did not (Pae et al., 2016; Suskind et al., 2013; Zhang et al., 2015). This is an important point to which we will return later. The goal of giving feedback generated by the LENA system was to provide parents with information about their existing quantity/quality of verbal interactions and to encourage them to increase the quantity or improve the quality of the interactions. Three studies randomly assigned participants to experimental or control groups (Gilkerson et al., 2017; Pae et al., 2016; Suskind et al., 2015). The sample size, the total duration of LENA recordings, the duration of the studies, and frequency and nature of feedback varied across studies and is shown in Table 2. In our description of each study below, we focus only on LENA outcome variables relevant to our goal (i.e., AWC, CTC, CVC).

The first three studies summarized below reported no statistically significant changes in the quality or quantity of caregiver child language interactions following LENA-based feedback in families of young children with normal hearing. Zhang et al. (2015) studied twenty-two 5- to 30-month-old children with typical hearing. Each family was given a LENA system to complete weekly or bi-weekly recordings. Feedback was given (at monthly workshops) to parents about their individual LENA AWC and CTC scores as well as the average scores of other families. Pre-post scores over a six month period for AWC and CTC were used to determine if parents' language behavior had changed. For the full sample, although AWC and CTC showed significant increases from baseline to Month 1 and Month 3, the increase was not sustained and returned to baseline levels by 6 months. Families who were below the median at baseline increased more than 7,500 words per day (a 50% gain) from baseline through the first recording that occurred post-feedback and maintained the increase at 6 months significantly above baseline by 3,000 words per day (20%). This finding is indicative of regression to the mean and therefore may not be good evidence that LENA feedback improves language interactions. Given the lack of a control group, a modest sample size, and the wide age-range of children, the need for further research and replication was emphasized by the authors.

Similar results were observed in children with typical hearing by Pae et al. (2016) where ninety-nine families were randomly assigned to either experimental (received weekly LENA-based feedback, one workshop, monthly guidance over the phone, story books at 6 months, and an online book reading guide) or control group (no feedback or support). No significant differences were observed between groups on LENA measures (AWC, CTC) at baseline and at post-test. Pae et al. (2016) reported significant improvements in parent language behavior (AWC) and CTC at 6 months for those families who were below the 50th percentile at baseline (effect sizes = .81 and 1.23 respectively, $p < .01$).

Table 1
Summary of Studies Using LENA-Based Feedback as an Intervention Tool

Author	Sample size	Age at recruitment (months)	SES	LENA recording	Feedback frequency	Duration	Location	SMDES			Design, population, and home language	Overall study quality for evaluating outcome of LENA feedback
								AWC	CTC	CVC		
Beecher & Van Pay (2020)	56	0–30	Middle-High	1 per week, at least 9 recordings over 13 weeks	Weekly	13 weeks	At least 9/13 weekly classes	.36 [#]	.80 [#]	.67 [#]	Quasi-experimental Comparison NH English	Satisfactory
Elmqvist et al. (2020)	56	1–36	Low-Mid	16-hr weekly recordings, at least 12 over 13 weeks	Weekly	13 weeks	Weekly classes for 13 weeks	.20	.52	.59	Non-equivalent group design NH English & Others	Satisfactory
Gilkerson et al. (2017)	72	9–21	Middle-High	16 hrs/week	Monthly	3 months	Online + Phone	.53	.28	NR	Randomized NH English	Satisfactory
Pae et al. (2016)	99	4–16	Middle-High	16 hrs/week	One workshop and weekly LENA reports accessible at home	6 months	Center-based & online	-.26	-.44	NR	Randomized NH Korean	Satisfactory
Suskind et al. (2016)	32	< 54	Low	16 total day-long recordings	Weekly	10 weeks	Home visits	.20	-.14	NR	Quasi-experimental DHH English	Unsatisfactory
Suskind et al. (2015)	23	18–36	Low	10 total day-long recordings	Weekly	8 weeks	Home visits	.47	.53	.56	Randomized NH English	Satisfactory
Zhang et al. (2015)	22	5–30	High	Varied (from 3 day-long recordings first 10 days, 1/week, 1/ two weeks, 1/week)	Monthly	6 months	Center-based	-.07	-.28	NR	Pre-Post NH Chinese	Unsatisfactory
Sacks et al. (2014)	11	5–72	Low	5 total 16 hr. recordings	One home visit + 3 phone sessions	NR	Home visit + phone sessions	.71	1.21	.84	Pre-Post DHH English/Spanish	Unsatisfactory
Suskind et al. (2013)	17	10–40	High	8 total recordings	One educational session + weekly LENA feedback	6 weeks	Home-based	.62	.66	NR	Pre/Post NH English	Satisfactory

Note. LENA = Language ENvironment Analysis; SMDES = Standard Mean Difference Effect Size; [#]Cohen's d as reported by the authors; AWC = Adult Word Count; CVC = Child Vocalization Count; CTC = Conversational Turn Count; NR = not reported; NH = normal hearing; DHH = deaf or hard of hearing; SES = socioeconomic status as reported based on parent education and income.

Table 2*Brief Description of Intervention in Studies Using LENA-Feedback and Quality of Feedback for Interpreting LENA Use*

Author; Population	Brief description of intervention	Feedback quality rating				
		Frequency	Customized	Access mode	Average	Overall rating
Beecher & Van Pay (2020) NH	Community-based parent education curriculum (LENA Start™) that included weekly LENA quantitative feedback, a workbook, teacher-facilitated visual presentations, and videos on spoken language and literacy stimulation activities and strategies. Positive reinforcement, encouragement, and help was provided to participants to set goals in addition to weekly text message reminders to report the reading duration (minutes) for the week.	1	1	1	1.00	Good
Elmqvist et al. (2020) NH	Same parent education program as Beecher and Van Pay (2020): (LENA Start™) 13-week educational program with 1-hour weekly sessions. The sessions included LENA quantitative feedback reports and their interpretation, presentation, and video modeling of spoken language tips, shared story book reading, use of songs and rhymes and sharing knowledge of children's brain development. Age appropriate reading book provided weekly.	1	1	1	1.00	Good
Gilkerson et al. (2017) NH	Combined interventions that included web-based educational materials (print materials, webinars, videos) and LENA feedback reports viewed using LENA software at home, discussion forums with other parents, and coaching support by trained research staff online or by phone (minimum 1 session to any number; encouraged to engage in three monthly coaching sessions for 3 months). Frequency of feedback not consistent across participants and how often parents accessed materials not confirmed.	2	3	3	2.66	Unsatisfactory
Pae et al. (2016) NH	Video demonstrations, discussions, motivational talks during a single workshop. Individualized LENA reports explained at workshop and weekly LENA reports were accessible to parents on their home computers. Monthly phone calls for encouragement and checks. At 6 th month, five story books and an online book guide provided.	1	1	3	1.66	Satisfactory
Suskind et al. (2016) DHH	Caregiver focused language intervention curriculum + video modeling and analysis of learned behaviors by caregivers + goal setting. Intervention provided by a certified early interventionist. In addition, LENA quantitative data were provided. Each home visit was 1 hour long and was provided weekly (10 weeks).	1	1	1	1.00	Good
Suskind et al. (2015) NH	Caregiver focused language intervention curriculum + video modeling and analysis of learned caregiver behaviors + goal setting. In addition, LENA quantitative data provided by early interventionist during eight weekly 1-hr home visits.	1	1	1	1.00	Good
Zhang et al. (2015) NH	Monthly 90 min feedback workshops (for 6 months) led by senior pediatrician and supported by assistants. Included explanation of LENA reports individually while in a group + group feedback + group discussions, advice, demonstration videos on enhancing home language environment.	2	1	1	1.33	Satisfactory
Sacks et al. (2014) DHH	Educational module developed by authors reviewed and LENA quantitative feedback charts provided and discussed with parents by deaf educator during one 60-min home visit after two baseline recordings and subsequently via phone sessions after each of three LENA recordings + goal setting.	2	1	2	1.66	Satisfactory
Suskind et al. (2013) NH	One-time language focused educational intervention for 1 hr that included LENA data interpretation and goal setting guidance. Weekly LENA quantitative feedback provided for 6 weeks to non-parental caregivers by trained graduate research assistants in the form of paper results with no active discussion or goal setting guidance.	1	1	1	1	Good

Note. LENA = Language ENvironment Analysis; NH = normal hearing; DHH = deaf or hard of hearing; 1 = Good; 2 = Satisfactory; 3 = Unsatisfactory.

The effects of LENA-based feedback were also studied by Gilkerson et al. (2017) in children 9 to 21 months of age. AWC and CTC automatically analyzed by the LENA system were posted each week by the researchers on a website that parents in the treatment group were encouraged to access and use to increase their AWC and CTC scores during the next week. In addition, parents in the treatment group were provided online educational materials and coaching over the phone or online. Results from parents in the treatment group, who also had below average ratings at baseline on LENA measures, demonstrated significant improvement on the same measures at the end of two months (Mean difference_{AWC} = 5.61, $p = .01$; Mean difference_{CTC} = 6.85, $p = .003$). However, for the overall sample ($N = 72$), there were no significant differences in language behaviors of parents who received feedback versus parents who completed LENA recordings, but received no feedback.

In a series of studies, Suskind and colleagues (Suskind et al., 2013, 2015, 2016) showed gains in caregiver language input when using LENA-based feedback and parent coaching. The authors' initial studies (Suskind et al., 2013, 2015) included children with typical hearing and the third study included families of children who were DHH (Suskind et al., 2016). Suskind et al. (2013) evaluated the feasibility and efficacy of using quantitative linguistic feedback to influence adult language behavior (i.e., increase in LENA AWC, CTC scores), and as a consequence, a child's language environment. This study used a prospective case-crossover design, and was conducted with a group of non-parental caregivers (NPCs), who were chosen because of their extensive and consistent periods of time with the children in their care. Baseline scores were obtained from 17 NPCs at the child's home. Children were 10 to 40 months old. All children were from high SES households. During the initial visit, baseline recordings were completed, and each NPC participated in an educational session that focused on enriching a child's home language environment. In this 60-minute session, feedback from the baseline LENA recordings, language goals for the following session, and strategies to increase parental talk and conversational turns were discussed. LENA recordings were done at the child's home weekly for 6 weeks and quantitative LENA feedback was given to the NPC between each recording session. The NPCs were instructed to keep the device turned on for the maximum recording duration (16 hours) and to report on daily time logs on when their interaction time with the child ended for the day. Results at the end of the 6-week study indicated significant differences in language behaviors (AWC and CTC scores) between the pre and post results. The authors acknowledged that due to overlap between the educational session and initial baseline LENA feedback, it was impossible to isolate the influence of LENA feedback from coaching on caregivers' language behaviors recorded subsequently. In addition, the absence of a control group limited generalizability of the study results.

In 2015, Suskind and colleagues published an experimental study which evaluated the effectiveness

of a newly developed parent-directed spoken language intervention. This program was designed to increase parental knowledge of child language development and to support parental talk in low SES families. Twenty-three caregiver-child dyads were randomly assigned to an experimental group ($n = 12$) or a control group ($n = 11$). Families in the experimental condition received eight weekly 60-minute home visits from trained personnel. The visits included an interactive educational module, feedback about the amount of language the parent had used during the previous week using LENA data, and opportunity for mothers to practice language promoting strategies as modeled via videos, and a goal-setting activity to increase the LENA scores. The control condition consisted of a nutrition intervention that involved eight weekly 10-minute home visits from a research assistant. Home-based data were derived from the LENA system (i.e., AWC, CVC, and CTC). LENA outcomes increased significantly during intervention but did not show significant increase when examined 4 months post-intervention. Study results supported the short-term effects of parent directed intervention on children's home language environment. Potentially because of the limited duration of the study and a small sample size, results did not capture sustained changes in parent or child LENA outcomes.

In a subsequent study, Suskind et al. (2016) evaluated the effect of the parent-directed home-visit intervention curriculum (Project ASPIRE) on the language environment of low SES families with children who were DHH. All children were younger than 4.5 years of age and used hearing devices. Participants who completed the study included seven families in treatment and 15 in the control group. Group assignment was not random and children who received a cochlear implant from the first author were assigned to a treatment group whereas other participating children were assigned to a treatment or control group. Caregivers in the experimental group, received 10 weekly 60-minute feedback sessions over a six month period. During these sessions caregivers received quantitative LENA feedback regarding the amount of language the caregivers were using with the children in comparison to their previous recordings and the national average. In addition, they also received home visits by early interventionists during which video modeling and a spoken language curriculum were used to help improve learned parental language behavior. Participants in the control group did not receive home visits but completed LENA recordings. Results at the end of six months indicated no statistically significant differences in LENA scores (AWC and CTC) between the experimental group and the control group.

Sacks et al. (2014) also explored whether participating in Project ASPIRE and receiving weekly feedback about LENA scores would increase AWC, CTC, and CVC scores. Eleven families from low SES backgrounds with children who were DHH (average age 32 months) participated. Two 16-hour LENA recordings provided a baseline of the family's language environment. Using the baseline, a deaf educator conducted the 60-minute educational

home visit that included the ASPIRE spoken language curriculum and a discussion of LENA scores. Parents were asked to set realistic goals for their next LENA recording session. Following the one-time home visit intervention, parents completed three additional LENA recordings and continued to receive feedback about their LENA scores via phone sessions. Results at the end of the study indicated significant differences in language behaviors (53% increase from baseline in CTC, $p < .01$ and 43% increase from baseline in CVC scores, $p < .05$) between the pre and post results (AWC increased 20% above baseline, but was not statistically significant). However, there was no control group for reference in this study.

The studies by Beecher and Van Pay (2020) and Elmquist et al. (2020) were designed to evaluate the effectiveness of a community-based parent education program (LENA Start™). The program curriculum included parent coaching using strategies to improve spoken language input and thereby children's receptive and expressive language (e.g., shared reading, songs and rhymes, incorporating select vocabulary words, talking strategies, information about childhood brain development, and reflection exercises). The curriculum was implemented via weekly hour-long parent-educator sessions using lectures, discussions, videos and other materials. In addition, parents were provided graphical reports of LENA quantitative measures (AWC, CTC, amount of electronic sound exposure) from LENA recordings that the parents completed and reading times reported from the previous week. Pre-LENA and post-LENA outcomes were AWC, CTC, and CVC. The comparison group in Beecher and Van Pay (2020) included families who attended library visits at two locations and made LENA recordings but did not receive the curriculum or quantitative feedback until after study completion. Elmquist et al. (2020) used a non-equivalent comparison group that received general parent education as part of a statewide Early Childhood Family Education program but no LENA-based feedback or LENA Start™ curriculum. Multilevel linear modeling of growth curves as a function of time (longitudinal) were used by Beecher and Van Pay (2020) for examining outcomes in the intervention group and a propensity matched comparison group. Results suggested significant growth on AWC, CTC, and CVC for the intervention group but not for the comparison group. Pre- post- comparisons in Elmquist et al. (2020) showed that although the intervention group made gains and there was decline in the comparison group, these findings were not statistically significant. In contrast to the comparison group, small to medium effect size gains were found in the intervention group for CTC and CVC, but not for AWC.

In summary, results from the reviewed studies are mixed. The first three studies reviewed (Gilkerson et al., 2017; Pae et al., 2016; Zhang et al., 2015) did not demonstrate improvements on LENA outcomes from quantitative LENA feedback provided to parents when the full sample was considered. However, each study reported improvements for families below the 50th percentile. This regression to the mean poses a significant threat to a valid interpretation of the results. That is, because the families below the 50th

percentile scored on the lower extreme to begin with, there was a statistical tendency for improvement in scores (i.e., moving toward the average). Such gravitation of scores toward the mean could have occurred due to chance and not necessarily due to the feedback provided. Although two of the Suskind et al. studies (2013, 2015) supported parent-focused intervention and LENA feedback, study outcomes were not sustained post-intervention. In addition, the effects of LENA feedback could not be isolated due to additional interventions, one of the studies lacked a control group, and both studies included small samples. Similarly, studies by Beecher and Van Pay (2020) and Elmquist et al. (2020) supported the effectiveness of community-based parent education including the use of LENA-based feedback. However, the effectiveness of LENA quantitative feedback alone cannot be isolated in these studies due to inclusion of other intervention components. Suskind et al. (2016) reported no change in LENA outcomes between experimental and control groups, and the assignment to the experimental group was predetermined for families of children who received their cochlear implant from the first author. Finally, Sacks et al. (2014) reported gains in CTC and CVC following LENA feedback to families of children who were DHH, however, their study did not include a control group. Results from studies with no control group would generally not be taken as strong indicators of improvement resulting from feedback (Cuijpers et al., 2016). Despite this issue pre-post studies were included in this review because of the limited number of studies available on this topic.

We conducted analyses to evaluate the overall effect sizes from this literature (reported in Table 1). Standardized Mean Difference Effect Sizes (SMDES) following recommendations of Glass (1976) were calculated for each study. We also rated the studies on their ability to specifically interpret the utility of LENA-quantitative feedback (reported in Table 2). Finally, we evaluated threats to internal validity for each of the nine studies (Campbell & Stanley, 1966).

With the aim of reporting on the quality of LENA quantitative feedback, we rated each study based on (a) frequency of feedback, (b) whether feedback was customized for the family, and (c) the feedback access mode. Ratings (Table 2) provided were 1-*Good*; 2-*Satisfactory*; and 3-*Unsatisfactory*. To be clear, this rating was only related to how effectively the LENA feedback was provided to the families and did not take into consideration the use of other additional interventions. That is, this rating was not meant to classify the entire study components. For example, a rating of 3 was given when LENA feedback was made available to families online with lack of information on whether families actually viewed the data weekly. Similarly, a rating of 3 was given to studies when frequency of feedback was every few months. Monthly feedback and weekly feedback were rated as 2 and 1, respectively. Average scores suggested that one study was rated as *Unsatisfactory* for the quality of LENA-feedback provided. Three of the studies were rated to be *Satisfactory* and five were rated as *Good*.

Evaluating threats to internal validity of the studies was based on Campbell and Stanley (1966). Potential threats are discussed for each study. Based on this evaluation, six were rated as *Satisfactory* and three were rated as *Unsatisfactory* in quality (Table 1).

Discussion

The effect of using feedback from LENA audio sample recordings to increase parents' child-directed spoken communication was reported in nine published studies. In all these studies, the investigators evaluated whether LENA scores (i.e., AWC, CTC, and/or CVC) would increase as a result of giving parents feedback about their LENA scores from earlier sessions in addition to some form of parent coaching. We reviewed these studies and examined their results. Six studies included an experimental and control group in investigating the effects of LENA-based feedback and three used a pre-post design. We also examined the sources of internal validity threats for all the studies.

The first main observation was that all studies combined LENA quantitative feedback with other parent coaching activities, some more extensive than the others. This issue did not allow us to address the main research question which was whether or not LENA quantitative feedback when provided to caregivers leads to an increase in the quantity or quality of parent-child interactions. The effects of LENA feedback could not be isolated due to this confound in the majority of the studies with the exception of Suskind et al. (2013) which had minimal educational intervention for one session.

All studies reported LENA outcomes of AWC and CTC but only four of them examined change in CVC. Feedback to parents is expected to influence the language environment with the main goal of enhancing child language behavior. However, many of the studies did not analyze or report on CVC outcomes. Average SMDES across all the studies demonstrated that the overall effect size was small for AWC and CTC, but was large for CVC. However, more studies with CVC data are needed to substantiate this finding. Overall, for AWC and CTC the overall effect sizes were relatively small which may be due to the nature of methodological differences between the studies. For example, the Suskind et al. (2016) study that was conducted in a clinical population (children who were DHH) showed regression on the CTC score post-intervention in the treatment group after an initial improvement. Furthermore, there was almost a 50% attrition of participants in their treatment group at post-intervention measurement. The studies by Suskind et al. (2016), Elmquist et al. (2020), and Beecher and Van Pay (2020) were also limited by a quasi-experimental design in which the equivalence of the participants in experimental and control groups was not achieved. In three studies, subjects were randomized to control and treatment groups. However, internal validity limitations were noted in the majority of studies.

To better quantify and interpret these limitations we examined the scientific quality of each of the studies

(Campbell & Stanley, 1966). Multiple sources of threats to internal validity were examined across all studies. Based on this, as shown in Table 1, six studies were rated as *Satisfactory* (Beecher & Van Pay, 2020; Elmquist et al., 2020; Gilkerson et al., 2017; Pae et al., 2016; Suskind et al., 2013, 2015) and three as *Unsatisfactory* in quality (Sacks et al., 2014; Suskind et al., 2016; Zhang et al., 2015). None were rated as *Good*. As expected, this examination indicated that generally, randomized studies had fewer threats to internal validity. However, this was not the case for all randomized studies. For example, the study by Pae et al. (2016) although randomized had many plausible threats to internal validity such as attrition, regression, and selection and therefore it was categorized as *Satisfactory* in quality.

Three of the studies used a pre-post design without a comparison group (Sacks et al., 2014; Suskind et al., 2013; Zhang et al., 2015). Results from these studies would generally not be taken as strong indicators of improvement resulting from feedback because of the lack of a control group (Cuijpers et al., 2016). Despite this issue all studies were included in SMDES calculation because of the limited number of studies available on this topic. Despite the limitations of pre-post designs, one of these studies was rated to be *Satisfactory* in quality because it was less affected by most sources of internal invalidity that were examined (Suskind et al., 2013). The use of evidence-based criteria, that is, sources of internal invalidity threats to examine the quality of individual studies provided additional important information which was not reflected via SMDES alone. This finding is relevant to designing, implementing, and interpreting studies especially in clinical populations. The major factors that were serious plausible threats to those studies that were categorized as *Unsatisfactory* were attrition, participant selection, history (i.e., plausible events other than LENA-quantitative feedback during the study), and maturation.

Participant factors of some of the studies included recruitment specific to certain socioeconomic groups and the broad age-range of children. Specific to children who are DHH, we noted that only two studies had children with hearing loss as part of their participant pool. The paucity of studies is a limiting factor in arriving at any conclusions about children who are DHH in relation to LENA-based parental feedback.

A design issue in the studies was the mixed nature of the intervention (inclusion of intervention/coaching in addition to LENA-based feedback). Four of the studies used a combined intervention in which feedback about the frequency and quality of parent language was combined with the ASPIRE spoken language intervention program. ASPIRE is an educational intervention curriculum that includes video-modelling of the language behaviors targeted at each module (Sacks et al., 2014; Suskind et al., 2013, 2015, 2016). The five other studies also had additional intervention components such as webinars, parents discussion forums, video demonstrations, motivational talks, and workshops (Beecher & Van Pay, 2020; Elmquist et al., 2020; Gilkerson, 2017; Pae et

al., 2016; Zhang et al., 2015). The fact that there were several intervention components being implemented simultaneously made it impossible to estimate the actual effect of only providing parents with feedback about the frequency and quality of their language with the child. Studies that examine the effectiveness of LENA feedback in isolation are needed to substantiate its utility.

