

## Research Article

# Modeling Lost to Intervention in Early Hearing Detection and Intervention: A Modified eDelphi Study

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## ARTICLE INFO

## Article History:

Received March 4, 2022

Revision received June 3, 2022

Accepted April 25, 2023

Editor-in-Chief: Erin M. Picou

Editor: Nicholas S. Reed

[https://doi.org/10.1044/2023\\_AJA-22-00046](https://doi.org/10.1044/2023_AJA-22-00046)

## ABSTRACT

**Purpose:** The purpose of this study was to develop a functional model of the drivers behind why families may decline early intervention services following the identification of a child as D/deaf or hard of hearing.

**Method:** This model was developed using a modified eDelphi method. Invited experts ( $N = 155$ ) were provided proposed models of why families may decline early intervention services in accordance with current literature. In the first phase of feedback, participants ( $n = 23$ ) provided changes they would make to the model to be more in line with their perceptions of lost to intervention. These changes were implemented, and a second phase of feedback with participants ( $n = 25$ ) moved to accept the model as presented.

**Results:** Agreement was reached on five main barriers to early intervention access for children who have been identified as D/deaf or hard of hearing (family experience, family culture, perceived vulnerability, perceived benefits, and perceived barriers). Each of these main barriers has associated examples of how they may manifest across different early intervention programs and situations.

**Conclusions:** This is the first theoretical model of why loss to intervention happens within early hearing detection and intervention. Having a model provides the opportunity for future work to implement novel approaches to support families during the early intervention enrollment process.

Early hearing detection and intervention (EHDI) systems across the United States report data to the Centers for Disease Control and Prevention (CDC) yearly regarding the number of children who have their hearing screened and receive diagnostic evaluations, the results of those evaluations, and how many children enroll in early intervention services. The minimum expectations are that children should have their hearing screened by 1 month of age; for those who refer on that screening, a diagnostic

evaluation of hearing should be conducted by 3 months of age; and early intervention for children who are identified as D/deaf and hard of hearing should be started by 6 months of age (Joint Committee on Infant Hearing, 2019). Programs meeting these age-specific benchmarks are encouraged to have diagnostic evaluations by 2 months of age and early intervention by 3 months of age (Joint Committee on Infant Hearing, 2019).

If a child does not make it to the next clinically indicated step at any point in this progression, they are deemed lost to follow-up/documentation (LTFUD). In this study, the term *LTFUD* is broken down into children who do not receive a screening (lost to screening), children who do not receive diagnostic evaluations after referring on their screening (lost to identification), and children who do not enroll in early intervention services after identification as D/deaf and hard of hearing (lost to intervention [LTI]). Specifically for children who are LTI, they

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have a diagnosis that may put them at an increased risk of developmental challenges without appropriate support. Children and their families being LTFUD at any point is counter to EHDI goals, is not supportive of age-appropriate development, and may put these children at risk for “[l]anguage, speech, social-emotional, and academic” needs due to inadequate linguistic access (Hall, 2017; Joint Committee on Infant Hearing, 2019, p. 4; LeClair & Saunders, 2019; Yoshinaga-Itano, 1999, 2003, 2013). As the individual transitions from childhood to adulthood, these challenges can create ripple effects impacting productivity of an individual and increasing the cost of care in the public sector, increasing costs for public education, and the exacerbating social stigma (Grosse, 2007; Hearing Industries Association, 2004; LeClaire & Saunders, 2019; World Health Organization, 2021).

Each family has its own strengths, needs, and preferences for early intervention services, and the individual family service plan (IFSP) that shapes the services provided is structured to meet the family’s goals (Individuals with Disabilities Education Act of 2004). With this individualization in the IFSP and the wide range of services available to children and their families, the consideration of preferences for how services are provided also allows for refusal of any services (Individuals with Disabilities Education Act of 2004). In fact, over 38% of the children reported as D/deaf or hard of hearing to the CDC by EHDI programs in 2019 did not receive early intervention services and are LTI (CDC, 2021c). Historically, data available from the CDC on EHDI (2005 to 2019) demonstrate that there is consistently over 20% of those identified that are not enrolling in early intervention services (CDC, 2010a, 2010b, 2010c, 2010d, 2011, 2012, 2013, 2014, 2016a, 2016b, 2019a, 2019b, 2019c, 2020, 2021c). The most commonly known reason children identified as D/deaf and hard of hearing do not receive services is that their families declined early intervention services (CDC, 2021c).

### ***Need for a Model***

Children who are LTI make up a population where all members have been identified as D/deaf and hard of hearing yet are not accessing services. In this population, compared to children lost before diagnostic services, all the children who are LTI are D/deaf or hard of hearing and presented with hearing level differences. Thus, the ratio of children who are D/deaf or hard of hearing who are at risk of language deprivation after being LTI is higher than that of children who are LTFUD before diagnostic services, as the majority of these individuals who are LTFUD before identification are not expected to have hearing thresholds outside of the typical range

(–10 to 15 db HL; American Speech-Language-Hearing Association, n.d.).

While each state has the flexibility to determine its own path to services and programmatic goals, current discussions around children who are LTFUD tend to focus on the need for screening and identification (Cockfield et al., 2012; Hunter et al., 2016; Yarbrough et al., 2018). However, these discussions provide a window into potential LTI topics if viewed with the understanding that while LTI is a type of LTFUD, it is unique in that drivers are not logistical in the same way as other forms of LTFUD (CDC, 2021a, 2021b, 2021c; C. Liu et al., 2008; Scheepers, et al., 2014). The health belief model (HBM) can be used to provide structure to LTI by outlining common parameters that drive health decisions (Bartholomew Eldridge, et al., 2016; Champion & Skinner, 2008). The HBM has been used to understand hearing-related health behaviors (Saunders, et al., 2012) and other pediatric health care topics (Ghomi, et al., 2019; Khoramabadi et al., 2016; Y. Liu et al., 2018). As shown in Figure 1, when adapted to LTI, these HBM parameters are family perceptions of the seriousness of hearing differences/lack of linguistic access, perceptions of their susceptibility to the adverse sequelae of not accessing language, perceptions of engagement benefits in the EHDI system, perceptions of barriers to accessing services, interactions with the cues available in the environment to prompt them to follow EHDI suggestions, and perceptions of their readiness for change/self-efficacy in implementing EHDI concepts/practices.

