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Provider Perspectives: Identification and Follow-up of Infants who Are Deaf or Hard of Hearing

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Abstract

Objective—Without timely screening, diagnosis, and intervention, hearing loss can cause significant delays in a child’s speech, language, social, and emotional development. In 2019, Texas had nearly twice the average rate of loss to follow-up (LFU) or loss to documentation (LTD; i.e., missing documentation of services received) among infants who did not pass their newborn hearing screening compared to the United States overall (51.1 vs. 27.5%). We aimed to identify factors contributing to LFU/LTD among infants who do not pass their newborn hearing screening in Texas.

Study Design—Data were collected through semistructured qualitative interviews with 56 providers along the hearing care continuum, including hospital newborn hearing screening program staff, audiologists, primary care physicians, and early intervention (EI) program staff located in three rural and urban public health regions in Texas. Following recording and transcription of the interviews, we used qualitative data analysis software to analyze themes using a conventional content analysis approach.

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Conflict of Interest
None declared.

Results—Frequently cited barriers included problems with family access to care, difficulty contacting patients, problems with communication between providers and referrals, lack of knowledge among providers and parents, and problems using the online reporting system. Providers in rural areas more often mentioned problems with family access to care and contacting families compared to providers in urban areas.

Conclusion—These findings provide insight into strategies that public health professionals and health care providers can use to work together to help further increase the number of children identified early who may benefit from EI services.

Keywords

infant hearing; early detection; early intervention; newborn hearing screening

Without timely screening, diagnosis, and early intervention (EI), children born deaf or hard of hearing (D/HH) are at increased risk for delayed speech, language, social, and emotional development.^{1,2} Prior to the establishment of universal newborn hearing screenings, children who were D/HH were identified on average between 2 and 3 years of age, and often presented with severe language and developmental challenges.³ The Healthy People 2000 goal to “reduce the average age at which children with significant hearing impairment are identified to no more than 12 months”⁴ and a call from the National Institutes of Health recommending universal newborn hearing screening in 1993⁵ were followed by research highlighting the importance of early intervention for children who are D/HH.^{6,7} In 1999, the United States passed early hearing detection and intervention (EHDI) legislation (42 U.S.C. § 247b–4a) and provided funding to support the establishment of state EHDI programs to help ensure newborns undergo hearing screening and receive recommended follow-up diagnostic testing and EI services. Federal legislation to further support EHDI activities within jurisdictions and research was reauthorized in 2017 through 2022 (42 U.S.C. § 208g-1) which expanded the program to also include children under 3 years of age.⁸ Currently, the Joint Committee on Infant Hearing recommends hearing screening no later than 1 month, diagnostic evaluation no later than 3 months, and enrollment in EI no later than 6 months, known as the 1-3-6 plan.^{9,10} A growing body of literature has documented effectiveness of the 1-3-6 plan among children who are D/HH in the United States, including positive associations with vocabulary,^{11,12} reading proficiency,¹³ kindergarten readiness,¹⁴ and pragmatic language ability.¹⁵ In addition, children enrolled in EI later than 12 months have been shown to have a greater intensity of specialized D/HH service use compared to children enrolled in EI by 6 months.¹⁶

States annually submit aggregated screening, diagnostic, EI, and demographic data through the Hearing Screening and Follow-up Survey (HSFS), a web-based survey tool developed by the U.S. Centers for Disease Control and Prevention (CDC) EHDI program in collaboration with state and national stakeholders to monitor progress in meeting benchmarks for the 1-3-6 plan.¹⁷ Data from HSFS show that the majority of infants are screened for hearing in the United States by 1 month of age.¹⁸ However, it is not clear exactly how many receive recommended diagnostic and EI services (i.e., follow-up services) because one in four infants who do not pass their newborn hearing screening are categorized as either lost to follow-up (LFU) or lost to documentation (LTD) before receiving a diagnosis.¹⁹ LFU

occurs when an infant needs a recommended follow-up service, such as a diagnostic test but does not receive it. LTD occurs when an infant receives follow-up services, but their information is not reported back to the state EHDI program. LFU/LTD can occur at the screening stage (i.e., inpatient and outpatient newborn hearing screenings), diagnostic stage (i.e., infant did not get a diagnostic test to determine if the infant is D/HH), or at the EI stage (i.e., infant who was identified as D/HH did not receive EI services). It is difficult to distinguish between LFU/LTD; thus, the two categories are often presented as a combined percentage when evaluating EHDI tracking surveillance activities.¹⁷

The state of Texas has the second largest annual birth cohort in the country, behind California, with 385,277 total occurrent live births in 2019.¹⁸ According to CDC 2019 HSFS data, 10.6% of all D/HH infants born in the United States were born in Texas.¹⁹ In 2019, Texas had a higher than average rate of LFU/LTD for diagnosis among infants who did not pass their newborn hearing screening compared to the United States overall (51.1 vs. 27.5%), contributing to nearly one in seven infants who are LFU/LTD nationally.¹⁹ This translates to 2,373 children in Texas who might not have received recommended follow-up services in 2019.

Child and family-related factors associated with LFU have been extensively examined in the literature. For example, children with normal birth weight or less severe hearing loss, or children of mothers who were non-White, were smokers, had less than a high school education, had public health insurance, or resided in rural areas are more likely to be LFU or LTD.^{20,21} In addition, a lack of education and training surrounding state EHDI reporting systems can lead to LTD. A recent survey of U.S. audiology facilities found lack of knowledge about how to report the data to the EHDI program, reported by 60% of the 88 noncompliant facilities included in the survey,²² was the most common barrier to reporting diagnostic results to EHDI. Private practices were most likely to be noncompliant, and hospital settings were least likely to be noncompliant (39.5% compared to 1.1%, respectively). In addition, an evaluation of audiologists' perceptions of the acceptability of the EHDI reporting process across 39 states found the most common barriers to reporting was a nonuser friendly system design, lack of audiologist time, and a lack of knowledge of state reporting requirements.²³ However, as far as we are aware, challenges to meeting benchmarks for the 1-3-6 plan among providers across the hearing care continuum have not yet been described. The objective of this investigation was to elucidate challenges related to LFU/LTD and identify potential opportunities to reduce LFU/LTD among infants in need of diagnostic or EI services from the provider perspective. Results from this investigation may help public health professionals and health care providers in Texas, and potentially other large annual birth cohort states with high LFU/LTD to formulate strategies to improve care coordination for children born D/HH.

Materials and Methods

Participants

Texas EHDI health care providers including hospital newborn hearing screening program staff, audiologists (e.g., audiologists with otolaryngology, i.e., ear–nose–throat [ENT] specialty), physicians (primary care or ENT), and EI program staff (e.g., Part C which

includes Medicaid programs, and non-Part C which includes for-profit and non-for-profit programs) were eligible for inclusion. We focused the investigation on providers practicing in three public health regions of Texas to capture diverse experiences: two with high LFU/LTD (regions 11, located in south Texas/lower Rio Grande Valley, and including the city of Brownsville, and 4/5N, located in east Texas and including the city of Tyler) to help identify challenges with implementing the 1-3-6 plan, and one with average LFU/LTD (Region 7, located in central Texas, including the city of Austin) for Texas to highlight typical experiences within the state.