In addition, there was variability across studies on the quality of feedback. We therefore rated each study based on frequency of feedback, customization, and access mode (Table 2). Based on average scores, the Suskind studies (Suskind et al., 2013, 2015, 2016), Beecher and Van Pay (2020) and Elmquist et al., (2020) were rated as *Good* for the quality of LENA-feedback. Three of the other studies were rated to be *Satisfactory* and one as *Unsatisfactory*. Furthermore, we noted that only four studies used LENA CVC as an outcome (Beecher & Van Pay, 2020; Elmquist et al., 2020; Sacks et al., 2014; Suskind et al., 2015). Finally, there is a need for studies evaluating the effects of feedback that are also based on theoretical principles for supporting behavior change (Prochaska & Velicer, 1997). Researchers have supported factors such as timely and frequent goal-oriented feedback as being critical to promote behavior change (Schembre et al., 2018). As an example, to achieve the goal of 10,000 steps per day, feedback would occur during the day to increase the chances of achieving that goal and would include an update on step counts at specified intervals.

Because of the limited number of studies and the scope for methodological improvements, more research is needed to establish whether giving parents LENA-quantitative feedback about the amount of language they are using and encouraging them to use more language will increase the amount and quality of language that parents use with their children. Importantly, future studies using evidence-based theoretical approaches to guide behavior change in language use are needed, similar to approaches more widely used for health related behavior modification such as pedometers.

Future directions

Based on this review several important insights were gained. First, there is a paucity of studies that address the key research question of whether LENA-quantitative feedback when provided to parents results in changing the quality and quantity of parent-child interactions. Existing studies have provided LENA-feedback in combination with other parent coaching interventions thus confounding the study results. Second, the quality of the feedback is influenced by the frequency of feedback and how the quantitative feedback is presented to the parents. Monitoring whether and how parents access the LENA feedback and how often, is crucial. Third, large-sample randomized studies in children who are DHH are much needed given the paucity of studies and the known importance of parent-child interactions to improve language outcomes in children who are DHH. Future studies should be designed to incorporate these factors.

For example, LENA recordings should be attempted at least 2 to 4 days per week to capture adequate data for measurements. This is because of the day to day variation that may occur in the number of opportunities for interactions across families. To measure its effectiveness, LENA quantitative feedback should be provided with no additional parent coaching and must be consistent in frequency and quality across participants.

Conclusions

The importance of helping children develop good language skills, including children who are DHH, is widely recognized. Substantial evidence suggests that the quantity and quality of caregivers' language is positively correlated with their children's language development. Considering this, there is a need to facilitate parents to acquire skills that help increase the quantity and quality of their language interactions with their children, and effectively integrate these skills into their daily routines. It is critical that this facilitation occurs early during the child's development and is provided with adequate frequency and dosage. Even though caregivers may be willing and eager to make a change in their communication behavior, they may not have all the tools needed to make the change effectively. The availability of the LENA system makes it economically and logistically practical to systematically gather a large amount of language interaction data. The LENA system can capture communication patterns and help guide needed changes by providing objective, easy to use, and timely feedback about language usage and parent-child interactions. It is important to determine if providing parents with such feedback will promote change in parental behavior, leading to healthier and more productive language environments and outcomes for children. Our evaluation and discussion of existing studies provides a framework for future studies in children, including children who are DHH.

References

- Ambrose, S. E., VanDam, M., & Moeller, M. P. (2014). Linguistic input, electronic media, and communication outcomes in toddlers with hearing loss. *Ear and Hearing, 35*(2), 139–147. <https://pubmed.ncbi.nlm.nih.gov/24441740/>
- Ambrose, S. E., Walker, E. A., Unflat-Berry, L. M., Oleson, J. J., & Moeller, M. P. (2015). Quantity and quality of caregivers' linguistic input to 18-month and 3-year-old children who are hard of hearing. *Ear and Hearing, 36*(Supp. 1), 48S–59S. <https://doi.org/10.1097/AUD.000000000000209>
- Aragon, M., & Yoshinaga-Itano, C. (2012). Using Language ENvironment Analysis to improve outcomes for children who are deaf or hard of hearing. *Seminars in Speech and Language, 33*(4), 340–353. <https://doi.org/10.1055/s-0032-1326918>

- Beecher, C. C., & Van Pay, C. K. (2019). Small Talk: A community research collaboration to increase parental provision of language to children. *Child & Youth Care Forum, 50*, 13–38.
<https://doi.org/10.1007/s10566-019-09507-7>
- Beecher, C. C., & Van Pay, C. K. (2020). Investigation of the effectiveness of a community-based parent education program to engage families in increasing language interactions with their children. *Early Childhood Research Quarterly, 53*, 453–463.
<https://doi.org/10.1016/j.ecresq.2020.04.001>
- Bulgarelli, F., & Bergelson, E. (2019). Look who's talking: A comparison of automated and human-generated speaker tags in naturalistic day-long recordings. *Behavior Research Methods, 52*, 641–653.
<https://doi.org/10.3758/s13428-019-01265-7>
- Busch, T., Sangen, A., Vanpoucke, F., & van Wieringen, A. (2018). Correlation and agreement between Language ENvironment Analysis (LENA™) and manual transcription for Dutch natural language recordings. *Behavior Research Methods, 50*(5), 1921–1932.
- Campbell, T. F., Dollaghan, C. A., Rockette, H. E., Paradise, J. L., Feldman, H. M., Shriberg, L. D., Sabo, D. L., & Kurs-Lasky, M. (2003). Risk factors for speech delay of unknown origin in 3-year-old children. *Child Development, 74*(2), 346–357.
- Campbell, D. T., & Stanley, J. C. (1966). Experimental and quasi-experimental designs for research. Reprinted from N. L. Gage (Ed.), *Handbook of Research on Teaching*. Rand McNally & Co.
- Carrow-Woolfolk, E. (1999). *Comprehensive Assessment of Spoken Language*. Pearson assessments.
- Caskey, M., & Vohr, B. (2013). Assessing language and language environment of high risk infants and children: A new approach. *Acta Paediatrica, 102*(03), 1–11.
<https://doi.org/10.1111/apa.12195>
- Charrón, C., Fitzpatrick, E. M., McSweeney, E., Rabjohn, K., Somerville, R., & Steacie, P. (2016). Language ENvironment Anlysis (LENA) with children with hearing loss: A clinical pilot. *Canadian Journal of Speech-Language Pathology and Audiology, 40*(1), 93–104.
- Ching T. Y., Crowe, K., Martin, V., Day, J., Mahler, N., Youn, S., Street, L., Cook, C., & Orsini, J. (2010). Language development and everyday functioning of children with hearing loss assessed at 3 years of age. *International Journal of Speech Language Pathology, 12*, 124–131.
- Ching, T. Y., Dillon, H., Leigh, G., & Cupples, L. (2018). Learning from the Longitudinal Outcomes of Children with Hearing Impairment (LOCHI) study: Summary of 5-year findings and implications. *International Journal of Audiology, 57*(Supp. 2), S105–S111.
<https://doi.org/10.1080/14992027.2017.1385865>
- Ching, T. Y., Day, J., Seeto, M., Dillon, H., Marnane, V., & Street, L. (2013). Predicting 3-year outcomes of early-identified children with hearing impairment. *B-ENT, 9*, 99S–106S.
- Ching, T. Y., & Dillon, H. (2013). Major findings of the LOCHI study on children at 3 years of age and implications for audiological management. *International Journal of Audiology, 52*, 65S–68S.
- Ching, T. Y., Dillon, H., Marnane, V., Hou, S., Day, J., Seeto, M., Crowe, K., Street, L., Thomson, J., Van Buynder, P., Zhang, V., Wong, A., Burns, L., Flynn, C., Cupples, L., Cowan, R. S., Leigh, G., Sjahalam-King, J., & Yeh, A. (2013). Outcomes of early-and late-identified children at 3 years of age: Findings from a prospective population-based study. *Ear and Hearing, 34*(5), 535–552.
- Cross, T. G., Johnson-Morris, J. E., & Nienhuys, T. G. (1980). Linguistic feedback and maternal speech: Comparisons of mothers addressing hearing and hearing-impaired children. *First Language, 1*(3), 163–189.
- Cristia, A., Lavechin, M., Scaff, C., Soderstrom, M., Rowland, C., Räsänen, O., Bunce, J., & Bergelson, E. (2020). A thorough evaluation of the Language Environment Analysis system. *Behavior Research Methods, 53*, 467–486.
- Conway, L. J., Levickis, P. A., Smith, J., Mensah, F., Wake, M., & Reilly, S. (2018). Maternal communicative behaviours and interaction quality as predictors of language development: Findings from a community-based study of slow-to-talk toddlers. *International Journal of Language and Communication Disorders, 53*(2), 339–354.
<https://doi.org/10.1111/1460-6984.12352>
- Cuijpers, P., Weitz, E., Cristea, I. A., & Twisk, J. (2016). Pre-post effect sizes should be avoided in meta-analyses. *Epidemiology and Psychiatric Sciences, 26*(4), 364–368.
<https://doi.org/10.1017/S2045796016000809>
- DesJardin, J. L., & Eisenberg, L. S. (2007). Maternal contributions: Supporting language development in young children with cochlear implants. *Ear and Hearing, 28*(4), 456–469.
<https://doi.org/10.1097/AUD.0b013e31806dc1ab>
- Elmqvist, M., Finestack, L. H., Kriese, A., Lease, E. M., & McConnell, S. R. (2020). Parent education to improve early language development: A preliminary evaluation of LENA Start™. *Journal of Child Language, 48*(4), 1–29.
<https://doi.org/10.1017/S0305000920000458>
- Fernald, A., Marchman, V. A., & Weisleder, A. (2013). SES differences in language processing skill and vocabulary are evident at 18 months. *Developmental Science, 16*(2), 234–248.

- Ganek, H., & Eriks-Brophy, A. (2018). Language ENvironment analysis (LENA) system investigation of day long recordings in children: A literature review. *Journal of Communication Disorders, 72*, 77–85.
<https://doi.org/10.1016/j.jcomdis.2017.12.005>
- Gilkerson, J., Richards, J. A., & Topping, K. (2017). Evaluation of a LENA-Based Online intervention for parents of young children. *Journal of Early Intervention, 39*(1), 1–10.
<https://doi.org/10.1177/1053815117718490>
- Glanemann, R., Reichmuth, K., Matulat, P., & Zehnhoff-Dinnesen, A. A. (2013). Muenster Parental Programme empowers parents in communicating with their infant with hearing loss. *International Journal of Pediatric Otorhinolaryngology, 77*(12), 2023–2029.
<https://doi.org/10.1016/j.ijporl.2013.10.001>
- Glass, G. V. (1976). Primary, secondary, and meta-analysis of research. *Educational Researcher, 5*(10), 3–8.
<https://doi.org/10.3102/0013189X005010003>
- Greenwood, C. R., Schnitz, A. G., Irvin, D., Tsai, S. F., & Carta, J. J. (2018). Automated Language Environment Analysis: A Research Synthesis. *American Journal of Speech-Language Pathology, 27*(2), 853–867.
https://doi.org/10.1044/2017_AJSLP-17-0033
- Guralnick, M. J., Neville, B., Hammond, M. A., & Connor, R. T. (2008). Mothers' social communicative adjustments to young children with mild developmental delays. *American Journal of Mental Retardation, 113*(1), 1–18.
[https://doi.org/10.1352/0895-8017\(2008\)113\[1:MSCATY\]2.0.CO;2](https://doi.org/10.1352/0895-8017(2008)113[1:MSCATY]2.0.CO;2)
- Hirsh-Pasek, K., Adamson, L. B., Bakeman, R., Owen, M. T., Golinkoff, R. M., Pace, A., Yust, P. K. S., & Suma, K. (2015). The contribution of early communication quality to low-income children's language success. *Psychological Science, 26*(7), 1071–1083.
<https://doi.org/10.1177/0956797615581493>
- Hoffman, L., Hersey, A., Tucker, R., & Vohr, B. (2020). Randomised control language intervention for infants of adolescent mothers. *Acta Paediatrica, 109*(1), 1–10.
<https://doi.org/10.1111/apa.15261>
- Huttenlocher, J., Haight, W., Bryk, A., Seltzer, M., & Lyons, T. (1991). Early vocabulary growth: Relation to language input and gender. *Developmental Psychology, 27*(2), 236–248.
<https://doi.org/10.1037/0012-1649.27.2.236>
- Huttenlocher, J., Vasilyeva, M., Waterfall, H. R., Vevea, J. L., & Hedges, L. V. (2007). The varieties of speech to young children. *Developmental Psychology, 43*(5), 1062–1083.
<https://doi.org/10.1037/0012-1649.43.5.1062>
- Huttenlocher, J., Waterfall, H., Vasilyeva, M., Vevea, J., & Hedges, L. V. (2010). Sources of variability in children's language growth. *Cognitive Psychology, 61*(4), 343–365.
<https://doi.org/10.1016/j.cogpsych.2010.08.002>
- Kuhl, P. K. (2010). Brain mechanisms in early language acquisition. *Neuron, 67*(5), 713–727.
<https://doi.org/10.1016/j.neuron.2010.08.038>
- Leffel, K., & Suskind, D. (2013). Parent-directed approaches to enrich the early language environments of children living in poverty. *Seminars in Speech and Language, 34*(4), 267–278.
<https://doi.org/10.1055/s-0033-1353443>
- Lehet, M., Arjmandi, M. K., Houston, D., & Dilley, L. (2021). Circumspection in using automated measures: Talker gender and addressee affect error rates for adult speech detection in the Language ENvironment Analysis (LENA) system. *Behavior Research Methods, 53*, 113–138.
- Moeller, M. P. (2000). Early intervention and language development in children who are deaf and hard of hearing. *Pediatrics, 106*(3), E43.
<https://doi.org/10.1542/peds.106.3.e43>
- Moeller, M. P., & Tomblin, J. B. (2015). An introduction to the outcomes of children with hearing loss study. *Ear and Hearing, 36*(Suppl. 1), 4–13.
- Mullen, E. M. (1995). *Mullen Scales of Early Learning*. Pearson assessments.
- Nienhuys, T. G., Horsborough, K. M., & Cross, T. G. (1985). A dialogic analysis of interaction between mothers and their deaf or hearing preschoolers. *Applied Psycholinguistics, 6*(2), 121–139.
- Nott, P., Cowan, R., Brown, P. M., & Wigglesworth, G. (2009). Early language development in children with profound hearing loss fitted with a device at a young age: Part I—the time period taken to acquire first words and first word combinations. *Ear and Hearing, 30*(5), 526–540.
<https://doi.org/10.1097/aud.0b013e3181a9ea14>
- Pace, A., Luo, R., Hirsh-Pasek, K., & Golinkoff, R. M. (2017). Identifying pathways between socioeconomic status and language development. *Annual Review of Linguistics, 3*, 285–308.
- Pae, S., Yoon, H., Seol, A., Gilkerson, J., Richards, J. A., Ma, L., & Topping, K. (2016). Effects of feedback on parent-child language with infants and toddlers in Korea. *First Language, 36*(6), [online].
<https://doi.org/10.1177/0142723716649273>
- Pan, B. A., Rowe, M. L., Singer, J. D., & Snow, C. E. (2005). Maternal correlates of growth in toddler vocabulary production in low-income families. *Child Development, 76*(4), 763–782.
<https://doi.org/10.1111/j.1467-8624.2005.00876.x>

- Prochaska, J. O., & Velicer, W. F. (1997). The trans-theoretical model of health behavior change. *American Journal of Health Promotion, 12*(1), 38–48.
- Ramírez, N. F., Lytle, S. R., & Kuhl, P. K. (2020). Parent coaching increases conversational turns and advances infant language development. *Proceedings of the National Academy of Sciences, 117*(7), 3484–3491. <https://doi.org/10.1073/pnas.1921653117>
- Ramírez-Esparza, N., García-Sierra, A., & Kuhl, P. K. (2017a). The Impact of Early Social Interactions on Later Language Development in Spanish-English Bilingual Infants. *Child Development, 88*(4), 1216–1234. <https://doi.org/10.1111/cdev.12648>
- Ramírez-Esparza, N., García-Sierra, A., Kuhl, P. K. (2017b). Look who's talking NOW! Parentese speech, social context, and language development across time. *Frontiers in Psychology, 8*, 1008.
- Roberts, M. Y., & Kaiser, A. P. (2011). The effectiveness of parent-implemented language interventions: A meta-analysis. *American Journal of Speech-Language Pathology, 20*(3), 180–199. [https://doi.org/10.1044/1058-0360\(2011/10-0055\)](https://doi.org/10.1044/1058-0360(2011/10-0055))
- Rowe, M. L. (2012). A longitudinal investigation of the role of quantity and quality of child-directed speech in vocabulary development. *Child Development, 83*(5), 1762–1774. <https://doi.org/10.1111/j.1467-8624.2012.01805.x>
- Rufsvold, R., Wang, Y., Hartman, M. C., Arora, S. B., & Smolen, E. R. (2018). The impact of language input on deaf and hard of hearing preschool children who use listening and spoken language. *American Annals of the Deaf, 163*(1), 35–60. <https://doi.org/10.1353/aad.2018.0010>
- Sacks, C., Shay, S., Repplinger, L., Leffel, K. R., Sapolich, S. G., Suskind, E., Tannenbaum, S., & Suskind, D. (2014). Pilot testing of a parent-directed intervention (Project ASPIRE) for underserved children who are deaf or hard of hearing. *Child Language Teaching and Therapy, 30*(1), 91–102. <https://doi.org/10.1177/0265659013494873>
- Schembre, S. M., Liao, Y., Robertson, M. C., Dunton, G. F., Kerr, J., Haffey, M. E., Burnett, T., Basen-Engquist, K., & Hicklen, R. S. (2018). Just-in-time feedback in diet and physical activity interventions: Systematic review and practical design framework. *Journal of Medical Internet Research, 20*, e106. <http://www.jmir.org/2018/3/e106>
- Suskind, D. L., Graf, E., Leffel, K., Hernandez, M. W., Suskind, E., Webber, R., Tannenbaum, S., & Nevins, M. E. (2016). Project ASPIRE: Spoken language intervention curriculum for parents of low-socioeconomic status and their deaf and hard-of-hearing children. *Otology & Neurotology, 37*(2), e110–e117. <https://doi.org/10.1097/MAO.0000000000000931>
- Suskind, D. L., Leffel, K. R., Graf, E., Hernandez, M. W., Gunderson, E. A., Sapolich, S. G., Suskind, E., Leininger, L., Goldin-Meadow, S., & Levine, S. C. (2015). A parent-directed language intervention for children of low socioeconomic status: A randomized controlled pilot study. *Journal of Child Language, 43*(2), 366–406. <https://doi.org/10.1017/S0305000915000033>
- Suskind, D., Leffel, K. R., Hernandez, M. W., Sapolich, S. G., Suskind, E., Kirkham, E., & Meehan, P. (2013). An exploratory study of “quantitative linguistic feedback”: Effect of LENA feedback on adult language production. *Communication Disorders Quarterly, 34*(4), 199–209. <https://doi.org/10.1177/1525740112473146>
- Tamis-Lemonda, C. S., Bornstein, M. H., Kahana-Kalman, R., Baumwell, L., & Cyphers, L. (1998). Predicting variation in the timing of language milestones in the second year: An events history approach. *Journal of Child Language, 25*(3), 675–700. <https://doi.org/10.1017/s0305000998003572>
- Tomblin, J. B., Harrison, M., Ambrose, S. E., Walker, E. A., Oleson, J. J., & Moeller, M. P. (2015). Language outcomes in young children with mild to severe hearing loss. *Ear and Hearing, 36*(1), 76S–91S. <https://doi.org/10.1097/AUD.0000000000000219>
- Tomblin, J. B., Oleson, J., Ambrose, S. E., Walker, E. A., & Moeller, M. P. (2020). Early literacy predictors and second-grade outcomes in children who are hard of hearing. *Child Development, 91*(1), e179–e197. <https://doi.org/10.1111/cdev.13158>
- VanDam, M. (2014). Acoustic characteristics of the clothes used for a wearable recording device. *Journal of the Acoustical Society of America, 136*(4), EL263–EL267. <https://doi.org/10.1121/1.4895015>
- VanDam, M., Ambrose, S. E., & Moeller, M. P. (2012). Quantity of parental language in the home environments of hard-of-hearing 2-year-olds. *Journal of Deaf Studies and Deaf Education, 17*(4), 402–420. <https://doi.org/10.1093/deafed/ens025>
- Wang, Y., Hartman, M., Abdul Aziz, N. A., Arora, S., Shi, L., & Tunison, E. (2017). A systematic review of the use of LENA technology. *American Annals of the Deaf, 162*(3), 295–311.
- Wang, Y., Williams, R., Dilley, L., & Houston, D. M. (2020). A meta-analysis of the predictability of LENA™ automated measures for child language development. *Developmental Review, 57*, 100921.
- Weisleder, A., & Fernald, A. (2013). Talking to children matters: Early language experience strengthens processing and builds vocabulary. *Psychological*

Science, 24(11), 2143–2152.

<https://doi.org/10.1177/0956797613488145>

White, E. J., Hutka, S. A., Williams, L. J., & Moreno, S. (2013). Learning, neural plasticity and sensitive periods: Implications for language acquisition, music training and transfer across the lifespan. *Frontiers in Systems Neuroscience*, 7, 90.
<https://doi.org/10.3389/fnsys.2013.00090>

White, K. R. (2014). Newborn hearing screening. In J. Katz, M. Chasin, K. English, L. J. Hood, & K. L. Tillery (Eds.). *Handbook of Clinical Audiology* (7th ed.). Lippincott Williams & Wilkins.

Wiggin, M., Gabbard, S., Thompson, N., Goberis, D., & Yoshinaga-Itano, C. (2012). The school to home link: Summer preschool and parents. *In Seminars in Speech and Language*, 33(04), 290–296. Thieme Medical Publishers.

Yoshinaga-Itano, C. (2003). From screening to early identification and intervention: Discovering predictors to successful outcomes for children with significant hearing loss. *Journal of Deaf Studies and Deaf Education*, 8(1), 11–30.

<https://doi.org/10.1093/deafed/8.1.11>

Zhang, Y., Xu, X., Jiang, F., Gilkerson, J., Xu, D., Richards, J. A., Harnsberger, J., & Topping, K. J. (2015). Effects of quantitative linguistic feedback to caregivers of young children: A pilot study in China. *Communication Disorders Quarterly*, 37(1), 16–24.

<https://doi.org/10.1177/1525740115575771>

Zimmerman, F. J., Gilkerson, J., Richards, J. A., Christakis, D. A., Xu, D., Gray, S., & Yapanel, U. (2009). Teaching by listening: The importance of adult-child conversations to language development. *Pediatrics*, 124(1), 342–349.

