Variability in Part C Eligibility for Children who are Deaf and Hard of Hearing

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ABSTRACT

This paper describes the various Part C early intervention eligibility criteria for children who are D/deaf or hard of hearing (DHH). Researchers contacted state agencies to determine Part C eligibility criteria for children who are DHH. Two reviewers qualitively classified states on eligibility parameters. This study identified four broad categories of eligibility criteria for states; 1) no written policy; 2) eligibility based on hearing thresholds equal to or less than 25dB HL or "any level"; 3) eligibility based on hearing thresholds equal to or less than 25dB HL and additional components related to laterality, type, or permanency; 4) hearing thresholds exceeding 30dB HL, thus having a degree requirement, including those with additional requirements in terms of laterality. The directory developed in this study of eligibility criteria for children who are DHH serves as a requested tool for states to compare their current operationalized policies in detail to other states, for clinicians to support the families they work with, and for researchers in understanding this highly pragmatic component to early intervention access.

Keywords: EHDI, Part C Eligibility, Hearing, Deaf

INTRODUCTION

For infants who are born D/deaf or hard of hearing (DHH), Early Hearing Detection and Intervention (EHDI) services provide a specific mechanism for supporting language and the family (Early Hearing Detection and Intervention Act of 2017). EHDI is a national system that funds and organizes state programs to screen newborn hearing, evaluate children who refer for further testing on their hearing screening to identify if they are DHH, and help children and families access early intervention services after identification of hearing outside of the typical range (Early Hearing Detection and Intervention Act of 2017). The federal government provides funding and general recommendations on how to run these programs, but states have the flexibility to develop their own mechanisms to ensure access to care. While EHDI applies to infants and young children, there is a focus in the legislation and research on the impact that EHDI has on newborn infants.

At the federal level, state EHDI programs report their activities to the Centers for Disease Control and Prevention (CDC), and this state-level data is released to the public (CDC, 2020a). Within the United States, over 97.%7 of children born in 2020 had their hearing levels screened at birth (CDC, 2023a). This process led to the identification of 6,321 children as DHH (CDC, 2023b).

Identifying children early as DHH but not intervening and providing support is counter to the goals of EHDI and the benefits of early identification. Early intervention services benefit the development of children identified as DHH and can be accessed through private care providers by the family individually or through Part C of the Individuals with Disability Education Act (IDEA) of 2004 (Yoshinaga-Itano, 1999; 2003; 2013). The Joint Committee on Infant Hearing's (2007; 2013; 2019) recommendations for EI services by six months of age or sooner is the foundation of EHDI. Prompt access to language and language acquisition has monumental impacts on adult outcomes in cognitive and linguistic realms (Joint Committee on Infant Hearing, 2019; Yoshinaga-Itano, 1999; 2003; 2013). Individuals who do not have language access are at risk of challenges in language learning and mental health concerns (Hall, 2017). This risk is especially present in the over 40% of all children identified by EHDI programs in 2020 reported not to have accessed any forms of EI (Joint Committee on Infant Hearing, 2019; CDC, 2023b).

The most common avenue for families to access early intervention within the EHDI system is through Part C services (CDC, 2010a; 2010b; 2012a; 2012b; 2013; 2014; 2016a; 2016b; 2018a; 2018b; 2019a; 2023b; n.d.a.; n.d.b.). Families that are served by EHDI are typically also served by Part C services thus, understanding the interaction between diagnostic services in EHDI and early intervention services delivered as part of Part C is critical to seeing the mechanism and potential barriers to care access. Part C EI services are outlined and overseen at the federal and state levels to minimize the impact of developmental delays, reduce educational costs, and support independent living skills, all with the development of capacities for families, states, and local agencies in mind (Individuals with Disabilities Education Act of 2004). The Part C services for a family are selected and specialized to meet the individual family's goals and needs (Individuals with Disabilities Education Act of 2004). Early intervention services and providers work collectively to support the family and the child as they meet individualized goals. These can include a range of services such as family-based training and counseling, speech-language pathology and audiology services, sign, and cued language instruction, and more (Individuals with Disabilities Education Act of 2004).