The personalization and internalization of disengagement with the EHDI system in LTI mirrors motivators that are deeply engrained in an individual, much like the social determinants of health. Broadly, the social determinants of health are the parts of our world where we live, work, and play (U.S. Department of Health and Human Services, n.d.-e). The five determinants are economic stability, education access and quality, health care access and quality, neighborhood and built environment, and social and community context (U.S. Department of Health and Human Services, n.d.-f) The social determinants of health lay the foundation for the health care decisions that we all make on a daily basis, can highlight areas of need, and may be modifiable through programs like Healthy People 2030 that set actionable goals for governments to address inequalities in these determinants (Department of Health and Human Services, n.d.-f).

In order to understand how the social determinants of health impact LTI and keep in line with the Early Hearing Detection and Intervention Act of 2017, there is a need to engage stakeholders in this work. One approach to this would be the application of the Delphi method. Delphi

**Figure 1.** Initial model based on the health belief model used in phase one. Information drawn from Connecticut Birth to Three (2017), Donald and Kelly-Campbell (2016), Flores-Fenlon et al. (2019), Hackworth et al. (2018), Haddad et al. (2019), Kanji and Krabbenhoft (2018), Khoza-Shangase (2019), Krishnan et al. (2019), Kutzer-White and Luterman (2003), Larsen et al. (2012), Litt and Perrin (2014), Little et al. (2014), McPherson et al. (2018), Nickbakht et al. (2019), Okoli and Pawlowski (2004), Pendersen and Olthoff (2019), Razak et al. (2020), Sax et al. (2019), Tran et al. (2016), Twardzik et al. (2017), van der Spuy and Pottas (2009), and Woodruff and Cienkowski (2021, 2023b). EHDl = early hearing detection and intervention; EI = early intervention.

### Perceived Seriousness

- Results of testing and information about how sensorineural hearing levels are typically permanent are not understood by parents.
- When referrals to other services are made, parents may not understand.

### Perceived Susceptibility

- Information about how hearing levels of any degree or laterality can impact the developmental trajectory for a child is not understood.

### Perceived Benefits

- Parents do not recognize early intervention services as a way of supporting their child's development.
- There is a need for more accessible information on intervention, parent support services, and EHDl.

### Perceived Barriers

- Current educational materials for parents and intervention system structures may not be comprehensible to parents of children and there is a need for more accessible information on hearing aids and technology.
- Depending on the state and financial situation of the family, some services will come at a cost to families.
- The social and physical environment and accessibility of the environment that these children and families are in can pose specific challenges.
- The presence of medical complexity, risk factors, and additional disabilities complicates the process of accessing services.

### Cues

- There are few cues to remind families when a child is diagnosed that they need services since many families and individuals do not have any experience with EHDl or hearing.
- Providers and informational sources are not making the referral to EI/other services in a manner that highlights to parents its importance.

### Parental Readiness for Change/Self-efficacy

- Early identification may lead to the experience of shock/stress along with grief if this is not what the parent hoped to find.
- Parents see themselves as not having enough information on topics like EI.
- Fathers parenting self-efficacy is positively associated with being involved with interventions.

methods directly address this need by engaging stakeholders in iterative cycles of individual judgment and reflection on a specific topic or question (McPherson et al., 2018; Okoli & Pawlowski, 2004; Skulmoski et al., 2007). Variations of Delphi methods such as eDelphis, which uses online response systems, and modified Delphis that start with a proposed answer to the question can be used to address questions as well. Delphi studies implement qualitative and quantitative components and have been used in health care and inquiry in audiology to understand clinician training, core competencies, and the development of models for care (Henderson et al., 2016; McPherson et al., 2018; Meibos

et al., 2019; Nickbakht et al., 2022; Xue et al., 2017). However, to date, neither approach has not been used to address LTFUD or LTI specifically.

## Purpose

This specific investigation and methodology was developed to engage researchers, program developers, and implementers in a process to better understand the needs of each family they serve. The outcome of this study is a theoretically and empirically sound model to understand

and eventually address LTI that is grounded in the principles of stakeholder engagement.

## Method

Institutional review board approval was granted for this study at the University of Connecticut in September of 2020.

### Recruitment

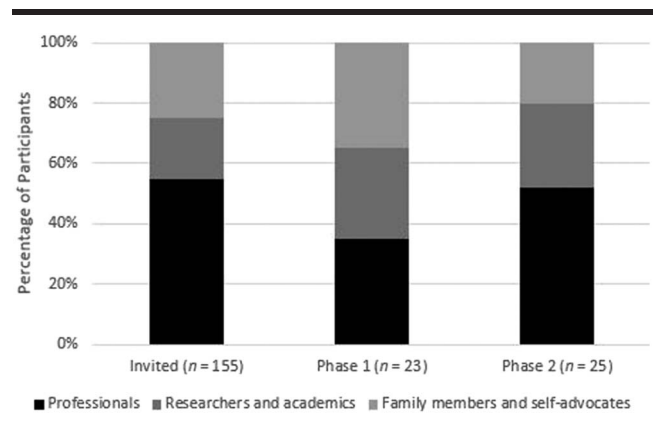
The experts recruited for this study were stakeholders in the EHDI system including those employed within EHDI, direct service providers, academics, and family members/self-advocates. The primary source of identification for all experts was individuals listed as having presented at a previous EHDI conference. Additional resources to identify professional experts included directories such as the National Center for Hearing Assessment and Management and research publications identified through research databases. Families/self-advocate identities were also collected from national and local parent support, advocacy, and educational groups.

There was a specific effort to represent states with different LTI needs. Professionals from states with both less than 50% and over 90% enrollment in early intervention following identification via EHDI were specifically invited to participate. In addition, representation of all communication modes was a goal as there is a wide range of communication options and services available to individuals. Hearing status was not a parameter that was explicitly used to invite participants, but 10% of invited experts publicly identified as D/deaf or hard of hearing. Once the initial experts were identified, all individuals listed were reviewed to ensure their expertise was relevant to the study. The protocol for inviting experts into this study was similar to that set by Okowi and Pawlowski (2004), with an emphasis on creating panels of participants who represent the invited groups and are not limited by the social network of the research team.