<https://doi.org/10.1542/peds.2008-2267>

EHDInfo

(Click graphic to register for the conference)



2023 EARLY HEARING DETECTION & INTERVENTION CONFERENCE

MARCH 5-7, 2023 • CINCINNATI, OH

OVERVIEW

PRESENTER INFORMATION

WHO SHOULD ATTEND

REGISTRATION

SCHEDULE & PRESENTATIONS

INSTRUCTIONAL SESSIONS /
FIELD TRIPS

EXHIBITS & SPONSORSHIPS

STAKEHOLDERS' MEETING

AWARDS



Application of Intervention Mapping to Address Lost to Intervention in Early Hearing Detection and Intervention

Torri Ann Woodruff-Gautherin, PhD¹
 Kathleen M. Cienkowski, PhD²

¹Center for Excellence in Developmental Disabilities Education, Farmington, CT

²University of Connecticut, Mansfield, CT

Abstract

Purpose: Detail the application of intervention mapping as a protocol for developing a novel way to address lost to intervention within the early hearing detection and intervention systems.

Design: Intervention mapping (IM) is an approach to behavior change that is typically used in public health initiatives. This six-step process walks health program developers, researchers, and policy makers through a rigorous research and community-based approach to understanding why a health concern or problem is present in a community. When using IM to address lost to intervention in Early Hearing Detection and Intervention programs, the focus is on why families choose to not enroll in early intervention services covered by part C of the Individuals with Disabilities Education Act of 2004 after identification of their child as D/deaf or hard of hearing.

Results: This process culminated in the development of “Swaddling Ear to Ear” as a novel approach to the implementation of behavior change theory and early intervention access.

Conclusion: Intervention Mapping is posed to support policy makers, care providers, and families with the requisite tools to navigate early intervention services and begin a systematic line of research working to access barriers to care and access inequality for newborns identified via Early Hearing Detection and Intervention programs across the United States. The educational program designed and described here is currently under evaluation.

Keywords: Early hearing detection and intervention, IDEA, Intervention Mapping, Public Health

Acronyms: EHDI = early hearing detection and intervention; IM = intervention mapping; LTI = lost to intervention

Acknowledgments: We would like to thank the entirety of Torri Ann Woodruff’s dissertation committee (Drs. Kim Gans, Beth Russell, Mary Beth Bruder, Bernard Grela, and Sarah Woulfin) for their service on the committee and feedback during the development stages of the program described in this article. Emily LaSpada provided critical insight as the trained implementor for this program. The authors declare they have no conflicts of interest. This research did not receive any specific grant from funding agencies in the public, commercial, or not for profit sectors.

Correspondence concerning this article should be addressed to: Torri Ann Woodruff-Gautherin, PhD, and Kathleen M. Cienkowski, PhD, 2 Alethia Drive, U-1085, Storrs, CT 06269. Email: torri.woodruff@uconn.edu; Phone: 860-420-2161.

What is EHDI?

Early Hearing Detection and Intervention (EHDI) programs work to screen the hearing of all newborns, identify children who are D/deaf or hard of hearing, and support access to early intervention services with families (Early Hearing Detection and Intervention Act, 2017). These programs typically fall in line with the recommendations of the Joint Committee on Infant Hearing (JCIH, 2019) to screen the hearing of all newborns before they are one month of age, ensure that all children who refer on this screening receive a diagnostic evaluation by three months of age, and those identified as D/deaf and hard of hearing receive early intervention services by six months of age. Early intervention services include a wide range of supports tailored to meet the family’s needs and can

include the support of audiologists, speech language pathologists, sign language instructors, Deaf mentors, teachers of the deaf, and many more (Individuals with Disabilities Education Act, 2004). These services can be provided by various state agencies under Part C of the Individuals with Disabilities Education Act or those procured privately by families from community providers (Centers for Disease Control and Prevention [CDC], 2021; Individuals with Disabilities Education Act, 2004). Although EHDI programs are called for and funded at the national level as a part of public health law, within required components, each state can build its program to meet the specific needs of its community (Individuals with Disabilities Education Act, 2004).

The success of EHDI programs in the United States during 2019 resulted in the screening of over 97% of births and the identification of 5,934 children as D/deaf or hard of hearing. However, only 3,662 (less than 2/3 of those identified) are reported to have accessed early intervention services (CDC, 2021). This creates a critical population of those who were lost to intervention (LTI). The LTI population is comprised of individuals and families that have been identified as having a potential developmental risk factor and are not accessing the supports to ensure linguistic and emotional development. From a philosophical standpoint, LTI is in direct conflict with the intervention goals of EHDI and negates the success of screening and diagnostic efforts for those who are LTI. The value in screening and identification of children who are D/deaf and hard of hearing is tied to the positive impact that timely identification has on intervention services and supporting the linguistic and emotional development of the child and their families (Yoshinaga-Itano, 1999, 2003, 2013). When children are LTI they have been successfully screened and identified, but that information does not transition into actionable steps and supports. The screening and diagnostic information loses much of its potential impact and value.

With this conflict within the EHDI system, those who are LTI represent a critical breakdown in the support and facilitation of accessible information for children who are D/deaf or hard of hearing and their families. Kingsbury and colleagues (2022) highlight that the language used to discuss when families and children do not make it to the next clinically indicated step does not separate the population of those who are LTI and those who have been found to require a diagnostic evaluation. It is critical to recognize the experiences and needs of families who are LTI are unique to those who have been identified as D/deaf or hard of hearing. Recent work on LTI has highlighted that online information for families preparing to enter early intervention (those on the verge of being LTI) is not written in a manner that is linguistically accessible or in alignment with federal readability guidance (Woodruff & Cienkowski, 2021). Inaccessible information about early intervention compounds with these highly personal decisions across five main domains: family culture, family experience, perceived barriers, perceived benefits, and perceived vulnerability to exacerbate misinformation and misinformation that prevents service access (Woodruff & Cienkowski, 2022b). There is now a critical need to address the challenge of LTI by infusing new research on this population with existing information about the successful implementation of public health programs.

What is Intervention Mapping?

Intervention Mapping (IM) is a protocol that walks through program development to support community-centered, research-driven, and theory-based interventions (Bartholomew Eldridge et al., 2016). This step-by-step protocol has a history in public health as a means of designing and evaluating intervention to change health behavior around topics such as preventative medicine, cardiovascular health, and cancer (Majid et al., 2018).

The six steps (Figure 1) that make up IM are a means of making sure that research questions and approaches are consistent with behavior change theory, as well as what clinical providers need and families deserve (Bartholomew Eldridge et al., 2016). This function-driven education makes the use of IM more applicable and supports the use of articles, like this one, detailing the application of the approach within the realm of EHDI.

Purpose

Walking through the individual steps to apply IM to LTI within EHDI chronicles the novel, yet merited use, of the IM procedure. Documenting the multiple components to the application of IM within this area also serves to delineate the level of rigor inherent in this type of work. Future works looking to capitalize on the literature about behavior change in public health may use this article as a formula for the application of IM to topics within the realm of supporting children who are D/deaf or hard of hearing and their families. This article will further the conceptualization of EHDI as an interdisciplinary service, specifically inclusive of public health services and theory.

Intervention Mapping Steps

Step 1

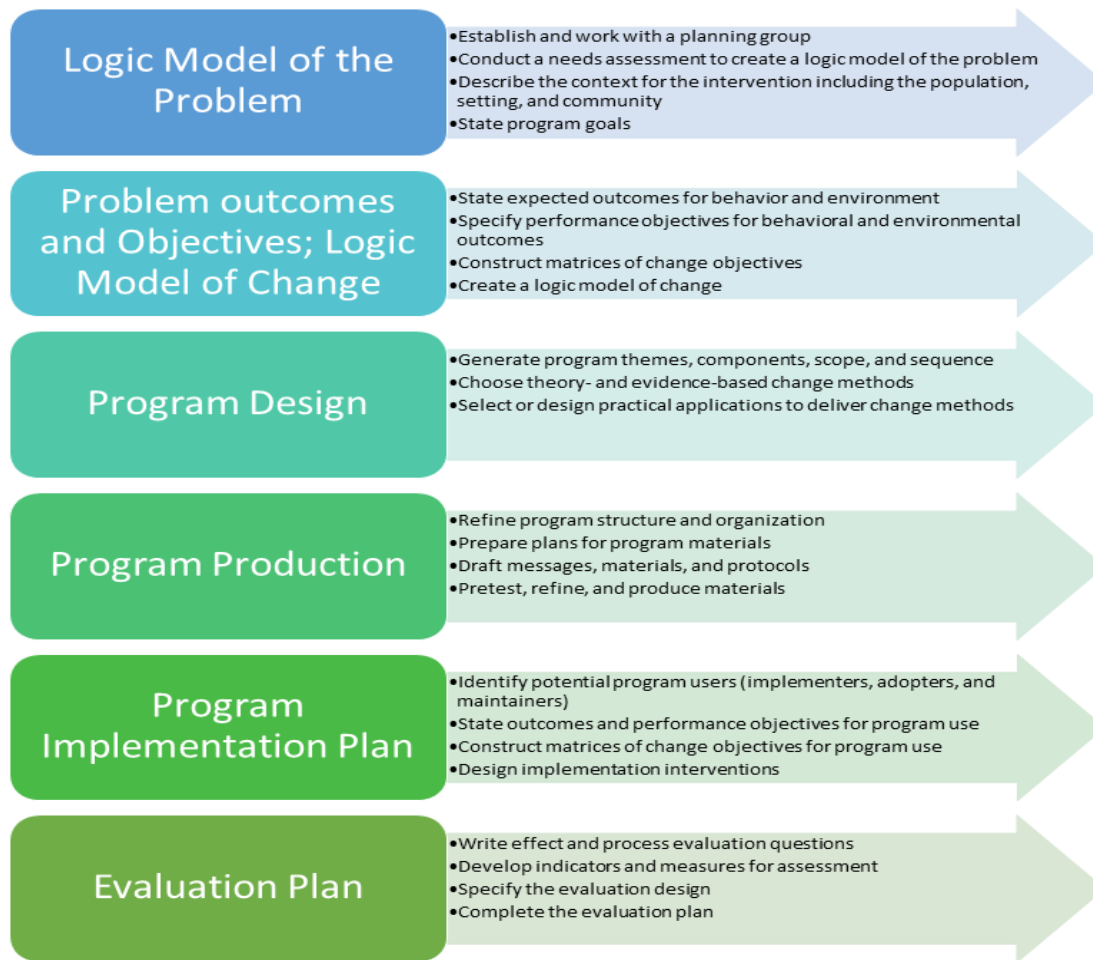
Step 1 of IM explicitly calls for the development of a working group of experts to come together to state the goals of the program (Bartholomew Eldridge et al., 2016). The working group should include individuals from a range of stakeholder groups and specialties that are primed to address the health concern in question (Bartholomew Eldridge et al., 2016). The working group for the current study included experts in the following areas: IM, early intervention in speech language pathology, aural rehabilitation, qualitative research methods, developmental disabilities, and parent education. Additional consultations through this process were made by (a) a culturally Deaf adult who identifies as a racial and linguistic minority and (b) the parent of a child who is under the age of three.

Members of the working group were educated on the problem of LTI by Torri Ann Woodruff-Gautherin through multiple meetings, written documents, and a culminating dissertation prospectus and grant application. To support understanding of LTI and begin the theory driven process of IM, a logic model of the problem for LTI was developed based on the framework from Bartholomew Eldridge et al. (2016; Figure 2). A logic model is a visual representation of the personal determinates and environmental factors that lead to a health problem. In this case LTI, and the larger quality of life concern of this health problem, leads to language deprivation.

This logic model highlights the personal determinates that are relevant to LTI and reinforces that there is a causal relationship between family culture, family experiences, perceived vulnerability, perceived benefit, and perceived barriers of EI and the experience of language deprivation by children and families who do not get the support they are entitled to as a part of EI (Woodruff & Cienkowski, 2022b). The working group of interdisciplinary professionals listed in the acknowledgments collectively accepted

Figure 1

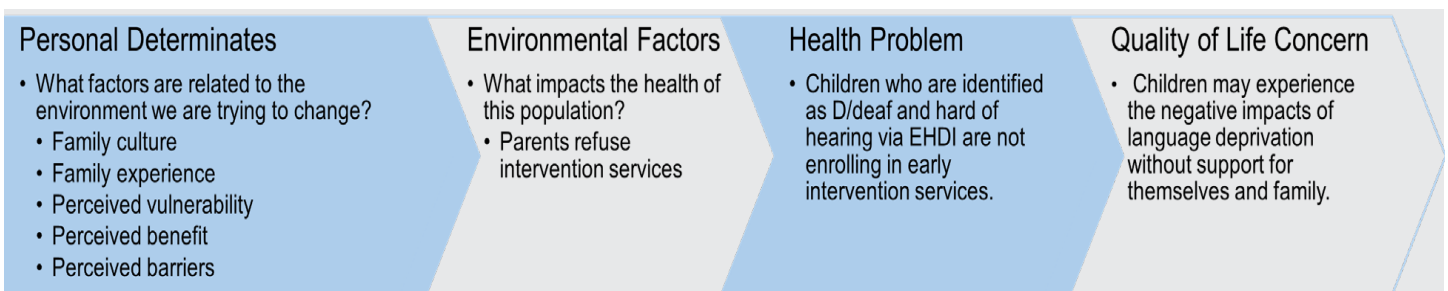
The Six Steps of Intervention Mapping



Note. The information has been adapted from Batholomew Eldridge, L. K., Markham, C. M., Ruter, R. A. C., Fernandez, M. E., Kok, G., & Parcel, G. S. (2016). *Planning health promotion programs: An intervention mapping approach* (4th ed.). Jossey-Bass & Pfeiffer Imprints: Wiley.

Figure 2

Logic Model of Lost to Intervention



Note. Information was adapted from Woodruff, T. A., & Cienkowski, K. M. (2022b). Modeling lost to intervention in early hearing detection and intervention: A modified eDelphi study. [Manuscript submitted for publication]. Department of Speech, Language, and Hearing Sciences, University of Connecticut. EHDI = Early Hearing Detection and Intervention.

the purpose of increasing access to early intervention services through one-on-one parent education for families of children who are D/deaf or hard of hearing. Members provided feedback on the approach to modeling during group meetings as well as individually in some cases. As

such, the goal of this program is to address LTI within the state of Connecticut using novel behavior change methods with parents and caregivers to children who have recently been identified as D/deaf or hard of hearing.

Step 2

With the logic model established, the focus of IM moves to individual steps outlined by Bartholomew Eldridge et al. (2016), rather than overarching topics and challenges. The next product is a matrix of performance and change objectives. Performance objectives are the smallest steps that can be taken in this order toward addressing LTI (Bartholomew Eldridge et al., 2016). Some examples are shown in Table 1, column A. Each one of these performance objectives is then crossed with the determinates that were identified in Figure 2. Crossing the performance objectives with each determinate creates a cell in Table 1 where a change objective can be created. Change objectives are the outcomes from the intervention that work to move through the performance objectives while systematically addressing the determinates (columns B and C of Table 1). The goal of combining performance objectives with determinates to develop change objectives is to have distinct skills that participants can demonstrate as a means of having outcome measures for the program and a systematic approach to addressing all facets of the health problem.

Step 3

Once the individual expectations for each participant across all determinates and performance objectives have been identified, the mechanisms to engage each of these change objectives must be selected (Bartholomew Eldridge et al., 2016). Step 3 represents a critical shift in how IM pushes LTI interventions compared to that of current scripting or programs to address lost to screening or identification, given the interactive component with parents and the focus on theory-driven topics (National Center for Hearing Assessment and Management, 2010). This interaction addresses parental disengagement directly by developing an environment where engagement in the educational module is expected and creates an opportunity to practice engagement skills, consistent with the foundational practices of early intervention and the parental behaviors required to enroll in intervention services.

Step 3 develops the mechanics of how the intervention will be implemented with participants. The intervention materials created are focused on transitioning the participant from an educational setting to a point of critical thinking and empowerment to ensure the coordination of services to support access. Each activity to elicit the completion of the change objective is derived from behavior change theory as it relates to the determinate being addressed. Table 2 shows the linkage of a few change objectives and the research-backed approach to changing that at the cognitive level (Bartholomew Eldridge et al., 2016). We called our intervention *Swaddling Ear to Ear* and focused on supporting families in the process of accessing early intervention service. The ultimate goal of *Swaddling Ear to Ear* is to ensure enrollment in Early Intervention. Once engaged in EI, families will be able to collaborate with self-advocates, professionals, other families, and stakeholders to build the constellation of services that best supports children and families.

Step 4

In Step 4 of IM, the planning moves from theory-based to physical production (Bartholomew Eldridge et al., 2016). We selected online as the method of dissemination. Although there is work to support the use of tangible reminders and reinforcers to elicit behavior change, the unique public health climate of this program could not be ignored. With COVID-19 at the top of many Americans minds and the continued variability in safety for gathering and physical contact, online dissemination methods allowed for the creation of materials that were accessible regardless of current public health guidance. Also, building an online resource to move in tandem with the educational program increases the reach possible for the information. The website itself was built in Google to have compatibility with a variety of web enabled devices, including cellphones. With over 91% of the United States population having access to the internet through their cellphone, this confounding barrier is limited (Statista, 2022).

Table 1

Matrix of Change Objectives

A	B	C
Performance Objective	Determinants	
	Family Culture	Family Experience
Respond/Answer attempts to connect from Connecticut Early Intervention before the child is 6 months of age	<ul style="list-style-type: none">• Explain the language used in the home and describe how to request interpretation services.• Describe the unique role of each person in the family as it relates to the Early Intervention (EI) process.	<ul style="list-style-type: none">• Express confidence in ability to discuss child's development, needs, recommendations, and current concerns of families and providers.• List the different ways that EI may contact the families.• Add the state hotline for EI referral to phone or address book.• State that their child is at risk for language deprivation as a result of their hearing loss if not addressed through intervention.

Table 2*Change Objectives and Research-based Methods to Address Needs*

Change Objective	Method
Add the state hotline for EI referral to phone or address book.	Guided Practice/Implementation Intention
Connect experiences with strengths-based observations provided from other families.	Cultural Similarity
Demonstrate record keeping by retaining notes from the call with EI and appointments in a dedicated handbook.	Chunking/Advanced Organization/Imagery/ Guided Practice/Implementation Intention
Demonstrate the ability to interpret their child's audiogram including type, configuration, and recommendations.	Direct Experience/Guided Practice
Describe the unique role of each person in the family as it relates to the EI process.	Implementation Intention
Diagram the number of different steps of EI referral.	Direct Exposure
Explain the importance of developmental needs and the impact of delayed intervention/language deprivation.	Fear Arousal/Personalized Risk
Express confidence in ability to discuss child's development, needs, recommendations, and current concerns of family and providers.	Role Play
Identify what logistical supports will be needed to meet needs.	Implementation Intention/Guided Practice/ Discussion
List local family support services available in their town or county.	Implementation Intention
List the benefits of EI compared to not accessing services.	Personalized Risk
Match the job title of common EI providers with their general job descriptions, roles, skills, and value of involvement.	Direct Experience/Personalized Risk/Verbal Persuasion
State that EI will only contact them/provide services if they provide consent.	Discussion
State that the family is the most important component of the EI system while working to ensure that children who are D/deaf or hard of hearing do not experience language deprivation.	Repeated Exposure

Note. EI = Early Intervention

Within the website a color scheme and simple branding (Figure 3) were selected to support participants in associating the key components of enrolling in early intervention with their daily lives. The four steps to enrolling in early intervention (knowing your eligibility based on hearing test results, connecting with the service, making relevant appointments, and staying engaged) were each assigned their own graphic and color that permeated the webpage. This consistency and repetition in message are consistent with behavior change work as a whole (Bartholomew Eldridge et al., 2016) and specifically with regards to barriers to early intervention access in EHDI (Woodruff & Cienkowski, 2022b). Once the general structure of the four steps were selected, each step had its own webpage created that featured a graphic organizer at the top of the page with key points and the associated symbol. Below this graphic organizer were prompting questions to help families navigate through the functional steps of addressing these key points.

In line with national recommendations, each page was reviewed for readability to ensure it was written at a 6th

Figure 3*Branding Used for Program*

Note. SETE = Swaddled Ear to Ear.

grade or below reading level (Safer & Keenan, 2005; Sax et al., 2019; U.S. Department of Health and Human Services, n.d.; Weiss, 2006; Woodruff & Cienkowski, 2021). An online accessibility expert was brought on to review all pages on the site for screen reader compatibility and visual contrast acceptability. The videos posted were ensured to have accurate captioning and all images included an image description. Consultations with the parent of a child under the age of three, a culturally Deaf adult with experience in social services for children who are D/deaf and hard of hearing, an IM expert, skilled providers of early intervention services for children who are D/deaf and hard of hearing (audiology, speech-language pathologist, teacher of the deaf) and an individual working at the state-level to implement EHDI were also completed to ensure accuracy of information and presentation. Given that this is a pilot, it is anticipated that following the completion of this study, materials will be further refined by future users.

Steps 5 and 6

Steps 5 and 6 of IM focus on taking the program that is developed in Step 4 and ensuring that it is applicable to the population of interest (Bartholomew Eldridge et al., 2016). Given the unique position of EHDI as a system called for at the federal level but devised to be responsive at the state level, the processes of Steps 5 and 6 should be developed in conjunction with the individual EHDI program and community where the program will be implemented. These steps used in the state of Connecticut are covered by Woodruff et al. (2022a).

Step 5: Development of an Implementation Plan for the Adaptors, Implementers, and Maintainers of the Program

The goal is to ensure that the intervention will be agreeable to those who will use it (Bartholomew Eldridge et al., 2016). An effective intervention requires developing a list of all potential users (implementers who will deliver the messaging, adaptors who will create the community's structure for the program, and maintainers who will keep the program running over time). These individuals will need their own outcome and performance objectives along with change objectives for the use of the program.

Step 6: Point of Evaluation for the IM Protocol

The outcomes for each IM program will be different and need evaluation (Figure 4; Bartholomew Eldridge et al., 2016). For Swaddling Ear to Ear, as a novel behavior change program focused on changing perceptions of early intervention to support engagement for children who are D/deaf and hard of hearing, the evaluation must look at outcomes in terms of behavior and perception of early intervention. Fidelity of the implementation, the function of the implementers (who they are, the training of the implementers, and implementer oversight) is critical to ensure consistency of the program and the control of outside variables. Woodruff et al. (2022a) will cover the evaluation of this program along with more expansive qualitative examples of the content designed for this population.

