



**PUBLIC INPUT  
CLERC CENTER**

# **Public Input 2018 Survey Findings: Lack of Understanding as a Barrier to Deaf and Hard of Hearing Children's Development and Potential**

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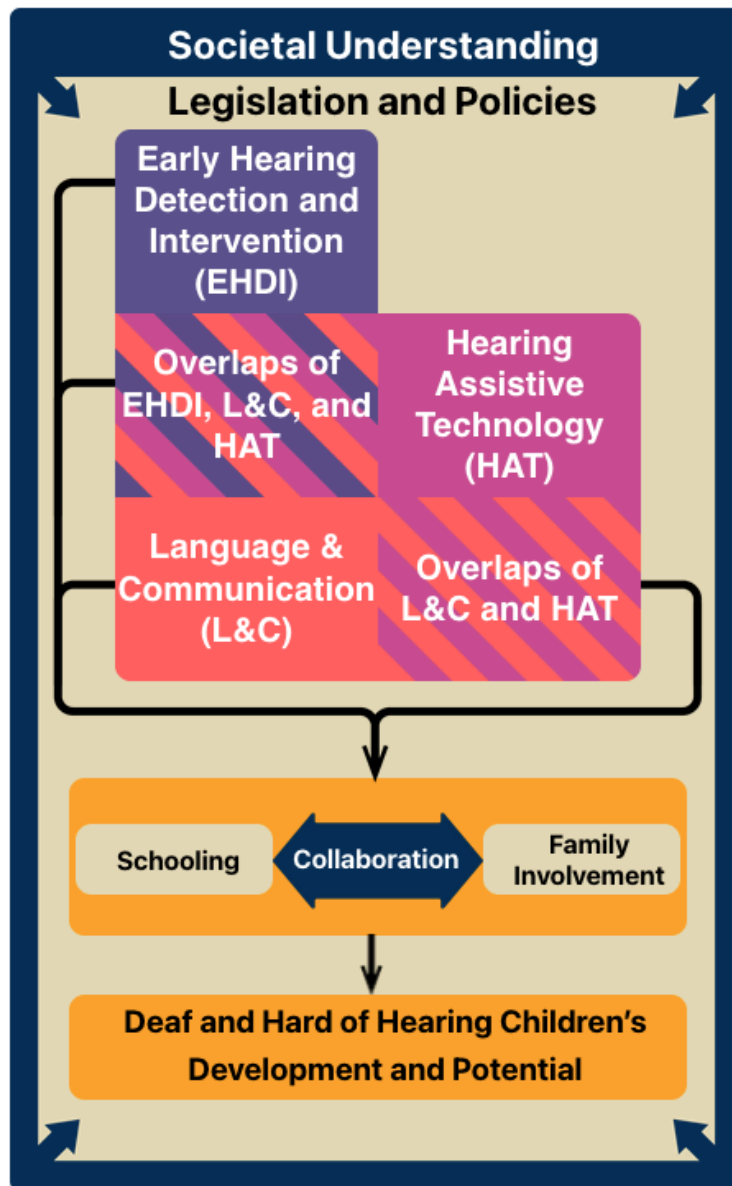
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### Overview

The Lack of Understanding model is an interpretation based on respondents' feedback about "Lack of Understanding," one of the 14 barriers identified in the national public input survey disseminated by Gallaudet University's Laurent Clerc National Deaf Education Center in 2017 and 2018. Respondents include parents and caregivers of deaf and hard of hearing children as well as professionals who work with those children and families. This survey asked respondents to comment on the barriers that prevent deaf and hard of hearing students from achieving their academic, linguistic, and socio-emotional potential. Lack of Understanding was one of the identified barriers, and

respondents discussed how there are varying levels of understanding regarding the needs of deaf and hard of hearing students and how the variation impacts their overall development and their capacity to achieve their highest potential.

This starts with Societal Understanding, a general perspective of deaf and hard of hearing people, which impacts seven categories:

1. Legislation and Policies
2. Early Hearing Detection and Intervention (EHDI)
3. Language and Communication
4. Hearing Assistive Technology (HAT)
5. Family Involvement
6. Schooling
7. Collaboration

Societal understanding consists of perspectives, experiences, and knowledge of various people and groups. These influence how legislation and policies are ratified and enacted. The mandates of Legislation and Policies influence how EHDI systems are coordinated and implemented, how HAT is emphasized and provided, and how the language and communication needs of deaf and hard of hearing children are met. This impacts resource allocation and information sharing among families and educational professionals about language and communication and HAT. In turn, how families and educational professionals collaborate is influenced by the aforementioned categories in what they understand and what they can access; this affects their perspectives on how to support deaf and hard of hearing students and how to work together. This leads to knowledge needs, including training, education, more effective resource allocation, and information sharing, ultimately impacting the development of deaf and hard of hearing children and their ability to achieve their fullest potential.

All these categories influence families with various backgrounds in different ways, including those who are considered part of traditionally underserved groups (TUGs). The Lack of Understanding model shows how these categories are interrelated, and this relationship is elaborated on below. Each category will be discussed individually, and then the overlaps (shown in diagonal strips) and relationships among these categories will be elaborated on.

### **Societal Understanding**

Beginning at the top of the model, the overarching category that shapes all other categories is the societal understanding of what it means to be deaf or hard of hearing. Lack of understanding about deaf and hard of hearing children—both as individuals and as a part of a community—begins with society, which includes families, professionals working with deaf and hard of hearing children and their families, government officials (e.g., legislators), decision makers, potential employers and work environments, local

communities, and the general public. Respondents discussed that being deaf or hard of hearing is a “low-incidence” occurrence, contributing to society’s limited knowledge and experience regarding people who are deaf or hard of hearing. These limitations also are associated with negative biases about those who are deaf or hard of hearing, highlighting the need for resources, training, and collaboration to improve understanding of these individuals. Better understanding can lead to more effective support and a greater willingness to meet the needs of deaf and hard of hearing children, helping them achieve developmental milestones.