These resources and reviews led to 155 individuals identified as experts. The breakdown of the expert panels is displayed in Figure 2. Experts who represented more than one stakeholder group, such as a self-advocate who is an academic, were categorized as a part of their identity with the least representation in the population of identified experts. In our example, the self-advocate who is also an academic would be conceptualized as a self-advocate as more academics were identified to participate than self-advocates.

These experts were then ranked based on their recent work in EHDI/LTI/early intervention. Those individuals who were active from 2020 or more recently were

**Figure 2.** Stakeholder identities recruited and participating.



ranked higher than those whose most relevant engagement was further in the past. Similarly, individuals with multiple activities relevant to this study were ranked higher than those with a singular engagement. Also, a higher ranking was given to those experts with leadership positions. For example, in a family support group, parents who held board positions were ranked higher than those with membership positions.

Recruitment e-mails were sent out in two phases. In Phase 1, invitations to participate were sent out to experts on a weekly basis in batches of 10 experts in each category until all experts had been invited. This approach was taken to allow for equal representation of experts across the categories. In Phase 2, all invitations were sent at the same time. These invitations included a personalized e-mail detailing the study goals, why individuals were selected, the time commitment, and a link to participate.

### Phase 1

After the consent process, experts were able to enter into the survey in Qualtrics. The panel of experts was presented with Figure 1 to provide feedback on in guided questions. Experts were presented with Likert scale questions indicating the clinical utility of each element presented in Figure 1. This Likert data were used to bolster the comments elicited and coded during the free-response section. Free-response space was also available on the same page for qualitative comments.

One month after all Phase 1 invitations were sent out, the link to provide feedback was closed. Using nVivo software, all responses were coded in the qualitative tradition with an inductive thematic approach. Inductive thematic coding works to identify unifying themes across the data set in a bottom-up approach where codes are derived from the data itself (Creswell & Poth, 2018). All

qualitative data were coded independently by two coders: author Woodruff-Gautherin and a research assistant. Any disagreement in coding was met with discussion until consensus was reached. These qualitative codes were crossed in matrices with the stakeholder category the respondent endorsed and then collapsed into actionable steps that were triangulated with the Likert-like scales to update the model to reflect expert opinions.

## **Phase 2**

Phase 2 of this study aimed to develop a consensus around the appropriate drivers and organization within the model and LTI. Based on Phase 1, a revised model was shared with the participants via e-mail link in the spring of 2021. Once this link was opened, participants entered Qualtrics and were shown an updated model based on the feedback from Phase 1. Their feedback was solicited in open-response blocks on the overall fit of this model to the problem of LTI and Likert scales to indicate the degree of clinical utility. These qualitative comments were coded and crossed in matrices with the stakeholder category the respondent endorsed. Then, these matrices were collapsed into actionable steps that were triangulated with the Likert-like scales to update the model to reflect expert opinions. The final question on the page was a culminating dichotomous yes/no question to ask the expert participant if they agreed with this as a model to describe LTI. This question was specifically created to determine if a third round of feedback was needed. The criterion set was for a third phase of feedback if less than 66% of respondents responded “yes” to this question.

## **Results**

### **Phase 1**

During Phase 1, 23 participants entered the survey and completed varying components. The stakeholder identities (see Figure 2) were separated into family ( $n = 8$ ), research/academic ( $n = 7$ ), and professional/service provider ( $n = 8$ ). Comments on this model were then collected and aggregated by stakeholder category (see Table 1). These comments are the foundation for action items (see Table 2) and were reviewed with the Likert data (see Table 3) to triangulate responses. Action items (see Table 2) were functional steps taken to address comments and themes from participants and create the model shown in the Appendix. Comparing Figure 1 and the Appendix provides the most insight into the results of Phase 1, the specific changes that were made as called for in the action items (see Table 2).

The primary outcome of this phase is this iteration of the model (see the Appendix). The overarching

directives and results from this phase of the eDelphi included the addition of two new categories: family experience and family culture. These highlight the impact of past experiences, biases, and culture in decision making. Other changes to the structure of model included the combination of perceived severity and perceived vulnerability to better reflect how participants conceptualized these concepts and the removal of cues and self-efficacy as separate categories so that these concepts could be redistributed into other categories. Additions to the model included explicit examples into each category such as a call out to unilateral hearing differences in perceived vulnerability and an overhaul of the language used in the model to be more strengths based. Likert data were treated as supplementary support for qualitative comments in this study and were not subjected to statistical analysis. Rather, the focus was on triangulation with changes requested and Likert scoring. The Likert data bolster qualitative comments and call for the removal/reorganization of concepts presented as part of cues and self-efficacy with the least favorable scores in terms of utility and quality of description represented by more positive scores.

### **Phase 2**

Twenty-five participants responded to the Phase 2 model shown in the Appendix. Participants represented family/self-advocate ( $n = 5$ ), research/academic ( $n = 7$ ), and professional/service provider ( $n = 13$ ) groups. As participation was anonymous, the individuals who returned to do the second phase were not explicitly tracked and those who did not respond to requests to participate in Phase 1 were allowed to participate in Phase 2. Of the Phase 2 participants, 24% ( $n = 6$ ) endorsed that they had been participants in Phase 1 and an additional 32% ( $n = 8$ ) reported that they may have participated in Phase 1. Comments on this iteration were coded and again sorted into categories (see Table 4).

Unique to this phase, participants were asked to respond to a dichotomous statement about their agreement with the model as presented. With majority acceptance of the current iteration of the model by 19 of 22 participants who responded to this question (86.3%), the criterion for acceptance set forth (> 66%) was met and the primary result was acceptance of the model provided in the Appendix. At this point, Likert data were excluded from analysis as only respondent-provided edits for clarity were implemented into the final model. There was not another phase to allow for content changes. Following the implementation of the clarity edits, the final model and outcome (see Figure 3) was completed.