Swaddling Ear to Ear: Addressing LTI in EHDI

Swaddling Ear to Ear represents the first time that IM has been used to address LTI in EHDI. As a program, Swaddling Ear to Ear is delivered on a one-on-one basis in virtual format. The implementer trained in the program leads a hands-on practice session covering skills related to advocacy. A link to the family-facing website that accompanies this educational session can be found at <https://sites.google.com/uconn.edu/early-intervention-swaddling/home?authuser=1>. This website includes primarily the educational materials used in the session with the implementer leading the hands-on sessions. The semi-structured script used by the implementer is in the Appendix. An abbreviated example with actors of what one of the hands-on session can look like can be found at https://kaltura.uconn.edu/media/Swaddling+Ear+to+Ear/1_yyfxlz64.

Figure 4

Evaluation Plan for Program

Implementation	Feasibility	Impact	
Transcription of 25% of sessions and assess performance objectives	Semi structured interviews with parents post-intervention	Pre and Post design related to the determinates	Early Intervention Enrollment

Conclusion

Intervention Mapping exists to bridge the translational gap between behavior change theory, research on behavior change interventions, and public health initiatives (Bartholomew Eldridge et al., 2016). Within EHDI, there is a need to translate what research tells us about the benefits of early intervention into information that is useable by parents and providers when making enrollment decisions. Further, this need is best addressed at the level of the family with the input of system stakeholders, as IM supports. Tapping into IM's history in public health, the application of it to EHDI reaffirms that since EHDI is governed by public health law, it can and should be viewed as an interdisciplinary concept inclusive of public health principles. The inherent connection between IM and public health uniquely poises it to capitalize on the strong tradition of and legislative push for parent, advocate, and professional input on program development in EHDI (Early Hearing Detection and Intervention Act, 2017).

Although Step 6 of IM was described in this article, the actual evaluation of Swaddle Ear to Ear has not yet been completed. It is critical that programs that are developed through IM be subjected to evaluations with quantitative and qualitative rigor to assure the feasibility, fidelity, and utility of these programs. Evaluation procedures provide EHDI programs with publishable data that may be useful for other state programs that are looking to better embody the goals of EHDI while addressing LTI. While under-represented in the literature, these evaluations are critical to ensuring the credibility of IM and further evidence-based work in EHDI to support children and families.

References

- Bartholomew Eldridge, L. K., Markham, C. M., Ruitter, R. A. C., Fernandez, M. E., Kok, G., & Parcel, G. S. (2016). *Planning health promotion programs: An intervention mapping approach*. (4th Ed.). Jossey-Bass & Pfeiffer Imprints, Wiley.
- Centers for Disease Control and Prevention (CDC). (2021, May). *2019 Summary of national CDC EHDI data*. <https://www.cdc.gov/ncbddd/hearingloss/2019-data/01-data-summary.html>
- Early Hearing Detection and Intervention Act of 2017, Pub. L 115-71, 131 Stat. 1218, 1219, 1220, 1221, 1222 and 1223, codified as amended at title 42 USC §§ 280g and 280g-1.
- Individuals With Disabilities Education Act, 20 USC § 1400 (2004).
- Joint Committee on Infant Hearing. (2019). Year 2019 position statement: Principles and guidelines for early hearing detection and intervention programs. *Journal of Early Hearing Detection and Intervention*, 4(2), 1–44. <https://doi.org/10.15142/fptk-b748>
- Kingsbury, S., Khavalabov, N., Strin, J., Held, C., Fleckenstein, S. M., Hendrickson, K., & Walker, E. A. (2022). Barriers to equity in pediatric hearing health care: A review of the evidence. *Perspectives*, 7, 1060–1071. https://doi.org/10.1044/2021_PERSP-21-00188
- Majid, U., Kim, C., Cako, A., & Gagliardi, A. R. (2018). Engaging stakeholders in the co-development of programs or interventions using intervention mapping: A scoping review. *PLoS One*, 13(12). <https://doi.org/10.1371/journal.pone.0209826>
- National Center for Hearing Assessment and Management. (2010, September). *Newborn Hearing Screening Training Curriculum*. <http://www.infanthearing.org/resources/>
- Safeer, R. S., & Keenan, J. (2005). Health literacy: The gap between physicians and patients. *American Family Physician*, 72(3), 463–468.
- Sax, L., Razak, A., Shetty, K., Cohen, M., & Levi, J. (2019). Readability of online patient education materials for parents after a failed newborn hearing screen. *International Journal of Pediatric Otorhinolaryngology*, 125, 168–174. <https://doi.org/10.1016/j.ijporl.2019.07.009>
- Statista. (2022). Internet user penetration in the United States from 2018 to 2027. <https://www.statista.com/statistics/590800/internet-usage-reach-usa/>
- U.S. Department of Health and Human Services. (n.d.). *Making health communication programs work*. <https://www.cancer.gov/publications/health-communication/pink-book.pdf>
- Weiss, B. D. (2006, June). *Health literacy: A manual for clinicians: Part of an educational program about health literacy*. <http://lib.ncfh.org/pdfs/6617.pdf>
- Woodruff, T. A., & Cienkowski, K. M. (2021). Readability of online hearing-based early intervention materials. *Journal of Early Hearing Detection and Intervention*, 6(2), 39–44. <https://doi.org/10.26077/2c6d-c243>
- Woodruff, T. A., & Cienkowski, K. M. (2022a). *Application of intervention mapping to address lost to intervention in early hearing detection and intervention*. [Manuscript in preparation]. Department of Speech, Language, and Hearing Sciences, University of Connecticut.
- Woodruff, T. A., & Cienkowski, K. M. (2022b). *Modeling Lost to Intervention in Early Hearing Detection and Intervention: A modified eDelphi study*. [Manuscript submitted for publication]. Department of Speech, Language, and Hearing Sciences, University of Connecticut.
- Yoshinaga-Itano, C. (1999). Benefits of early intervention for children with hearing loss. *Otolaryngologic Clinics of North America*, 32(6), 1089–1102.
- Yoshinaga-Itano, C. (2003). From screening to early identification and intervention: Discovering predictors to successful outcomes for children with significant hearing loss. *Journal of Deaf Studies and Deaf Education*, 8(1), 11–30.
- Yoshinaga-Itano, C. (2013). Principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing. *Journal of Deaf Studies and Deaf Education*, 19(2), 143–175. <https://doi.org/10.1093/deafed/ent043>

Appendix

Semi-structured Script for Implementer

Thank you so much for signing up for today! Today we will be using this website and the pages you sent earlier like these. Do you have any questions before we start?

I will tell you a little about me, you can ask me questions, and then I want to know your family.

Name

Student at UConn

Working with Torri

Today we are going to be talking about early intervention for your baby. What is important to know is that everyone you meet on your journey wants to and has to make themselves easy to understand. That can mean getting an interpreter, repeating things, or asking for something to be written down with drawings or handouts. We will be going to this website and I am also sending you a workbook with everything we talked about so that you can look at things again later if you have questions or bring them to your audiologist to use when talking.

Tell how to get to website.

HEARING TESTS

Tell how to navigate to this page.

Hearing differences are not common at birth. Many people may have never met someone with hearing different than themselves.

What experiences does your family have with hearing?

Probe looking to see if they have experience—if yes

What were those interactions/experiences like?

Look to create either positive associations (telling good stories) or create cognitive dissonance between the negative experiences they report and the positive things they plan to do with their baby.

What do you think contributed to that?

If no—normalize that many people do not and that this gives them the opportunity to learn more about hearing.

We asked these types of questions to some people who are similar to you or know people like you. And the things you are feeling are normal.

There has been a lot going on in your life since your baby joined the family! Who have you met related to your baby's hearing?

IF having trouble - Some people you might have met are:

Audiologists

Pediatricians

Hearing Screeners

Each of these people has different but related jobs.

You have seen a lot of people at this point and know different names or phone numbers. If you have any papers, please grab those too! We will add everyone to your phone and figure out what they do for you and your family.

Add each person they already met to their phones.

The next thing I want to chat about is your hearing test and the form they filled out for you. This is called an audiogram and is how your baby's hearing is shown. I think Melissa does a nice job reminding us what an audiogram is.

VIDEO

This is a lot to remember! You can watch this video whenever you want. Audiologists go to school for 8 years to be able to do this! I have this handout for you with a link to that video to review it if you want to later.

What does that mean for when they are learning to communicate?

Appendix (contd.)

Go through the audiogram - For a language that uses speech, if they don't have access to high frequencies they might not use s or mispronounce words. If they don't have access then they might not develop spoken language.

This isn't going to be the only audiogram your baby gets. As your baby gets older, you will need them less often, but for the next few months, you are going to be with your audiologist a lot. What makes it easier or harder for you to get to these appointments?

For each concern the family brings up, nod, tell them it makes sense, and offer a solution/support from the central 211 line.

Also we have that list in their download.

A lot of the things you mentioned are challenges many families face. You have a newborn! Some big concerns from other families are:

Getting to appointments: There are programs that will pay you back for the miles you drive.

Getting time off of work: Appointments are made around your schedule! People can come to your home or the child's daycare.

Finding child care for siblings: At-home appointments can be done with your whole family there, it is encouraged! We will also work to build a community around you to help with these types of challenges.

Affording this: In Connecticut, early intervention from the state is free. There are also groups that can help you learn sign language, get hearing devices, and much more for no or less cost.

Not understanding what people say: You are the most important person in your child's life. Ask questions. Get hand-outs. Ask for interpreters. All of these are things that you are entitled to. There are also parent organizations who are here to help you understand everything that is going on.

Not feeling ready or sure: This can be a confusing time. All you want to do is love on your new baby. Everyone you are meeting wants to help you and your baby grow. Share what you are feeling with those around you. There are ways to connect with parents who have taken this journey and learn from them.

CONNECT

Tell how to navigate to this page.

You might hear the term language deprivation to describe when someone does not have language access. This does not mean that you are taking anything from your child! All it means is there isn't language access.

Early Intervention services can mean a lot of things when supporting language, and it all depends on what you as a family WANT for the baby. You might also hear it called EI or Birth to Three. These are all the same thing, and you can get them for free in Connecticut because of your baby's audiogram.

Some common things that families ask for to meet goals are:

Hearing Evaluations

Speech and Language Therapy

Sign Language Instruction

Hearing Aids/Cochlear Implants

Family Support Groups

and anything else that the child needs to grow.

What are some of your goals for the baby?

List 3 to start, encourage them!

If you go back into your phone, scroll back to the first contact we put in NAME, and let's write down what goal they can help you with as a note in that contact.

As you open up each contact you can also "link" them to the other providers you know.

Now that we know what early intervention is, it is time to talk about getting it! There is a process for getting early intervention, and everyone involved wants to give your family what you need.

Appendix (contd.)

This picture shows how to get early intervention. Since you are in control of early intervention, I thought we could run through how it might go. Who in the family will be in charge of making the appointments and contacting early intervention? Do you have 211 saved on your phone? Great, we are going to do a practice call.

(If one person, have them take on the parent role and the facilitator will be the operator. If 2 people, the person calling is the parent and the one not calling is the 211 operator with the list of questions to ask as seen in the diagram.)

What is important to know is that you are in charge of every step. No one will contact you if you don't agree, and you can ask for as much or as little help as possible.

Early intervention and the phone numbers that you have saved are not the only people here to support you. Who in your family and friends do you feel comfortable talking with or asking for help?

Congratulate for naming people and probe what they think might be the most helpful to ask each person to do.

Talk about family supports.

APPOINTMENTS

Tell how to navigate to this page.

Once you have contacted early intervention that first time, things will move very quickly! You will need to answer your phone when people call—even if you do not know the number. The goal will be to make sure that your family is getting all of the services you want, by the time your baby is 6 months old.

DESCRIBE DIAGRAM and congratulate that they are already $\frac{2}{3}$ of the way done.

If we look back on your goals for the baby, each one of those will have a meeting and provider connected to it. We can use this to walk through all the steps, who you will contact, and what that process will be like.

Discuss each point—this is planning intention and key

For when—have them set reminders on their phone

That can be hard to do when you are trying to learn all this information and take care of your baby. With that, I thought we could do a practice of what that might look like. You can ask me a specific question about what we have covered, a goal you have, or a question you want to answer, and I will explain in a “not so clear” way. You should stop me to ask questions, get additional materials, or take notes. This will help you hear the information again and get you used to advocating for your baby!

KEEP GROWING

Tell how to navigate to this page.

Once you are in early intervention, everything is set up to get you where you want to be. With that, you will have to advocate for your baby.

That is a pretty big task. To help wrap your head around that, I want to go over how you advocate. To get that started, you will see that the final page of your download is a “family plan of care.” This will be able to go into the front of your planning so that you have all the tools you need to advocate. We will go over this form together, fill it out and consider what it would be like to start a conversation using it.

Talk through and make sure each line is understood—basically what is your role? Then How do you ask for help? Then How do you educate? And such

Ask “How do you start a conversation when you need someone's help?”

Congratulate any step towards advocacy.

Reminder about asking for better explanations, things in writing, interpreters, and such

A reminder that people have to give them this—it is the law.

Reminder they are not alone and do not have to advocate alone—parent groups.

The most important thing for you to know is that you control this. Everyone you meet is here to help you learn. If you ever think the person you are talking to is unclear, you should ask for an interpreter, take-home materials, and follow-up questions.

We have talked about a lot today and have tried to set you up for everything. How can we get through this to-do list?

“It’s About Walking Alongside a Family”: Practitioner Perspectives on Caregiver Coaching With Families of Children Who Are Deaf or Hard of Hearing

Dorie Noll, PhD^{1,2}

Sheila Moodie, PhD³

Ian D. Graham, PhD^{4,5}

Beth Potter, PhD⁴

Elizabeth M. Fitzpatrick, PhD^{1,2}

¹University of Ottawa, Ontario, Canada

²Child Hearing Lab, CHEO Research Institute, Ontario, Canada

³Western University, London, Ontario, Canada

⁴University of Ottawa, Ontario, Canada

⁵Ottawa Hospital Research Institute, Ontario, Canada

Abstract

Practitioners use caregiver coaching in early intervention services, but coaching principles and practices are not well understood in the context of listening and spoken language (LSL) services with families of children who are deaf or hard of hearing. The purpose of this study was to examine practitioners’ experiences with coaching, including definitions, training, and practices they use in their work with families. Using semi-structured, qualitative interviews and video observation discussions, this study examined the perspectives of 14 practitioners providing LSL services to families at three intervention sites in the United States and Canada. Results indicate that practitioners’ underlying beliefs about their coaching proficiency and caregivers’ capacity impact their coaching practices and how they engage with caregivers. Results highlight practices such as mentoring and accountability that supported practitioners’ coaching skills. This study contributes to the understanding of caregiver coaching in LSL practice and has implications for practitioners working to improve their coaching skills, which may improve LSL services and optimize child outcomes.

Keywords: deaf or hard of hearing, early intervention, listening and spoken language, caregiver coaching

Acronyms: CoP = community of practice; DEC = Division for Early Childhood; EI = early intervention; DHH = deaf or hard of hearing; FCEI = family-centered early intervention; LSL = listening and spoken language

Correspondence concerning this article should be addressed to: Dorie Noll, PhD, Faculty of Health Sciences, University of Ottawa, 451 Smyth Road, Ottawa, ON K1H 8M5, Canada. Email: dnoll067@uottawa.ca

The Division for Early Childhood has established evidence-based recommended practices to guide practitioners in implementing family-centered early intervention (FCEI) with families of children with disabilities, including caregiver coaching to build on families’ strengths and impact child outcomes (Division for Early Childhood [DEC], 2014). Coaching empowers caregivers by building their capacity, confidence, and competence to support their child’s development and maximize learning opportunities throughout their daily routines (Dunst & Trivette, 2009a; Rush & Shelden, 2019; Woods et al., 2011). Caregiver coaching increases both the quality and quantity of intervention that children receive, and as a result, improves child outcomes (Heidlage et al., 2020; Roberts, 2019; Roberts & Kaiser, 2011; Sone et al., 2021).

The Joint Committee on Infant Hearing (2019) recommends FCEI services provided by professionals with expertise in hearing loss as the most appropriate way to meet the needs of children who are deaf or hard of hearing (DHH) and their families (Moeller et al., 2013). For families who choose listening and spoken language (LSL),

practitioners abide by principles that prioritize caregiver involvement in all aspects of intervention, and caregiver coaching is used to achieve this goal (AG Bell Academy for Listening and Spoken Language [AG Bell Academy], 2017; Kendrick & Smith, 2017; Moeller et al., 2013). Caregiver coaching necessitates that practitioners engage caregivers as the primary learners in intervention sessions, facilitating and enhancing caregiver-child interaction rather than teaching the child directly. Through coaching, practitioners teach caregivers specialized LSL skills, provide opportunities for them to practice, and offer feedback in the context of an intervention session. Coaching enables caregivers to learn strategies to embed intervention within their daily routines, providing the intensity of services needed for their child to develop language.

Coaching positions caregivers as the primary learners in the intervention process, therefore, practitioners must use practices geared toward adult learners. Adult learning refers to a collection of theories about processes and conditions that optimize learning for adults (Dunst & Trivette, 2012; Trivette et al., 2009; Yang, 2003). Adult

learners must be ready to learn, actively participate in the learning process, be self-directed, and the learning must be solution-centered and contextual (Cox, 2015; Dunst & Trivette, 2009b, 2012). Active learner participation, opportunities to practice new knowledge and skills, and reflection are important components for effective adult learning (Dunst & Trivette, 2009b; Trivette et al., 2009). However, practitioners providing intervention services to families of children with disabilities often report a lack of training in adult learning principles (Douglas et al., 2020; Meadan et al., 2018). Even when practitioners claim to implement caregiver coaching, research suggests that a significant amount of time is spent engaging the child directly during intervention sessions (Campbell & Sawyer, 2007; Salisbury & Cushing, 2013), suggesting a need for training and accountability in coaching.

There is lack of consensus on the principles and practices of caregiver coaching in the FCEI literature (Friedman et al., 2012; Ward et al., 2020). However, most coaching models contain elements of the following evidence-based practices, as outlined by Rush and Shelden (2005, 2019): (a) joint planning, (b) observation, (c) action, (d) reflection, and (e) feedback.

The lack of consensus about best practices in coaching for families raising children with disabilities also applies to the specialized intervention services provided by LSL practitioners (Noll et al., 2021). Practitioners can pursue a Listening and Spoken Language Specialist (LSLS) certification through the AG Bell Academy, which requires 3 to 5 years of mentorship and extensive professional development, and results in a professional designation of LSLS Auditory-Verbal Educator (AVEd®) or Auditory-Verbal Therapist (AVT®; AG Bell Academy, 2017). Practitioners abide by principles for the provision of high-quality services to children who are DHH, including guiding and coaching caregivers (AG Bell Academy, 2017). However, these principles lack specificity and guidance on specific practices for coaching as suggested by Rush and Sheldon (2005, 2019) and it is unclear whether LSLS practitioners incorporate well-established FCEI practices (Noll et al., 2021).

Recent research has begun to explore caregivers' experiences participating in FCEI services, including coaching. Families of children who are DHH have reported positive experiences with coaching in LSL services, indicating that participation increased their skills and confidence in supporting their child's speech and language development (Josvassen et al., 2019; Noll et al., 2022; Stewart et al., 2020). In addition, caregivers have reported that a supportive, collaborative coaching relationship that involved shared decision-making and working together with their practitioner in the context of their daily routines was key to building their knowledge and skills (Salisbury et al., 2018). In interviews with caregivers participating in LSL intervention, three factors were indicated that contributed to a positive caregiver coaching relationship: (a) practitioner attributes, (b) how expectations are set for caregiver participation, and (c) the evolution of the coaching relationship over time in response to changing caregiver needs (Noll et al., 2022).

Fewer studies have examined the perspective of practitioners who use caregiver coaching. In previous research examining the perspectives of general FCEI practitioners, participants reported challenges with implementing coaching due to incongruent expectations and family characteristics. The incorporation of pre-coaching strategies, such as trust-building, facilitated caregiver engagement and helped to overcome these barriers (Douglas et al., 2020; Meadan et al., 2018). Practitioners reported that meeting families' needs required flexible, individualized practices, and that engagement in intervention through positive caregiver/practitioner relationships promotes caregiver competence and empowerment (Meadan et al., 2018). Similarly, practitioners implementing a highly structured model of coaching reported that although they felt it to be worthwhile, it was challenging to implement despite participating in professional development activities to support their skills (Salisbury et al., 2018). In a study specific to LSL practitioners, King and colleagues (2021) reported providers' perceptions that services for families of children who are DHH differ from other FCEI services due to the specialized nature of developing LSL skills through audition, and there is a need for intensive and continual professional development to develop and maintain the requisite skills.

Although the use of caregiver coaching is supported in the literature and LSL practice guidelines, a recent scoping review found that the current literature lacks a clear description of caregiver coaching with families of children who are DHH (Noll et al., 2021). Furthermore, very little research has examined caregiver coaching from the perspective of LSL practitioners. Gaining greater insight into LSL practitioners' knowledge, coaching practices, and professional preparation can identify changes in practice and professional development that could ultimately result in higher quality services for children and families. Therefore, the purpose of this qualitative study was to understand practitioners' experiences with coaching in LSL early intervention (EI) services, including how they define coaching, how they learned to coach, how they engage caregivers in coaching, and practices they use in their work with families. The specific research questions addressed were:

1. How do LSL practitioners conceptualize coaching?
2. How do LSL practitioners describe how they coach caregivers?
3. How do LSL practitioners incorporate and encourage active caregiver participation and reflection in their coaching practices?

Method

This qualitative research study included semi-structured interviews and video observation discussions with practitioners providing LSL services at one of three sites. The design and methods were informed by the principles of interpretive description (Teodoro et al., 2018; Thorne, 2016; Thorne et al., 1997, 2004). The foundation of this applied qualitative research approach is to investigate a

clinically relevant phenomenon and generate an inductive interpretation to advance clinical understanding (Burdine et al., 2020; Thorne et al., 2004). Research ethics approval for this study was obtained from the University of Ottawa and the CHEO Research Institute in Ottawa, Ontario (19/106X).

Participants

Participants were selected from one LSL program in Canada and two programs in the United States. These sites were purposively selected to represent diversity in service delivery models and chosen for their reputation for providing exemplary LSL services. The sites were accessed through personal networks of two authors, and some of the practitioners were familiar with the first author, who completed the interviews. Service delivery differs between sites: on-site (Site 1), in the home (Site 2), and an approach that includes both in-home and school-based service delivery (Site 3). All practitioners at each site met the following eligibility criteria and were therefore invited to participate: (a) providing LSL services to families of children who are DHH from birth to 3 years of age, and (b) implementing family-centered services using a caregiver coaching model, per each organization's intervention model. Practitioners were invited to participate in an interview and guided discussion based on a short, self-selected segment of a video-recorded coaching exchange between the practitioner and a caregiver. Permission was obtained from site administrators to contact practitioners directly via email. Information about the study was sent by email, followed by a group meeting to allow practitioners to ask questions and make an informed decision about participation. The goal was to interview all practitioners to gain an understanding of the coaching principles and practices at each site, and all agreed to participate. Informed consent was obtained from practitioners prior to each interview and from caregivers prior to viewing each video.