Data Collection

We selected semistructured interviews as the optimal methodology for understanding provider perspectives with respect to barriers and facilitators to identify and follow-up with infants who may be D/HH. We created four semistructured qualitative interview guides tailored for provider types across the continuum of care. We adapted interview guides from the National Center for Hearing Assessment and Management (NCHAM) SNAPSHOT Study! Audiology Survey Questions²⁴ to answer two guiding questions: (1) what barriers contribute to LFU/LTD in Texas; and (2) what factors (i.e., facilitators and suggestions) may reduce LFU/LTD among infants in need of diagnostic or EI services. Questions were refined based on discussions with CDC EHDI subject matter experts and five known Texas Early Hearing and Detection Intervention (TEHDI) “champions”, individuals identified by TEHDI staff as knowledgeable about and supportive of TEHDI. Questions common to all providers included “How would you describe your role in your day-to-day job with respect to the TEHDI program?” and “Do you think loss to follow-up and/or loss to documentation is a problem among infants who are deaf or hard of hearing? If so, what specifically are the problems contributing to each? What do you think could be done to address these issues?”. The CDC team performed mock interviews with staff prior to departing to the field to ensure each interviewer understood the questions on the interview guides, reviewed suggested probing questions to elicit detailed responses from participants, and had practice administering the interviews.

We recruited a convenience sample of participants for interviews from a list of providers whom TEHDI knew were involved with delivering EHDI services through e-mail, phone, or in-person visits (without a prearranged appointment). Providers gave oral consent prior to the beginning of each interview. Interviewers informed providers their participation was voluntary and that responses would not be associated with their name but may be associated with their place of work to support outreach efforts. We conducted all provider interviews during a 3-week investigation period in 2018. If the provider consented, we recorded the interview, and for all interviews, a second interviewer typed notes by hand. Recordings were sent securely to a CDC contractor who transcribed interviews verbatim. Interviewers recorded new overarching barriers, facilitators, and suggestions reported by providers each day. No additional categories of barriers, facilitators, and suggestions were identified during the last 2 days of the investigation, suggesting that saturation was reached.²³

Data Analysis

We inductively developed codes using a conventional content analysis approach²⁵ capturing barriers, facilitators, and suggestions mentioned by providers during the interviews related to the EHDI 1-3-6 process. Barriers included factors that providers felt contributed to difficulties for adhering to 1-3-6 reporting requirements or meeting service delivery benchmarks for the 1-3-6 plan. Facilitators included concepts providers mentioned that assist with their day-to-day jobs or help families receive needed care. Suggestions included concepts providers mentioned that would improve any aspect of the 1-3-6 process, although not necessarily explicitly stated as a suggestion. For example, statements following “I wish...” or “It would be great if...” were coded as suggestions. Providers did not always mention facilitators and suggestions in direct reference to specific barriers. The lead investigator (R.A.C.) read text line-by-line and created a preliminary codebook comprised of codes representing facilitators, barriers, and suggestions, using providers’ own words, where possible, to accurately capture the meaning of the speaker. We refined codes based on feedback from TEHDI staff to help ensure accuracy of our interpretations of provider sentiment. Coders could apply multiple codes to the same line of text if applicable, and the same code could be applied multiple times throughout the same interview transcript.

Following coding of the 56 interviews, two CDC coinvestigators (E.C. and A.N.) validated four randomly selected interviews (one for each provider type) to examine intercoder agreement. Code discrepancies were discussed until agreement was reached. The lead investigator (R.A.C.) applied all decisions across the remaining interviews. We examined codes (i.e., facilitators, barriers, and suggestions) for common themes related to LFU/LTD. We counted the number of interview transcripts where each code was applied (i.e., interview transcript coded multiple times with the same code was only counted once) to explore potential differences in provider-reported facilitators, barriers, and suggestions by location (Texas public health regions 7, 4/5N, and 11) and provider type (hospital newborn hearing screening program staff, audiologists, physicians, and EI program staff). These results represent ideas mentioned by providers and do not necessarily reflect the views of the Texas Department of State Health Services (TDSHS) or CDC. All coding and analyses were manually completed and organized by the lead investigator using qualitative data analysis software Atlas.ti, version 7. This work was deemed a nonresearch public health investigation according to the CDC’s interpretation of federal regulations defining research (<http://aops-mas-iis.cdc.gov/Policy/Doc/policy557.pdf>) and exempt from CDC and TDSHS IRB approval.

Results

Provider Characteristics

Table 1 describes the 56 providers who consented to be interviewed. The CDC team conducted most ($n = 31$; 55%) interviews in-person, and the remaining by telephone (Fig. 1). Providers worked in 46 distinct sites across three public health regions in Texas, including birthing centers, hospitals, private practices, and programs. The average length of time per interview was approximately 30 minutes regardless of whether the interview was conducted in person or by telephone (range: 14–61 minutes). Most providers (32 of 55; 58%) had >15

years of experience, 14 (26%) had 5 to 15 years of experience, and 9 (16%) had <5 years of experience (one did not specify). Five screeners, nine audiologists, and 17 primary care providers reported they saw at least one infant under the age of 3 months, on average, per month. Two of 11 EI staff reported seeing at least one infant under the age of 6 months (five did not specify). Of the four EI staff who reported that they typically see no infants under the age of 6 months, two worked in a school setting serving older children. When asked the typical age when children were referred to their EI program, 4 of 11 EI staff reported receiving referrals for infants who were D/HH prior to the 6-month mark, while 6 reported they typically receive referrals after the 6-month mark (one did not specify).

Qualitative Analysis

Following analysis of the coded interview transcripts, five themes related to LFU/LTD in Texas emerged as follows: (1) coordination across the continuum of care, (2) geography and access, (3) education and training, (4) insurance, and (5) confidentiality. Table 2 summarizes barriers organized by theme; Table 3 provides frequencies of mentioned barriers by provider type and public health region. All 56 providers interviewed in the investigation mentioned provider- and family-related barriers that may contribute to LFU/LTD, each falling under one of the five themes. Provider-related barriers included barriers providers face in their day-to-day jobs, while family-related barriers included barriers that families face that may prevent them from receiving timely services. Table 4 summarizes facilitators and suggestions to improving delivery of EHDI services mentioned by providers by theme and relevance to 1-3-6 process.

Theme 1. Coordination across the Continuum of Care

Problems with Communication and Referrals—The most mentioned barriers related to coordination across the continuum of care were noted as problems with communication and referrals ($n = 45$), reported across all provider types and regions. The most common complaint reported was a lack of communication between different practices, although this was also a problem within practices. One audiologist illustrated this point, stating “I’m sitting right here and kids are coming in deaf with (other providers) that could walk over (to me)...and they don’t... even across the hall it’s difficult.” Providers expressed that an absence of communication can lead to a lack of timely information shared between health care providers and delay the timeline for infants and families getting needed services. One audiologist explained they see children later when they visit pediatricians or ENT physicians first:

“I see them later when so much time has been wasted when they (infants) go to the ENTs first. They go to the ENT’s and they’re the ones that are like, let’s wait six months, let’s do it again in 6 months, he’s too young to wear hearing aids anyway. By the time I get them, they’re way behind in their speech and it’s just a mess. It’s the ENT’s and the PCP’s (primary care providers) but really the ENT’s because they’re the ones doing diagnostics.”

Another related challenge mentioned was providers may not know where to refer children with hearing loss. One audiologist stated that “sometimes there can be a delay because the pediatrician does not know where to send the child, and so they end up sending the child

somewhere else and then it might take a while before they get to us”. A related problem mentioned was that providers may be unclear on who is responsible for patient follow-up. One primary care provider noted that once the information has been relayed to the parent, the next step is out of the provider’s control: “I think it comes down to the parents who are accountable, because how do you assign that test to a provider in the community to follow-up on that?”

