

Are Audiologists Directly Referring children Who are Deaf or Hard of Hearing to Early Intervention?

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Abstract:

Purpose. This study investigated audiologists' perceived roles and responsibilities when making direct referrals to Early Intervention (EI) upon an infant's initial diagnosis of being deaf or hard of hearing.

Method. A national survey was distributed via email and social media networks to pediatric audiologists. A total of 132 anonymous surveys were completed.

Results. 94% of respondents reported that it is within audiologists' scope of practice to directly refer children who are deaf or hard of hearing to EI, however, only 78% of respondents reported ever making this direct referral. Direct referral methods varied across states. Audiologists identified parent resistance and being unsure of the EI eligibility criteria in their state as potential barriers to making direct referrals. Additional analysis was completed on results obtained from Arizona, Illinois, Massachusetts, Ohio, Pennsylvania, and Tennessee, which highlight the various systems used for direct referrals across states. Suggestions for improving the direct referral system include creating universal guidelines across states and an online referral system.

Conclusion. There is variation in how audiologists refer children who are deaf or hard of hearing to EI. Systematic changes to the direct referral system may improve EI enrollment of children who are deaf or hard of hearing prior to 6 months of age.

Key Words: EHDI, Early Intervention, deaf or hard of hearing, direct referral

Acronyms: ASHA = American Speech-Language-Hearing Association; CDC = Centers for Disease Control and Prevention; DHH = deaf or hard of hearing; EHDI= Early Hearing Detection and Intervention; EI = Early Intervention; JCIH = Joint Committee on Infant Hearing

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Introduction

The first universal newborn hearing screening programs were established in the early 1990s. Prior to this, the average age of identification of hearing loss was between 2 and 3 years of age, when children demonstrated limited receptive and expressive language. The universal newborn screening movement built momentum with evidence that children identified as deaf or hard of hearing (DHH) before age 6 months could match language development of their hearing peers (Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998). In 2000, early hearing detection and intervention (EDHI) legislation was passed to develop newborn hearing screening follow-up services. Since 2000, the EHDI Act has been reauthorized and expanded to include diagnostic

services and to require federal administration to recruit, retain, educate, and train qualified personnel to implement the program (Joint Committee on Infant Hearing [JCIH], 2007).

Currently, the primary goals of the EHDI system focus on timely screening, identification, and intervention. These are often called the "1-3-6 goals" as they promote newborn hearing screening by 1 month of age, diagnosis of hearing loss by 3 months of age, and implementation of appropriate early intervention by 6 months of age. Early intervention (EI) services consist of evaluations and therapies for infants and toddlers with developmental delays and established risk conditions, and provision of support to families during the first three years of their

child's life. Services may include the provision of assistive technology, audiology services, speech and language therapy, special education services by a teacher of the deaf or hard of hearing, counseling for the family, medical assistance, nursing services, nutrition services, occupational therapies, physical therapies, or physiological services. Infants who are diagnosed as DHH, have age-appropriate cognitive abilities, and begin receiving EI services before 6 months of age have significantly better outcomes in language, speech, and social-emotional development (Yoshinaga-Itano, 2003) compared to children who begin receiving therapies after 6 months of age. They also have significantly better scores in receptive IQ and have age-appropriate expressive language quotient (Meinzen-Derr, Wiley, & Choo, 2011) compared to children who begin receiving therapies after 6 months of age.

EI eligibility criteria for children who are deaf and hard of hearing varies by state. In some states, unilateral or mild hearing losses do not qualify. In addition, depending on the state, families may be charged for EI services. However, many state programs provide services to children with any type or degree of permanent hearing loss, including unilateral and mild hearing loss, free of charge.

Most recent national EHDI statistics as reported by the CDC indicate that, although 96.1% of all newborns were screened before 1 month of age for hearing loss in 2014, only 67.9% of newborns identified as DHH received EI before 6 months of age (CDC, 2016). There are multiple barriers that may impede enrollment in EI, such as lack of availability of service providers, geographical location of families to EI centers, family refusal of services, and lack of provider referral. It is the belief of these authors that the pathway between the frontline professional (i.e., diagnosing audiologist) and the EI system is the shortest and least susceptible to loss of referral. Our clinical experience indicated that not all audiologists were making direct referrals to EI. The discrepancy noted between the number of infants diagnosed as DHH during diagnostic follow-up and the number of these same infants enrolled in EI before 6 months of age may also reflect children falling through the cracks or obtaining delayed enrollment because the audiologist did not make a direct referral. The purpose of this study was to survey practicing pediatric audiologists about their current practices and perceptions of direct referrals to EI for children who are DHH.