This final version of the model (see Figure 3) is the primary outcome of Phase 2 and the study as a whole.

**Table 1.** Comments from Phase 1 (*n* = 23).

Participant	Content								Structure	
	Barrier	Cues	Self-efficacy	Benefits	Seriousness	Susceptibility	Culture	Special populations	Wording	Survey logistics
Noted researchers/ academics	<ul style="list-style-type: none"> <li>Failure to make referral</li> <li>Lack of trust in systems, government, professionals</li> <li>Privacy concerns</li> <li>Immigration status</li> </ul>	<ul style="list-style-type: none"> <li>Unclear concept</li> <li>Rename to follow up support</li> <li>Children may not provide behavioral cues to hearing</li> <li>Cues are location dependent; only some states have this challenge</li> </ul>	<ul style="list-style-type: none"> <li>Separate readiness from self-efficacy</li> <li>Father comment is unclear</li> <li>Second parental readiness comment is redundant with other sections</li> </ul>	<ul style="list-style-type: none"> <li>Address parents who are DHH and do not do EI</li> <li>Stronger representation of perceived importance and motivation</li> <li>Parents do not understand their role in EI</li> <li>Not true that parents do not see that value in EI</li> </ul>	<ul style="list-style-type: none"> <li>Does not make note of the variation in training for those doing diagnostics</li> </ul>	<ul style="list-style-type: none"> <li>Statements should be under seriousness</li> </ul>	<ul style="list-style-type: none"> <li>Lack of diverse providers</li> <li>Lack of diverse materials</li> <li>Lack of materials in home language</li> <li>Lack of cultural understanding</li> </ul>		<ul style="list-style-type: none"> <li>Model has negative tone</li> <li>Use of word parents</li> </ul>	<ul style="list-style-type: none"> <li>Participant hearing status and language</li> <li>Likert sections too similar across pages</li> <li>Not options to select more than one</li> </ul>
Those employed within EHDI	<ul style="list-style-type: none"> <li>Families concealing preferences and home behaviors to not jeopardize services</li> </ul>			<ul style="list-style-type: none"> <li>Need to focus on language and the brain</li> </ul>			<ul style="list-style-type: none"> <li>Focus on amplification</li> <li>Spoken language and ASL are not mutually exclusive</li> </ul>	<ul style="list-style-type: none"> <li>Thank you for including DeafPlus</li> <li>DeafPlus as a different topic</li> </ul>		<ul style="list-style-type: none"> <li>Not option to select more than one</li> </ul>
Family members/ self-advocates	<ul style="list-style-type: none"> <li>Transient families are hard to track</li> <li>Providers not perceived as having needed skills</li> <li>Need for multiple attempts to educate on EI</li> <li>Need for increased accessibility</li> </ul>	<ul style="list-style-type: none"> <li>Cues are unclear</li> <li>Move second cues to barriers</li> <li>Need for coordination with other services</li> <li>Need for connection with medical home</li> </ul>	<ul style="list-style-type: none"> <li>This is an overwhelming time for families</li> <li>Parents need to see benefits</li> <li>Father comment is unclear</li> </ul>	<ul style="list-style-type: none"> <li>Where families get support (parent to parent, deaf mentor)</li> <li>Benefits are psychosocial as well</li> <li>Need for hearing-specific services</li> <li>COVID-19 and remote services do not feel effective</li> </ul>	<ul style="list-style-type: none"> <li>First cues to seriousness</li> </ul>	<ul style="list-style-type: none"> <li>Unclear</li> <li>Statements should be under seriousness</li> </ul>	<ul style="list-style-type: none"> <li>Explicit inclusion of visual language</li> </ul>	<ul style="list-style-type: none"> <li>Unilateral hearing (focus on good ear, not see impact of other ear)</li> </ul>	<ul style="list-style-type: none"> <li>Model has negative tone</li> <li>Wording is confusing</li> </ul>	<ul style="list-style-type: none"> <li>Not option to select more than one</li> </ul>

*Note.* DHH = D/deaf or hard of hearing; EI = early intervention; EHDI = early hearing detection and intervention; ASL = American Sign Language.

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This final model includes five primary drivers as to why families decline early intervention services in EHDI: family culture, family experience, perceived vulnerability, perceived benefit, and perceived barriers.

## **Discussion**

Through qualitative methods, a model of why the family of a child who is D/deaf or hard of hearing may decline early intervention services was developed. The action items described above were distilled from the qualitative coding process and resulted in Figure 3. This model provides a theoretical foundation for understanding why LTI exists within EHDI. The components presented (family culture, family experience, perceived vulnerability, perceived benefit, and perceived barriers) highlight key components of what drives LTI based on research, professional experience, and the insight from family and self-advocates.

While this model is the first of its kind and probes the novel question of why there is a population of children who are LTI due to family refusal of services, existing approaches such as the social determinants of health provide one way of considering why these specific factors were selected by participants as drivers in the decision to not access early intervention services. These components can be seen across the five categories of the final model; however, the model developed in this study organizes the manifestations of each determinant based on how it presents in the community. This sets up future investigations to view these manifestations of determinants as actionable areas of change that are amenable to interpersonal interventions at the public health level and provides a foundation for understanding how the social determinants of health may be the drivers behind why these factors impact enrollment in early intervention. Each social determinant can be discussed and illustrated with elements from the final model (see Figure 3) and how it relates to Healthy People 2030 as a means of addressing health care inequalities due to the social determinants of health.

### ***Economic Stability***

The social determinant of economic stability is broadly centered around the Healthy People 2030 goal of helping people earn steady incomes that allow them to meet their needs, specifically health care needs (U.S. Department of Health and Human Services, n.d.-a). Conversely, economic instability and the inability to afford various health care needs detrimentally impact the health of individuals and their communities. In LTI, the concept is ever present in the perceived barriers related to concerns about the cost of accessing early intervention services. The statement from one respondent, “Depending on the state

and financial situation/economic background of the family, some early intervention services will come with direct costs for enrollment and tangential costs, such as that of transport, that limit accessibility of services,” hits at this concept and overlays of how economics can compound with other challenges, like limited access to transportation.