Facilitators and Recommendations Related to Problems with Communication and Referrals—Providers commonly reported successful communication and coordination across providers as facilitators to the 1-3-6 process. Most often, providers spoke of mutual exchange or information sharing across providers, and coordination across different practices and providers. A pediatrician explained one example of successful information sharing with the Part C EI program: “so from the (Part C) EI stand-point, I think we have good communication because they send me back reports, and I have those reports ready and available at the next well visit or the next visit I see them.”

To improve communication, one provider suggested increasing face-to-face time between providers. Another explained that verbal communication between providers is essential for working together effectively. Four providers reported that automatic information exchange across provider types could facilitate the process. Eleven providers (primarily screeners) mentioned several TEHDI program activities that facilitated their reporting and following up with families, such as TEHDI phone and e-mail reminders to follow-up with infants who were not documented in the system (TEHDI currently sends automated emails through the online reporting system to program managers when a record is in need of attention and an infant needs additional care; however, TEHDI lacks the resources to do this on a case-by-case basis).

Five respondents recommended that providers should be held accountable for reporting to TEHDI. One screener stated, “If I could fix anything out of this, it would be somebody definitely has to hold physicians accountable because I think that that’s where that link is broken.” Similarly, other providers expressed desire for increased TEHDI follow-up of providers who are not reporting, explaining that this would help ensure infants are not lost to follow-up.

Another provider from Region 11 recommended having a local EHDI committee to facilitate their work. Describing a TEHDI Regional Summit in their region, the provider expressed that networking with the TEHDI program helped “move things along and keep us focused.” Similarly, a different provider in Region 11 reported that increased TEHDI face-to-face time would be beneficial and expressed a desire to build a relationship with the TEHDI program, stating, “we don’t really have that kind of a relationship with them, so that would be nice to have that as kind of a human bridge between the paperwork and what’s going on.”

Lack of Provider Time—Lack of provider time was mentioned as a common barrier to reporting or following up with families, mentioned by 22 providers. Providers also mentioned their heavy caseload of patients contributed to their lack of time. Lack of provider time was mentioned frequently by providers, ranging from 33 to 59% across provider types

and 39 to 43% across the three regions. A screener explained that high caseloads among audiologists can result in a delay in hearing-related services for children: “Some audiologists won’t see the patient until after 6 months because they’re so inundated. They’re so inundated with so many patients, they can’t fit them in. So now what happens to that 1-3-6 rule? It’s out the door.”

In addition to delayed services, some children may not receive needed services at all. One educator of children who are D/HH explained that they did not have time to serve all the students seeking their services, stating that “everyone is stretched to the nth degree. People are just working so hard just to try to keep up, let alone break the status quo.” Providers also had trouble making time to report to TEHDI in their already busy work schedules.

Facilitators and Recommendations Related to Lack of Provider Time—Providers did not mention any facilitators for reducing time constraints, but one audiologist suggested taking advantage of audiology schools to perform rescreening for infants who did not pass their initial birth screen in areas where audiologists are overburdened with extremely high caseloads; however, in practice students may not assist with diagnosing (though may be able to assist with reporting).

Logistical Difficulties Related to Personnel and Equipment—Seventeen providers across the three regions mentioned logistical difficulties related to personnel and equipment (22–29% per region); screeners most reported such difficulties (83%). Most commonly, providers described problems with referrals (e.g., not receiving faxed referrals), and provider turnover that resulted in lost relationships with outside provider communities and a need to train new staff. A screener noted that this turnover can result in inconsistencies in reporting to TEHDI. Another commonly mentioned problem was a lack of personnel or resources to provide hearing-related services to families or to report to TEHDI. One primary care provider expressed the need for an audiologist to help them determine whether the infant needs further evaluation for hearing loss but did not have the resources to hire one.

One screener explained that the Newborn Admission Notification Information (NANI) tool, an optional module of the online reporting system that facilitates direct transfer of demographic data captured in electronic medical records to the online reporting system, caused logistical difficulties by overwriting demographic information in the online reporting system. They explained “you can edit all those records but at midnight, when the whole new group comes in, when they import or generate the whole new admission file for that day, it overrides everything you did on all those records.”

This screener went on to explain that this issue affects all hospitals that use the NANI tool and that although they are working to fix the problem, they are not sure how to solve it and do not have time to continuously update the record. Therefore, infants may be lost if the address or phone number is overwritten which affects the ability to contact the family for an outpatient screen or audiology visit.

Facilitators and Recommendations Related to Logistical Difficulties Related to Personnel and Equipment—Despite problems mentioned by a screener with NANI

overwriting patient records, this same individual did note that the NANI tool helps them keep track of patients. An EI provider mentioned a separate system, the Public Education Information Management System, as a facilitator for school districts to ensure children receive needed intervention services. Recommendations to address logistical concerns offered by providers were to improve the NANI tool, switch from paper-based to an electronic medical record system, and for practices to set up an internal system where providers would receive automatic referrals or no-show notifications.

Problems Using the Online Reporting System—Eighteen providers mentioned a range of problems using the online reporting system used for managing, tracking, and reporting data to TEHDI. In general, problems with the online reporting system were most reported among audiologists (65%) and in Region 7 (56%), although concerns were noted by other provider types (screeners and pediatricians) and across all regions. The most common complaint was that the system is not user friendly (e.g., challenging to input data, difficult to navigate, complex interface). Providers also reported difficulty accessing the web-based system due to lost passwords, not remembering how to log on or believing they do not have access to the system, finding patients, reaching technical support, and accessing specific patient records, and finding health-related information (e.g., infant risk factors; screening or diagnostic results).

In addition to technical concerns, one audiologist expressed concern that the online reporting system allows entry of a third hearing screen result, which may result in overscreening among providers:

“I’ve definitely seen a patient who had a bilateral profound hearing loss and passed on her third inpatient screen. She wasn’t supposed to have one. I think there is wiggle room in how many screens are allowed to enter into the (Texas online reporting system) and there shouldn’t be.”

Facilitators and Recommendations Related to Problems Using the Online Reporting System—Fifteen providers mentioned aspects of the online reporting system worked well, facilitating their day-to-day jobs with respect to TEHDI. Most commonly, providers stated that the online reporting system has a user friendly interface, and facilitated data entry, making or receiving referrals, and getting patient medical information or medical history. One EI provider explained: “I think it’s good because it’s a universal process for the state so that all state providers can enter information. It’s great that our (part C EI) programs can get referrals via that mechanism.”

Recommendations that providers proposed to improve the online reporting system included providing easier access to the system (e.g., fewer password changes and easier password resets), and listing all possible patient names (e.g., in case the infant’s name changed shortly after birth). An audiologist suggested more education and training on the online reporting system. Several providers gave recommendations to improve the online reporting system that have already been implemented, indicating these providers are unaware of existing system functionality (e.g., allowing searches for patients by region, patient follow-up notes, and system access for midwives and Regional Day School Programs).

Theme 2. Geography and Access

Challenges with Access to Care—Providers mentioned challenges families face related to the unique geography of Texas, including a large, mostly rural geographic area and proximity to Mexico and neighboring states. Specifically, providers mentioned that families face challenges with access to care ($n = 32$), including long distance to services, limited providers in the area, limited access to hearing aids, and immigration and border issues. Other barriers included getting timely appointments, language barriers, poverty, rurality, and transportation. Challenges with access to care were most reported in rural Regions 4/5N (71%) and 11 (67%) compared to urban areas (Region 7; 33%). This sentiment was expressed across all provider types. One provider in Region 4/5N described the situation that families living in poverty face in rural regions:

“I think it’s more loss to follow-up in my area, rural east Texas. People may get a result, but not to say it’s not a priority but they’re just trying to get food on the table, keep the lights on. So it’s just hard for them to get away.”