Methods

Participants

Participants in this national study included pediatric audiologists who performed diagnostic evaluations for children ages 0 to 3. Participants were excluded if they were not performing diagnostic evaluations and if their caseload included less than 25% of diagnostic testing for children ages 0 to 3. A total of 132 respondents from 29 U.S. states successfully completed the survey.

The Survey

The instrument used in this study was developed by the audiology externs at Boston Children's Hospital with input from the Director of Audiology and five audiology site managers. The survey included 19 questions and was designed to be completed in less than ten minutes. The questions were related to audiologists' perceived roles and responsibilities when directly referring to EI. A direct referral was defined as a direct contact between the audiologist and the EI provider (with parents' consent). This direct contact would include the audiologist beginning the enrollment process for any child diagnosed as deaf or hard of hearing. An indirect referral was defined as instructions, brochures, or a verbal/written recommendation to the parent or physician to initiate enrollment in EI. The survey was comprised of a variety of question types including free response sections where respondents described the protocol for referring to EI in their state and provided suggestions for improvement to the direct referral system. The survey questions are shown in Appendix A.

Procedure

Research Electronic Data Capture (RedCAP), a secure web application for building and managing online surveys and databases (Harris et al., 2009), was used to develop and track the results of the survey. A specific link to the survey was generated through RedCAP and was distributed via email to various pediatric audiology contacts at hospitals and institutions, social media outlets including Facebook audiology groups, and forwarded via email or word of mouth. All responses from participants were voluntary and anonymous. The survey was available for completion from December 2016 to February 2017. The survey met the Boston Children's Hospital Institutional Review Board's guidelines for exemption from the requirements of 45 CFR 46.101(b).

Results

A total of 151 participants began the survey, but only 132 completed the survey because of eligibility criteria or other factors. Completion rate was 86% and only completed surveys were included in the analysis. Responses were collected from pediatric audiologists practicing in 29 different states. Respondents varied in experience, ranging from 10 or more years of experience (46%) to 6 to 10 years of experience (17%) and 0 to 5 years of experience (36%). Respondents worked in a variety of settings including hospital (72%), clinical (29%), academic (12%), private practice (7%), and educational (6%).

Ninety-four percent of respondents stated that they believed audiologists had a role in directly referring children to EI. However, only 78% of those respondents

reported ever making a direct referral to EI upon initial diagnosis of a hearing loss. The audiologist was rated as the most important referral source for EI by 74% of respondents, the otolaryngologist by 31% of respondents, and parents by 12% of respondents.

Direct referrals were reportedly made using fax (48%), phone (34%), email (15%), and other methods (14%). Other methods for making a direct referral included an online referral form available for the audiologist to complete and a direct referral generated through the Electronic Medical Record. Respondents were asked to rate the direct referral process on a 10-point scale (Figure 1). The direct referral process was rated as extremely easy by 36% of respondents and extremely time efficient by 15% of respondents. Mean ratings were 7.99 for ease of direct referral process and 7.02 for time efficiency. Additionally, 74% of respondents reported ever making an indirect referral to EI upon initial diagnosis of a hearing loss. Indirect referrals were reportedly made by providing verbal instructions to the parents (88%), providing the family with the EI brochure (70%), and writing a recommendation for a referral to EI that was included in the report to the physician (73%).

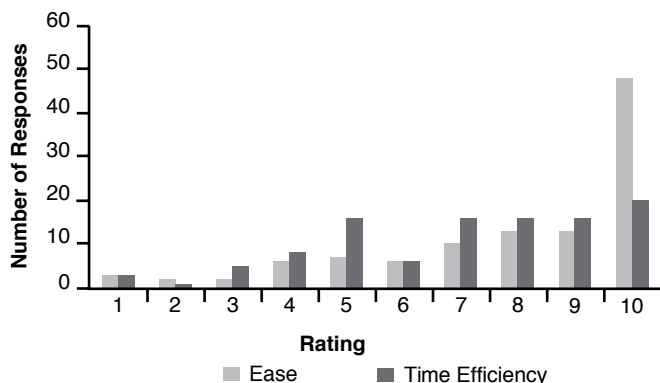


Figure 1. Ratings of direct referral process for ease and time efficiency. A rating of 1 indicates most difficult/least efficient; a rating of 10 indicates easiest/most efficient.