Examples of responses related to societal understanding:

*“... In general, society has a lack of understanding about the needs of D/HH [deaf and hard of hearing] people. When the parents have a lack of understanding, they are unable to advocate appropriately for the needs of their child ....”*

*“The hearing still consider deaf people novelties. Due to this lack of understanding, unless the child’s parents are deaf, there are no expectations, little to no family involvement and support. The child is thus deprived of any meaningful communication early in life ....”*

*“... Lack of understanding - I feel we still need to educate the public regarding deaf education and how it is very different from regular education and special education. With continued education on the public, I think the perspective and attention will change/improve ....”*

*“We [hearing people] expect too little of the deaf and hard of hearing. Most people have had very little exposure to either (with the exception of elderly relatives) ....”*

*“The hearing world does not understand hearing loss. And they cannot imagine the daily and hourly impact on the DHH. So they don't know how urgent the problem is and what needs to be done ....”*

*“Lack of adequate and appropriate resources, alongside years of misconception and misguidance, creates many barriers for all involved ....” (Parent)*

*“I think everyone expects [deaf and hard of hearing] students will not do as well as others, but with early screening and proper technology like CART, the students can achieve as well as hearing students.”*

*“Hearing loss is a very low incidence disability, so there’s a lack of understanding ....”*

*“Many hearing people out there really lack understanding of deaf meaning, ASL meaning, and their culture! Deaf people’s language is ASL, mean[ing] their communication [is a] possible struggle for hearing people to understand .... Many jobs and others barely hire or allow deaf people [to] join/get [a] job due [to the fact that] deaf[ness] is considered [a] disability. They need to understand that deaf people are not disabled. They just can’t hear and speak, that’s all! We all are human beings. That is #1 that they need to work on that!!”*

## **Legislation and Policies**

A lack of understanding about effective legislation and policies (which is the next category in the Lack of Understanding model) has adverse impacts on deaf and hard of hearing children and their schooling (e.g., school placement and accommodations). Some of this legislation includes the Individuals with Disabilities Education Act (IDEA), and Individualized Education Programs (IEPs). This section specifically focuses on formally enacted legislation and policies and the need to review them to better benefit deaf and hard of hearing students, their families, and the professionals who work with them.

Respondents discussed the need to address this lack of understanding and recommended more interactions between decision makers and deaf and hard of hearing individuals, specifically having deaf and hard of hearing individuals lead some of the decision-making efforts. Legislation and policies appear frequently in quotes in different sections, demonstrating how these legislation and policies were implemented without an in-depth understanding of how to best support deaf and hard of hearing students and their families. Therefore, there is a need to establish better legislation and policies to support these families and their children. As a result of this need, deaf and hard of hearing students, their families, and the professionals working with them experience more challenges in ensuring these students achieve their fullest potential. The prevalence of legislation and policies shows the overall impact of the Legislation and Policies category on the next six categories.

Examples of responses related to legislation and policies:

*“... [The state] needs to allow the deaf professionals/interns to interact within the building so that’s where the lawmakers will better understand about the spectrum of deaf (i.e., hearing loss, hearing impaired, modes of communication, and so on) ....”*

*“... First, national and state policy and legislation drive funding and create laws that positively or negatively affect our d/hh population. The lack of understanding in this sector puts our students [at] a grave disadvantage. As a country, we do not give our d/hh students what they need; they are provided the minimum,*

*sometimes the bare minimum. Their needs are not valued due to lack of education by lawmakers and the Department of Education ....”*

*“... Government needs to understand D/HH students’ needs and better funding for schools in order to provide our students with quality education, resources, etc., ....”*

*“... However, one of the biggest hurdles is policy and legislation. When deafness is viewed from a medical perspective, as something to be fixed, little about deafness and language is truly embraced or celebrated and laws are enacted that do more to hinder rather than help fix a broken system.”*

*“The number one barrier is the lack of ASL input from birth, or as soon as hearing loss is detected. This is the watershed moment—the moment when a child’s ease of success will be determined by the parents and the services rendered at that time. The intensity of all else that follows is dialed up and down by that alone. Children with disabilities on top of deafness have an even harder time and need appropriate services as early as possible. The barrier is made worse by lack of awareness of Deaf issues at the state level of government. Selfish ambition of politicians and political in-fighting is detrimental to state schools for the deaf. For example, a hearing superintendent is chosen to run the state Deaf system simply because they happen to have policy experience, are the right political party, and have an inside track, rather than hiring actually qualified, Deaf or Deaf-intelligent-and-aware people who can see and label issues within the Deaf delivery system and make appropriate, swift changes ....”*

*“... Policy and legislation will need to be learning more about Deaf culture, and deaf and hard of hearing [people] need to teach the doctors who favor their CI [cochlear implant].”*

### **Early Hearing Detection and Intervention**

An important category identified by respondents regarding lack of understanding is Early Hearing Detection and Intervention (EHDI), as shown at the top left of the Lack of Understanding model. Some families and EHDI professionals lack understanding about how to best support deaf and hard of hearing infants at every stage, from hearing screening assessments to service provisions. Respondents shared that families may not fully utilize what EHDI has to offer due to a lack of awareness and understanding of what it entails and the implications for their deaf or hard of hearing children, such as the need for early language acquisition or for the follow-up appointments and therapy after cochlear implants. Similarly, some EHDI professionals lack the necessary experience, knowledge, and training to work effectively with deaf and hard of hearing children and their families. Some respondents discussed that these professionals, including affiliated medical professionals, may be biased toward a disability lens, disadvantaging deaf and

hard of hearing children. For example, they may not understand the benefits of American Sign Language (ASL) for early language acquisition. This lack of understanding and bias impacts how some professionals support families, thus influencing how families can support their deaf or hard of hearing children's ability to reach their fullest potential. The connections of EHDI with Language and Communication and HAT will be elaborated on later in this report.