The intent of this study was to capture the diversity of approaches among practitioners with regard to coaching, while also gaining a broader understanding through identifying similarities between practitioners implementing LSL services in different contexts (Braun & Clarke, 2021; Burdine et al., 2020; Thorne et al., 2016). The principles of interpretive description informed efforts to generate a deeper understanding of practitioners' perspectives and experiences, while recognizing the variability inherent in applied practice (Abdul-Razzak et al., 2014; Burdine et al., 2020; Thorne, 2016).

Data Collection and Analysis

Individual, semi-structured interviews were conducted in person at the two intervention sites in the United States from February to March 2020. Interviews with the Canadian practitioners were completed from July to August 2020 using Zoom video conferencing software due to COVID-19 pandemic restrictions put into place during data collection. Practitioners were asked to describe how they learned to coach and to share their overall experiences with caregiver coaching (see Appendix A for interview guide). Although examining how each practitioner defined

coaching was part of the purpose of these interviews, the interviewer provided a cursory definition of coaching to facilitate deeper discussion as the point at which they "coach or teach caregivers to implement intervention strategies themselves, throughout their daily routines, in-between intervention sessions."

To supplement the interviews, practitioners self-selected a portion of a video-recorded session and participated in a guided discussion with the interviewer about the interaction they selected (see Appendix B for video observation guide). Practitioners chose a 10-minute segment that contained a coaching exchange between the practitioner and the caregiver. Since there is no agreed-upon definition of coaching components or procedures (Noll et al., 2021), the practitioners' selection provided insight into what they consider coaching and allowed for rich discussion of their beliefs and practices in the context of the practitioner/caregiver interaction. This component was not evaluative, but rather was used to augment the interviews, giving the practitioners an opportunity to explain their decisions and coaching behaviors during an interaction with a caregiver. This type of video-elicitation has been shown to facilitate reflection and enable a deeper understanding of participants' thought processes (Hamel & Viau-Guay, 2019; Paskins et al., 2017).

Interviews and guided video discussions were audio recorded, transcribed verbatim, and verified before being uploaded into NVivo 12 (QSR International Pty Ltd., 2020), a qualitative data analysis software used to organize and facilitate analysis. The interview transcripts were combined with the video-based guided discussion transcripts for interpretation and analysis. Participant and site names were removed and assigned pseudonyms to preserve confidentiality in the final report. Videos were viewed on the practitioners' devices and not collected by the researcher.

To ensure rigor and trustworthiness and account for potential bias (Holmes, 2020), credibility processes were incorporated throughout this study (Cypress, 2017). The primary researcher conducted all interviews to maintain consistency, critically reflected on her positionality, participated in reflexive memo writing throughout data collection and analysis, maintained a careful audit trail and detailed field notes, and participated in frequent debriefing sessions with members of the research team to challenge assumptions, reflect, discuss, and refine codes and themes. Practitioners were de-identified and quoted directly to ensure adequate representation and thick description of their perspectives. This study followed the Standards for Reporting Qualitative Research (O'Brien et al., 2014).

The primary researcher who completed the interviews and data analysis is the parent of a child who is DHH and an experienced LSL EI practitioner. This dual perspective, along with experience in caregiver coaching, provides a unique lens through which to identify and examine matters of clinical significance, and informed the design of this research.

Results: Underlying Beliefs Drive Process and Promote Participation

All practitioners recruited at each intervention site agreed to participate, as did the program directors at two sites, both of whom are still providing services to families, for a total of 14 interviews (see Table 1 for demographics). The site distribution was as follows: Site 1, $n = 4$; Site 2, $n = 6$; Site 3, $n = 4$. Eight practitioners supplied video clips to supplement their interviews. Video recordings were prohibited once pandemic restrictions were implemented, limiting the number submitted.

The video discussions provided rich and informative insight into practitioners' conceptualization of coaching and illustrated differences in their approaches that were not evident in the interviews. The majority of practitioners reported that they chose clips that demonstrated a *typical* rather than *ideal* coaching exchange with caregivers. The videos allowed the practitioners to elaborate on and explain their coaching practices and decisions in real time.

All practitioners ascribed to caregiver coaching and reported efforts to actively engage caregivers in intervention. However, variations existed between sites

and among practitioners as to the definition and specific practices they incorporate in their LSL intervention with families. As understanding of the practitioners' perspectives increased, an overarching concept became clear: the underlying beliefs practitioners held about the role and capacity of caregivers impacted both the process of coaching and the ways in which they engaged caregivers. As such, we identified themes in three categories: (a) underlying beliefs: caregiver capacity, conceptualizing coaching, and perspective shifting; (b) process: equipping and shared understanding of concepts and procedures; and (c) participation: built on relationship, engagement leads to empowerment, matching goals to caregiver priorities, and recognizing challenges. See Figure 1 for a graphic representation of themes and subthemes.

Underlying Beliefs

Practitioners revealed how they conceptualize coaching and their underlying beliefs related to caregiver capacity, and many of the practitioners discussed how experience and new learning shifted their beliefs over time. These underlying beliefs impacted how they talked about the process of coaching and expectations for caregiver participation in intervention sessions.

Caregiver Capacity

Practitioners discussed their views about caregiver capacity and desire to engage in coaching as certain and expected of all caregivers or based on extenuating circumstances, and therefore variable. The majority of practitioners expressed belief in caregiver capacity; however, five practitioners from one site expressed that although they believe caregiver coaching is ideal, it is not always feasible.

Of Course They Can. All practitioners from two sites and one from the third site expressed the belief that caregivers can and will engage meaningfully in caregiver coaching. Several participants recounted instances in which caregivers chose not to participate in coaching, but indicated that it was rare and they were "not okay" with it, but ultimately, they indicated that choice belonged to the caregiver. In some cases, the practitioner provided direct service to the child rather than coaching and in others, the caregivers sought services elsewhere. Alexis shared her frustration with other practitioners in this way: "Therapists... make assumptions on what the parents are feeling. 'Oh, they're not ready...they've already been through too much.' And it's like, 'No, let's ask them, because it might be the one thing they think they *can* do.'"

The assumption that the majority of caregivers will engage in coaching was particularly evident in the self-selected video clips. Several practitioners chose families who were facing significant challenges that might have impacted their ability to fully engage in coaching. However, the practitioners shared the obstacles the caregivers had overcome and how proud they were of the progress they had made, indicating that they believed in their capacity to engage and benefit from coaching despite the challenges they faced.

Coaching is Conditional. In contrast, five practitioners talked about coaching as the ideal, but not always

Table 1

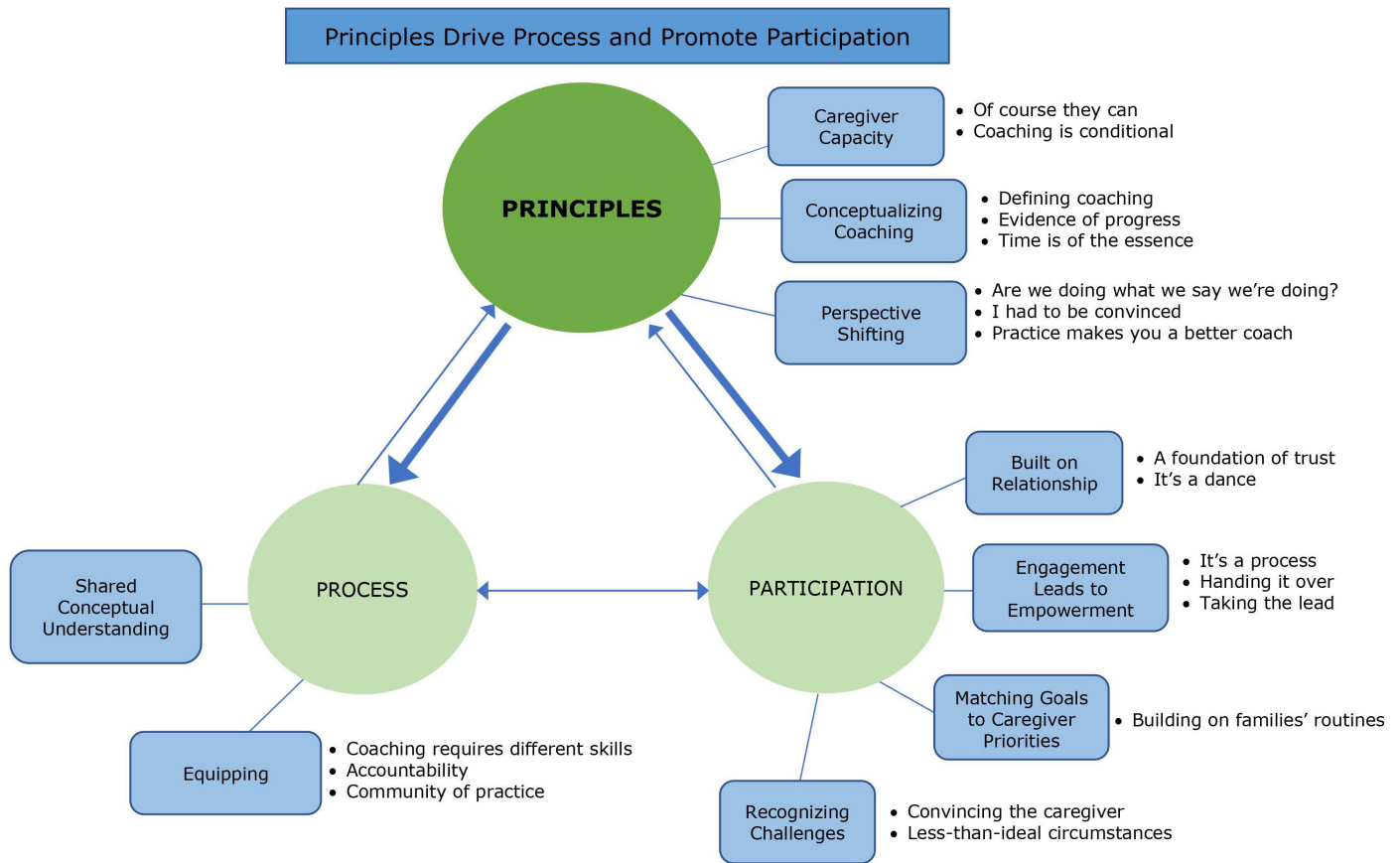
Demographics

Variable	Number	Percentage
Time in Early Intervention		
1–4 years	3	21.43%
5–10 years	3	21.43%
11–15 years	1	7.14%
16–19 years	1	7.14%
20+ years	6	42.86%
Professional Designation		
ToD	10	71.43%
SLP	3	21.43%
AVT only	1	7.14%
Certification Status		
LSLS Cert. AVEd®	4	28.57%
LSLS Cert. AVT®	1	7.14%
Not certified	9	64.29%
Highest Degree		
Masters	13	92.86%
Bachelors	1	7.14%
Country Where Degree Conferred		
USA	10	71.43%
Canada	2	14.29%
Australia	1	7.14%
Egypt	1	7.14%

Note: ToD = Teacher of the Deaf; SLP = Speech-Language Pathologist; AVT = Auditory-Verbal Therapist (practicing, but without official certification; undergraduate degree in special education); LSLS Cert. AVEd®/ AVT® = Listening and Spoken Language Specialist Certified Auditory-Verbal Educator/Therapist

Figure 1

Practitioners' Experiences with Caregiver Coaching in Listening and Spoken Language Practice



Note: This is a visual representation of the themes (circles), subthemes (rectangles), and codes within the subthemes (bullet points) from the data. The arrows indicate directional relationships between the themes.

possible, citing reasons such as caregiver personality and family situational factors. These practitioners used words such as “awkward” and “uncomfortable” to describe coaching interactions and described some caregivers as “pretty fragile,” and, as such, they did not want to push them too hard to engage in coaching. Ann reported, “Sometimes it just, it does not matter how well you explain it, it’s not going to happen.”

These practitioners identified strategies they might use to encourage engagement, such as using siblings as an example and “indirectly modeling” in an effort to encourage the caregiver to take a turn. These practitioners, all from one site, discussed coaching as if it were the exception, rather than the norm. These same practitioners reported lower levels of self-efficacy with regard to their coaching practices and were less likely to report supervisor and/or colleague accountability as a regular part of their practice.

Conceptualizing Coaching

Defining Coaching. The definition and practices of coaching varied widely. According to Kelly:

Everybody gets this big global idea, but then when it comes down to how you implement it and which parts are really the most important, you probably get many varied answers...the

biggest definition I would have is...it’s about walking alongside a family.

In general, practitioners within each site shared similar viewpoints of what caregiver coaching is and the practices that comprise it, although differences between sites were considerable. These differences included which parts of an intervention session are considered coaching, specific practices that should or should not be included during coaching, and the terminology used to describe specific coaching practices. Site 1 practitioners conceptualized coaching as the teaching portion of a session, when practitioners provide information or explain strategies, rather than the activity part of the session, when strategies are applied and practiced. Site 2 practitioners considered coaching to encompass most of an intervention session, including providing information, explaining and/or demonstrating a strategy, practicing in the context of an activity, and reflecting with the caregiver. Site 3 practitioners conceptualized coaching as a specific part of the intervention session, when the caregiver engages in an activity with their child, incorporating LSL strategies while the coach sits back to observe and provide feedback, and reflection with the caregiver after the completion of the activity.

These differences were especially apparent as the practitioners discussed their video clips and shared what

they considered to be a typical example of a coaching exchange. One site has developed specific criteria and protocols for coaching practices, and accountability is built into their organizational professional practices through regular reflective supervisory and collaborative team meetings. Practitioners at this site, in particular, clearly articulated their coaching practices using shared language as a staff. Practitioners from the other sites shared the same general criteria for coaching as their coworkers, although more variability existed in how they talked about their coaching practices.

Evidence of Progress. Practitioners discussed methods for determining whether caregiver coaching was effective in terms of caregiver learning and the child's LSL outcomes. All practitioners reported using a variety of formal and informal assessments to document child progress, and several talked about attributing child progress to their caregivers learning LSL skills and implementing them at home. No practitioners reported the use of a formal measure for documenting caregiver learning through coaching. A few mentioned informal measures for assessing caregiver learning, such as observing their interactions with their children during intervention sessions. Sara indicated that observing how a caregiver talks with her child provides insight into how well she has learned intervention strategies, saying, "She will talk to him, she will tell him, she will comment about what's going on, parallel talk, self-talk. She will be a talkative parent."

Time is of the Essence. Another conceptualization of coaching was evident in how practitioners viewed their time with families. Several of them talked about the value of the length of time they are able to work with families—typically approximately three years—which afforded them the opportunity to establish trust and develop a meaningful coaching relationship. Several practitioners viewed caregiver coaching as a way to make the most of a 45–60-minute intervention session, and indicated that they value the time caregivers commit to intervention and do not want to waste a moment of it. The value of time was also evident in the emphasis practitioners placed on teaching caregivers concrete skills to carry over into naturalistic environments, to optimize their child's learning during the critical period for language development. Sara shared that it upsets her when she sees other practitioners "waste the critical age" for a child's language development. She went on to explain that intensive intervention during this critical period is crucial, stating, "I'm very keen for all my kids not to waste a day."

Perspective Shifting

All practitioners indicated that perspectives about caregiver coaching can change over time, through experience and professional development. Eight of the practitioners have worked in EI for more than 10 years, and many discussed how their understanding and expectations for caregiver coaching in LSL practice have evolved over the course of their career. However, even the less-experienced practitioners mentioned that their perspective about caregiver coaching has evolved since they began working with families.

Are We Doing What We Say We're Doing? Five of the practitioners described the shift to caregiver coaching as an internally-motivated decision to more explicitly engage caregivers in intervention sessions. Practitioners questioned whether their intervention practices reflected their conceptualization of caregiver coaching, as they claimed, or if they needed to implement changes to best serve families. Olivia described a desire for improvement, stating, "I knew what we were doing was good work, but I also knew that what we were doing could of course be better, because it can always be better." She recalled a conversation with her coworkers during which they agreed that the caregivers should be making the decisions and engaging with their child during sessions, and, as a result, they decided to change their coaching practices. However, they were not without doubts. Olivia recalled that they initially "did not trust that the parents would be able to rise to the occasion," indicating a skepticism that had to be overcome to change their practice, despite their conviction that it was a worthwhile change.

I Had to Be Convinced. Nine practitioners shared that their reasons for changing their coaching practices were more externally-motivated. They described a shift in thinking after learning about changing recommendations in the field; however, several reported that the decision to change their practices ultimately resulted from being held accountable to implement coaching by a supervisor and their colleagues. Several of these practitioners reported doubt that relinquishing control of the intervention would be effective, but were convinced after caregivers were willing and able to actively participate in coaching. Susan described this initial hesitation and how she was eventually convinced of the feasibility of coaching:

I didn't believe it at first...I thought parents needed me to be telling them everything...I just didn't really realize the power of empowering them...When we really started doing it...we saw the parents be more responsible and kind of doing things on their own...I think it empowered us, as well, to believe this was a good thing.

Four practitioners reported learning about coaching and believing that it should be implemented, but are still working to change their practice. This was reflected in their reported perception that coaching is conditional, impacted by external circumstances.

Practice Makes You a Better Coach. Although a few practitioners reported feeling confident in their ability to coach from the beginning, most said that they gained confidence with experience, which changed their perspective on coaching. Kelly described making the adjustment from teaching in an LSL classroom to coaching caregivers, indicating that there was a significant learning curve. Over time, she reported gaining confidence, stating, "More practice with coaching just makes you a better coach." However, four practitioners indicated that although they feel more confident now than they did when they began coaching, they still feel uncertain about their coaching abilities. Interestingly, this included two

practitioners with more than ten years of experience who reported that they are still working to gain confidence in their skills as a coach.

Process

Coaching practices varied among practitioners and sites, including coaching components and how they are implemented. Practitioners described how they learned to coach and discussed factors that facilitate their coaching practice, including ongoing professional development, systems of accountability, and support from colleagues sharing similar experiences.

Equipping

Practitioners indicated that caregiver coaching requires specialized training and ongoing support that they did not necessarily gain in their professional preparation programs. Practitioners highlighted several components that went into equipping them with the knowledge, skills, and confidence necessary to effectively coach caregivers.

Coaching Requires Different Skills. All practitioners acknowledged that coaching caregivers requires a different skillset than teaching children, which is primarily what they learned in their professional preparation programs. Jessica shared, “I was...very nervous because...the whole responsibility of...teaching a family... versus working with a child...I knew that required a whole other set of skills.” Four practitioners reported learning about coaching in their graduate programs, although only two of them reported this as a primary focus of their training. Other ways practitioners reported learning coaching skills included professional development activities, on-the-job learning, and mentoring from more experienced practitioners. Nine practitioners reported that providing tele-intervention services sharpened their coaching skills, and six reported refining their skills through teaching other professionals.

Many practitioners reported a desire for more opportunities to develop their skills, including Hannah, who put it this way: “I want to...coach the parents to teach their child. I feel like a link that’s missing is—who’s coaching me to do that?”

Accountability. Several practitioners mentioned accountability as a facilitator for coaching. They described accountability as answering to and brainstorming with a supervisor and colleagues about their coaching practices and challenges, as well as the responsibility inherent in training others to coach. The practitioners at Site 3 in particular shared how much they value having a supervisor who has high expectations and holds them accountable, to which they attributed gaining confidence in their ability to coach caregivers.

Practitioners from Site 3 also shared that part of their accountability practice included video recording sessions and reviewing them with a supervisor as well as using them regularly for self-reflection. When discussing her self-selected video clip, Ann shared an example of supervisory reflection when she stated, “This is a moment where (director) helped me through a part that could be coaching

or strategy.” Olivia felt strongly about using video for self-reflection, declaring, “The most enlightening thing is to videotape yourself.”

Community of Practice. Another facilitator for coaching was regular interaction with colleagues with whom practitioners can share ideas, problem-solve, and pursue professional learning and development. Several practitioners mentioned the value of learning and growing together and stated that they appreciated having someone with whom to problem-solve difficult situations. Paula articulated the importance she places on sharing with her colleagues by saying, “It’s nice to have peers with experience in the same boat as you, that you can talk to...I’m not an individual provider out there by myself. Because we do give each other a lot of feedback.”

Shared Understanding of Concepts and Procedures

According to the practitioners, a shared and clear understanding of coaching principles, components, and procedures was a facilitator for gaining confidence and implementing coaching with fidelity. Susan reported that “there’s certain components of every session that we know need to happen in order for it to be well done.” Alternatively, a lack of clarity impeded coaching practices, resulting in a lack of confidence in coaching skills for some practitioners.

Several specific coaching practices were identified during the interviews including: checking in, setting goals, explaining the strategy, demonstration, observation, an opportunity to practice, providing feedback, reflection, planning for carryover, and wrapping up. Of these, reflection was reported as most difficult by many practitioners. They described it as “difficult,” “challenging,” and “uncomfortable,” and several considered it “an area of growth,” and, as a result, they did not always include it as a component of their coaching. Two practitioners reported that it was difficult when they first incorporated reflection into their coaching practice, but, as Kelly stated, “Now it feels pretty natural.”

Practitioners also shared practices that supported the coaching exchange, including establishing the expectation for caregiver engagement and providing information to caregivers. Practitioners felt that these practices were particularly important at the onset of EI services and during transitions, such as preparing to exit EI services. As coaching practices varied between sites, not all of these components were included by all practitioners in every coaching session.

Participation

Practitioners’ expectations and experiences regarding caregiver participation derived from their underlying beliefs about the capacity of caregivers to engage in coaching. Their expectations for participation ranged from full, active participation in all aspects of the session, including choosing goals, to expecting caregivers to take a turn after the practitioner modeled a strategy with the child. All practitioners agreed that caregiver engagement is a crucial criterion for coaching.

Built on Relationship

A Foundation of Trust. All practitioners reported that a foundation must be built with a family before establishing a meaningful and effective coaching relationship, and eight practitioners specifically mentioned trust as an important component of that foundation. For example, when asked, “What makes coaching work?” Kelly replied, “I think trust is the most important thing.”

It’s a Dance. Twelve of the practitioners mentioned that every family is different and adapting coaching to meet individual needs is an important skill for a practitioner to develop. Stephanie described adjustments made to coaching practices to meet families “where they are” in this way: “So, it’s sort of a dance...it’s so different for different parents and different children.”

Engagement Leads to Empowerment

All practitioners agreed that the goal of caregiver coaching is to empower and equip caregivers to facilitate language growth in their children and the most effective way to do that is to actively engage caregivers in sessions. According to Susan, “It’s all about empowering the parents and helping them believe that they have the skills in order to do this.” However, they all reported that this is challenging at times. Practitioners reported expectations for engagement on a continuum, ranging from observing to taking the lead in all aspects of the session.