Of the 132 respondents, 22% reported not ever making a direct referral to EI upon initial diagnosis of a hearing loss. Barriers to making a direct referral were identified as parent resistance to the referral (33%), audiologist unsure of state EI referral protocol (23%), the direct referral was too time consuming (18%), audiologist unsure of the eligibility criteria for EI in his/her state (8%), direct referrals out of the scope of practice for an audiologist (7%), and other barriers (45%; see Figure 2). Respondents noted other barriers to directly referring to EI including patient already enrolled or referred by another professional and belief that it is the parent's responsibility to initiate EI services. Seventy percent of all responding audiologists who are not directly referring to EI reported relying on the parents to self-enroll in EI.

Barriers for NOT directly referring to Early Intervention

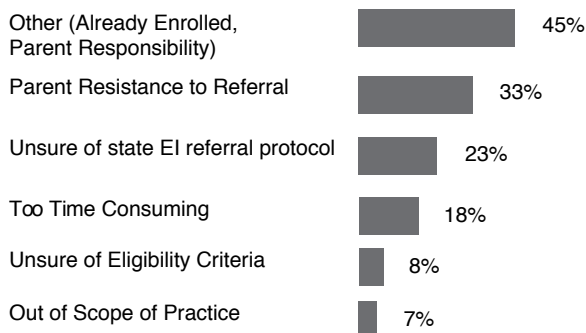


Figure 2. Barriers to direct referrals to Early Intervention (EI). Audiologists were able to select more than one barrier for this question. Total n = 132.

Additional analyses were performed on the 6 states from where the majority of responses came (64%): Arizona, Illinois, Massachusetts, Ohio, Pennsylvania, and Tennessee. Table 1 highlights the number of pediatric audiologists in the aforementioned states who reported ever making a direct referral to EI upon initial diagnosis of hearing loss. The methods for direct referral varied per state. The methods included a faxed Department of Public Health form to the state Parent-Infant Program (Arizona), a designated Aural Rehabilitation provider who assisted parents to initiate services (Illinois), a regionally based telephone number for the audiologist to call and begin the EI intake process (Massachusetts), Electronic Medical Record referral through the EPIC system and a care coordinator to initiate services (Ohio), a written report and direction to the parent (Pennsylvania), and a faxed form directly to EI (Tennessee).

Table 1
Percentage of Direct Referrals Reported by Respondents in Top Six Responding States

State	Percentage of direct referrals reported
Tennessee	90%
Pennsylvania	88%
Ohio	85%
Arizona	83%
Illinois	62%
Massachusetts	54%

When asked how the respondent decided whether to make a direct or indirect referral for a family, 52 of the 132 audiologists provided a written response. Of those, 11 of the 52 audiologists stated that the decision to make a direct or indirect referral is reliant on the parent's understanding of the hearing loss and perceived capability of the family to initiate services. Ten of the 52 respondents noted that direct referrals are made consistently based on state policy and center protocol.

When asked what methods are used to ensure the child who is DHH is enrolled in EI, 17 audiologists provided a written response. Consistent family follow-up was noted by 6 of the 17 audiologists and communication with the care coordinator or social worker was noted by 5 of the 17 audiologists as methods for ensuring the child who is DHH is enrolled in EI.

In response to a request for suggestions for improving the EI direct referral system, 57 respondents provided an answer. The top suggestions were an online referral system (30%); universal guidelines across states, particularly in locations where providers are working with families from multiple states (12%); and a directory of regionally based EI providers as a reference (12%).

Discussion

In this survey, the majority of respondents (94%) believe that audiologists have a role in directly referring children who are DHH to EI. A direct referral was defined as the audiologist directly contacting the family's local EI program with parental consent. This direct contact would include the audiologist beginning the enrollment process for any child diagnosed as DHH. According to American Speech-Language-Hearing Association (ASHA; 2004), audiologists are responsible for "provision of comprehensive audiologic rehabilitation services, including management procedures for speech and language habilitation and/or rehabilitation for persons with hearing loss or other auditory dysfunction, including but not exclusive to speechreading, auditory training, communication strategies, manual communication, and counseling for psychosocial adjustment for persons with hearing loss or other auditory dysfunction and their families/caregivers." According to the ASHA directive, a direct referral from the audiologist to EI is appropriate and within the scope of practice. However, only 78% of audiologists reported ever making a direct referral to EI upon initial diagnosis of a hearing loss. This reveals a discrepancy between audiologists' perceived roles and responsibilities and current clinical practice.