Examples of responses to related to EHDI:

*"... We do know aggregately, though, that children with mild and unilateral hearing are much less likely to receive services, and sometimes this is due to lack of understanding by early intervention."*

*"Early childhood intervention staff are not well trained in working with children who are D/HH, and this can create problems with IFSP [Individualized Family Service Plan] meetings, outcomes, and developmental services to children and families. Because of this, expectations can be low because these professionals don't know what appropriate expectations are when it comes to hearing status ...."*

*"The first agency to have access to children identified as having a hearing loss are the people the parents trust. In some states, these agencies and the itinerant teachers for DHH or EHDI case workers are overseen by individuals who have zero training in working with DHH babies/children/adults. This is an enormous disservice to parents who do not know better. Often, these agencies evaluate the needs of children based on to what capacity that agency can serve the children as opposed to evaluating what the child actually needs. These biased assessment practices undoubtedly bar DHH students from achieving their academic, linguistic, and social-emotional potential ...."*

*"Even with universal newborn hearing screening, there is a challenge of appropriate follow-up with families who refer on the newborn screen. Many families do not understand the importance of returning for a diagnostic hearing evaluation to confirm the child's hearing levels. This is a barrier to appropriate services. Additionally, many families with young children who are identified as deaf or hard of hearing do not receive appropriate interventions when their child is young. This is due to lack of understanding of the importance of services [and] also to lack of qualified direct service personnel. So many of the providers who serve young d/hh children do not have adequate training in early intervention with specific content knowledge in the needs of d/hh children."*

*"I work for the [state] EHDI program and realize the problems associated with acceptance, lack of understanding, and support for the parents' experience."*

*Oftentimes parents are in denial about possible hearing loss and the need to get early detection and intervention, which delays their child's speech and language."*

*"... Early intervention - I think it would be beneficial to continue to train teachers, develop materials, and teach strategies that help parents realize the importance of early intervention and that their early involvement is key to their child's success ...."*

*"... Parents do not get a full range of options from providers, but often get what the provider knows or supports themselves. Thus parents are not always informed consumers for their infants. This affects the education of their children as they age thru the system ...."*

*"Due to the lack of language at an early age, due to not having early intervention, ignorance of deafness, and/or a home environment that utilizes ASL the child that is deaf or HH will not achieve their full potential ...."*

*"... There is poor understanding by physicians and families as to what to expect, and there aren't enough qualified providers to educate and support the families ...."*

## **Language and Communication**

A crucial role in the development of deaf and hard of hearing children is language and communication, shown at left in the Lack of Understanding model. Respondents discussed how there is limited understanding regarding the language and communication needs of deaf and hard of hearing children, students, and those in different workplaces. Addressing how to communicate with these individuals and how to ensure they meet age-appropriate developmental milestones (e.g, the need for ASL) is imperative for potential achievement. Further, there are misconceptions about how much deaf and hard of hearing children can understand or access language in their immediate surroundings, and this may cause miscommunication and limited access for them. Additionally, respondents shared how language acquisition can impact other developmental milestones, including academic and socio-emotional skills. The Language and Communication category overlaps with the EHDI and HAT categories, which will be elaborated on later in this report.

Examples of responses related to language and communication:

*"... lack of understanding why students who are mainstreamed with no language do not improve greatly."*

*“... Lack of knowledge of the language and communication acquisition of a D/HH child, as this relates to literacy in understanding word meanings ....”*

*“Lack of understanding about speech and language development ....”*

*“... I believe that lack of understanding of ASL as a study of language and as a language of instruction impedes our Deaf/HH children’s development ....”*

*“Language and communication can be a huge barrier, particularly because DHH students must learn two languages in order to read and write, which are two necessary skills for success in school. So many people do not realize this. Literacy is directly tied to that, and if DHH students are expected to perform at the same level as students who have grown up with English and are reading, writing, and completing assignments in English, the DHH students are at a complete disadvantage. When people don’t recognize that DHH students must work harder to learn a second language, they may think DHH students are performing at a lower level when in fact they are working twice as hard.”*

*“... Too many deaf/hoh children are assumed to be hearing all the words spoken because they “look” like they are listening ....”*

*“In my experience as a parent of a deaf high schooler with additional disabilities, one of the big problems is that hearing people forget she is deaf and do not do even the simple things that would improve communication and understanding: facing, getting attention, talking clearly. They also think/ behave as if just using the same English—but louder/slower—will fix everything without understanding the language and general knowledge gaps that deaf individuals frequently experience. This affects all aspects of life: academic instruction, extracurriculars, and social interactions ....” (Parent)*

*“Collaboration - Often we feel left out in groups. Language and communication - There were many times we needed hearing people to repeat, and sometimes hearing people would say, “Never mind,” or they [would] refuse to repeat. In groups, no one wants to interpret for me since I’m hard of hearing. People would question me [about] how come my voice sounds funny ....”*

*“... Given 90% of DHH children have parents who are hearing and don’t know ASL, the assumption that ASL will be these children’s first language is not always accurate ....”*

### **Hearing Assistive Technology**

The hearing assistive technology (HAT) category is shown in the Lack of Understanding model on the right side. Deaf and hard of hearing students are often provided with HAT.

However, respondents shared that there are varying levels of understanding and misconceptions about these technologies. For example, there is a lack of understanding of the appropriate use and maintenance of HAT. Additionally, there are incorrect assumptions that HAT is a “cure,” leading professionals and families to treat deaf and hard of hearing students as if they have typical hearing. These issues show that even with HAT provisions, there are issues that need to be addressed. This includes recognizing the high costs of HAT and the implications for families with a low socioeconomic background. Due to lack of understanding and misconceptions, some deaf and hard of hearing students may struggle to access information they need. This category is closely connected with the Language and Communication category, which will be elaborated on later in this report.