Facilitators and Recommendations Related to Challenges with Access to Care—Facilitators related to access to hearing related services for families included providing transportation services, access to hearing aids through schools, and reduced or lower cost services to families. One EI provider recommended increasing existing services to non-English speakers or people with disabilities. Another suggested colocating EI services with schools, explaining that this has worked for other school districts in their area.

Difficulty Contacting Families—The most mentioned provider-related barrier to the 1-3-6 process was difficulty contacting families ($n = 30$), including when families could not be reached or were unresponsive to follow-up staff. A greater percentage of providers in Regions 4/5N (57%) and 11 (63%) mentioned difficulty contacting families as a barrier, compared to Region 7 (22%). Although screeners most commonly reported this as a barrier (83%), all provider types mentioned this relatively frequently (audiologists = 41%; primary care providers = 41%; and EI = 55%).

Of the 30 providers who mentioned difficulty contacting families, the most reported problems were family no-shows for appointments and incorrect contact information. For example, the follow-up staff may have mailed letters or left voicemails, but the family/parents never returned their calls or scheduled an appointment. Other difficulties providers mentioned were families declining services, lack of service providers follow-up protocols, and infant name changes after leaving the birth hospital. When speaking about difficulty contacting families and the impact on children, one provider in Region 4/5N stated “we see them at four or five because they’re starting school programs and they’re speech delayed and they aren’t communicating”.

Facilitators and Recommendations Related to Difficulty Contacting Families—Providers did not mention facilitators to contacting families; however, one primary care provider suggested that providers ask patients for updated contact information during each visit.

Theme 3. Education and Training

Lack of Provider Knowledge—All provider types in all three regions mentioned lack of provider knowledge surrounding the EHDI 1-3-6 plan and best practices ($n = 26$), including a general lack of understanding of the importance of the 1-3-6 plan. Providers also noted that they see too few infants or children who are D/HH, or they are inundated with information, making it difficult to remember best practices or reporting requirements. Two providers mentioned that infant cooccurring conditions, such as Congenital Cytomegalovirus (CMV) or developmental delays could result in late identification of infants who are D/HH due to providers focusing on treating other conditions. Another provider noted: “I think sometimes a child has multiple disabilities and the deafness or the hearing loss is not the primary concern initially.”

Providers also mentioned a lack of knowledge about reporting hearing screening results to TEHDI. For example, one primary care provider stated: “I’ll tell you the truth; I really don’t know that anyone’s ever sat down and explained to me what I should be doing.” Later when asked about reporting requirements, this provider stated: “I really don’t (know). It’s sad, but I’ve just been plugging away.” An audiologist suggested that a lack of knowledge might be more common among ENT physicians or pediatricians.

Facilitators and Recommendations Related to Lack of Provider Knowledge—

Screeners mentioned that holding regular screening process trainings and online reporting system trainings have been helpful in increasing their knowledge surrounding the 1-3-6 plan and best practices. Providers gave suggestions to promote education, such as increasing education and training opportunities for providers, offering continuing education credits for provider trainings, educating providers on their role in the 1-3-6 process (i.e., their responsibility for ensuring that infants receive the care they need and that they report screening, diagnostic, and intervention information), and disseminating EHDI-related research findings more widely. Providers also mentioned appreciation for a report card/rating system monitoring the reporting of information pertaining to the 1-3-6 plan. One screener spoke positively of the report card system, explaining that although they do not like to be penalized for entering information in wrong sections, the rating system has helped them improve.

Lack of Parental Knowledge—Providers stated that many families have a limited understanding of the importance of the 1-3-6 plan and limited educational information given to them when their child does not pass their hearing screening or upon receipt of hearing-related services ($n = 21$). All provider types in all three regions mentioned lack of parental knowledge related to the 1-3-6 plan; however, this barrier was mentioned more often by EI staff (73% compared to 17–32% among the other provider types). Providers explained that a lack of parental understanding of the importance of the 1-3-6 plan can lead to parents waiting to bring their child in for services until they have noticeable delays.

Facilitators and Recommendations Related to Lack of Parental Knowledge—

To increase parent understanding of the importance of the 1-3-6 plan, providers suggested providing education/knowledge to parents immediately at the time of service (i.e., at

the initial birth screen) rather than waiting until another appointment. One EI provider recommended that providers receive training to increase provider appreciation of the emotional impact of a parent learning that his/her child is D/HH, and the importance of educating parents on next steps in a way that is not overwhelming and will help them understand the process:

“You have to be so careful in that you don’t give parents too much and overwhelm them, and you feed it to them as they’re processing it and build that relationship... and then in that relationship hopefully they’ll feel comfortable in being real candid with some of their questions.”

Nine providers (eight EI staff and one primary care provider) cited EI outreach to communities, including providers and families, as a facilitator to addressing lack of knowledge among both providers and families. One EI provider explained: “You know, having that, build that relationship between referral sources and the community and when they have events that we are present as an organization makes a difference.” Another EI provider explained how outreach events that include the broader community can provide an opportunity for parents to obtain information and connect with other families.

Theme 4. Insurance

Problems with Insurance Coverage—Among the 21 providers who mentioned insurance as a barrier to families, many described a lack of insurance coverage for certain benefits among families with insurance, or the family not having any kind of insurance. All provider types mentioned challenges with insurance coverage; however, insurance challenges were more commonly reported by the providers in rural Regions 4/5N and 11. One provider in Region 4/5N explained that they see families who refuse timely hearing screens in the birth hospital because of a lack of insurance coverage among families with insurance: “I’d say four out of five times when they refuse, it’s because their insurance covers it here and it does not cover it in the hospital.... I really think that is a travesty.”

Facilitators and Recommendations Related to Insurance Coverage—Insurance facilitators were mentioned by two providers in Region 11, including Medicaid incentives and Medicaid requirements that encourage families to come in for follow-up hearing-related visits. One provider in Region 4/5N recommended facilities have insurance coordinators: “They (hospitals) need to have somebody in-house who knows this insurance, they need to go to X facility, and if they have that insurance, they know to go to Y facility.” The provider noted that insurance coordinators could assist families with referrals that often differ depending on the type of insurance.

Problems with Insurance Reimbursement—Among the 10 providers who mentioned issues with insurance as a barrier to carrying out their day-to-day job responsibilities, difficulties getting timely or sufficient Medicaid reimbursement for hearing-related services were mentioned most often (provider reimbursement insufficient or slow), and one noted that making referrals for families with Medicaid adds additional work for providers making the referral (provider referrals are insurance dependent, causing complications). All provider types mentioned problems with insurance reimbursement; however, like insurance coverage

problems for families, problems were more commonly reported by the providers in rural Regions 4/5N and 11.

Providers mentioned that a lack of timely or sufficient Medicaid reimbursement for medical services has contributed to the closing of practices and providers not accepting Medicaid to cover hearing aids, resulting in fewer options for families. One provider from Region 11 highlighted the impact of insurance barriers on infants' receipt of timely 1-3-6 services:

"I think the whole hearing assessment 1-3-6 is totally lost... these little kiddos can't even get hearing aids... there's no incentive for audiologists to do it because people are losing money left and right. Then these kids are just gonna go without hearing until they're 8, 9, and then, you know, where are we at?"