Audiologists reported certain barriers to making direct referrals to EI. Some audiologists felt that the direct referral process was too time consuming and may be neglected to allow completion of more pressing responsibilities. Audiologists reported parent resistance to the direct referral to EI or that the referral to EI had previously been made by another physician. Lastly, a small number of audiologists do not believe directly referring to EI falls within their scope of practice and should be the responsibility of the child's pediatrician and/or parent. 70% of audiologists who are not making consistent direct referrals reported relying on parents to make the referral. It can be argued that this method empowers the parent in helping them learn to be an advocate for their child. However, this approach may put a child at risk as it creates an additional step in the

referral process where enrollment may become delayed, or fail to occur at all. Additionally, at initial diagnosis, parents are often feeling overwhelmed and adding an additional responsibility to the parent to contact EI may cause more burden than empowerment. Considering the national investment in early enrollment into EI, audiologists should consider making the direct referral and find alternative ways for parents to develop their advocacy skills. An audiologist making direct referrals for children who are DHH to EI is particularly advisable for families who have limited income, education, or have a minority status, as this population is more likely to experience delays in enrollment (Bailey, Hebbeler, Scarborough, Spiker, & Mallik, 2004).

By initiating EI services for children who are DHH, the audiologist is acknowledging the benefits EI has on the child's speech and language development and social-emotional outcomes. It can be argued that some families may be resistant to the direct referral to EI if the family and child are DHH and do not wish to pursue amplification for their child. However, the initiation of these services can further support the family in making decisions about the appropriate communication mode for their child. In Massachusetts, there are multiple specialty programs for children who are DHH that the family can choose to access. These specialty programs include oral, total communication, and American Sign Language based programs. Information about these Massachusetts specialty programs are provided in a document titled Specialty Services for Children who are Deaf or Hard of Hearing through the Universal Newborn Hearing Screening Program (2016). Audiologists should be aware of the specialty services available for children who are DHH in their state as these services may vary. By making a direct referral to EI, the audiologist is connecting the family to important resources that can educate them about the options available in their state and can support them in choosing a communication mode for their child.

Overall results indicate that direct referrals to EI programs vary from state to state. With 78% of audiologists reporting experience making direct referrals, it can be concluded that most states already have a means for direct referral by audiologists. The subgroup analysis further supported this notion. Each state reported different rates and methods of direct referrals based on protocol and the structure of their EI system. For example, the states that reported the highest rate of direct referrals were faxing the patient information either directly to EI or to the state EHDI program or making the direct referral to the EI program through the electronic medical record. Eligibility for EI is different across states and 8% of the respondents reported being unsure of the eligibility criteria for the state in which they practice. In Massachusetts, the Early Intervention Operational Standards is a guideline that outlines eligibility criteria for EI and states that permanent hearing loss of any degree deems an infant

eligible for services. This guideline is available through the Massachusetts Department of Public Health (2013) and is accessible on the Massachusetts government website. In light of EI programs varying at the state level, providers should contact their state EHDI or EI program to determine where further information related to EI eligibility for children who are deaf and hard of hearing can be obtained.

In the survey audiologists were asked to provide suggestions for improvement of current direct referral processes. Suggestions included an online referral system, universal guidelines across states, and a directory of regionally based EI providers. An online referral system would reduce paperwork, increase efficiency in making the direct referral, and eliminate referral losses that may take place with faxing, mailing, and other methods currently in practice. This system could be available to the referring audiologist 24 hours per day. This would have an advantage over telephone referral systems as an audiologist could make a referral when their busy schedule permits, without concern of whether an EI employee is available to answer a phone. An online system also has the potential to easily track data for the state on referral trends and support quality assurance initiatives around enrollment in EI. A website hosting the referral system could also provide information related to state laws and guidelines related to EHDI and EI eligibility criteria and references to better connect families with the appropriate EI program or provider. Online referral systems would require capital to create and the direction of state funding toward development of such a system may require advocacy and lobbying.

Although a universal guideline would be ideal, some barriers to such a system would exist. Because EI is funded and operated at the state level, creating a system that could easily be adopted across state lines would require negotiation and buy-in from all states. Collaboration between bordering states, specific to region, could be a more feasible solution. For example, having a collaborative system between nearby states such as Massachusetts, New Hampshire, Connecticut, Maine, New York, and Rhode Island could allow audiologists to provide direct referrals for the majority of patients. This collaborative system could be implemented in states where providers are seeing out-of-state patients on a regular basis.