Examples of responses related to HAT:

*“... Kids are expected to aurally listen (even get publicly yelled at for ‘not listening’) with nobody checking their hearing aids on a regular basis ....”*

*“In my community, the current, popular, and wrong assumption is that any school can teach a DHH child as long as there is an FM.”*

*“... Regular education teachers do not fully understand what a student who is deaf/HH can do and that CIs and hearing aids are not like glasses.”*

*“... Regular education teachers don’t understand that hearing aids don’t magically mean students hear ‘like normal,’ that hearing aids or an FM don’t make speech clearer, or that they can’t process rapid speech as well as their hearing peers ....”*

*“Expectations: Adults who work with deaf/hard of hearing children, in cases where the children wear assistive listening devices like hearing aids/cochlear implants, don’t understand that it is imperfect technology [and] that it does not correct the hearing loss and make the child hear perfectly. So, often caregivers, teachers, etc., will think, “I KNOW he/she can hear me!” when, really, the child cannot hear them. But these adults hold the belief that the child can hear them because of their expectations of what the technology in the listening devices should provide ....”*

*“... Hearing aids are usually lower-end and are not maintained well. Most of my students did not receive amplification till [age] 3-4 and had inconsistent usage until school.”*

*“... Many families and other professionals aren’t quite aware of the limitations of how much aided gain the hearing aid device/FM system/cochlear implants really gives our students ....”*

*“... families have chosen cochlear implants and did not do any follow-up therapy; they thought the implants made their children hearing, etc., ....”*

*“... Many low and middle income families struggle to pay for hearing aids and are unclear about why they’re so important, especially for use by children younger than school age and for school-age children outside of school hours ....”*

## **Family Involvement**

Another category in the Lack of Understanding model is Family Involvement, which is found at the lower right. Respondents highlighted that families often lack understanding of how to meet the needs of their deaf or hard of hearing children and how to best support their children’s development, impacting how they are involved and provide support. For instance, they might not recognize the benefits of learning ASL or the importance of following up after cochlear implantation. Respondents emphasized the critical role of family involvement, noting that many families lack prior experiences with deaf or hard of hearing children and require information, resources, and support so they can make well informed decisions. Additionally, societal biases against deaf and hard of hearing individuals can misinform families, affecting their perception of their children’s abilities and how to support them. Further, families may be unfamiliar with relevant legislation, such as the Americans with Disabilities Act (ADA), and how to advocate effectively for their deaf or hard of hearing children.

Examples of responses related to family involvement:

*“Many families are making decisions based on the first experts they meet. Information should be discussed in totality so the parents understand the various outcomes upfront. This way when things don’t ‘pan out’ as planned, they are not going through the process of acceptance all over again. I’ve seen it many times that parents are devastated because they are not aware of all options available and have a hard time when different paths are necessary to help their child receive the education that is better suited to their needs.”*

*“It starts with the parents. If the parents don’t believe the diagnosis or are too consumed by grief or disbelief, they cannot move forward with education and obtaining resources. If the parents are willing to move forward but have friends and family who are not supportive based on lack of understanding, it can hinder the timeline of acquiring needed resources.”*

*“Had I known about my son’s deafness sooner, I believe he would have had his hearing impairment assessed sooner. I had expected him to be talking by the time he was 3 or sooner. It was hard to accept his deafness because we didn’t know anything about it. My whole family was affected by it ....”*

*“... Translated materials for families to understand the impact of deafness and additional disabilities on their child’s future opportunities post high school.”*

*“In my area, families are most often from a lower socioeconomic class. They do not have the knowledge or resources to understand the special needs that children with hearing loss have as they develop language and enter school ....”*

*“... Once diagnosed, it’s important that family members and care providers understand the level of hearing loss and what that means for day-to-day activities so they know how best to communicate and teach the child ....”*

*“... Parents need to learn about ADA law. I do not think many parents are aware of the ADA law and their rights ....”*

*“... Family involvement/support/lack of understanding: Many times, we see families who are far too dependent on the system/government to ‘fix’ or ‘provide’ when, in reality, they hold the power to be the change agents in their homes ....”*

*“... Parents understanding options available to them in an unbiased fashion is also crucial ....”*

*“Family involvement, support, and lack of understanding - Some families are still not comfortable with the various modes of communication offered (e.g., ASL, Cued Speech). They are uncomfortable engaging in the Deaf community or not familiar with Deaf culture. They don’t know where to turn to get the best information for their youngsters. Families with students with disabilities might have no time to engage or participate in various activities or professional development due to working overtime to support their children.”*

*“... There are times that misinformed family members do not have the appropriate resources to help themselves in the community, so a more aggressive outreach would definitely play a significant role ....”*

## **Schooling**

A component of Lack of Understanding that respondents discussed is Schooling, shown on the left lower part of the model, which refers to formal educational contexts (e.g., classroom, mainstream programs), teaching methods or approaches, and the system of meeting the academic needs of deaf and hard of hearing students.

There is a dearth in knowledge, understanding, and experience regarding education of deaf and hard of hearing students and those with additional disabilities in schooling. This

lack of understanding impacts the decisions made by legislators and administrators at the state and school levels in the best interest of deaf and hard of hearing students, such as enacting IDEA requirements. These decisions influence schools from hiring practices to resources allocation, including obtaining resources that are not designed for deaf and hard of hearing students. As a result, these students may not obtain the support or resources they need academically and linguistically.

Additionally, there are educational professionals ranging from school administrators to audiologists, especially those in general education or mainstream settings, who may lack the needed knowledge to work with deaf and hard of hearing students. Some respondents discussed that there are low expectations, misconceptions, and assumptions about these students' abilities and behavior, leading to academic difficulties and limited language and communication access for deaf and hard of hearing students.

A few respondents discussed how some of these professionals are not fluent in sign language and may not understand the importance of language accessibility and cultural awareness. Other respondents shared a concern about peers and how their lack of understanding may negatively affect how they interact with deaf or hard of hearing students. Some of the aforementioned concerns may be influenced by a lack of university programs or inadequate academic curriculum, which may be more acute in rural areas.