Facilitators and Recommendations Related to Insurance Reimbursement—

Providers did not mention facilitators or recommendations related to problems with insurance reimbursement.

Theme 5: Confidentiality

Problems with Patient Confidentiality—Eight providers across all three regions, including screeners, audiologists, and EI providers, mentioned problems with patient confidentiality requirements.

Several providers noted that they believed consent requirements may prevent hand-off between providers along the continuum of care. One EI provider explained they believed they were not receiving referrals, and therefore were not obtaining information needed to assist a child who is D/HH, until the family provided consent. Several additional providers reported that their understanding of consent requirements in the hearing screening law prevented them from reporting data to TEHDI. Similarly, another EI provider specified that one aspect they disliked about the 1-3-6 reporting process was "knowing what happened with the case and not being able to report it into TEHDI and having that LTD list."

Facilitators and Recommendations Related to Problems with Patient Confidentiality—Providers did not mention facilitators related to patient confidentiality. One EI provider suggested sending a consent form automatically with patient referrals which might address problems with patient confidentiality. This EI provider also suggested allowing parents to give verbal consent over the phone (however, based on TDSHS interpretation of Family Educational Rights and Privacy Act and Individuals with Disabilities Education Act rules, verbal consent is not permitted).

Discussion

LFU and LTD among infants who are D/HH remains a national challenge, despite improvements over the past decade.²⁶ This investigation identified five themes encompassing complexities and barriers contributing to LFU/LTD in Texas, across the continuum of care. Barriers identified by providers, such as problems with communication and referrals, lack of provider time, problems using the online reporting system, and logistical difficulties related to personnel and equipment, are consistent with challenges

documented in other states.^{22,27} Despite challenges, providers highlighted facilitators and suggestions that could improve the EHDI 1-3-6 process to increase the number of children who receive timely follow-up services. Our findings, in combination with relevant individual family-level characteristics, for example,^{20,28,29} paint a complex web of factors potentially influencing LFU/LTD and offer potential solutions to help reduce LFU/LTD. Findings from this work, such as suggestions providers mentioned for improving coordination of care for infants with suspected hearing loss, might extend to general perinatal and pediatric care where information must be transferred between multiple providers and time points.

A lack of provider education on the importance of the 1-3-6 process, as well as a lack of provider understanding of their role in reporting and providing services, was a common problem mentioned among providers. Provider misunderstanding around the 1-3-6 process is not unique to Texas^{22,27}; however, educational outreach is particularly challenging due to Texas's large geographic area and correspondingly large birth cohort. Our investigation expands on prior work demonstrating that a lack of knowledge on reporting data to the EHDI program is a common barrier to reporting diagnostic results among noncompliant audiology facilities,²² suggesting providers experience similar barriers across the continuum of care. Provider champions, such as those serving in the American Academy of Pediatrics EHDI Chapter Champion Program,³⁰ could augment state outreach efforts through advocacy and education, reaching a larger number of providers than possible with limited state resources.

Providers noted problems with finding patients in the online reporting system, not only because of search function difficulties, but also because infants may not appear in the system due to problems obtaining parental consent, or infants may not have been documented in the system in the first place. State public health departments could consider linking individual infant information in the online reporting system to claims data (e.g., Medicaid claims or MarketScan data) to allow analysis of information of child hearing-related outcomes (e.g., receipt of a hearing aid or cochlear implant) following the initial reporting of an infant not passing their newborn hearing screen. Linking EHDI online reporting systems to claims data could help providers know which patients are receiving follow-up services based on billing data, potentially allowing differentiation between children who are LFU versus LTD. Although claims data have limitations, such as a time delay, provider use of incorrect billing codes, and confidentiality concerns, these data could help provide a more complete picture of data for infants who are LFU/LTD than otherwise would be available. Data linkage could also allow for more targeted follow-up with providers and families of children who may not be receiving needed services.

Providers, particularly EI staff, mentioned difficulties in attaining information about children they are serving because of the perception (accurate or not) that confidentiality policies restrict sharing of information, even when this information is needed for routine public health practice (follow-up) that benefits D/HH children. Consent requirements do not limit referrals to services; Texas Health and Safety Code, Chapter 47, requires EI referral when an infant is suspected to be D/HH (does not pass the outpatient screen). Health departments could consider working with their state legal departments to develop resources (e.g., fact sheet) for hospitals and birthing facilities that summarize optimal newborn screener

requirements regarding confidentiality protections and sharing of information that permits public health practice.

Providers mentioned Medicaid reimbursement is slow or insufficient, causing many practices in rural areas to discontinue services. Providers explained that a lack of availability of local providers, particularly those that accept Medicaid, results in families having to drive long distances for their children to receive needed services and assistive devices, such as hearing aids, that are covered by Medicaid. Public health professionals and policy makers could consider reviewing Medicaid provider reimbursement policies and practices to address barriers Medicaid patients living in rural areas are experiencing in finding local providers who could dispense hearing aids.

Limitations

This investigation had at least the following limitations to consider. First, results are not representative of the entire state of Texas, or specific regions and provider types within Texas. Only a small subset of public health regions in Texas were included, and the CDC field team relied on a convenience sample due to the rapid, short-term requirements of the investigation, limiting generalizability of results. For example, the CDC team relied heavily on referrals, comprising 25% of scheduled interviews. Few providers responded to e-mail attempts (12%) and telephone calls (9%); however, of the providers with whom we were able to speak with in person ($n = 8$), all agreed to participate (note some providers were contacted through multiple outlets). Telephone numbers not in service or providers the TEHDI program were unaware of were differentially excluded. Additionally, there could be differences between providers who did and did not participate. For example, providers who appreciated the importance of the 1-3-6 plan might have been more motivated to participate. Fewer screeners and EI providers participated relative to audiologists and primary care providers. Although the CDC team did not identify additional categories of barriers, facilitators, and suggestions during the last two days of the investigation, suggesting that saturation was reached (Glaser, 1978), it is possible that participation of additional screeners and primary care providers could have provided further insight that was not captured. Second, some participants did not agree to have their interview recorded, therefore important information may have been missed on a subset of providers. However, a second interviewer was dedicated to taking detailed notes, and agreement to be recorded did not seem to vary by participant profession. Third, to protect respondents' confidentiality, differences in responses by subtype of provider (e.g., nurses, physician assistants, and pediatricians were all categorized as primary care providers) were not documented. Fourth, because this was a qualitative investigation, numbers presented in this report do not indicate the magnitude of the identified challenges in Texas. However, the specific themes that emerged highlight important considerations for public health professionals and policy makers. Fifth, the CDC team could not come to an agreement with a large newborn hearing screening contractor in Texas on their participation in this investigation. The exclusion of this contractor could have limited the understanding of birth screener perspectives on LFU/LTD; however, health care providers who worked in hospitals served by this contractor were interviewed, as well as representatives from additional contractors conducting newborn screening in Texas. Sixth, 21.4% ($n = 12$) of providers did not specify whether they typically see infants under 3

months of age (6 months for EI), with nonresponse to this question varying by provider type; EI providers (45%) and audiologists (30%) were more likely to omit this information compared with screeners (17%) and primary care providers (4.5%). It is unclear why EI providers and audiologists included in our investigation were less likely to respond to this question; however, it is possible this information may have been perceived as more sensitive among providers who do not typically see children in accordance with 1-3-6 guidelines.