In Part C EI, federal funding is provided to states to develop their own "comprehensive, coordinated, multidisciplinary, interagency system" that aligns with the requirements of the IDEA (Individuals with Disabilities Education Act of 2004). At the federal level, an eligible child for Part C services is under the age of three years and 1) "experiencing developmental delays" or 2) "has a diagnosed physical or mentation condition that has a high probability of resulting in developmental delay" (Individuals with Disabilities Education Act of 2004). States can also provide services to additional children who are "at-risk" (Individuals with Disabilities Education Act of 2004). The second type of eligibility, the most flexible in terms of states setting specific criteria that only impacts the individual state structure, covers hearing differences and is based on the concern that their hearing thresholds have "a high probability of resulting in developmental delays" as delays may not be present at birth but are possible later in life (Individuals with Disabilities Education Act of 2004). In section 1435 of Part C in the IDEA, it is highlighted that each state has the right to delineate the specific criteria for what a developmental delay is, and thus the requisite hearing levels "in order to appropriately identify infants and toddlers with disabilities that are in need of services."

In the situation of children who are DHH, this is the ability of each state to determine the hearing threshold/audiologic elements that are an indicator of a high probability of future delays. This flexibility highlights that while there are federal standards for service access, state-level variability may exist and is a parameter that future work needs to consider as it relates to access. Before assessment of the potential connection between this variability and outcomes, it is critical to understand the current makeup of the EI landscape for children who are DHH.

Understanding how eligibility criteria interact with EI enrollment for children who are DHH is the first step to understanding what drives enrollment in Part C EI. Past research has investigated general Part C eligibility criteria across states and found associations between decreased EI enrollment and how "restrictive" eligibility criteria in terms of the degree of developmental delay (McManus et al., 2009; Elbaum et al., 2017). Part C of the IDEA treats hearing levels differently as they are not part of a documented delay. Instead, they are an existing condition with a risk for impacting development.

The National Center for Hearing Assessment and Management (2015) categorized operationalized eligibility definitions for children ages 3-5, as covered by Part B Section 619 of the IDEA.At the time of this study, there is no current comprehensive listing of the operationalized hearing-specific eligibility criteria that include thresholds requirements in all relevant states for Part C EI in each state easily accessible by professionals or parents through academic search tools or Google (Early Childhood Technical Assistance Center, 2015; n.d.; Laurent Clerc National Deaf Education Center, 2003). This study uses publicly accessible data to identify each state's Part C EI eligibility criteria. This information is a critical foundation for future works interested in looking at state-level needs and challenges related to access to early intervention for children who are D/deaf and hard of hearing.

METHODS

This study was determined to be non-human subject work by the University of Connecticut Institutional Review Board and analyses exclusively publicly accessible data from individual state Part C EI offices and the CDC.

Individual state webpages do not universally indicate what criteria determine if a child is eligible for Part C EI. With that, the research team attempted to contact each of the 50 states and the District of Columbia to ascertain eligibility criteria for children who are DHH and seeking Part C EI. The research team sent one initial point of contact and up to one follow-up two weeks later. The research team began communication with the next point of contact within two weeks of the follow-up if no response was received. The procedure for identifying points of contact is summarized in Figure 1 and was as follows:

1. All web pages associated with Part C EI were collected from the CDC (2020b) and searched for a contact email address. A hierarchy of relevancy helped identify whom to contact first (individuals associated with Part C EI enrollment specifically, Part C EI coordinators or department heads, general question contacts, points of referral) in situations of multiple contact points.

a. Contact information was collected through the CDC as it is a major repository for EHDI program data and has an intrinsic connection to children who are DHH than other resources such as the Department of Education (CDC, 2021).

b. The research team initiated step two if there was no successful contact.

2. The research team contacted EHDI coordinator(s) via the National Center for Hearing Assessment and Management (2018)'s Contacts for Early Hearing Detection and Intervention.

a. The research team initiated step three if there was no successful contact.

3. The research team reviewed state webpages for contact phone numbers to call and leave a message inquiring about this topic.

a. Up to 10 attempts across all three of these steps (five initial contacts and five follow-ups), or until all contact avenues were exhausted, continued to ascertain these criteria.

4. With contact established and initial questions answered, the research team asked additional follow-up questions as needed.

a. Respondents who did not provide operationalized definitions were provided with a summary of their responses and asked to correct any misunderstandings or ambiguities with up to two follow-ups for clarification.