An important part of meeting and supporting deaf and hard of hearing children's needs is to understand how their educational experiences and performances can be connected to their hearing levels in different ways. Further, it is important to understand the unique needs of deaf and hard of hearing students and ensure those needs are met. This includes:

- Setting up and implementing IEPs
- Ensuring appropriate assessment and educational placement
- Adopting best instructional practices
- Promoting incidental learning and peer socialization opportunities
- Collaborating more effectively
- Providing and using accommodations (e.g., interpreters) appropriately

Examples of responses related to schooling:

*"I think one of the biggest barriers for students who are deaf or, as in my case, hard of hearing is the lack of understanding from peers. Many students, in grade school or high school, are not familiar with hearing loss. This can lead to the child with hearing loss facing ridicule or bullying from peers. Additionally, an important part of standardized testing or gaining information from class is based on listening. This may also present barriers in understanding important tasks or concepts for students with hearing loss."*

*“... Often the direct service personnel are not able to communicate effectively with children (or parents who are themselves DHH) and are also not familiar with Deaf culture and the Deaf experience (Deaf history, norms of behavior, audism, oppression, discrimination, etc.).”*

*“... Often school personnel have a lack of understanding of the impact of hearing loss on students as well as a lack of understanding that cochlear implants are not a ‘cure.’ ...”*

*“... having individuals supervise DHH programs when they have no knowledge of Deaf culture, DHH methodology, DHH curriculum, or ASL.”*

*“... Curriculum, instruction, assessment/lack of understanding: Many public schools are not aware of curricular opportunities for DHH students and/or are not willing to purchase. Many are unaware of the special assessment needs of our students ....”*

*“... Additionally, the lack of understanding in the mainstream about how deaf/hh students are not all the same is crippling. Different students need different services (inherent in the IEP process) but [these are] missed by cookie cutter style mainstream programs.”*

*“I have a son with mild-moderate hearing loss and no concurrent disabilities or delays. This means he belongs in a typical preschool setting with some support and evaluation. However, the lack of understanding of hearing loss, acoustics, and even regular child development threatens to narrow his options, cause misreads of typical behavior, and put him in a context of greater disability.”*  
(Parent)

*“I feel that general education teachers who are not familiar with having Deaf students in their classroom have a hard time making their classroom, instructions, and interactions Deaf friendly ....”*

*“As a nationally certified interpreter (Ed: K12) and instructor of interpreters working in education, I believe that standards need to be raised to a required 4-year degree, EIPA 4.0, and passing a written test. Further, my experience in the educational system demonstrates that all other stakeholders, e.g., teachers of the deaf, special education, state leaders, are making the decisions for these professionals without understanding the work. This includes stakeholders that are supervising interpreters without any knowledge of interpreting or sign systems.”*

*“Teachers initially have low expectations for speech or ability to learn—warranted or not. Many teachers do not understand the importance of technology and how*

*to utilize it to support the deaf child. Questions to interpreters, such as, ‘Will you be here every day?’”*

*“... As a parent of a young adult who is deaf, looking back I see her education suffered due to her additional disabilities and the lack of support and understanding about how to provide an education to a unique student ....” (Parent)*

*“In rural areas, it can be difficult (or impossible) to procure access to qualified TODs [teachers of the deaf] and interpreters. Students who may already have learning delays are then left to attempt to catch up without educators who speak their language or fully understand their educational and social needs.”*

*“Administration that has no knowledge on deaf and hard of hearing students wants to program them the same as other special education students ....”*

*“... The schools for the deaf may have all accommodations, but not all staff understand the basics such as technology, audiograms, or even the decisions families face.”*

*“A huge barrier is ESL students who also have a hearing loss. A better understanding and knowledge of working with these students would be helpful.”*

*“Administrators (directors of special education, superintendents) who continue to demand that ‘least restrictive environment’ means in the neighborhood school, even if there are limited services available, no peers, no acceptance that D/HH students have language issues, etc., ....”*

*“... Curriculum, instruction, assessment - Gen ed classes are paced very fast; many of our kids have a hard time keeping up. Instruction is done by gen ed teachers that don’t use as many visuals or understand the language barriers. Many classes are going to computer-based instruction that our kids can’t access ....”*

### **Family and School Collaboration**

Respondents discussed how families and schools need to collaborate to support deaf and hard of hearing students more effectively (shown as a double-headed shape in the lower central part of the Lack of Understanding model). Currently, there is a gap in understanding and resources among both groups, causing difficulties for them to provide optimal support, including maintaining appropriate expectations and addressing needs.

Collaboration between educational professionals and families is essential to ensure deaf and hard of hearing students receive the best possible education, including appropriate school placement, educational planning, accommodations, and academic and

socio-emotional guidance. There are challenges regarding collaboration development and maintenance, including a lack of effort on both sides to work together, being misinformed, and not having clarification regarding their roles and responsibilities. As a result of the collaboration gap, deaf and hard of hearing students may struggle to achieve their fullest potential.

Examples of responses related to family and school collaboration:

*“... Many schools do not encourage parent participation. Many times they don’t want the parents to be involved at all. Instead of educating them on resources for their children and encouraging activity in the Deaf community, public schools tend to shut them out. The parents then allow the schools to raise their kids because they don’t know what else to do. Frustrating ....”*

*“... It is people’s attitudes about deafness that impact education. The students don’t know. The parents don’t know. The teachers (meaning teachers who are not teachers of the deaf) don’t really know ....”*

*“... In places where there is no school for the deaf, parents have even fewer resources, contributing to a lack of knowledge and understanding about deafness, ASL, Deaf community ....”*

*“... Even if students are in relatively big cities, they and their parents often are unaware of their option to attend residential/day schools for the deaf or mainstream ....”*

*“... Sometimes parents think the professionals will take care of things and they don’t understand the importance of working with the young child at home ....”*

*“... Lack of understanding: Often parents will say at an IEP, ‘You are the professional’ and trust what the school district is recommending. Parents need to fight for resources and appropriate goals in the IEP process; they often walk into it with little to no understanding of what it actually means ....”*