Although this investigation elucidated several challenges contributing to LFU/LTD in Texas, several questions remain. Analyses of deidentified, individual-level characteristics potentially associated with LFU/LTD, such as family language, race/ethnicity, and degree of hearing loss, could confirm or dig deeper into findings from the qualitative interviews. In addition, many providers mentioned difficulties with Medicaid coverage and provider reimbursement of hearing aids and related services. Analyses of Medicaid claims data could generate hypotheses on whether a simple billing code change for hearing-related services could potentially alleviate these difficulties. Finally, providers often cited distance to services as a common problem among families. Future work could map distance from family residence to hearing-related services to quantify whether this barrier disproportionately affects certain groups. Understanding demographic differences in proximity to services would help better characterize the barriers affecting families and children and potentially reveal patterns of unmet need.

Conclusion

Newborn hearing screening, diagnosis, and EI in line with the EHDI 1-3-6 plan is essential for optimal speech, language, social, and emotional development among children who are D/HH.¹¹ Although most infants in the United States are receiving a newborn hearing screen before 1 month of age,¹⁸ many children may not be receiving diagnostic or EI services according to guidelines. This investigation identified barriers across the hearing care continuum that may contribute to LFU/LTD, as well as facilitators and provider suggestions to documenting the diagnostic and intervention status of infants who did not pass the newborn hearing screening. Results from this investigation highlight important challenges for policymakers and stakeholders, including families, across the 1-3-6 continuum of care. These findings suggest specific strategies public health professionals, policy makers, and health care providers can use to improve coordination of care and increase the number of children identified early who may benefit from diagnostic and EI services.

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Key Points

- Infants with suspected hearing loss may not receive timely diagnosis or early intervention.
- We interviewed healthcare providers in Texas along the hearing care continuum.
- Findings suggest strategies to increase the number of children with hearing loss identified early.

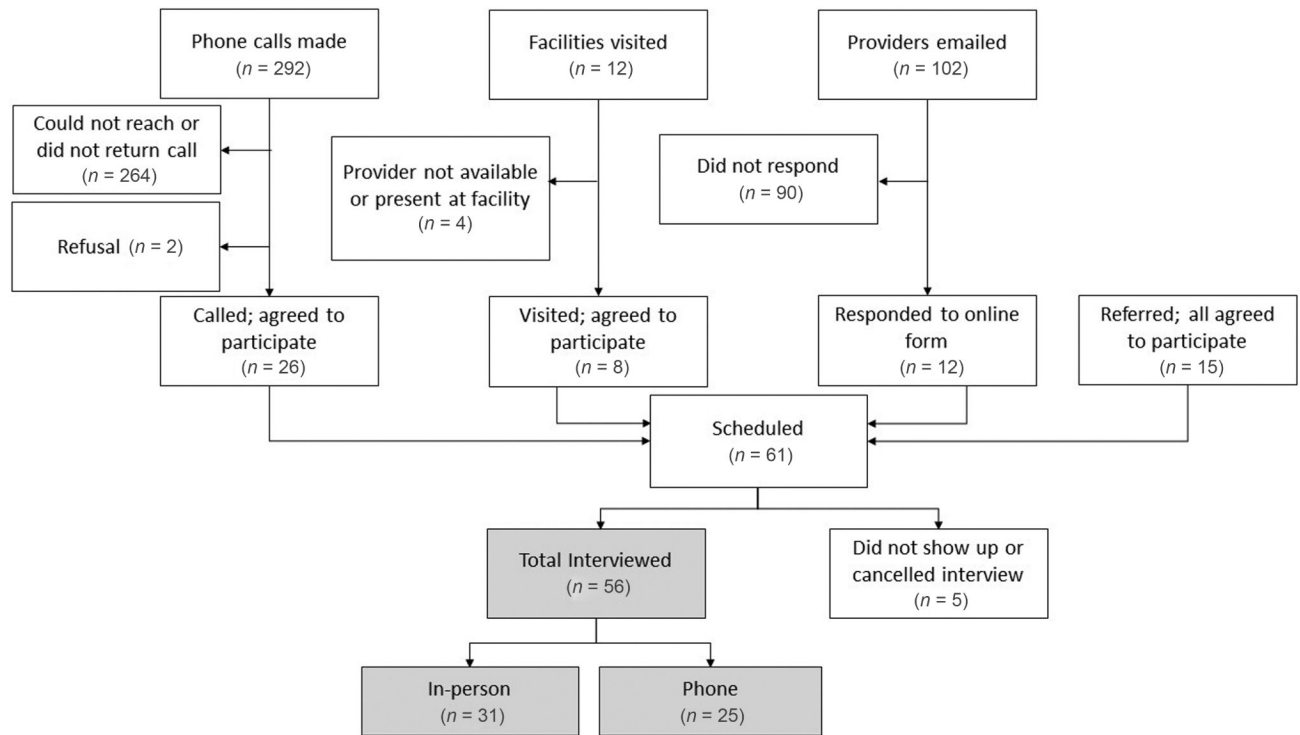


Fig. 1. Participant flowchart of providers interviewed involved with delivering EHDI-related services in three public health regions—Texas, 2018. Note: Providers may have been contacted through multiple outlets; for example, some of the referrals also received an email and responded to the online form. EHDI, early hearing detection and intervention.

Table 1

Characteristics of providers interviewed involved with delivering EHDI-related services in three public health regions—Texas, 2018

| Provider characteristics | <i>n</i> | % |
|--|-----------------|----------|
| Public health region | | |
| Region 7 (Central; includes Austin, TX) | 18 | 32 |
| Region 4/5N (East; includes Tyler, TX) | 14 | 25 |
| Region 11 (South/Lower River Grande; includes Brownsville, TX) | 24 | 43 |
| Provider type | | |
| Screener | 6 | 11 |
| Audiologist | 17 | 30 |
| Primary care provider | 22 | 39 |
| Early Intervention (Part C or non-Part C) ^a | 11 | 20 |
| Years of work experience (1 did not specify) | | |
| Highly experienced (>15 years) | 32 | 58 |
| Experienced (5–15 years) | 14 | 26 |
| New in career (<5 years) | 9 | 16 |
| Typically sees infants under 3 months of age (6 months for EI) | | |
| Screener (1 did not specify) | | |
| Yes | 5 | 100 |
| No | 0 | 0 |
| Audiologist (5 did not specify) | | |
| Yes | 9 | 75 |
| No | 3 | 25 |
| Primary care provider (1 did not specify) | | |
| Yes | 17 | 81 |
| No | 4 | 19 |
| Early intervention (5 did not specify) | | |
| Yes | 2 | 33 |
| No | 4 | 66 |

^aEarly Intervention (EI) can include Part C Medicaid programs and non-Part C (non-Part C includes for-profit and non profit programs)