### ***Education Access and Quality***

Healthy People 2030 focuses on increasing educational opportunities for children and adolescents to address this determinant (U.S. Department of Health and Human Services, n.d.-b). When looking at the decision-making process in families who decline early intervention for children who are D/deaf and hard of hearing, the inverse holds true as not accessing intervention services creates challenges in accessing language and education. When applying this determinant to a family who declines early intervention services, the implications of not having access to educational opportunities, both in the past and in the moment, are to be considered. For example, the expressed comment by one participant of “There is a need for more accessible information on intervention, family support services, hearing-specific intervention services, and language acquisition to support families in understanding the benefits of early intervention for their child, and the psychosocial functioning of the family” may point to a lack of background education or literacy in terms of accessing written or presented materials about early intervention stemming from the types of educational opportunities the family was provided during their own development. At the same time, the need for increased educational opportunities for family is called for with the statement by a participant stating, “Multiple approaches are needed, as are attempts, to share information on and connect individuals to interventions and various service providers.”

### ***Health Care Access and Quality***

Increasing access to comprehensive and high-quality health care is the driver used to understand how this determinant can be used to improve community health and, in the case of this study, how access to early intervention can be supported when a child is identified as D/deaf or hard of hearing (U.S. Department of Health and Human Services, n.d.-c). Given that early intervention is a health care service, this determinant is present through the model. The primary manifestations of this determinant in the model are a call for more accessible content in terms of understanding and culture. The first two statements under family culture where the disconnect between families served and providers is highlighted and calls for improvement in provider–patient/family communication are made both in general and specifically when language

**Table 2.** Action steps developed in Phase 1.

Content				
Perceived barrier	Perceived cues	Perceived self-efficacy	Perceived benefits	Perceived seriousness
<p>Failure to make referral/data management</p> <ul style="list-style-type: none"> <li>• Transient families are hard to track</li> </ul> <p>System-level barriers in the way enrollment referrals are made and tracked.</p> <ul style="list-style-type: none"> <li>• Lack of trust in systems, government, professional <ul style="list-style-type: none"> <li>○ Privacy concerns</li> <li>○ Immigration status</li> <li>○ Families concealing preferences and home behaviors to not jeopardize services</li> </ul> </li> </ul> <p>Individuals and families may be uncomfortable or distrusting of involving themselves in state-run services</p> <ul style="list-style-type: none"> <li>• Need for multiple attempts to educate on EI</li> </ul> <p>Multiple approaches and attempts are needed to share information on and connect individuals to interventions</p> <ul style="list-style-type: none"> <li>• Need for increased accessibility</li> </ul>	<p>Unclear concept</p> <ul style="list-style-type: none"> <li>• Children may not provide behavioral cues to hearing</li> <li>• Rename to follow up support</li> <li>• Going forward, we will also have definitions of each category</li> </ul> <p>All components moved to other columns and this was removed. The use of the words cues was misleading.</p> <ul style="list-style-type: none"> <li>• Cues are location dependent; only some states have this challenge <ul style="list-style-type: none"> <li>○ Moved to barriers (with failure to refer)</li> </ul> </li> <li>• Move second cues to barriers <ul style="list-style-type: none"> <li>○ Moved to barriers</li> </ul> </li> <li>• Need for coordination with other services <ul style="list-style-type: none"> <li>○ Moved to barriers</li> </ul> </li> <li>• Need for connection with medical home <ul style="list-style-type: none"> <li>○ Moved to barriers</li> </ul> </li> </ul>	<p>Feedback that needs to be added</p> <ul style="list-style-type: none"> <li>• This is an overwhelming time for families</li> <li>• Parents need to see benefits</li> </ul> <p>Separate readiness from self-efficacy</p> <ul style="list-style-type: none"> <li>• Rename concept "Family Experience"</li> </ul> <p>Father comment is unclear</p> <ul style="list-style-type: none"> <li>• Removal</li> </ul> <p>Second parental readiness is redundant with other sections</p> <ul style="list-style-type: none"> <li>• Delete</li> </ul>	<p>Address parents who are DHH and do not do EI</p> <ul style="list-style-type: none"> <li>• Additional research on this population and move to new "Family experience"</li> </ul> <p>Stronger representation of perceived importance and motivation</p> <ul style="list-style-type: none"> <li>• Additional research on this concept and emphasize this in the descriptions.</li> </ul> <p>Not true that parents do not see that value in EI</p> <ul style="list-style-type: none"> <li>• Remove and reframe according to the point below</li> </ul> <p>Parents do not understand their role in EI</p> <ul style="list-style-type: none"> <li>• Reframe to get at this point</li> </ul> <p>Need to focus on language and the brain</p> <ul style="list-style-type: none"> <li>• Add to what needs to be more accessible</li> </ul> <p>Benefits are psychosocial as well</p> <ul style="list-style-type: none"> <li>• More research on thisWhere families get support (parent to parent, deaf mentor)</li> <li>• Fold in with the above point</li> </ul> <p>Need for hearing specific services</p> <ul style="list-style-type: none"> <li>• Add to what needs to be more accessible</li> </ul> <p>Providers not perceived as having needed skills</p> <ul style="list-style-type: none"> <li>• Research this question and fold in with comment below</li> <li>• Add</li> <li>• COVID-19 and remote services do not feel effective</li> </ul>	<p>Feedback that needs to be added</p> <ul style="list-style-type: none"> <li>• Does not make note of the variation in training for those doing diagnostics</li> </ul> <p>Add a comment here about how the structure might start with minimization</p> <ul style="list-style-type: none"> <li>• First cues to seriousness</li> </ul> <p>Reframe and move this here</p>

used in the home is not English. Of note is that access to early intervention services is a benchmark of Healthy People 2030 in terms of addressing this determinant (U.S. Department of Health and Human Services, n.d.-c).

### **Neighborhood and Built Environment**

The determinant of Neighborhood and Built Environment is addressed through the creation of neighborhoods and environments that promote health and safety (U.S. Department of Health and Human Services, n.d.-d).