*“So many of our DHH students in my community have other factors playing into their education. Some also come from families from immigrant/minority cultures which don’t always have the same understanding of the role of the school and the role of the family in working together to maximize their child’s success. I think many of those families don’t always have the time or understanding of what they can do at home.”*

*“... Students with disabilities - Our son happens to have multiple disabilities, with some symptoms that fall into multiple categories. It is difficult to get teachers and specialists to understand or agree that different behaviors mean different things at different times. Often our explanation is dismissed and behaviors are seen as*

*“acting out,” which then avoids the proactive approach of addressing the problem and teaching healthy coping techniques.” (Parent)*

*“... When we tried to move our late-identified hard of hearing child to the HI [sic] classroom, we were told he wasn’t ‘deaf enough.’ He remained in a special education preschool room despite the fact that his largest lags in development were in receptive language skills. He speaks so therefore he must be able to hear. They didn’t provide for his hearing needs. We requested an interpreter and finally got an FM system. When it was discovered that he had Usher syndrome, his teacher said, ‘He’s not going to need to learn sign if he’s going blind.’ ...”*

*“... When it became time that she integrate her into the public school setting, they just were not equipped to work with her. ASL is her FIRST language and she prefers to receive her instruction in THAT language, and yet the public school dragged its heels to put an agreement in place with the deaf school to provide the interpreter. They wanted to hire someone personally, and they couldn’t understand WHY we wanted the deaf school to do the hiring. Even now that she’s in the public school, the teachers are POORLY trained to work with deaf/hh students ....” (Parent)*

*“... There is also a lack of understanding of the cultural and linguistic differences when working with families of color; assumptions are often made without clarifying if the barriers encountered are cultural or not ....”*

## **Overlaps Overview**

There are overlaps between the EHDI, HAT, and Language and Communication categories, shown in diagonal strips, and those overlaps impact Family Involvement and Schooling. The overlaps and impacts are elaborated on below.

### **Impact and Overlaps of EHDI on and with Other Model Categories**

EHDI, as indicated by the survey responses, highlights the cruciality of early hearing screening and comprehensive and appropriate early intervention services that are accessible for all families and their deaf or hard of hearing babies. Partly because of this cruciality, EHDI plays an important role in family involvement and schooling in that: 1) the quality and availability of EHDI influences how families can support their deaf or hard of hearing children, and 2) how the needs of these children are met by EHDI can influence their subsequent schooling.

The EHDI category overlaps with the Language and Communication and HAT categories since these last two categories are often embedded in EHDI infrastructure and services.

### ***Impact of EHDI on Family Involvement***

Some respondents discussed the need for early intervention providers to work with families to provide resources and support.

Responses related to the impact of EHDI on family involvement:

*“Families need qualified direct service providers working in the home with them from the very start to provide exposure, information, resources, and cultural awareness so there is less ‘catching up’ to do.”*

*“... Direct service personnel need to completely understand that families need early introduction to other families with DHH children and DHH adults so that they can visualize their child’s future.”*

### ***Impact of EHDI on Family Involvement AND Schooling***

A few respondents discussed how families of deaf and hard of hearing children need more support once their child is diagnosed with a specific hearing status that qualifies them for early intervention support. Also, schools and programs should provide support so families, in turn, know how to best support their deaf or hard of hearing children.

Responses related to the impact of EHDI on family involvement and schooling:

*“... Finally, expectations and family involvement and support. I’m grouping these together because I have known multiple parents/families who don’t have high enough expectations for their DHH child. From the family that held on to the statistics provided by the doctor when the hearing loss was diagnosed (which were totally not applicable to that child), to the parent who couldn’t understand how an itinerant teacher with hearing loss could teach their child - these beliefs are detrimental to children’s confidence and self-esteem, especially because the child tends to be present when parents make these remarks. Do parents need to know what the implications of hearing loss are? Yes, of course. But it should be all angles, and most should relate to the child, and they shouldn’t be stated as facts. And it should NOT be the lowest statistics someone can find at the time. Parents and families need more. They shouldn’t be left alone to navigate the stages of grief by themselves. And we can’t expect that they have the means to find help on their own. It would be great if districts/programs/RDSPDs [residential day school programs for the deaf] could provide more support for families. They need to know **THEIR CHILD CAN**. And they need to know that, when they accept that they can and exude high expectations, that they will reach higher than ever!”*

*“... Many organizations like AG Bell, Hands & Voices, and more cause message [confusion for] the parents ....”*

### **Overlaps Between EHDI, Language and Communication, and HAT and Their Impacts on Family Involvement**

The EHDI, Language and Communication, and HAT categories are closely intertwined in that many elements of EHDI and HAT focus on meeting the language and communication needs of deaf and hard of hearing youngsters and provide families with the support they need to provide language access and support language acquisition for their children.

These model categories impact the Family Involvement category. HAT overlaps with EHDI and Language and Communication because respondents discuss how HAT can either support or interfere with language development and language access. While HAT is not discussed within each quote, a part of EHDI that respondents did discuss is the use and support of HAT as part of early intervention support.

Respondents shared that early screening is needed to identify hearing status; however, some medical professionals and early intervention providers may lack understanding or appear biased by focusing on the need for spoken language development and the use of HAT, such as cochlear implants and hearing aids, while excluding the use of ASL. These biases impact the information and support families receive and, in turn, affect how they support their deaf or hard of hearing children. Therefore, comprehensive early intervention services are needed to support and educate families, EHDI professionals, and medical professionals on how to meet deaf and hard of hearing children’s language and communication needs, provide full language access, and support language acquisition.