Summary of barriers related to delivering early hearing detection and intervention services mentioned by health care providers in three public health regions, categorized thematically—Texas, 2018

| Theme | Barrier ^a | Group | Description | Provider quote |
|--|---|----------|---|--|
| Coordination across the continuum of care (<i>n</i> = 52) | Problems with communication and referrals (<i>n</i> = 45) | Provider | Problems with referrals; lack of consistency across providers; communication challenges | "Sometimes there can be a delay because the pediatrician doesn't know where to send the child and so they end up sending the child somewhere else and then it might take a while before they get to us." |
| | Lack of provider time (<i>n</i> = 22) | Provider | Lack of time for reporting or seeing patients | "Some audiologists won't see the patient until after 6 months because they're so inundated. They're so inundated with so many patients, they can't fit them in. So now what happens to that 1-3-6 rule? It's out the door." |
| | Logistical difficulties related to personnel and equipment (<i>n</i> = 17) | Provider | Difficulties with personnel or equipment; paper medical records are a challenge for online reporting; lack of personnel | "(Our contractor has) been trying to train new people to (report to TEHDI), but the more people that you have, the more inconsistencies you'll have as well." |
| | Problems using the online reporting system (<i>n</i> = 16) | Provider | Non user-friendly interface; difficulty finding patients in the system | "I have a hard time figuring out how to navigate the website.... If it was just more intuitive, it would make the process a lot easier." |
| Geography and access (<i>n</i> = 40) | Difficulty contacting families (<i>n</i> = 30) | Provider | Problems with patient name and address changes | "I think we have a number of patients that probably are hard of hearing that we identify late because... we couldn't get a hold of them or they kept canceling their appointments.... And then we see them at four or five because they're starting school programs and they're speech delayed and they aren't communicating." |
| | Challenges with access to care (<i>n</i> = 32) | Family | Challenges related to distance to services; getting timely appointments; language, immigration/border issues; limited number of providers; poverty; rurality; transportation; school and part C EI hours do not match up making it difficult for children to receive care | "I think it's more loss to follow up in my area, rural east Texas. People may get a result, but not to say it's not a priority but they're just trying to get food on the table, keep the lights on. So it's just hard for them to get away." |
| | Lack of provider knowledge (<i>n</i> = 26) | Provider | Lack of knowledge surrounding 1-3-6 guidelines and best practices; hearing loss may be missed or a secondary concern among infants with CMV or other developmental delays | "A lot of ENTs I think aren't aware of the 1-3-6, and so they'll take longer to refer or push ABRs and just keep doing ABRs. A lot of (children who were identified late)... have other issues going on... and the hearing loss kind of gets put on the back burner or is not even thought about." |
| Insurance (<i>n</i> = 22) | Lack of parental knowledge (<i>n</i> = 21) | Family | Lack of knowledge about the importance of timely identification and intervention | "That family was... totally and completely in denial and did not agree to pick up services at all... when the child got to kindergarten... they realized how desperate the situation was for their child." |
| | Problems with insurance reimbursement (<i>n</i> = 10) | Provider | Medicaid reimbursement is slow or insufficient; referrals are insurance-dependent which makes referral process more complicated | "I think the whole hearing assessment 1-3-6 is totally lost... these little kiddos can't even get hearing aids... there's no incentive for audiologists to do it because people are losing money left and right. Then these kids are just gonna go without hearing until they're 8, 9, and then, you know, where are we at?" |
| | Problems with insurance coverage (<i>n</i> = 21) | Family | Difficulty finding Medicaid providers that will cover hearing aids; patients lack insurance | "I'd say four out of five times when they refuse, it's because their insurance covers it here and it does not cover it in the hospital; therefore, the hearing screen at the hospital is more expensive. I really think that is a travesty. There's so many barriers in the state of Texas with Medicaid right now that it would just make your heart lay down and cry... If you can't get early amplification and access, I |

| Theme | Barrier ^a | Group | Description | Provider quote |
|---------------------------------|--|----------|---|--|
| Confidentiality (<i>n</i> = 8) | Lack of reporting or providing services due to perceptions of patient confidentiality requirements (<i>n</i> = 8) | Provider | Providers unable to access or report patient data because of consent issues | think we'd be totally remiss to look at this without looking at this piece (Medicaid) in the state of Texas." "We may know about a family but if we're going through the proper channels we cannot get [the names of children] until (we have) the consent (of parents)." |

Abbreviations. CMV, cytomegalovirus; TEHDI, Texas Early Hearing Detection and Intervention Program.

^aProviders may have mentioned multiple barriers under the same theme; therefore, barriers *n*'s may not sum to theme *n*.

Summary of barriers to early hearing detection and intervention services mentioned by health care providers, by provider type and public health region—Texas, 2018

Table 3

| Theme | Barrier | Provider type, n (%) | | | Region ^b , n (%) | | | |
|--|--|----------------------|-------------|--------------|-----------------------------|--------------------------|------------|---------------|
| | | Group | SCR (n = 6) | AUD (n = 17) | PCP (n = 22) | EI ^a (n = 11) | 7 (n = 18) | 4/5N (n = 14) |
| Coordination across the continuum of care (n = 52) | Problems with communication and referrals (n = 45) | Provider | 5 (80) | 14 (82) | 17 (77) | 9 (82) | 13 (72) | 13 (93) |
| | Lack of provider time (n = 22) | Provider | 2 (33) | 10 (59) | 7 (32) | 4 (36) | 7 (39) | 6 (43) |
| | Logistical difficulties related to personnel and equipment (n = 17) | Provider | 5 (83) | 3 (18) | 2 (12) | 5 (46) | 4 (22) | 4 (29) |
| Geography and access (n = 40) | Problems using the online reporting system (n = 18) | Provider | 2 (33) | 12 (65) | 0 (0) | 4 (36) | 10 (56) | 3 (21) |
| | Difficulty contacting families (n = 30) | Provider | 5 (83) | 7 (41) | 12 (55) | 6 (55) | 5 (28) | 9 (64) |
| | Challenges with access to care (n = 32) | Family | 3 (50) | 10 (59) | 13 (59) | 6 (55) | 6 (33) | 10 (71) |
| Education (n = 32) | Lack of provider knowledge (n = 26) | Provider | 3 (50) | 10 (59) | 6 (27) | 7 (64) | 10 (56) | 6 (43) |
| | Lack of parental knowledge (n = 21) | Family | 1 (17) | 5 (29) | 7 (32) | 8 (73) | 7 (39) | 6 (43) |
| | Problems with insurance reimbursement (n = 10) | Provider | 2 (33) | 4 (24) | 3 (14) | 1 (9) | 1 (6) | 4 (29) |
| Insurance (n = 22) | Problems with insurance coverage (n = 21) | Family | 2 (33) | 7 (41) | 10 (46) | 2 (18) | 3 (17) | 8 (57) |
| | Lack of reporting or providing services due to perceptions of patient confidentiality requirements (n = 8) | Provider | 2 (22) | 1 (6) | 0 (0) | 5 (46) | 4 (22) | 2 (14) |
| | | | | | | | | |

Abbreviations. AUD, audiologist; EI, early intervention staff; PCP, medical staff (e.g., otolaryngologists, primary care nurses, physicians, and physician's assistants); SCR, newborn hearing screening staff.

^aEI can include Part C Medicaid programs (EI) and non-Part C (non-Part C includes for-profit and non-profit programs).

^bPublic Health Region 11 is located in south Texas/lower Rio Grande Valley and includes the city of Brownsville; 4/5N is located in east Texas and including the city of Tyler; Region 7 is located in central Texas, including the city of Austin.