It’s a Process. Practitioners reported that some caregivers are hesitant to engage during sessions, preferring to observe rather than participate, and described efforts to increase engagement as a process that can take time. Patrice described using demonstration to help caregivers understand the expectation: “Even the families who aren’t there yet, you’re mostly demonstrating...they’re the ones who won’t take a turn, even in spite of your best efforts...still it’s engaging them and pulling them into seeing their role.”

Handing it Over. One level of engagement that practitioners reported was that of taking a turn following demonstration of a strategy. In this scenario, practitioners lead the session and expect the caregivers to actively participate. Most practitioners described this as an acceptable level of engagement, as it gives caregivers an opportunity to practice skills during the session, during which the practitioners can offer feedback and encouragement. Carrie described her approach in this way: “I will say, ‘Ok, so I will start. So, the cow says moo, and then I wait.’ And then I’ll just take the bag and give it to the parent, ‘your turn.’”

Taking the Lead. Some practitioners expect an even greater level of engagement from caregivers, in which they take the lead and participate in all aspects of the session, including establishing goals for the session and deciding which activity they would like to use to target them. For these practitioners, the primary focus of the session is the caregiver/child interaction, and they see their role as facilitators who observe and provide feedback. One site’s approach to coaching hinges on this premise;

their practitioners generally do not engage with the child directly and use demonstration minimally. When describing this level of engagement, Paula said, “The parents would do the activity with the baby. My goal is to sit there and coach...offering suggestions, making comments about what’s good and what needs work.”

Matching Goals to Caregiver Priorities

Practitioners talked about the value of partnering with caregivers to choose goals that are meaningful to them. Kelly described a time when she struggled to get a caregiver to engage, and once she realized that her goals for sessions did not necessarily match what the caregiver wanted for his child, she elicited his ideas, and his engagement completely changed. She said this helped her realize the importance of listening to caregivers when choosing goals because, “It’s just something that sticks and it has more value to them because they were engaged in making the decision.”

Building on Families’ Routines. Twelve practitioners talked about the importance of teaching LSL strategies in the context of a family’s daily routines to optimize language learning. They achieved this by using routines for their session activities, such as snack time and outdoor play, or teaching strategies using specific toys or activities, making sure to discuss ways caregivers could use the same strategies in the natural context of their everyday lives. Dawn reported that she teaches families that specialized toys or structured activities are not required for implementing LSL strategies, telling them, “If you don’t do anything else, narrate life...talk to them all the time and make them aware of things they hear and see.”

Recognizing Challenges

In addition to the challenges practitioners reported with implementing coaching related to their principles and process, they shared perceived challenges related to caregivers’ active participation in coaching.

Convincing the Caregiver. Twelve practitioners mentioned the perception that a caregiver’s lack of buy-in is a barrier that must be overcome to establish a good coaching relationship. Some practitioners attributed lack of buy-in to the fact that some families expect direct therapy for their child and do not understand or subscribe to the coaching model. They talked about strategies they use to convince the caregiver of the effectiveness of coaching, including clearly explaining the expectations and setting them up for success so they experience the benefits first-hand. Susan reported that most of her caregivers eventually “come around.” She said, “It’s not very natural for some parents...it takes a little while...once they see that the suggestions I’m giving them...helping the speech get better or helping the language get better...then they start believing that my suggestions are good.”

Less-than-ideal Circumstances. Other perceived barriers that practitioners reported were difficult family situations, including low socio-economic status, single parenthood, and having a child with complex needs in addition to

hearing loss. They shared that they were empathetic to families' struggles and understood that not all of them would be able to fully engage in coaching. Brenda shared, "There are families who...never bought in...maybe it's too much work and they are already overwhelmed with other things...their kids are maybe more complex...are not as successful."

Discussion

The results of this study contribute to the literature by explicating the perspective of LSL practitioners using caregiver coaching in their work with families of children who are DHH. It is clear that LSL practitioners value caregiver coaching and believe it is an effective means for impacting child outcomes, and they work to actively engage caregivers during intervention sessions. The findings indicate that the underlying beliefs practitioners hold about caregivers' capability and their own coaching competency impact their coaching practices and how they partner with caregivers in LSL intervention. This study highlights practical actions practitioners can take to facilitate caregiver coaching.

Although the conceptualization and practices of coaching varied between sites, the common thread was active caregiver participation during intervention sessions. This supports previous research that reported EI practitioners' perspectives that active engagement in coaching promotes caregiver competence and leads to empowerment as caregivers realize their crucial role in supporting their child's development (Meadan et al., 2018). In this study, how practitioners engaged caregivers was linked to the practitioners' underlying beliefs in the caregivers' willingness and ability to engage in their child's intervention. This aligns with principles of adult learning, particularly the need for caregivers to practice skills in a meaningful context and receive feedback on their performance (Dunst & Trivette, 2009b). All practitioners maintained that caregivers can and should be involved in the coaching process, although their expectations for the extent of involvement varied. Expectations of caregiver participation ranged from leading the sessions to actively taking a turn following practitioner demonstration. However, some of the practitioners discussed the challenges of engaging caregivers and shared what they felt were valid reasons for lack of participation, indicating an implicit belief that active engagement in caregiver coaching is the exception and some caregivers may be unwilling or unable to participate. This aligns with recent research in which practitioners reported difficulty getting caregivers to engage and step out of their comfort zone in sessions (Douglas et al., 2020). Practitioners in the present study who successfully engaged caregivers reported that they did so by establishing clear expectations and matching goals to caregiver priorities.

The results from this study indicate that practitioners must believe in a caregiver's willingness and ability to engage meaningfully in coaching, as well as have confidence in their own coaching abilities, to establish a consistent and successful coaching relationship. These two fundamental

beliefs are inexplicably linked; as practitioners become convinced of caregivers' capacity, their feelings of self-efficacy increase because they experience coaching as successful. Likewise, as their self-efficacy increases, they are better able to engage with caregivers in ways that facilitate their active engagement in sessions. Research relating to self-efficacy suggests that it is a malleable concept that can be influenced by intensive and specialized professional development and training (Bruder et al., 2013). Our results support this finding, as practitioners reported that underlying beliefs can change, either through successful coaching experiences or professional development specifically targeted at improving caregiver coaching skills.

However, our results suggest that knowledge of coaching alone is not enough to change practitioner behavior. It is evident from the results that pairing knowledge with accountability and a community of practice (CoP) facilitates the implementation of caregiver coaching. A CoP is a group of individuals with shared expertise and a desire to learn together (Li et al., 2009; Wenger, 2010; Wenger & Snyder, 2000) and has been recommended as a means to bridge the research-to-practice gap in a variety of health contexts, including audiology and speech-language pathology (Li et al., 2009; McCurtin & O'Connor, 2020; Moodie et al., 2011). CoPs can be informal or formal in structure, and have been used to provide mentorship, learn and share new knowledge, and foster a sense of belonging between members (Li et al., 2009). This aligns with early childhood intervention professional development research that found several key components of successfully implementing newly learned practices: (a) opportunities to discuss and reflect on practice experiences; (b) coaching, mentoring, and performance feedback during training; and (c) ongoing follow-up by supervisors, mentors, and peers to reinforce learning (Dunst, 2015). All of these can be accomplished through establishing a reflective community of like-minded practitioners who are working to implement coaching practices in their work with families and the accountability that stems from actively learning and growing together.

Several of the practitioners shifted their understanding of coaching, but not enough to change their belief in caregiver capacity. The way that they described their coaching practices and level of confidence did not align with a change in their underlying beliefs. Whether practitioners adopted caregiver coaching due to extrinsic or intrinsic factors or started this work convinced that caregiver coaching works or had to be convinced, their underlying beliefs guided their coaching practices. Our results suggest that although practitioners can decide to change their behavior, fully embracing the fundamental beliefs of caregiver capacity and their own self-efficacy may be what facilitates a lasting change in coaching practices. Therefore, intentionally adding accountability and a reflective CoP into a program may scaffold the shift in underlying beliefs that facilitate caregiver coaching.

Although not designed as a comparative study, a few important differences in how practitioners talked about

caregiver coaching between the three sites were noted. The literature has long reported a lack of operationalized definitions and practices in caregiver coaching (Friedman et al., 2012), and more recent research indicates that this lack of standardization persists in both the EI and LSL literature (Noll et al., 2021; Ward et al., 2020). Similarly, the practitioners in this study differed in their conceptualization of coaching. Practitioners from one site defined coaching narrowly and the practitioners operated from a very specific set of procedures. These practitioners expressed confidence in their approach because they knew exactly what they were expected to do and were held accountable for doing so. Another site defined coaching more broadly and the practitioners described their practices more variably. Both of these sites loosely based their practices on the Rush and Shelden (2005, 2019) framework for caregiver coaching. The final site, however, did not use the same language when talking about their coaching practices, and reported that they coached according to the conventions of AVT, even though they did not all hold LSL AVT® certification. It is likely that differences in training and background tradition at the three sites accounted for some of these differences. Interestingly, the specific conceptualization of coaching seemed to have a lesser impact on practitioner confidence in the implementation of coaching than having a clear understanding of the distinct practices they considered to comprise coaching. This suggests that caregiver coaching may be facilitated by well-defined and clearly articulated coaching practices.

The practitioners at one of the sites were more likely to talk about coaching as conditional and seemed to have less confidence in their ability to engage the caregivers in coaching consistently. Previous research suggests that practitioners sometimes find coaching challenging due to conflicting expectations or family circumstances, such as a perceived lack of motivation, stress, or socioeconomic factors, which they consider barriers that may preclude families from actively engaging in coaching (Douglas et al., 2020; Meadan et al., 2018). In this study, some practitioners talked about coaching with more variability and less certainty than others. Practitioners who used words like “awkward” and “indirect modeling” when talking about their interactions with families indicated ambiguity in what coaching should entail, which likely impacted their ability to implement it with confidence and consistency. The practitioners who talked about coaching this way also detailed a lack of confidence in their ability to coach. The practitioners who articulated clear expectations for coaching practices reported greater confidence in their coaching ability, which aligned with previous research indicating that clearly-defined procedures facilitated practitioners’ confidence in implementing coaching practices (Salisbury et al., 2018). This indicates a need for the development of clear standards of practice and high-quality professional development to address caregiver coaching in LSL practice.

Implications for Practice

It was clear from our results that caregiver coaching was facilitated at sites that had established well-defined

coaching practices. As suggested by previous researchers (King et al., 2021), a need exists for the establishment of a standard of practice for caregiver coaching among programs offering LSL services to families. This presents an opportunity for professional preparation programs to evaluate whether they are developing proficiency specific to caregiver coaching in future LSL practitioners, as well as for the establishment of targeted professional development and mentoring programs to support practitioners working with families. There have been recent efforts by seven national professional organizations, including the American Speech-Language-Hearing Association, to establish cross-disciplinary competencies for EI practitioners, including family-centered practices, although not specific to caregiver coaching (Bruder et al., 2019). Certification bodies specific to LSL practice such as AG Bell Academy may wish to consider establishing standards and embedding targeted training for coaching caregivers in the certification process, as well. According to the practitioners in this study, coaching caregivers requires different skills than teaching children who are DHH. There is a need to define practitioner competencies for effectively teaching adult learners and to develop robust and highly specialized pre-service and in-service professional development programs.

The results of this study suggest that underlying perceptions can impact coaching practice, so the inclusion of intentional reflective practices may facilitate a change in practice. Additionally, establishing a CoP, which facilitates peer-to-peer reflection, problem-solving, and learning, as well as accountability practices that promote caregiver coaching may improve practitioners’ confidence in coaching caregivers. Programs that provide LSL services to families of children who are DHH can incorporate these elements into their practice to foster the development of coaching skills, as well as develop consistency and fidelity of implementation.

Limitations

This study was not without limitations. The Canadian practitioners were interviewed after their sessions shifted to online service delivery due to COVID-19 restrictions. Although most practitioners indicated that tele-intervention was a facilitator for their coaching, it was not without its challenges, and may have impacted their perceptions about the coaching experience. COVID-19 restrictions also limited the number of videos we obtained due to privacy concerns arising from recording intervention sessions conducted on Zoom. The videos we did receive were fairly well distributed across all three sites, added depth to our interviews, and strengthened our analysis of coaching practices. Using video for reflective discussions on a broader scale would be an interesting direction for future research.

Personal connections were used to access the intervention sites and the first author was familiar to some of the practitioners due to shared professional experiences. Although this may have impacted how freely practitioners shared their experiences, intentional procedures were followed to reduce bias and ensure that practitioners

understood the non-evaluative intentions of the inquiry. While shared disciplinary understanding of clinically-relevant issues is a hallmark of Interpretive Description and the researcher's pre-understandings are critical for generating meaningful and practical findings (Thorne, 2016), we took steps to ensure rigor, including careful reflexivity, frequent debriefing, transparency, and maintaining strict confidentiality (McDermid et al., 2014; Shenton, 2004). As a result, we believe the author's disciplinary experience provided deep insight and resulted in practical, applicable findings that provide new understanding of caregiver coaching in LSL practice.

Additionally, although it was valuable to elicit the perspectives of practitioners from three different sites, a larger study would provide more information about coaching practices of LSL practitioners, and comparative case studies would be beneficial to understand the differences among intervention sites. It would also be interesting to examine the perspectives of practitioners following the wide-spread implementation of tele-intervention due to COVID-19 restrictions. Future research could include an examination of differences in training (speech-language pathology versus deaf education), service delivery models, LSL certified versus non-certified, and characteristics of the demographic of caregivers served. Additionally, there is a significant need for studies that measure caregiver and child outcomes as a result of caregiver coaching.

This study provides a unique contribution to the LSL literature by examining caregiver coaching from the perspective of the practitioners who implement it. The results indicate an interplay between practitioners' underlying beliefs and their practices, including how they engage caregivers in intervention. Our results suggest that a practitioner's beliefs, especially about caregiver capacity and self-efficacy, are the key to implementing caregiver coaching with confidence and consistency. If practitioners have a clear understanding of coaching components, build skills through professional development and a supportive CoP, and are held accountable for implementing coaching practices, they are more likely to report positive experiences with coaching caregivers. Ultimately, increasing practitioners' self-efficacy may lead to more fully engaging caregivers in intervention, which is likely to improve LSL services and optimize child outcomes.

References

- Abdul-Razzak, A., You, J., Sherifali, D., Simon, J., & Brazil, K. (2014). 'Conditional candour' and 'knowing me': An interpretive description study on patient preferences for physician behaviours during end-of-life communication: Table 1. *BMJ Open*, 4(10), e005653. <https://doi.org/10.1136/bmjopen-2014-005653>
- AG Bell Academy for Listening and Spoken Language. (2017). *The LSL certification handbook*. <https://agbellacademy.org/certification/forms-fees-and-faqs/>
- Braun, V., & Clarke, V. (2021). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health*, 13(2), 201–216. <https://doi.org/10.1080/2159676X.2019.1704846>
- Bruder, M. B., Catalino, T., Chiarello, L. A., Mitchell, M. C., Deppe, J., Gundler, D., Kemp, P., LeMoine, S., Long, T., Muhlenhaupt, M., Prelock, P., Schefkind, S., Stayton, V., & Ziegler, D. (2019). Finding a common lens: Competencies across professional disciplines providing early childhood intervention. *Infants & Young Children*, 32(4), 280–293. <https://doi.org/10.1097/IYC.000000000000153>
- Bruder, M. B., Dunst, C. J., Wilson, C., & Stayton, V. (2013). Predictors of confidence and competence among early childhood interventionists. *Journal of Early Childhood Teacher Education*, 34(3), 249–267. <https://doi.org/10.1080/10901027.2013.816806>
- Burdine, J. T., Thorne, S., & Sandhu, G. (2020). Interpretive description: A flexible qualitative methodology for medical education research. *Medical Education*, 55(3), 336–343. <https://doi.org/10.1111/medu.14380>
- Campbell, P. H., & Sawyer, L. B. (2007). Supporting learning opportunities in natural settings through participation-based services. *Journal of Early Intervention*, 29(4), 287–305. <https://doi.org/10.1177/105381510702900402>
- Cox, E. (2015). Coaching and adult learning: Theory and practice. *New Directions for Adult and Continuing Education*, 2015(148), 27–38. <https://doi.org/10.1002/ace.20149>
- Cypress, B. S. (2017). Rigor or reliability and validity in qualitative research: Perspectives, strategies, reconceptualization, and recommendations. *Dimensions of Critical Care Nursing*, 36(4), 253–263. <https://doi.org/10.1097/DCC.0000000000000253>
- Division for Early Childhood. (2014). *Recommended practices in early intervention and early childhood special education*. The Division for Early Childhood of the Council for Exceptional Children. www.dec-sped.org/recommendedpractices
- Douglas, S. N., Meadan, H., & Kammes, R. (2020). Early interventionists' caregiver coaching: A mixed methods approach exploring experiences and practices. *Topics in Early Childhood Special Education*, 40(2), 84–96. <https://doi.org/10.1177/0271121419829899>

- Dunst, C. J. (2015). Improving the design and implementation of in-service professional development in early childhood intervention. *Infants & Young Children, 28*(3), 210–219. <https://doi.org/10.1097/IYC.0000000000000042>
- Dunst, C. J., & Trivette, C. M. (2009a). Capacity-building family-systems intervention practices. *Journal of Family Social Work, 12*, 119–143. <https://doi.org/10.1080/10522150802713322>
- Dunst, C. J., & Trivette, C. M. (2009b). Let's be PALS: An evidence-based approach to professional development. *Infants & Young Children, 22*(3), 164–176. <https://doi.org/10.1097/IYC.0b013e3181abe169>
- Dunst, C. J., & Trivette, C. M. (2012). Moderators of the effectiveness of adult learning method practices. *Journal of Social Sciences, 8*(2), 143–148. <https://doi.org/10.3844/jssp.2012.143.148>
- Friedman, M., Woods, J., & Salisbury, C. (2012a). Caregiver coaching strategies for early intervention providers: Moving toward operational definitions. *Infants & Young Children, 25*(1), 62–82. <https://doi.org/10.1097/IYC.0b013e31823d8f12>
- Hamel, C., & Viau-Guay, A. (2019). Using video to support teachers' reflective practice: A literature review. *Cogent Education, 6*(1), 1–14. <https://doi.org/10.1080/2331186X.2019.1673689>
- Heidlage, J. K., Cunningham, J. E., Kaiser, A. P., Trivette, C. M., Barton, E. E., Frey, J. R., & Roberts, M. Y. (2020). The effects of parent-implemented language interventions on child linguistic outcomes: A meta-analysis. *Early Childhood Research Quarterly, 50*, 6–23. <https://doi.org/10.1016/j.ecresq.2018.12.006>
- Holmes, A. G. D. (2020). Researcher positionality—A consideration of its influence and place in qualitative research—A new researcher guide. *Shanlax International Journal of Education, 8*(4), 1–10. <https://doi.org/10.34293/education.v8i4.3232>
- Joint Committee on Infant Hearing. (2019). Year 2019 position statement: Principles and guidelines for early hearing detection and intervention programs. *The Journal of Early Hearing Detection and Intervention, 4*(2), 1–44. <https://doi.org/10.15142/fptk-b748>
- Josvassen, J. L., Percy-Smith, L., Tanning, T. L., Dieleman, E., Sandager, T. P., Hallstrøm, M., & Cayé-Thomasen, P. (2019). Parental perceptions of auditory-verbal therapy: A longitudinal study of Danish children with hearing loss. *The Volta Review, 119*(1), 4–28. <https://eric.ed.gov/?id=EJ1236883>
- Kendrick, A., & Smith, T. (2017). AV practice: Principles, mentoring, and certification process. In *Auditory-verbal practice: Family-centered early intervention* (2nd ed., pp. 20–33). Charles C Thomas.
- King, A., Gilles, D., & Xu, Y. (2021). Investigating caregiver coaching in an early intervention model for children with hearing loss. *Early Child Development and Care, 1*–19. <https://doi.org/10.1080/03004430.2021.1989424>
- Li, L. C., Grimshaw, J. M., Nielsen, C., Judd, M., Coyte, P. C., & Graham, I. D. (2009). Evolution of Wenger's concept of community of practice. *Implementation Science, 4*(1), 11. <https://doi.org/10.1186/1748-5908-4-11>
- McCurtin, A., & O'Connor, A. (2020). Building a collaborative research community of practice and supporting research engagement in speech-language pathology: Identification of stakeholder priorities. *International Journal of Evidence-Based Healthcare, 18*(4), 368–375. <https://doi.org/10.1097/XEB.0000000000000229>
- McDermid, F., Peters, K., Jackson, D., & Daly, J. (2014). Conducting qualitative research in the context of pre-existing peer and collegial relationships. *Nurse Researcher, 21*(5), 28–33. <https://doi.org/10.7748/nr.21.5.28.e1232>
- Meadan, H., Douglas, S. N., Kammes, R., & Schraml-Block, K. (2018). "I'm a different coach with every family": Early interventionists' beliefs and practices. *Infants & Young Children, 31*(3), 200–214. <https://doi.org/10.1097/IYC.0000000000000118>
- Moeller, M. P., Carr, G., Seaver, L., Stredler-Brown, A., & Holzinger, D. (2013). Best practices in family-centered early intervention for children who are deaf or hard of hearing: An international consensus statement. *Journal of Deaf Studies and Deaf Education, 18*(4), 429–445. <https://doi.org/10.1093/deafed/ent034>
- Moodie, S. T., Kothari, A., Bagatto, M. P., Seewald, R., Miller, L. T., & Scollie, S. D. (2011). Knowledge translation in audiology: Promoting the clinical application of best evidence. *Trends in Amplification, 15*(1), 5–22. <https://doi.org/10.1177/1084713811420740>
- Noll, D., DiFabio, D., Moodie, S., Graham, I. D., Potter, B., Grandpierre, V., & Fitzpatrick, E. M. (2021). Coaching caregivers of children who are deaf or hard of hearing: A scoping review. *The Journal of Deaf Studies and Deaf Education, 26*(4), 453–468. <https://doi.org/10.1093/deafed/enab018>
- Noll, D., Moodie, S., Graham, I. D., Potter, B., & Fitzpatrick, E. M. (2022). "It gives me confidence": Caregiver coaching from the perspective of families of children who are deaf or hard of hearing. *Journal*