It is noted in the literature that the U.S. population, and thus, the need for audiologists, is expected to continually increase, with the 65- to 85-year age bracket experiencing the most rapid growth (Windmill & Freeman, 2013). This increased need for audiologists could be felt across all age brackets as many providers provide care over the life course and the attrition of audiologists will further lessen access. Many of the challenges that are noted to be related to physical location are more so tied to forms of lost to follow-up that occur before intervention services are indicated such as diagnostic



**Table 2.** (Continued).

Content			Structure	
Perceived susceptibility	Culture	Special populations	Wording	Survey logistics
<p>Unclear concept: “statements should be under seriousness”</p> <ul style="list-style-type: none"> <li>Combine the two and make it about vulnerability</li> </ul>	<p>Feedback that needs to be added</p> <ul style="list-style-type: none"> <li>Lack of diverse providers</li> <li>Lack of diverse materials</li> <li>Lack of materials in home language</li> <li>Lack of cultural understanding</li> <li>Explicit inclusion of visual language</li> <li>Focus on amplification</li> <li>Spoken language and ASL are not mutually exclusive</li> </ul> <p>This is a new component that has been added</p>	<p>Feedback that needs to be added</p> <ul style="list-style-type: none"> <li>Thank you for including DeafPlus                             <ul style="list-style-type: none"> <li>DeafPlus as a different topic</li> </ul> </li> </ul> <p>Move this to new parental experience</p> <ul style="list-style-type: none"> <li>Unilateral hearing                             <ul style="list-style-type: none"> <li>Focus on good ear</li> <li>Not looking at impact of other ear</li> <li>Move this to about perceived susceptibility and see if there is more on these behaviors in bilateral hearing differences</li> </ul> </li> </ul> <p>This will not become a component as the comments here are folded in elsewhere</p>	<p>Model has negative tone</p> <ul style="list-style-type: none"> <li>Reframe</li> </ul> <p>Use of word parents</p> <ul style="list-style-type: none"> <li>Move to families where possible, where not parents/caregivers</li> </ul> <p>Wording is confusing</p> <ul style="list-style-type: none"> <li>Review each</li> </ul>	<p>Participant hearing status and language</p> <ul style="list-style-type: none"> <li>Too much that might reduce anonymity. Also, recruitment looks to create diversity in this specifically so it will not change</li> </ul> <p>Likert sections too similar across pages</p> <ul style="list-style-type: none"> <li>Reformat so that the difference key words are bolded.</li> </ul> <p>No options to select more than one</p> <ul style="list-style-type: none"> <li>Fix that</li> </ul>

Note. DHH = D/deaf or hard of hearing; EI = early intervention; ASL = American Sign Language.

**Table 3.** Likert data from Phase 1.

Category	Clinical utility		Quality of description	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Perceived seriousness	-1.96	0.9	-1.91	1.0
Perceived susceptibility	-2.24	0.8	-1.64	1.3
Perceived benefit	-2.46	0.6	-2.08	1.0
Perceived barriers	-2.12	0.8	-2.13	1.2
Cues	-1.56	1.3	-1.26	1.3
Self-efficacy	-1.74	1.1	-1.62	1.2

**Table 4.** Comments from Phase 2 (*n* = 25).

Participant	Copyedit	Add specific example of existing idea	Clarify present idea	Remove specific examples of existing ideas	Linguistic choice
Noted researchers/ academics	Copyedit Need more concise Cannot read Design of graphic	Some parents may believe that their child does not have a need for services Concern that the child is taking services from others Concerns about labeling a child so young Concerns with skills of providers	Providers lacking specialized training Training for professionals on equity, diversity, and inclusion Lack of understanding of parental benefit of EI Unclear comments about parents of children who are D/deaf and hard of hearing themselves Define “adequate” in concerns about providers More clarity with feelings mentioned post diagnosis Some comments could be interpreted as being about screening rather than EI as intended Impact of unilateral needs to be more clear Separate ideas in second bullet of benefits Concerns if statement on the cost is true Edit section of DeafPlus	Removed EHDI from list of places where info is needed Remove COVID-19 reference (this is transient) Medical home does not fit in this discussion	Deaf gain language
Those employed within EHDI		Concerns with skills of providers Physicians not responding to severity	Parents think costs are higher than they are What if the parents do not have access to peers? Parents do not see a benefit of the service Parental denial		More open to all communication modes Remove the word deprivation
Family members/ self-advocates	Copyedit	Educational background Economic background Accessibility of communication for parents Financial Access Cost of transport Idea parents have that child note not have needs Concerns with skills of providers EI providers not responding to severity	Internal systematic barriers Providers lacking specialized training The statement of utility of unilateral and mild are true Statements do not always fit with groups Perceived health risks	Remove COVID-19 reference (this is transient)	More open to all communication modes
Did not indicate	Cannot read Copyedit				Remove the word deprivation

*Note.* EHDI = early hearing detection and intervention; EI = early intervention.

**Figure 3.** Final model. EHDl = early hearing detection and intervention.

**Family Culture:** The intersection of an individual or family's cultural identity along with the decision to enroll in early intervention services

- The current make-up of the profession and common materials do not match the cultural, linguistic, and educational diversity that is represented by the families eligible for early intervention.
- Providers may not exhibit cultural understanding of each family's unique situation.
- There is a need for the inclusion of all forms of communication (visual, auditory, and tactile) as opportunities that are not mutually exclusive.

**Family Experiences:** The unique experiences and feelings that families bring into their decisions about medical care and enrolling in early intervention services

- Parents/caregivers and families who are D/deaf and hard of hearing themselves comprise a population that is underrepresented in the research. These individuals may bring their own experiences that shape their early intervention enrollment decisions.
- Families may be uncomfortable or distrusting of involving themselves with state-run services or with providers they perceive as inadequately skilled in providing services to children who are D/deaf and hard of hearing.
- Families may experience a range of emotions during the process of early identification and intervention. This range may include the expression of stress, grief, happiness, denial, guilt with accessing services in the place of others, and concerns about labeling a child at such a young age.