An additional barrier to an electronic universal system is the potential to violate protected patient health information, either inadvertently or through hacking. The system would need to be a secure site with access only to appropriate and accredited healthcare and EI programs. Such a system would need to be continuously monitored and secured to prevent breaches of private health information.

This study demonstrates that there are systemic changes that could be implemented to support direct referrals for children who are DHH from their diagnosing audiologist to EI. Some barriers reported by respondents in this study could be alleviated through education and technology. An online, universal referral system was the most popular suggestion for improving the direct referral process. Direct referral to EI is within the audiologist's scope of practice. It is the belief of these authors that the most direct route for enrollment into EI for children who are DHH is directly from the diagnosing audiologist to the EI program. Improvements in enrollment processes and audiology education may help states reach their target of enrolling infants with hearing loss in EI by six months of age.

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Appendix A

In this survey, we define direct referral as a direct contact between the audiologist and the early intervention provider (with parents' consent). This direct contact would include the audiologist beginning the enrollment process for any child diagnosed with a hearing loss.

In this survey, we define indirect referral as either instructions, brochures, or a verbal/written recommendation to the parent or physician to initiate enrollment in Early Intervention.

1. When you initially diagnose or confirm a hearing loss are you ever making a direct referral to early intervention?
 - a. Yes
 - b. No

2. When you initially diagnose or confirm a hearing loss are you ever making an indirect referral for early intervention services?
 - a. Yes
 - b. No

3. Do you feel it's appropriate for audiologists to directly refer to early intervention?
 - a. Yes
 - b. No

4. When diagnosing a hearing loss for children ages 0-3, what percentage of the time are you making a direct referral to early intervention?
 - a. 0% - 100% (Place a mark on the scale above)

5. How are you making the direct referral to early intervention?
 - a. Phone call
 - b. Email
 - c. Fax
 - d. Other
 - e. I am not directly referring to early intervention (Check all that apply)

6. Please specify other way(s) you are making direct referrals.
 - a. (Write In Option)

7. How are you making the indirect referral to early intervention?
 - a. Verbal instructions to parents
 - b. Early Intervention brochure
 - c. Other written material provided to parents
 - d. Referral included in report of physician
 - e. Other (Check all that apply)

8. Please specify other way(s) you are making indirect referrals.
 - a. (Write In Option)

9. On a scale of 1-10, rate the amount of difficulty for making a direct referral to early intervention in your state.
 - a. 1 (extremely difficult) - 10 (extremely easy)

10. On a scale of 1-10, rate the amount of difficulty for making a direct referral to early intervention in your state.

a. 1 (extremely difficult) - 10 (extremely easy)

11. In your opinion, who should be the primary person to make a referral to early intervention upon initial diagnosis of hearing loss in children? Please rank the following from most appropriate to least appropriate. 1 = most important 5 = least important

- | | |
|--------------------------------|-----|
| a. Audiologist | 1-5 |
| b. Otolaryngologist | 1-5 |
| c. Primary Care Physician | 1-5 |
| d. Parent/Guardian | 1-5 |
| e. Speech Language Pathologist | 1-5 |

12. If you are not making direct referrals to early intervention 100% of the time, what are some reasons/barriers?

- a. Unsure of eligibility criteria
- b. Unsure of the early intervention system protocol for referrals in my state
- c. Directly referring to early intervention is out of my scope of practice
- d. Too time consuming
- e. Parent resistance to the referral
- f. Other (Check all that apply)

13. Please indicate other reasons/barriers for not making direct referrals to early intervention.

a. (Write In Option)

14. If you are not making direct referrals to early intervention 100% of the time, how are you ensuring the child receives early intervention?

- a. Rely on parents to call/email the early intervention program in their area
- b. Rely on Primary Care Physician to make referral
- c. Rely on Otolaryngologist to make referral
- d. Rely on Department of Public Health to make referral
- e. Other (Check all that apply)

15. Please indicate other ways in which you are ensuring children with hearing loss are getting referred to early intervention.

a. (Write In Option)

16. How do you decide whether to make a direct or indirect referral for families?

a. (Write in Option)

17. Please share any suggestions you have for improving audiologists direct referral to early intervention.

a. (Write In Option)