- of *Early Hearing Detection and Intervention*, 7(1), 24–36.
<https://doi.org/10.26077/ff20-5e9d>
- O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine*, 89(9), 1245–1251.
<https://doi.org/10.1097/ACM.0000000000000388>
- Paskins, Z., Sanders, T., Croft, P. R., & Hassell, A. B. (2017). Exploring the added value of video-stimulated recall in researching the primary care doctor–patient consultation: A process evaluation. *International Journal of Qualitative Methods*, 16(1), 1609406917719623.
<https://doi.org/10.1177/1609406917719623>
- QSR International Pty Ltd. (2020). *NVivo 12* (1.6.2) [Computer software].
<https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>
- Roberts, M. Y. (2019). Parent-implemented communication treatment for infants and toddlers with hearing loss: A randomized pilot trial. *Journal of Speech, Language & Hearing Research*, 62(1), 143–152.
https://doi.org/10.1044/2018_JSLHR-L-18-0079
- Roberts, M. Y., & Kaiser, A. P. (2011). The effectiveness of parent-implemented language interventions: A meta-analysis. *American Journal of Speech-Language Pathology*, 20.
[https://doi.org/10.1044/1058-0360\(2011/10-0055\)](https://doi.org/10.1044/1058-0360(2011/10-0055))
- Rush, D. D., & Shelden, M. (2019). *The early childhood coaching handbook* (2nd ed.). Brookes Publishing.
- Rush, D. D., & Shelden, M. L. (2005). Evidence-based definition of coaching practices. *CASEinPoint*, 1(6), 1–6.
- Salisbury, C. L., & Cushing, L. S. (2013). Comparison of triadic and provider-led intervention practices in early intervention home visits. *Infants & Young Children*, 26(1), 28–41.
<https://doi.org/10.1097/IYC.0b013e3182736fc0>
- Salisbury, C., Woods, J., Snyder, P., Modellmog, K., Mawdsley, H., Romano, M., & Windsor, K. (2018). Caregiver and provider experiences with coaching and embedded intervention. *Topics in Early Childhood Special Education*, 38(1), 17–29.
<https://doi.org/10.1177/0271121417708036>
- Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22(2), 63–75.
<https://doi.org/10.3233/EFI-2004-22201>
- Sone, B. J., Lee, J., & Roberts, M. Y. (2021). Comparing instructional approaches in caregiver-implemented intervention: An interdisciplinary systematic review and meta-analysis. *Journal of Early Intervention*, 43(4), 339–360.
<https://doi.org/10.1177/1053815121989807>
- Stewart, V., Slattery, M., & McKee, J. (2020). Deaf and hard of hearing early intervention: Perceptions of family-centered practice. *Journal of Early Intervention*, 43(3), 1–14.
<https://doi.org/10.1177/1053815120962547>
- Teodoro, I. P. P., Rebouças, V. de C. F., Thorne, S. E., Souza, N. K. M. de, Brito, L. S. A. de, & Alencar, A. M. P. G. (2018). Interpretive description: A viable methodological approach for nursing research. *Escola Anna Nery*, 22(3).
<https://doi.org/10.1590/2177-9465-ean-2017-0287>
- Thorne, S. (2016). *Interpretive description: Qualitative research for applied practice* (2nd ed.). Routledge.
- Thorne, S., Kirkham, S. R., & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health*, 20(2), 169–177.
[https://doi.org/10.1002/\(SICI\)1098-240X\(199704\)20:2<169::AID-NUR9>3.0.CO;2-I](https://doi.org/10.1002/(SICI)1098-240X(199704)20:2<169::AID-NUR9>3.0.CO;2-I)
- Thorne, S., Kirkham, S. R., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, 3(1), 1–11.
<https://doi.org/10.1177/160940690400300101>
- Trivette, C. M., Dunst, C. J., Hamby, D. W., & O'Herin, C. E. (2009). Characteristics and consequences of adult learning methods and strategies. *Practical Evaluation Reports*, 2(1), 32.
- Ward, R., Reynolds, J. E., Pieterse, B., Elliott, C., Boyd, R., & Miller, L. (2020). Utilisation of coaching practices in early interventions in children at risk of developmental disability/delay: A systematic review. *Disability and Rehabilitation*, 42(20), 2846–2867.
<https://doi.org/10.1080/09638288.2019.1581846>
- Wenger, E. (2010). Communities of practice and social learning systems: The career of a concept. In C. Blackmore (Ed.), *Social Learning Systems and Communities of Practice* (pp. 179–198). Springer.
https://doi.org/10.1007/978-1-84996-133-2_11
- Wenger, E. C., & Snyder, W. M. (2000). Communities of practice: The organizational frontier by Wenger. *Harvard Business Review*, 78(1), 139–145.
- Woods, J., Wilcox, M. J., Friedman, M., & Murch, T. (2011). Collaborative consultation in natural environments: Strategies to enhance family-centered supports and services. *Language, Speech & Hearing Services in Schools*, 42(3), 379–392.
[https://doi.org/10.1044/0161-1461\(2011/10-0016\)](https://doi.org/10.1044/0161-1461(2011/10-0016))
- Yang, B. (2003). Toward a holistic theory of knowledge and adult learning. *Human Resource Development Review*, 2(2), 106–129.
<https://doi.org/10.1177/1534484303002002002>

Appendix A

Practitioner Interview Guide

Study ID _____

Date _____

Purpose: The purpose of this interview is to learn more about your experiences implementing AV/LSL services for families of children with hearing loss. Specifically, I am interested in learning about how you ‘coach’ or teach caregivers to implement intervention strategies themselves, throughout their daily routines, in between intervention sessions. I am also interested in learning about how you learned to coach caregivers.

Procedure: Before we begin, I’ll ask you to fill out a short information sheet about your work. Next, I will ask you some questions to guide our conversation, but please feel free to talk openly about your experiences and add anything that you think is important. Please don’t hesitate to ask questions.

Interview information:

Location of interview: Clinic School Other: _____

Informant’s professional background: SLP TOD Other: _____

LSLS certified: Yes No Working toward certification

Interview questions:

1. How long have you been in this field? How long have you been working with the birth–3 population specifically?
Prompt: Who participates in sessions, generally?
Prompt: Where do you normally have sessions?
Prompt: What kinds of activities do you do during sessions?
Prompt: Can you tell me a little about the structure and sequence of your sessions?
3. Can you describe an *ideal* session?
Prompt: Where would it be located? Who would participate?
4. What do you like about working with this age group? What do you find challenging?
5. I’m specifically interested in learning more about coaching in AV/LSL services. How would you define *coaching*?
Prompt: What does this look like in a typical session?
Prompt: In your opinion, what are key characteristics of coaching in an intervention session?
6. How did you learn about caregiver coaching?
Prompt: Did you learn about coaching during your graduate training? Through professional development trainings at your workplace or conferences?
Prompt: Please tell me more about how you learned to coach.
7. Do you use a particular model of coaching in your work?
Prompt: Did you learn about coaching models in your training? If so, which ones?
8. How do you incorporate reflection in your practice?
Prompt: What role did reflection play in your training?
Prompt: Did someone teach you how to reflect? What did that look like?
Prompt: Do you incorporate reflection in your sessions with parents? What does that look like?
9. When you began working with the birth–3 population, how confident were you in working with caregivers?
Prompt: How has your confidence changed with experience?
Prompt: What did you do to increase your confidence?
Prompt: How confident are you now?

10. Has your practice changed over time? If so, in what ways?

Prompt: Has your philosophy changed at all since you started practicing? If so, in what ways?

11. What do you think the caregivers' role should be in the early intervention or therapy process? How would you describe your role?

Prompt: How are targets for sessions determined?

Prompt: How are the overarching long-term goals determined, such as IFSP goals?

Prompt: What kinds of strategies do you use to establish roles or encourage caregivers to take on the role you feel is important in the intervention process?

12. How do you encourage caregivers to be actively involved in sessions? In the early intervention or therapy process in general?

Prompt: How do you elicit participation during an activity?

Prompt: What do you do if a caregiver is not actively involved?

13. What is your opinion about coaching caregivers as an intervention strategy?

Prompt: What do you think are the benefits of coaching? What are the challenges?

14. What would you say is the most important thing for a good coaching relationship? What is most important for effective services overall?

15. Is there anything you'd like to discuss about coaching caregivers that we haven't covered?

Appendix B

Practitioner Video Observation Guide

Study ID _____

Date _____

Purpose: The purpose of this observation is to provide you with an opportunity to explain your thoughts and decision-making process within a coaching interaction. My purpose is not to evaluate your coaching, but to better understand your thought process during a coaching exchange with a caregiver. In addition to the information you provided during our interview, this will add to my understanding of your coaching practices in intervention sessions with caregivers. I am also interested in how you reflect on your practices as we watch the video together.

Procedure: We are going to watch a 10-minute clip of an intervention session that you provided to me. I will stop the video at certain points to ask questions, and please feel free to ask me to stop it when you'd like to comment or explain something. I am specifically interested in talking about how you are coaching or teaching the caregiver in the interaction. Again, I will ask you some questions to guide our conversation, but please feel free to add anything that you think is important and don't hesitate to ask questions.

Session information:

Location: Home Clinic Other: _____

Caregiver(s): Mother Father Both Other: _____

Age of child: _____ Length of time working with the family: _____

Video observation questions:

Before

1. Have you ever watched your sessions on video before? If so, for what purpose (performance evaluation with your supervisor, personal reflection, peer reflection, certification purposes, etc.)?

Prompt: Have you found this useful in your work?

2. Is there anything you would like to tell me about this family or interaction before we begin?

During

Throughout the observation, the following prompts may be used, where appropriate:

- Can you explain to me what was happening there?
- I noticed that you paused there. What were you thinking?
- What prompted you to make that decision?
- What just happened there?
- How did that compare with what you were aiming for?

After

1. What are your general thoughts about this coaching interaction?

Prompt: What do you think went well? What do you think could have been better or different?

Prompt: How effective do you think this interaction was in achieving the goals for the session?

2. Do you think this is a good example of a coaching interaction? Why or why not?
3. How is this coaching exchange similar or different from your typical sessions with this family? What about with other families?

Prompt: Do you use similar or different coaching strategies with each family?

Prompt: How do you decide which strategies to use with each family?

4. Is there anything else you would like to share about this coaching interaction? Or about the video observation process in general?

An Assessment of 51 United States Early Hearing Detection and Intervention Websites: Is Needed Information Being Provided for Parent Decision Making?

Nichole Westin, MA¹

Donna Sorkin, MA¹

¹American Cochlear Implant Alliance, McLean, VA

Abstract

Growth of the Internet as an information resource has provided expanded opportunities for families to easily gather information on a range of topics, including those related to health. State Early Hearing Detection and Intervention (EHDI) websites and other electronic data sources are an important opportunity to support families seeking information on options for their children who have been identified as deaf or hard of hearing. A review was undertaken between August and September 2021 of the 51 United States EHDI (states and Washington DC) websites and related information (such as links to others' sites) to determine if information that is specifically discussed in the federal legislation is provided in a manner that is comprehensive, somewhat helpful, or inadequate.

Keywords: childhood hearing loss, early intervention, parent information

Acronyms: ASL = American Sign Language; EHDI = Early Hearing Detection and Intervention; LSL = Listening and Spoken Language; NCHAM = National Center for Hearing Assessment and Management; NOFO = Notice of Funding Opportunity

Correspondence concerning this article should be addressed to: Nichole Westin, MA, P.O. Box 103, McLean, VA 22101. Email: nwestin@acialliance.org

It is common practice that people will use the Internet to search for information on a range of topics including those of a medical concern. In 2001, the Pew Research Center reported that 72% of mothers sought medical information on the Web during the time frame March–May 2001 (Allend & Raine, 2002). Although Internet use is slightly lower among certain groups (lower socio-economic and education), it is still above 75% across race, income, and education. Among parents who actively use the Internet, 61% had made use of governmental websites (Allend & Raine, 2002). The most popular way of searching for information is a generic search engine (87%). Parents of children who are deaf and hard of hearing visit websites specializing in hearing loss (44%) or those recommended by other parents of deaf children (31%). In 2019, 94% of respondents to a survey on Internet use indicated that they used Facebook for health information (Houston, 2021).

A 2005 study published in *JAMA Otolaryngology* found that 48% of parents with Internet access searched for information regarding their child's diagnosis and surgical procedure (Boston et al., 2005). Further, 93% noted that they found information that was understandable and helpful (Boston et al., 2005). The study also found that 84% of parents using the Internet indicated that the information influenced or somewhat influenced the medical decisions they made on behalf of their child (Boston et

al., 2005). The findings of the JAMA study confirmed that parents visit websites that specialize in hearing loss (44%) or those recommended by other parents of deaf children (31%; Porter & Edirippulige, 2007).

Studies of general medical information on the Web is often incorrect, incomplete, or biased (Kothari & Moolani, 2015). The COVID-19 pandemic highlighted this with the influx of mass sharing of information on social media and the Internet. Reliable and balanced medical information on pediatric hearing loss on the Internet is a needed resource and can help reduce stress for families. Reducing overall stress in these families may result in better outcomes for deaf and hard of hearing children (Hintermair, 2006).

An international study of universal screening programs found that approximately half of parents with newly diagnosed deaf or hard of hearing children reported “a perceived lack of information provision” and “parents expressed a desire for more information than they have received” (Gilliver et al., 2013, p. 7). Many parents reported that a single booklet was provided for them by the audiologist, forcing them to seek out additional early intervention and communication options for their child through the Internet (Gilliver et al., 2013). Seeking comprehensive information is a consistent theme with parents noting they began searching the Internet soon after they received their child's diagnosis (Fitzpatrick,

Angus, et al., 2008; Haddad et al., 2019; Jackson, 2011; Yucel et al., 2008). People of all ages and across the socio-economic spectrum use the Internet to seek medical information as a first resort (Finney Rutten et al., 2019).

Early Hearing Detection and Intervention (EHDI) refers to the federal program that provides funding to states to carry out programs to screen infants for hearing loss soon after birth and further provides programmatic support for state early intervention services. EHDI was established by federal law in 2000 and the last reauthorization was in 2017. Before initiation of EHDI programs, the average age for identification of hearing loss in young children was 2 to 3 years of age. This delay meant that many children missed the critical period when language acquisition has already begun for most children (Centers for Disease Control and Prevention, 2003). State EHDI websites are an important opportunity for families seeking information on options for their children who have been identified as deaf or hard of hearing. Although audiologists rely on both verbal communication and visual aids to relay information on hearing loss to parents, early intervention systems remain the top referral by medical professionals (Davis et al., 2021). In a 2021 survey, parents and audiologists both stated that early intervention services were the top state resource provided by audiologists (55%) and to parents (52%) after the initial hearing screen (Davis et al., 2021). This article aims to provide guidance to states on the importance of the State EHDI websites on parent information, examples of states that have done a good job, and providing guidance for improvement. The National Center for Hearing Assessment and Management (NCHAM) emphasizes the importance of these websites, providing a resource guide on developing websites and hosting a “Website of the Year” award (NCHAM, April 2021).

Method

Our goal was to evaluate the accuracy and completeness of information provided on EHDI websites and how such information addressed the *need to know* data noted in federal guidance. The authors conducted a review of 51 websites (50 states and Washington DC) to assess whether components laid out in various federal laws and regulations were provided clearly, comprehensively, and in a balanced manner on four topics: (a) hearing loss information, (b) technology, (c) communication options, and (d) resources for family support. Table 1 gives a brief synopsis of each state’s website. The sources the authors drew from include the 2017 EHDI Reauthorization Bill, the 2019 Joint Committee on Infant Hearing (JCIH) 2019 Position Statement, and the FY2020 EHDI Notice of Funding Opportunity (NOFO). The website review was done between August and September 2021. We note that changes may have been made to these sites since the review. The website information was derived from NCHAM resources (NCHAM, October 2021).

The four topics were reviewed and rated as being comprehensive, somewhat helpful, or inadequate and our methodology can be found in the Appendix. Rating determination explored if the information was thorough, covered the range of options available (relative to

technology and communications options), answered questions that parents might have, and met the criteria laid out by the the sources listed above. The 2017 EHDI Reauthorization specifies that EHDI programs should be “specifically designed to meet the unique language and communication needs of deaf and hard-of-hearing children” (Early Hearing Detection and Intervention Act of 2017, p. 2). It goes on to say that programs should provide families information that is accurate, comprehensive, up-to-date, and evidence-based including the full range of assistive hearing technologies and communications modalities, as appropriate (EHDI 2017).

With respect to website development, the FY2020 EHDI NOFO states:

Develop, maintain, and promote a website or webpage for the state/territory that is user friendly with accessible, culturally appropriate information for families and professionals that is accurate, comprehensive, up-to-date, and evidence-based, as appropriate to allow families to make important decisions for their children in a timely manner, including decisions with respect to the full range of assistive hearing technologies and communication modalities, as appropriate. (Health Resources and Service Administration, 2019)

The NOFO also specifies that future planning should include plans for maintenance of the website. The review of information provided on amplification technology and language supports the Joint Committee on Infant Hearing 2019 Position Statement which recommended EHDI programs fully inform families on communication options and assistive technology (JCIH, 2019).

Results

Of the 51 sites examined (50 states and Washington DC), 26% were rated as *comprehensive*, 35% as *somewhat helpful*, and 39% as *inadequate* (which included four state websites—Alaska, Colorado, Florida, and Montana—that were not operational at the time of the review). Websites rated as comprehensive included thorough content on all of the information items mentioned in the NOFO. Somewhat helpful sites were lacking in one or more of the key topics evaluated or provided basic introductory content. Sites that were rated as inadequate included limited or none of the information that is noted in the EHDI legislation or the NOFO. A summary of the review by each rating criteria follows.

Information on Hearing Loss

Of the criteria reviewed, website information on hearing loss was somewhat helpful (37%) or comprehensive (39%) with 16% of websites judged as inadequate (see Figure 1). Most EHDI websites provided information on hearing loss basics and/or details on the EHDI hearing screening 1-3-6 guidelines recommended in the NCHAM Web Resource guide (NCHAM, December 2021). The websites rated comprehensive included information on hearing loss such as unilateral or bilateral, range of loss (mild, moderate, severe, profound) and what can cause progressive hearing

Table 1
Information on Hearing Loss

State	Information on Hearing Loss		Communication Options		Information on Technology		Resources	
Alabama	Basic information	Somewhat Helpful	Only American Sign Language (ASL) is discussed	Inadequate	None	Inadequate	List of links outdated. Does include Hands & Voices (H&V)	Somewhat Helpful
Alaska	Website down							
Arizona	Basic information	Somewhat Helpful	None	Inadequate	None	Inadequate	Basic but outdated	Somewhat Helpful
Arkansas	Included on the linked parent resource	Comprehensive	Detailed info in the parent resource	Comprehensive	Detailed info in the parent resource	Comprehensive	Limited website links, relies on parent resource pdf	Somewhat Helpful
California	Basic information	Somewhat Helpful	All are mentioned. Text states that Listening & Spoken Language (LSL) is harder, not successful.	Inadequate	Outdated/ incorrect info	Inadequate	Lacks diversity; link on Cochlear Implants (CI) is wrong	Inadequate
Colorado	Under construction							
Connecticut	Comprehensive info on hearing loss plus cytomegalovirus (CMV)	Comprehensive	Limited info but emphasizes importance of unbiased info	Somewhat Helpful	None	Inadequate	Comprehensive links, includes CMV	Comprehensive
Delaware	Limited information	Inadequate	None	Inadequate	None	Inadequate	Resources are limited to governmental agencies (i.e., child support, social services)	Inadequate
D.C.	Basic information	Inadequate	None	Inadequate	None	Inadequate	None	Inadequate
Florida	Link not working							
Georgia	Comprehensive information	Comprehensive	Comprehensive listing of communication options with guidance on choosing options for your family	Comprehensive	Detailed lists on variety of technology	Comprehensive	Comprehensive list including schools that focus on American Sign Language (ASL) and Listening and Spoken Language (LSL)	Comprehensive

Table 1 (cont.)*Information on Hearing Loss*

State	Information on Hearing Loss		Communication Options		Information on Technology		Resources	
Hawaii	Included brochure is comprehensive though little on website	Somewhat Helpful	Limited information. Notes importance of access to sound for development of spoken language, but no info on ASL or Cued Speech	Inadequate	None	Inadequate	Resources listed in brochures but not on website	Somewhat helpful
Idaho	Basic information	Somewhat Helpful	Comprehensive info listed in the resources section but webpage difficult to locate	Somewhat Helpful	Lists info on financial aid for hearing aids	Somewhat Helpful	Basic information but webpage difficult to find	Somewhat Helpful
Illinois	Comprehensive information on hearing loss	Comprehensive	Limited; states info should be unbiased	Somewhat Helpful	Comprehensive information	Comprehensive	Basic information	Somewhat Helpful
Indiana	Links to sources in brochures but nothing on website	Somewhat Helpful	None	Inadequate	None	Inadequate	Basic resources but difficult to locate on website	Somewhat Helpful
Iowa	Comprehensive and recently updated in 2021	Comprehensive	Discusses multiple options; explains based on hearing loss/ family choice.	Comprehensive	Comprehensive information	Comprehensive	Comprehensive links include medical research, companies, organizations, etc.	Comprehensive
Kansas	Limited information	Inadequate	None	Inadequate	None	Inadequate	Limited resources	Inadequate
Kentucky	Basic information	Somewhat Helpful	None	Inadequate	None	Inadequate	Limited resources	Inadequate
Louisiana	Comprehensive information of why/how/what	Comprehensive	Thorough discussion of all options	Comprehensive	None	Inadequate	Comprehensive list of resources	Comprehensive
Maine	Limited information	Inadequate	None	Inadequate	Limited resources	Inadequate	Limited resources	Inadequate
Maryland	Limited information	Somewhat Helpful	Limited information	Somewhat Helpful	None	Inadequate	Limited resources	Inadequate

Table 1 (cont.)*Information on Hearing Loss*

State	Information on Hearing Loss		Communication Options		Information on Technology		Resources	
Massachusetts	Limited, difficult to locate information on website	Inadequate	Basic information but difficult to locate on website	Somewhat Helpful	None	Inadequate	Comprehensive resources on the various education services available. Could be improved by including info on programs/other organizations	Somewhat Helpful
Michigan	Basic information	Inadequate	Mentions info provided to parents should be unbiased and refers to Hands & Voices (H&V)	Somewhat Helpful	None	Inadequate	Needs additional links in addition to H&V	Inadequate
Minnesota	Roadmap brochure is comprehensive, but nothing on website	Comprehensive	Comprehensive resources communication choices for parents	Somewhat Helpful	Multiple options on hearing aids. Little on other tech options	Somewhat Helpful	Comprehensive list of state, local, and national government and private organizations	Comprehensive
Mississippi	Comprehensive information throughout on the process, next steps	Comprehensive	Comprehensive list of education options for all options	Comprehensive	None	Inadequate	Comprehensive list of resources	Comprehensive
Missouri	Comprehensive information	Comprehensive	Comprehensive information that mentions should be unbiased	Comprehensive	None	Inadequate	Basic list of resources	Somewhat Helpful
Montana	Link not working							
Nebraska	Basic information	Somewhat Helpful	Mentions variety of options	Comprehensive	Limited information	Inadequate	Resources are mainly federal options, ASL focused	Inadequate
Nevada	Basic information on website	Somewhat Helpful	None	Inadequate	None	Inadequate	Basic list of resources	Somewhat Helpful
New Hampshire	Basic information in brochures	Somewhat Helpful	None	Inadequate	None	Inadequate	None	Inadequate