**Perceived Vulnerability:** The perceived risk and seriousness of not ensuring access to language following identification combined to form the perceived vulnerability of a family to adverse outcomes

- Results of testing and information, specifically about how sensorineural hearing levels are typically permanent, are not presented in a way that can be understood by families.
- When referrals are made or information about how hearing levels of any degree or laterality can impact the developmental trajectory for a child is presented, it is not done so in a way that families understand. Conversely, providers in early intervention systems and physicians may not be responding to the severity and critical nature of accessing support.
- There are few natural components to the environment to remind families when a child is identified as D/deaf or hard of hearing that early intervention may benefit them since many families and individuals do not have any experience with hearing differences.
- Families of children with unilateral hearing differences may focus on the ear with auditory access and not see the need for services to support the child.

**Perceived Benefit:** The possibility to address adverse impacts of reduced access to language and perceptions about the feasibility of achieving those positive outcomes

- Families may not understand their role in early intervention as a way of supporting their child's development.
- There is a need for more accessible information on intervention, family support services, hearing-specific intervention services, and language acquisition to support families in understanding the benefits of early intervention for their child, and the psychosocial functioning of the family.
- Families have concerns about the ability of providers to meet their child's needs and produce benefit especially when faced with other perceived health risks.

**Perceived Barriers:** The elements of enrolling in early intervention that make accessing early intervention more challenging or be perceived as a negative of enrolling

- Current educational materials for families and early intervention system structures may not be comprehensible to families. There is a need for more information on early intervention topics presented in formats that are accessible.
- Depending on the state and financial situation/economic background of the family, some early intervention services will come with direct costs for enrollment and tangential costs, such as that of transport, that limit accessibility of services.
- The presence of medical complexity, risk factors, and additional disabilities complicates the process of accessing services, and those who are a part of the DeafPLUS community may feel like a separate population.
- The structure of state-level early intervention and EHDl systems may impact how enrollment referrals are made and how families are tracked.
- Multiple approaches are needed, as are attempts, to share information on and connect individuals to interventions and various service providers.

services where IDEA policies on natural environments do not apply. While not heavily represented in this model, due to the type of lost to follow-up under investigation, it is critical to remember that this determinant can work with other determinants, such as economic

instability and increased travel needs for individuals living in more rural locations (Coco et al., 2018) that creative family-centered problem solving is trying to address. Demonstrating one creative solution to this concern is the use of telehealth services such as that coming out

of Cincinnati Children's Hospital (Evans et al., 2021; Steuerwald et al., 2018).

### Social and Community Context

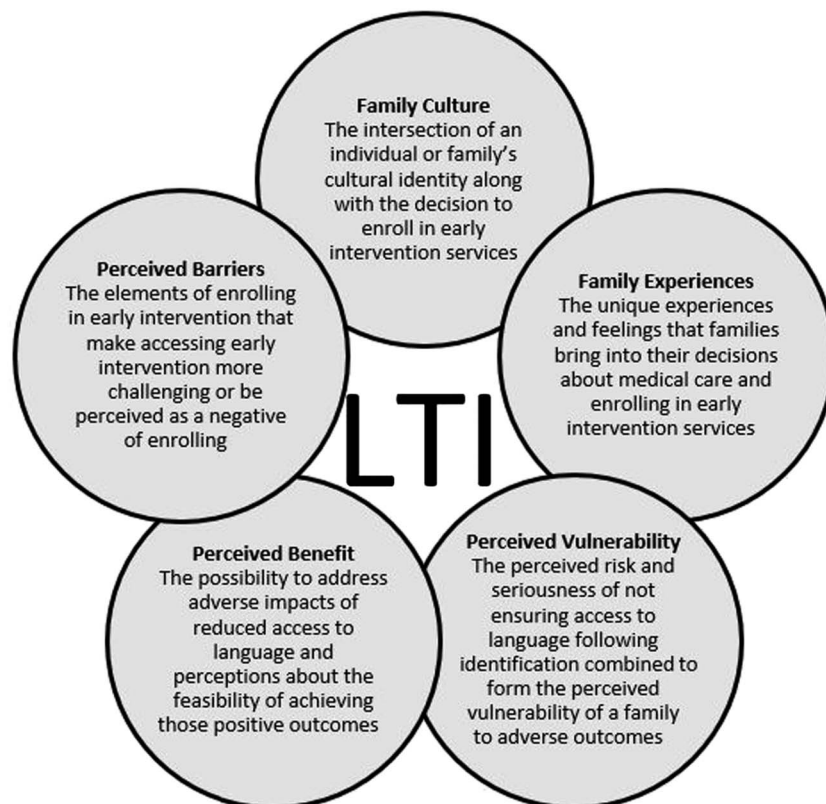
The determinant of social and community context is focused on how support and empowerment is transmitted within a community (U.S. Department of Health and Human Services, n.d.-e). To address this, Healthy People 2030 has the goal of increasing social and community support, similar to all the concepts endorsed as elements of family experiences in this study. How individual families and communities view early intervention services shapes involvement and how comfortable families are reaching out to state services for intervention or the ease they have finding social supports that are called for to address barriers present in family conceptualizations of perceived benefit as outlined by Point 2 of this section: "There is a need for more accessible information on intervention, family support services, hearing-specific intervention services, and language acquisition to support families in understanding the benefits of early intervention for their child, and the psychosocial functioning of the family."

The components in this model reinforce that the challenges associated with LTI are unique from those of lost to screening and lost to identification and the current logistical focus on care coordination does not address all factors in play. Instead, the focus for LTI intervention must be family centered with attention paid to the lens in which a family exists (culture and experience) and their perception of services and needs related to hearing.

### The Abridged Model

An abridged version of the model was also developed based on the results of Phase 2. This model (see Figure 4) includes the major categories and definitions only. The sub examples are not included to allow for a more straightforward presentation of the key components. The removal of sub examples in this abridged version of the model may provide states, agencies, and individual providers the flexibility to apply this model while keeping with a family-centered and individualized approach to supporting decision making on early intervention enrollment. By retaining only the key components and descriptors, the abridged models can be used as a starting point for future works looking to tailor this model to specific populations.

Figure 4. Abridged model. LTI = lost to intervention.