Examples of responses related to the overlaps between EHDI, HAT, and language and communication impacting family involvement:

*“... In the early intervention stage, I have seen that families just don’t get how important communication is. It doesn’t matter what I do (as well as colleagues in several states); it just seems as though parents and pediatricians don’t get it. If a doctor were to tell families to give their child a medication, they would do it without question. Doctors do everything possible to get the child to hear, yet they do nothing, say nothing, to the families about the importance of communication for every aspect of their child’s development. There needs to be Deaf Mentors for the families to interact with and learn from ....”*

*“Early hearing detection and intervention are critical to beginning the education process; it is also crucial to involve families and have their support, but many times language and communication are barriers—both with the parents and caregivers as well as in understanding the terminology and type of*

*communication needs of the deaf child. It is important to educate the parents to prevent lack of understanding and encourage their continued involvement ....”*

*“EHDI services often don’t provide every option available to families and, in turn, those families don’t learn sign language to communicate with their child. This all ties in with a lack of understanding and a lack of quality service personnel.”*

*“All of the areas are critical toward the development of D/HH students to reach their academic achievements. Any barriers occurred to those areas above will lead those students with struggle to self sufficiency into adulthood. Collaboration - Every person in a student’s life is important. Teachers, professionals, families, peers will make an impact in a student’s life - [They] will need good supports from them, and all need to be in the same loop with a goal in mind for this student to be successful. No collaboration will set up a student’s failure down the road. Early hearing detection and support - Important tool for parents to make a decision for [their] child’s hearing development that ties with language development early on. Parents really need access to all possible options: hearing aids, cochlear implants, and ASL. Resources to access those are very important; they need to hear all sides: pros and cons. Without this, the child will miss out on language development and access[ing] communication ....”*

*“Early detection is crucial for outcomes in all areas. This has not been a huge issue over the last few years but due to lack of funding is in jeopardy. That will be devastating. The core issue is the system not encouraging families to support each other or interact with other families. Resources are not freely provided to families, which all leads to a lack of understanding and ultimately affects the child’s language and communication. All agencies and entities involved are withholding information, resources, and services and doing the child a disservice. I’m not sure if there is a true shortage of qualified personnel or misappropriation of funds to employ these individuals.”*

*“I’ve seen many times where parents aren’t aware of research-based options for their deaf children. Doctors and professionals don’t have all the facts to provide families with unbiased options. They still see ASL as a last resort option ....”*

*“Families do not always understand that their child’s success often depends on their learning sign language and aspects of deafness which they do not realize because they lack understanding. Language and communication must be realized in the developmentally critical stages early in the child’s life, which is often before many parents have come to terms with their child’s deafness, so qualified direct service personnel are key in helping realize this necessary intervention. Parent’s often do not realize that what hearing children learn incidentally, deaf children must be directly taught due to all of the missed auditory input.”*

## ***Impact of EHDI on Family Involvement AND SCHOOLING***

This section focuses on the impact of EHDI, Language and Communication, and HAT on both Family Involvement and Schooling in the Lack of Understanding model.

Two respondents discussed the importance of early detection and intervention, emphasizing the role of educational professionals with in-depth knowledge regarding the language and communication needs of deaf and hard of hearing children and their families. They also shared the importance of using technology and ensuring families with deaf or hard of hearing children and the professionals working with them are well-informed so they can support the development of those children.

Responses related to the overlaps between EHDI, language and communication, and HAT impacting family involvement and schooling:

*“Given the role of hearing in English language learning and the role of language (spoken or signed) in all aspects of development, I feel strongly that early detection, understanding by family members and all educators and interventions from qualified individuals who understand the effects of hearing loss on learning (in aural/oral or predominantly visual language environments) are most critical.”*

*“There are several barriers that these students have for better development. [With] the early detection of hearing and with a highly qualified staff and the help and commitment of family and educational institutions with the support of technology, we can make learning and communication a little more feasible for these people and a more comprehensible learning.”*

## ***Impact and Overlaps of Language and Communication on and with Other Model Categories***

Responses show the centeredness of Language and Communication in Lack of Understanding, impacting Family Involvement and Schooling, and overlapping with EHDI and HAT.

Respondents discuss how early language acquisition and early language access are critical as a part of EHDI, and how learning a visible language and wearing HAT plays a role. Familial understanding of the importance of supporting their deaf or hard of hearing children’s language and communication needs impacts how they are involved with these children. This includes how families collaborate with educational professionals. This support and involvement impacts deaf and hard of hearing children’s development. Professionals’ understanding of language and communication impacts how they work with deaf and hard of hearing students academically and with these children’s families. This reflects the need to ensure families and professionals receive comprehensive and

accessible services, information, and resources so they can better support deaf and hard of hearing students.

### ***Impact of Language and Communication on Family Involvement***

Language and communication, as shared by respondents, impacts family involvement. The understanding of language and communication regarding deaf and hard of hearing children's needs influences how families are involved in supporting their deaf or hard of hearing children. Families new to having a deaf or hard of hearing child may lack knowledge or experience in how to meet their child's language and communication needs, thus impacting the child's ability to access language and acquire language at an early age. In some cases and for various reasons, families are not able to communicate with their deaf or hard of hearing child, impacting their abilities to support their child. This results in language development delays. Due to this lack of knowledge and experience, families need guidance on how to be involved in their child's language development and support them so the child meets age-appropriate milestones. This includes learning a language or communication mode that best meets the child's needs and providing language access

Examples of responses related to the impact of language and communication on family involvement:

*"... Lack of family involvement and support/lack of language and communication in the home: Parents/family members do not know/use ASL so what deaf students are learning at school is not reinforced or enhanced outside of school, which contributes to poor literacy skills, lack of understanding of the curriculum, instruction and assessment tools ...."*

*"... Children learn best when they are surrounded by a linguistically rich environment. Parents typically do not have the understanding or the expertise to provide that type of environment for their deaf/hh child ...."*

*"Lack of understanding - Hearing parents get mixed information about their DHH child. Should they talk or sign or both with their child? There is much confusion along with the grief that parents often encounter when they learn that their baby is deaf or hard of hearing ...."*