5. Once the state contact reported the eligibility criteria, it was copied verbatim into an Excel spreadsheet. A data coder broke down state criteria into key components and requirement categories (pure tone average or threshold in dB requirements, etiologic requirements, laterality requirements, permanency requirements), and if the criteria explicitly noted the eligibility of individuals identified with auditory neuropathy/ dyssynchrony or recurrent otitis media.

States were then grouped based on individual requirements to be eligible for services. Four broad categories of state policies were identified: 1) no written policy could be provided at that time; 2) eligibility based on hearing thresholds equal to or less than 25dB HL or "any level"; 3) eligibility based on hearing thresholds equal to or less than 25dB HL and additional components related to laterality, type, or permanency; 4) hearing thresholds must exceed 30dB HL, thus having a degree requirement, including states with requirements of thresholds above 30dB HL, including states with additional requirements in terms of laterality.

These groups highlight differences in the approach states take when determining edibility for Part C EI with children who are DHH in terms of approaching hearing as a quantitative variable in terms of threshold (group 3), that of a dichotomous variable that is absent or present (group 2), or a nominal variable with parameters such as laterality, type, and permanency (group 4). A research assistant cross-checked all data entries to ensure accurate presentations of individual state requirements as they were broken down and grouped. The first author and research assistant discussed and debated any disagreement to reach consensus.

The last successful point of contact for each state was reached out to up to twice more, over 12 months after initial contact, to ascertain the most up-to-date eligibility information for 2022. In these follow-ups, the research team asked the contact to confirm if the policy identified was accurate for 2022. States that did not respond within two weeks of the second point of contact were assumed not to have made any changes to their policy.

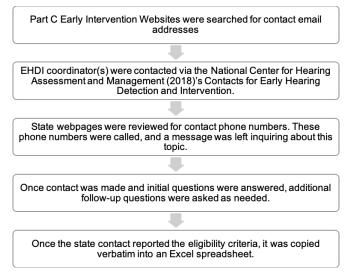


Figure 1

Process for identifying and contacting information sources.

RESULTS

In total, over 250 points of contact were attempted or made in an effort to collect this information. Of the fifty states and the District of Columbia that responded to requests for information, there was variability in the responses received across the different time points assessed. Criteria are broken down into two-year increments to show the limited instances of policy change (Figure 2). It is critical to note that literature does not support the policy groups that are reported here, as the Joint Committee on Infant without commentary on threshold values. Thus, a more dichotomous understanding of hearing differences such as those seen in states with policies in line with group 2 are supported.

2018

In the 2018 data analysis (n=49), one state reported their eligibility criteria actively changed mid-year in 2018 from hearing thresholds equal to or less than 25dB HL and additional components related to laterality, type, or permanency to hearing thresholds equal to or less than 25dB HL or "any level," This resulted in the final policies in 2018 to include three states that had no written policy; 23 states determined eligibility based on hearing thresholds equal to or less than 25dB HL or "any level"; 19 states determined eligibility based on hearing thresholds equal to or less than 25dB HL or "any level"; 19 states determined eligibility based on hearing thresholds equal to or less than 25dB HL or "any level"; 19 states determined eligibility based on hearing thresholds equal to or less than 25dB HL or less than 25dB HL and additional components related to laterality, type, or permanency; and four stated determined eligibility based on hearing thresholds must exceed 30dB HL, thus having a degree requirement, including states with requirements of thresholds above 30dB HL and those with additional requirements in terms of laterality.