## Future Directions

This model is poised for use in creating, implementing, and evaluating programs that support children and their families during the start of their early intervention journey. By understanding the drivers of what leads to LTI, and specifically focusing on why a family may decline services, interventions to support these individuals can be developed. This model will serve as the foundation for developing Woodruff Cienkowski's (2023b) "Swaddling Ear to Ear," a research-based, family-focused, data-driven parent education module to support early intervention enrollment. As the focus on supporting each family through the entire EHDI system continues to grow, the focus on LTI interventions will increase. Future work should consider the impact of each factor in the model to determine the relative effect of each discrete component. This future direction will provide a further strengthened foundation for future efforts to address model components and support early intervention enrollment.

Within the EHDI system, each state can structure its program to fit the needs and laws of that state. However, the population pulled for this study was from the national level. Moving forward, states can create their own focus groups or capitalize on task forces and boards already involved in EHDI to help refine the model to meet the circumstances in their state, specifically in terms of the EHDI system and noted challenges. As with any work, this model is a consensus for our identified experts and will benefit from cultural tailoring and family-centered implementation.

## Conclusions

Having a model of LTI that highlights the intrinsic differences between the various forms of lost to follow-up in EHDI is critical for understanding the unique situation and positionality of every family. This model is a step toward family-centered care and responsive interventions to meet each family where they are within EHDI, be that screening, identification, or intervention. This study joins the growing collection of research in speech, language, and hearing sciences that implement the Delphi method. The Delphi method's qualitative applications provide space for stakeholders in the EHDI system (parents, self-advocates, care providers, care coordinators, and program implementers) to provide meaningful feedback and genuinely engage in systems change work as intended within the EHDI legislation.

## Data Accessibility Statement

Due to the nature of this research and the small pool of experts, the risk of participant identification has

been deemed a primary risk; thus, supporting data are not available.

## Acknowledgments

The Educational Audiology Foundation awarded Torri Ann Woodruff-Gautherin, personally, the Student Research Award following completion of the study. The development of this article was supported, in part, by funding from the U.S. Department of Health and Human Services, Health Resources and Services Administration (Award T73MC30115) and the U.S. Department of Health and Human Services, Administration for Community Living, Administration on Intellectual and Developmental Disabilities (Award 90DDUC0071) awarded to the University of Connecticut Center for Excellence in Developmental Disabilities Education, Research, and Service. The opinions expressed, however, are those of the authors and do not necessarily reflect the official position of the departments. This work was completed as part of Torri Ann Woodruff-Gautherin's bound dissertation. Her committee, Bernard Grela, Beth S. Russell, Kim Gans, Sarah Woulfin, and Mary Beth Bruder and her major advisor Kathleen Cienkowski provided vital feedback and support over the course of this and many other projects. Melissa Karp was a critical resource and aid in the development of the sample, analysis of the data, and interpretation of results.

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<b>Family Culture</b>	<b>The intersection of an individual or family's cultural identity along with the decision to enroll in early intervention (EI) services</b>
<ul style="list-style-type: none"><li>•The current make-up of the profession and our materials do not match the cultural and linguistic diversity that is represented by the families that are eligible for early intervention</li><li>•Providers may not exhibit cultural understanding of each family's unique situation</li><li>•There is a need for the explicit inclusion and integration of visual language into EI that includes it and spoken language as not mutually exclusive options.</li></ul>	
<b>Family Experiences</b>	<b>The unique experiences and feelings that families bring into their decisions about medical care and enrolling in EI services</b>
<ul style="list-style-type: none"><li>•Parents/caregivers and families who are D/deaf and hard of hearing themselves represent a population that is under-represented in the research. These individuals may bring their own experiences that shape their EI enrollment decisions</li><li>•Families may be uncomfortable or distrusting of involving themselves in state-run services or with providers not perceived as adequate</li><li>•Early identification may lead to the experience of shock/stress along with grief if this is not a hoped for finding. This can be an overwhelming time for families and this may impact their ability to begin the EI process</li></ul>	
<b>Perceived Vulnerability</b>	<b>The perceived risk and seriousness of not ensuring access to language following identification combine to form the perceived vulnerability of a family to adverse outcomes</b>
<ul style="list-style-type: none"><li>•Results of testing and information about how sensorineural hearing levels are typically permanent are not presented in a way that can be understood by families</li><li>•When referrals are made, or information about how hearing levels of any degree or laterality can impact the developmental trajectory for a child is presented, it is not done so in a way that families understand. Conversely, because of the variability in who counsels on screening results, the importance of this may not be highlighted</li><li>•There are few natural components to the environment to remind families when a child is identified that that early intervention may benefit them since many families and individuals do not have any experience with hearing</li><li>•Families of children with unilateral hearing differences may focus on the ear with access and not see the impact of decreased access</li></ul>	
<b>Perceived Benefit</b>	<b>The possibility to address adverse impacts of language deprivation and perceptions about the feasibility of achieving those positive outcomes</b>
<ul style="list-style-type: none"><li>•Families may not recognize their role in EI services as a way of supporting their child's development</li><li>•There is a need for more accessible information on intervention, family support services, EHDI, hearing specific intervention services, and language in the brain to support families in understanding the benefits of EI for their child and the psychosocial functioning of the family</li><li>•Families have concerns about the ability of providers to meet their child's needs and benefit, especially in the time of COVID-19</li></ul>	
<b>Perceived Barriers</b>	<b>The elements of enrolling in early intervention that make accessing early intervention more challenging or is perceived as a negative of enrolling</b>
<ul style="list-style-type: none"><li>•Current educational materials for families and intervention system structures may not be comprehensible to families of children and there is a need for more accessible information on early intervention topics</li><li>•Depending on the state and financial situation of the family, some EI services will come at a cost</li><li>•The presence of medical complexity, risk factors, and additional disabilities complicate the process of accessing services and those who are a part of the DeafPLUS community may feel like a separate population</li><li>•The structure of state-level EI and EHDI systems may impact how enrollment referrals are made and how families are tracked</li><li>•There is a need for multiple approaches and attempts are needed to share information on and connect individuals to interventions, various service providers, and medical homes</li></ul>	

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