Table 1 (cont.)*Information on Hearing Loss*

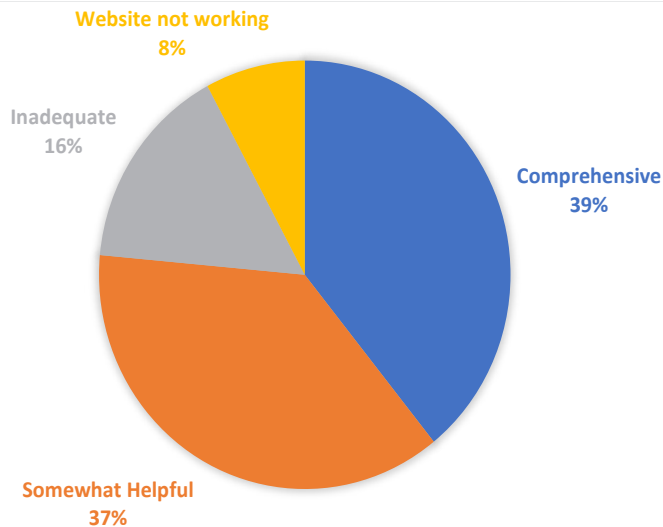
State	Information on Hearing Loss		Communication Options		Information on Technology		Resources	
New Jersey	Basic Information	Comprehensive	Helpful video on what it is like to be deaf/hard of hearing with demonstration of communication options	Comprehensive	Video mentions all types of tech	Comprehensive	Comprehensive resources	Comprehensive
New Mexico	Comprehensive info	Comprehensive	Basic information	Somewhat Helpful	Mentions importance of properly fitted technology	Comprehensive	Comprehensive list of resources	Comprehensive
New York	Limited, outdated information	Inadequate	None	Inadequate	None	Inadequate	Limited and outdated	Inadequate
North Carolina	Basic information	Somewhat Helpful	Mentioned in the links	Comprehensive	Comprehensive info on obtaining hearing aids	Comprehensive	Comprehensive, well organized resources	Comprehensive
North Dakota	Comprehensive information, thorough video introduction	Comprehensive	None	Inadequate	None	Inadequate	Basic list of resources	Somewhat Helpful
Ohio	Comprehensive information	Comprehensive	Mentions all options on parent guide, but guide is hard to locate on website	Somewhat Helpful	Limited info	Somewhat Helpful	Comprehensive info but hard to locate under links to multiple EHDI conference agendas	Inadequate
Oklahoma	Comprehensive information	Comprehensive	None	Inadequate	None	Inadequate	Limited and outdated	Somewhat Helpful
Oregon	Basic information	Somewhat helpful	Limited information	Inadequate	None	Inadequate	Basic links but is missing sites for ASL	Somewhat Helpful
Pennsylvania	Basic information	Somewhat Helpful	None	Inadequate	None	Inadequate	Basic information but difficult to find	Somewhat Helpful
Rhode Island	Basic information	Somewhat Helpful	Limited information but links focused on ASL only	Inadequate	None	Inadequate	Limited links; mainly to ASL focused organizations	Inadequate
South Carolina	Comprehensive information	Comprehensive	None	Inadequate	None	Inadequate	Comprehensive links for both state and national organizations	Comprehensive

Table 1 (cont.)*Information on Hearing Loss*

State	Information on Hearing Loss		Communication Options		Information on Technology		Resources	
South Dakota	Comprehensive information, thorough introduction videos	Comprehensive	Importance of language and communication is mentioned but no details on options	Somewhat Helpful	Tech is shown in introduction videos but no discussion of what they are	Somewhat Helpful	Comprehensive links to state and national organizations	Comprehensive
Tennessee	Basic information	Somewhat Helpful	Parent flyer includes all communication options	Comprehensive	None	Inadequate	Basic list of resources	Comprehensive
Texas	Under FAQs, basic information	Somewhat Helpful	Links to information on options	Somewhat Helpful	None	Inadequate	Related sites page includes comprehensive info	Comprehensive
Utah	Comprehensive information	Comprehensive	No information on website. Included in links	Somewhat Helpful	Comprehensive information including FM systems	Comprehensive	Comprehensive list of resources	Comprehensive
Vermont	Basic information. Website is being updated	Somewhat Helpful	None	Inadequate	None	Inadequate	Comprehensive list of resources	Comprehensive
Virginia	Comprehensive information, links to virtual meet-ups	Comprehensive	Multiple mentions on all communication options	Comprehensive	Thorough parent videos on technology	Comprehensive	Comprehensive list of resources	Comprehensive
Washington	Comprehensive information	Comprehensive	Comprehensive information	Comprehensive	Importance of technology is discussed	Comprehensive	Comprehensive list of resources	Comprehensive
West Virginia	Limited information	Inadequate	None	Inadequate	None	Inadequate	None	Inadequate
Wisconsin	Basic, out of date information	Somewhat Helpful	None	Inadequate	Basic information on hearing aids	Somewhat Helpful	Basic list of resources	Comprehensive
Wyoming	Thorough videos that include information on hearing loss	Comprehensive	Links to LSL and ASL tools	Comprehensive	None	Inadequate	Comprehensive list of resources	Comprehensive

Note. Rating scale is *Comprehensive*, *Somewhat Helpful*, and *Inadequate*. Table also includes website details that resulted in each rating.

Figure 1
Information on Hearing Loss



loss (e.g., a diagnosis of congenital Cytomegalovirus [cCMV]). These elements form a comprehensive picture for parents of recently diagnosed children and are an improvement over the type of information previously provided to parents; in the past most information discussed bilateral hearing loss present at birth (Porter et al., 2018).

Three state websites included thorough introductory videos from culturally diverse families on living with hearing loss and the importance of early intervention. These videos also highlighted different technologies and forms of communication as well as benefits of participating in early intervention programs.

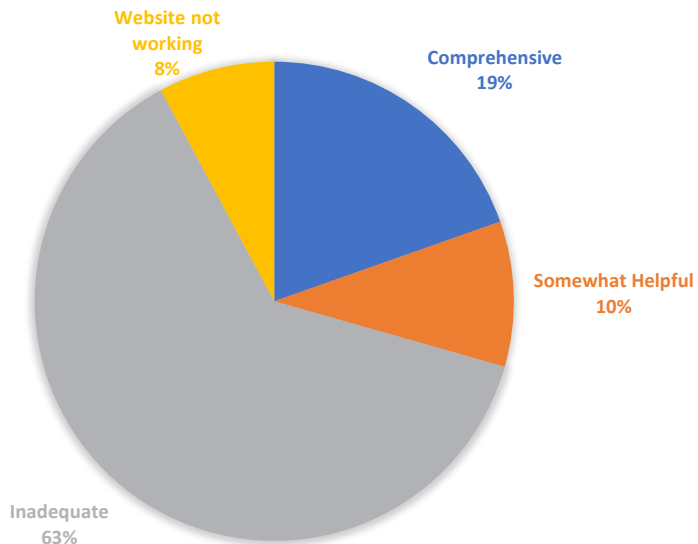
Information on Technology

Ten websites mentioned technology and were rated as comprehensive. The majority of state EHDI websites were found to be inadequate or somewhat helpful in this area; this topic was the most variable of the four examined (see Figure 2). Those rated comprehensive mentioned the importance of properly fitted technology and/or listed the options of hearing aids and cochlear implants. There was a single inclusion of the importance of an FM system. Most websites rated as comprehensive included links to information on hearing aid loan programs and financing. One site mentioned technology options but provided commentary and links that suggested that hearing technology was not effective, reflecting an unfortunate bias against technology.

Communication Options

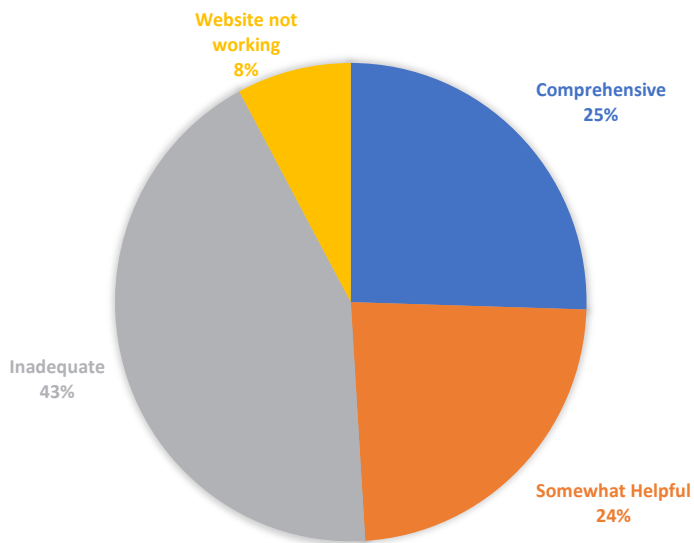
Information provided by EHDI websites on this topic was wide ranging. The most common communication options in the United States are American Sign Language (ASL), Listening and Spoken Language (LSL), total communication, and Cued Speech (White, 2018). In 2018, LSL was used by 49% of deaf or hard of hearing children, 17% used a combination of speech and ASL, and 6% used ASL only (White, 2018). EHDI website content

Figure 2
Information on Technology



on communication options ranged from containing no information to stating that any information on these options should be unbiased (see Figure 3). The more thorough sites discussed all available options.

Figure 3
Communication Options

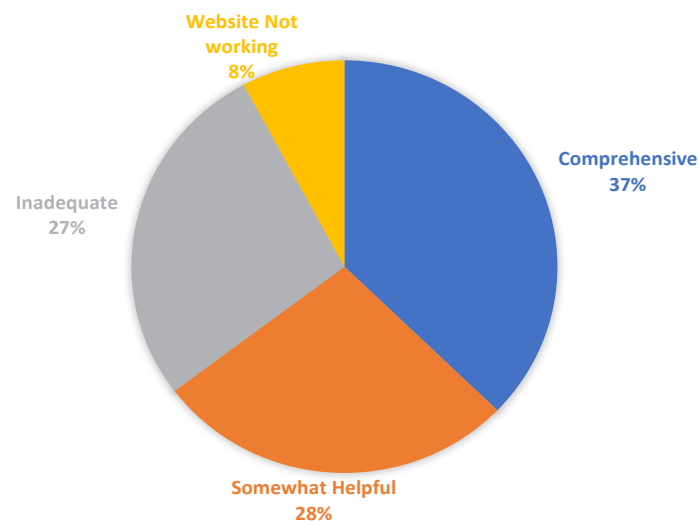


The review found that discussion of communication options (if provided) was most often in links provided to parent resource guides. Some parent resource guides provided detailed information about each communication option while others only provided a list. The reviews of the guides were rated as comprehensive if they were balanced in discussing each option. Three websites were overtly biased toward one option over another, but in those cases the bias was reflected in the provision of resources for one option without mention of the others.

Resources

When reviewing resources, the examination evaluated whether the websites included information from state and federal sources such as the U.S. Department of Education, the Centers for Disease Control, and the National Institutes of Health. Also considered were resources from nonprofit organizations such as Hands & Voices, Alexander Graham Bell Association, and local community organizations; schools for deaf or hard of hearing children; information on locating medical support teams; and other resources that support a family's journey. Ease of locating such information and if the information was current was another consideration. Four sites provided comprehensive resources though the information was difficult to locate on the webpage resulting in a downgrade to a *somewhat helpful* rating; 28% of the sites were rated *somewhat helpful* in this category. Webpages that included a link to a thorough parent resource handout that contained the information above were rated more highly in this evaluation, especially if the resource was easy to locate. Thirty-seven percent of the sites provided comprehensive, easy to find information with 27% rated as *inadequate* (see Figure 4).

Figure 3
Resources



Conclusions

Improving the information families receive on hearing loss and early intervention is the goal of EHDI programs, professionals, and parents. This review of the state websites from August and September 2021 highlights the need for more attention and resources to be dedicated to maintaining a valuable resource for parents of newly diagnosed children to help them find medically supported, unbiased information on hearing loss and next steps. The *2013 Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing* includes these concepts in the key principles and states that EHDI programs are often already enacting them in practice and in person (Moeller et al., 2013).

Although this review did not include readability as a criteria, others have shown that almost all sites dedicated to hearing intervention services are written above the recommended 6th grade reading level (Woodruff & Cienkowski, 2021). Anecdotally, parents have expressed frustration with websites using confusing terminology. Also not considered was the role of social media in sharing information despite the increasing reliance on Facebook, Instagram, and others for gathering information (Houston, 2021). Others have addressed the importance of providing information in a parent's native language (Munoz et al., 2016). Looking ahead, consideration should be given to ensuring information is readable, understandable, and accessible across multiple platforms.

Parents need timely information to make informed decisions regarding the early needs of their children with hearing loss and the Internet is increasingly a key source for health information. Accurate, easily available information was considered very helpful by families during the COVID-19 pandemic when access to services were limited or delayed (Yoshinaga-Itano, 2020). Although some states have used their EHDI website to effectively provide comprehensive information to parents, our review indicates that the majority of EHDI sites are not providing the information specified in the 2017 EHDI Reauthorization, the JCIH Position Statement (2019), and the 2019 NOFO. Interviews with EHDI personnel indicated that the difficulties that they had were part of a larger issue with state government website restrictions. We found that it is sometimes difficult to locate state EHDI websites on the Internet. Health Resources Services Administration (HRSA) could consider providing technical expertise to support state EHDI staff in knowing how best to make their web resources widely accessible upon Internet search given the importance of such sources for health information.

Few patterns emerged when reviewing the websites. Overall, the quality of information on hearing technology was rated as inadequate more often than other categories while resources was typically rated highly. However, there was no discernible pattern along political or geographical location. All geographic areas of the country had sites that were rated highly as well as sites that were rated poorly.

Noted are the difficulties in working with state governments in prioritizing resources for website updates—whether for staffing or financial reasons. We suggest that the HRSA, which administers the EHDI Program, be provided with additional funds to support state EHDI programs to help them improve web-based resources, especially in light of the NOFO requirements and other competing demands. Other suggestions for HRSA include the addition of support for EHDI web-based information such as developing and providing content on common topics (e.g., hearing technology and communication options), and staff support at the national level to provide guidance on website improvement and optimization. For those sites rated as somewhat helpful

or inadequate, such support may help programs make incremental improvements that support parents and guardians with needed information for decision-making. The comprehensive sites may serve as a guide for change as well as a tool to be used in advocacy for website improvements moving forward.

References

- Allend, K., & Raine, L. (2002, November 7). *Parents online*. Pew Research Center. <https://www.pewresearch.org/internet/2002/11/17/parents-online/>
- Boston, M., Ruwe, E., Duggins, A., & Willging, J. P. (2005). Internet use by parents of children undergoing outpatient otolaryngology procedures. *JAMA Otolaryngology*, *131*(8), 719–722. <https://jamanetwork.com/journals/jamaotolaryngology/fullarticle/649382>
- Davis, B., Knowd, E., & Jones, A. (2021). Hearing loss diagnosis provision of information and support: Audiologist and parent perspectives. *Journal of Early Hearing Detection and Intervention*, *6*(2), 45–61.
- Centers for Disease Control and Prevention. (2003). *Morbidity and mortality weekly report. Infants tested for hearing loss—United States, 1999–2001*. <https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5241a1.htm>
- Early Hearing Detection and Intervention Act of 2017, Pub. L No. 115–171, 131 Stat. 1218, 1219, 1220, 1221, 1222 and 1223, codified as amended at title 42 U.S.C. §§ 280g and 280g-1.
- Fitzpatrick, E., Angus, D., Durieux-Smith, A., Graham, I. D., & Coyle, D. (2008). Parents' needs following identification of childhood hearing loss. *American Journal of Audiology*, *17*, 38–49.
- Fitzpatrick, E., Grandpierre, V., Durieux-Smith, A., Gaboury, I., Coyle, D., Na, E., & Sallam, N. (2015). Children with mild bilateral and unilateral hearing loss: Parents' reflections on experiences and outcomes. *Journal of Deaf Studies and Deaf Education*, *21*(1), 34–43.
- Gilliver, M., Ching, T. Y., & Sjahalam-King, J. (2013). When expectation meets experience: Parents' recollections of and experiences with a child diagnosed with hearing loss soon after birth. *International Journal of Audiology*, *52*(Supp. 2), S10–S16.
- Haddad, K. L., Steuerwald, W. W., & Garland, L. (2019). Family impact of pediatric hearing loss: Findings from parent interviews and a parent support group. *Journal of Early Hearing Detection and Intervention*, *4*(1), 43–53. <https://doi.org/10.26077/6t2b-rx63>
- Health Resources and Service Administration. (2019). *EHDI Notice of Funding Opportunity*. <https://www.hrsa.gov/grants/find-funding/hrsa-20-047>
- Hintermair, M. (2006). Parental resources, parental stress, and socioemotional development of deaf and hard of hearing children. *The Journal of Deaf Studies and Deaf Education*, *11*(4), 493–513.
- Houston, K. T. (2021). Digital & social media: Using new tools to support the EHDI system. In *Resource Guide for Early Hearing Detection and Intervention* (Chap. 13). <http://www.infanthearing.org/ehdi-ebook/index.html>
- Jackson, C. W. (2011). Family supports and resources for parents of children who are deaf or hard of hearing. *American Annals of the Deaf*, *156*(4), 343–362.
- The Joint Committee on Infant Hearing. (2019). Year 2019 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. *Journal of Early Hearing Detection and Intervention*, *4*(2), 1–44. <https://doi.org/10.15142/fptk-b748>
- Kothari, M., & Moolani, S. (2015). Reliability of “Google” for obtaining medical information. *Indian Journal of Ophthalmology*, *63*(3), 267–269. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4448244/>
- Moeller, M., Carr, G., Seaver, L., Stredler-Brown, A., & Holzinger, D. (2013). Best practices in family-centered early intervention for children who are deaf or hard of hearing: An international consensus statement. *The Journal of Deaf Studies and Deaf Education*, *18*(4), 429–445. <https://doi.org/10.1093/deafed/ent034>
- Muñoz, K., Nelson, L., & Barker, B. (2016). A review of internet resources related to spoken language intervention for spanish-speaking parents of children who are deaf or hard of hearing. *Journal of Early Hearing Detection and Intervention*, *1*(2), 72–77.
- National Center for Hearing Assessment and Management. (2021, Oct.). *EHDI/UNHS program guidelines and websites by state*. Author. <https://www.infanthearing.org/stateguidelines/index.php>
- National Center for Hearing Assessment and Management. (2021, April). *Best of EHDI website awards*. Author. <https://www.infanthearing.org/webguide/best-of-ehdi.php>
- National Center for Hearing Assessment and Management. (2021, Dec.). *Web resource guide: Website improvement project*. Author. <https://www.infanthearing.org/webguide/index.html>
- Porter, A., & Edirippulige, S. (2007). Parents of deaf children seeking hearing loss-related information on the internet: The Australian experience. *Journal of Deaf Studies and Deaf Education*, *12*(4), 518–529.
- Porter, A., Creed, P., Hood, M., & Ching T. (2018). Parental decision-making and deaf children: A systematic literature review. *Journal of Deaf Study and Deaf Education*, *23*(4), 295–306.

- Finney Rutten, L. J., Blake, K. D., Greenberg-Worisek, A. J., Allen, S. V., Moser, R. P., & Hesse, B. W. (2019). Online health information seeking among US adults: Measuring progress toward a healthy people 2020 objective. *Public Health Reports, 134*(6), 617–625. <https://doi.org/10.1177/0033354919874074>
- White, K. (2018). Demographic considerations in serving children who are hard of hearing or deaf. *Journal of Early Hearing Detection and Intervention, 3*(2), 14–17. <https://doi.org/10.26077/k8j2-vp95>
- Woodruff, T., & Cienkowski, K. (2021). Readability of online hearing-based early intervention materials. *Journal of Early Hearing Detection and Intervention, 6*(2), 39–44. <https://doi.org/10.26077/2c6d-c243>
- Yoshinaga-Itano, C., (2020). Challenges to EHDI systems amid the COVID-19 crisis. *Hearing Journal, 73*(5), 43–45.
- Yucel, E., Derim, D., & Celik, D. (2008). The needs of hearing impaired children's parents who attend to auditory verbal therapy-counseling program. *International Journal of Pediatric Otorhinolaryngology, 72*(7), 1097–1111.

Appendix

Methodology for An Assessment of 50 State Early Hearing Detection and Intervention (EHDI) Websites: Is Needed Information Being Provided for Parent Decision Making?

EHDI websites were reviewed to evaluate whether they comply with the four key content topics laid out in the 2017 EHDI Reauthorization Bill, the 2019 Joint Committee on Infant Hearing 2019 Position Statement, and the FY2020 EHDI Notice of Funding Opportunity (NOFO). The review was conducted between August and September 2021 by the authors of this study. The authors were objective in assessing what was on the websites and whether it was accurate based on knowledge of childhood hearing loss. The criteria are summarized below.

Information on Hearing Loss

- To be rated *comprehensive*, a site needed to include information on types of hearing loss (unilateral, bilateral, levels of hearing loss), possible causes of a progressive hearing loss (such as a diagnosis of congenital cytomegalovirus), and what a family may expect during a hearing exam.
- To be rated as *somewhat helpful*, a site needed to include introductory information on hearing loss such as definitions of mild, moderate, severe, and profound. The review also assessed whether the website included the EHDI guidelines for when to have an audiology follow up and enrollment in intervention services.
- Sites that did not have any of the above information were rated as *inadequate*.
- Three websites included introductory videos; this inclusion contributed to their being rated as comprehensive

Information on Technology

- To be rated comprehensive, a site needed to provide information on cochlear implants, hearing aids, and any additional technology options.
- Further support for a comprehensive rating were those sites that included information on related topics such as FM systems, tips on using technology, and/or noninsurance financing options.
- To be rated as somewhat helpful, at least one option was mentioned. Usually this was hearing aids.
- A site was rated inadequate if technology options were not mentioned.
- A site's score was lowered when incorrect commentary on technology not being beneficial was provided.

Communication Options

- To be rated comprehensive, information on all options was provided as well as other key details such as where to find more information.
- If information was provided via a link to a thorough parent resource guide that included the above, that information contributed to a comprehensive rating.
- To be rated as somewhat helpful, a list of communication options was included.
- A site was rated inadequate if there was no mention of communication options or if not all options were noted equally.

Resources

The authors looked at whether the resources included information on state or Federal sources such as state departments of health and education, the Centers for Disease Control, the National Institutes of Health, and other governmental websites with related information.

- Resources that included mention of non-profit organizations such as Hands & Voices, AG Bell, or others were rated higher.
- Higher ratings were given if the website included comprehensive information on educational options including local schools for the deaf, private oral schools, and public schools with special programs for children who are deaf and hard of hearing.
- Ratings were lower if listed resources were focused on one communication mode with no mention of other options.