2020

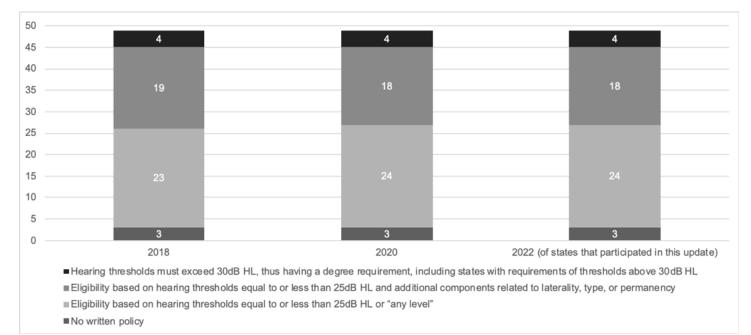
In 2020 the current policies for eligibility (n=49) were reported as three states had no written policy; 24 states determined eligibility based on hearing thresholds equal to or less than 25dB HL or "any level"; 18 states determined eligibility based on hearing thresholds equal to or less than 25dB HL and additional components related to laterality, type, or permanency; and four stated determined eligibility based on hearing thresholds must exceed 30dB HL, thus having a degree requirement, including states with requirements of thresholds above 30dB HL and those with additional requirements in terms of laterality. Between 2018 and 2020, one state moved to eligibility based on hearing thresholds equal to or less than 25dB HL and additional components related to laterality, type, or permanency from eligibility based on hearing thresholds must exceed 30dB HL, thus having a degree requirement, including states with requirements of thresholds above 30dB HL and those with additional requirements in terms of laterality.

2022

The data collection process for this analysis created a unique tool that combines the hearing-related eligibility requirements of various locations (Table 1). This table houses the operationalized eligibility criteria specifically for children who are DHH as it relates to Part C EI as of data collection in 2022. Of the 41 states and districts that responded (80.39% of those contacted), none reported a change in their eligibility criteria. The most up-to-date criteria between 2020 and 2022 for these eligibility policies are in Table 1.

DISCUSSION

Table 1 of this study includes a functional tool to support those within the Part C EI system in ensuring engagement with the system. An interactive map of state Part C Early Intervention programs has also been created and is accessible at https://www. google.com/maps/d/edit?mid=1ocSfH0Al9b7rR8QsTj4M8wDE_ IGw3wZp&usp=sharing with similar content to Table 1. The Aural Rehabilitation Lab at the University of Connecticut, and Dr. Torri Ann Woodruff-Gautherin, can be contacted at the email address at the opening of this paper. Any changes to Table 1 or the interactive map can be sent to that email address so that the map noted above can be updated.





The aggregation of this information is a new addition to the literature base. Clinicians, program administrators, and policymakers can now access the state-reported Part C enrollment criteria for children who are DHH. This information may support clinicians working with families across state lines, administrators understand how their system is structured compared to others, and policymakers advocate for more universal access to supports for children who are DHH. Table 1 also highlights the different conceptualizations of hearing differences at the state level. In 2022, 24 states' early intervention programs viewed hearing as a dichotomous variable consistent with JCIH (2003; 2007; 2019) and the 22 other states with written policies about early intervention who took a more nominal or quantitative approach to understanding the impact of hearing on development. These variations change the accessibility of services based on state lines and may create disparities in access and outcomes based on physical location.

This study benefited from high response rates and clarifications from states about public policies. However, not every state responded to attempts to contact. At the same time, this study investigates Part C EI. Private EI services are an option instead of or in tandem with Part C EI. The IDEA does not govern these services. Future assessments of the EI system for children who are DHH and their families must acknowledge the role of non-Part C EI in children and family life. A lingering question in this discussion is the drivers of eligibility criteria on EI enrollment for children who are DHH. It is possible that some states with more restrictive criteria serve more children, but it was beyond the scope of this study to address this question, given the nature of data collection.

CONCLUSION

Part C systems provide a critical link to early intervention services for children who are DHH and their families. At the federal level, the IDEA endows states with the ability to structure their Part C systems, including eligibility criteria, in a manner that best meets the needs and unique situation of that state. Table 1 and the interactive map above serve as a directory for professionals, families, policymakers, and researchers to use as they work to ensure care and support for children and families. Each stakeholder group will use this information differently, some for clinical service provision, some for legislative change, and others to better understand data sets. Understanding and now having access to the eligibility criteria for each state provides insight into barriers to access related to state structure, not family-level factors as have been identified in other works (Woodruff-Gautherin & Cienkowski, 2023). Further understanding barriers will provide more insight into inequities in access to intervention.

With the range of eligibility criteria in Part C EI now clearly defined for children who are DHH, location, specifically state, must be a factor that is assessed when looking at early intervention enrollment. It is not only critical to collect data on state of residency but ensure that future works consider the need to account for these differences across state lines by both collecting data from families

in different states and controlling for this.

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