Summary of facilitators and suggestions to improving delivery of EHDI services mentioned by health care providers in three public health regions, by theme and relevance to 1-3-6 process—Texas, 2018

Table 4

| Barrier | 1-3-6 Process | | | Overall process |
|---|--|--|--|---|
| | Screening (1 month) and diagnosis (3 months) | Early intervention (6 months) | | |
| Theme 1: coordination across the continuum of care (<i>n</i> = 52) | | | | |
| Problems with communication and referrals | Facilitators | <ul style="list-style-type: none">Hospital designates staff member to keep track of infant/reportHospital plan/protocol in place for infants who are D/HHHospital requirement that providers schedule follow-up appointment immediatelyProvider having a backup if patient doesn't bring in copy of screening resultContractor helping to coordinate careContractor scheduling outpatient re-screen at birth hospital | <ul style="list-style-type: none">Part C EI assisting with ensuring children receive servicesSchool allowing EI provider consult with families before Individual Family Service Plan is signedEI staff familiarity with signs of hearing lossProvider coordination with school district | <ul style="list-style-type: none">Coordination across different practices/providersTEHDI phone call/email reminders/follow-upProvider community held local stakeholder meetings |
| | Suggestions | <ul style="list-style-type: none">Hospital could appoint referral sourcesHospital could require scheduling an appointment/making a referral immediately before discharge after birthHospital could allow contractor access to hospital system to enter test resultsTEHDI or screening contractors could standardize protocol and training of screenersState could require providers to inform part C EI the moment child does not pass first hearing screen^aHospital could have in-house outpatient screening to eliminate need for referralHospital could implement referral/no-show notifications | <ul style="list-style-type: none">TEHDI could directly refer infants to Regional Day SchoolsSchools could assist with referrals and get involved earlier | <ul style="list-style-type: none">TEHDI could follow-up with patientsTDSHS could increase TEHDI staff |

| Barrier | | 1-3-6 Process | | | |
|--|--------------|---|--|---|--|
| | | Screening (1 month) and diagnosis (3 months) | | Early intervention (6 months) | Overall process |
| | | <ul style="list-style-type: none">Hospital could designate one person within facility to keep track of infants or report to TEHDI | | | |
| Lack of provider time | Facilitators | None mentioned | | None mentioned | None mentioned |
| | Suggestions | <ul style="list-style-type: none">Extend the audiology workforce by using audiology school students^a | | None mentioned | None mentioned |
| Logistical difficulties related to personnel and equipment | Facilitators | <ul style="list-style-type: none">NANI tool helps keep track of patients in health care organizations | | <ul style="list-style-type: none">Public Education Information Management System helps schools keep track of EI services received by students | None mentioned |
| | Suggestions | <ul style="list-style-type: none">TEHDI could improve NANI tool to keep track of patients | | None mentioned | <ul style="list-style-type: none">Health care organizations could switch to electronic medical records |
| Problems using the online reporting system | Facilitators | None mentioned | | <ul style="list-style-type: none">Reporting system is useful for making EI referrals | <ul style="list-style-type: none">System provides a universal process for providers in the stateReporting system is: user friendly; convenient; not too time consuming; useful for data entry, finding family contact information, family follow-up, and for obtaining patient medical information/medical history; useful for searching for patients when provider has consent to view |
| | Suggestions | <ul style="list-style-type: none">Allow midwives access to reporting system^a | | <ul style="list-style-type: none">Allow Schools for the Deaf access to reporting system^a | <ul style="list-style-type: none">Changes to the reporting system could include: allow searches by region^b; add section in reporting system for patient follow-up notes^b; improve interface; list all possible patient names (e.g., name given at birth may be different)Changes to the reporting process could include: allow providers to fax results in; provide easier access to system; allow automatic upload of data instead of asking providers to enter data^b; increase provider training in use of online reporting system |
| Theme 2: geography and access (<i>n</i> = 40) | | | | | |
| Difficulty contacting families | Facilitators | None mentioned | | None mentioned | None mentioned |

| Barrier | 1-3-6 Process | | | Early intervention (6 months) | Overall process |
|-----------------------------------|---------------|---|--------------|--|---|
| | Suggestions | Screening (1 month) and diagnosis (3 months) | Facilitators | | |
| Challenges with access to care | | None mentioned | | None mentioned | <ul style="list-style-type: none"> Providers could ask family for updated contact information at each visit |
| | Facilitators | None mentioned | | <ul style="list-style-type: none"> Family access to hearing aids/ services through schools | <ul style="list-style-type: none"> Caseworker, parent advisor^c, care coordinator referral, or case manager helps families navigate a complex healthcare system to get the care they need |
| | Suggestions | <ul style="list-style-type: none"> Health care organizations might consider increasing number of providers | | <ul style="list-style-type: none"> EI services could be available in schools (co-location of care) EI could expand services to non-English speakers and people with disabilities | <ul style="list-style-type: none"> Transportation services for families (e.g., Medicaid travel assistance) |
| Theme: education (<i>n</i> = 32) | | | | | |
| Lack of provider knowledge | Facilitators | <ul style="list-style-type: none"> Regular hospital-led online reporting system trainings and screening process trainings for screeners | | <ul style="list-style-type: none"> EI program outreach to providers involved with screening and diagnosis | <ul style="list-style-type: none"> TEHDI report card/rating system monitoring reporting of information pertaining to 1-3-6 TEHDI state trainings and resources |
| | Suggestions | None mentioned | | None mentioned | <ul style="list-style-type: none"> TEHDI could provide community/statewide communication and training about 1-3-6, including amplification options and provider responsibility for informing families about 1-3-6 TEHDI could distribute informational guides, flyers, brochures, instructions etc.^b Providers could hold community outreach events |
| | Facilitators | <ul style="list-style-type: none"> Education/knowledge given to parents at time of service | | <ul style="list-style-type: none"> EI program outreach to community | None mentioned |
| Lack of parental knowledge | Suggestions | <ul style="list-style-type: none"> Providers could educate parents if refuse testing Providers could conduct outreach to communities and families | | None mentioned | None mentioned |

| Barrier | | 1-3-6 Process | | Early intervention (6 months) | Overall process |
|--|--------------|--|---|---|--|
| | | Screening (1 month) and diagnosis (3 months) | | | |
| | | Providers could not tell parents baby barely passed (causes unnecessary concern) | | | |
| | | | • | | |
| | | Providers could educate in a way that is not overwhelming to parent | | | |
| | | | • | | |
| | | Providers could reassure parents | | | |
| | | | • | | |
| Theme: insurance (<i>n</i> = 22) | | | | | |
| Problems with insurance reimbursement | Facilitators | None mentioned | | None mentioned | None mentioned |
| | Suggestions | None mentioned | | None mentioned | None mentioned |
| Problems with insurance coverage | Facilitators | • Medicaid incentives or requirements get more families to come in for diagnostic appointments | | None mentioned | • Providers who offer reduced/low cost services |
| | Suggestions | None mentioned | | • Medicaid could document failed hearing screen or diagnosis of children who are D/HH and refer them for next steps | • Providers could have an insurance coordinator to assist families |
| Theme: confidentiality (<i>n</i> = 8) | | | | | |
| Lack of reporting or providing services due to perceptions of patient confidentiality requirements | Facilitators | None mentioned | | None mentioned | None mentioned |
| | Suggestions | None mentioned | | • Health care provider could routinely send consent form with referral to EI | None mentioned |
| | | | | • State could allow verbal consent for reporting EI services from parents over the phone | |

Abbreviations: EHDI, early hearing detection and intervention; EI, early intervention (can include Part C Medicaid programs and non-Part C; non-Part C includes for-profit and non-profit programs); NANI, newborn admission notification information; D/HH, deaf or hard of hearing; TEHDI, Texas Early Hearing Detection and Intervention Program.

Note: All barriers, facilitators, and suggestions listed in the results section are ideas mentioned by providers interviewed during this investigation, and do not necessarily reflect the views of TDSHS or CDC.

^a Provider did not specify who could implement this suggestion; student may be able to assist with reporting but not diagnosing.

^b Recommendation has previously been implemented.

^c Parent advisor, or “Follow Through Guides” through Texas Hands and Voices are utilized in Texas to help educate families on the importance of identification (screening/diagnosis and intervention).