*"... Families often have little information or inclination to learn communication strategies, including sign language. In fact, many are cautioned against using sign, and the learning curve for sign is high so it is easy for them to not learn and not want their kids to learn ...."*

*"Frequently parents are given a 'choice' of language modes to communicate with their deaf/hh child, and the majority of them come from a hearing-centered*

*perspective and choose the cochlear/oral route without ever considering the benefits of ASL. I strongly feel that regardless of the hearing loss, all children should learn ASL. The research proves that children who are bi/multilingual thrive academically. Parents who feel they have a choice go the 'easy' route because they are overwhelmed. If we can pass legislation to ensure all children learn ASL and oral (if appropriate), then we will fill in the gaps of underachieving children who suffer from language deprivation from birth-5. I see this every day in the school where I work, and it is so sad to see so many children lose their desire to understand the world around them because they are used to not understanding and it becomes their norm. Parents don't truly understand the detrimental impact this has on children until it is too late. Parents have NO idea what their child is missing, and neither does the child regardless of their hearing loss ...."*

*"Parents do not know what it is like to have a DHH child, and what language deprivation is. The effects that language deprivation has on a child and a family are so huge, but families aren't educated, so they have no idea."*

*"... Most students' families continue to speak and not learn ASL because the student goes to a deaf school (so they're thinking it should be enough for them) when it is not enough at all."*

*"... Family involvement/language/resources: Hearing parents need to be informed on language milestones for deaf students and led through appropriate resources to help their child be on level and kindergarten ready."*

*"... Social concerns/language/communication: Often many families do not realize how critical [it is] for their deaf/hoh children to develop language early in order to develop healthy social/emotional skills and have a better chance of learning higher academic levels ...."*

### ***Impact of Language and Communication on Schooling***

This section focuses on the impact of Language and Communication on Schooling, as shown in the Lack of Understanding model. An essential component of supporting the development of deaf and hard of hearing students is to address their language and communication needs, which respondents noted that some educational professionals lack understanding in and experience with. This includes understanding Manual Coded English systems, providing appropriate accommodations, and being fluent in sign language. To better support deaf and hard of hearing students, educational professionals need training, comprehensive information, and resources.

Examples of responses related to the impact of language and communication on schooling:

*“... Lack of understanding: By teachers and presenters of their needs regarding logistics (within the classroom and larger assembly-type programs) so they can see and hear comfortably, require the presenter to use a microphone, etc., ....”*

*“Related to curriculum, instruction, and assessment, teachers and school professionals often don’t understand the impact of hearing loss on how a student accesses the academic environment. When a student’s hearing loss is minimized because they ‘seem to hear me fine,’ students end up being unfairly characterized as ‘just not paying attention’ or ‘daydreaming.’ ....”*

*“In our area of the country, school personnel often don’t assess the listening and English language abilities of children using SEE [Signing Exact English]. Many times people have misinformation about this valuable system and don’t know the current research about its effectiveness ....”*

*“... I have found coworkers ignorant of what MCE systems are and in the case of one school, none of the staff working with a group of D/HH children understood that there are multiple MCE [Manually Coded English] systems with their own rules ....”*

*“The general education does a poor job educating many children with disabilities. When it comes to deaf and hard of hearing services, I feel mainstream wants to educate with little accommodations and not consider what the student needs. My personal preschooler they wanted to not include her in pre-k class but only 2 hours for the day and pull her back down into a younger class for ASL support. My older daughter who is HH was given little ASL support because she had some hearing. It is definitely a lack of understanding and necessary communication needed.” (Parent)*

*“... Language is key to all. (Of course I am an SLP so I believe this!) It still concerns me when people misunderstand the difference between LANGUAGE and SPEECH. Schools that have children with hearing loss often do not have adequate information about technology—or the financial resources for this technology. So, they see a “hard of hearing” child who can do okay with hearing aids and speech and think that there are no concerns. I see that child and am concerned about the phonological and articulatory systems as well as their language development. (What don’t they hear that is grammatical?) ...”*

*“We have come into contact with teachers of the deaf who don’t know how to sign or [who] claim to sign and then do so very poorly. Our speech therapist assigned to us knew nothing about working with deaf children. The school system didn’t know the needs of my child and her language needs. Lots of misunderstanding on their part about [name of school]. They spoke inaccurately*

*about [name of school]. Our audiologist in diagnosis never mentioned sign to me. My child spent much of her first year without language. I wish the audiologist had encouraged sign while going through the technology process.” (Parent)*

*“... Misunderstanding of LRE [least restrictive environment] for D/HH students - Oftentimes administrators cite LRE as a reason for placing D/HH students in general education with POOR classroom acoustics! These students cannot ACCESS verbal instruction due to noise level in the room ....”*

*“... Students who use ASL or a signed form of communication are not being given opportunities to interact with Deaf peers. Self-contained classrooms where students can focus on their language skills in either a sign-based or auditory/oral-based mode are being eliminated slowly, thus, not giving DHH students equal access in a manner that will provide them with the BEST options for learning language and catching up with their hearing peers.”*

*“Many of the schools that I have serviced have been in rural areas. I have seen a lack of understanding and innovations in addressing language and literacy needs for children with hearing loss.”*

*“They all work together. The lack of understanding leads to lack of language and literacy. We also do not have a curriculum designed for Deaf English learners. Everything is based on children with a strong L1 [first language]. Most of our students do not have that ....”*

*“... More schools are relying on technology. For those students without good reading skills, captions are not an option for accessibility. For those who do read well, often teachers need support to get captioned materials and don’t ask or don’t know how to get information ....”*

### ***Impact of Language and Communication on Schooling AND Family Involvement and Their Collaboration***

Several responses highlighted the interconnectedness of Language and Communication, Schooling, and Family Involvement, and the collaboration between Families and Schools in the Lack of Understanding model.

There needs to be a stronger collaboration between schools and families to effectively support deaf and hard of hearing children. Some schools, as discussed by respondents, do not address families’ requests regarding the language and communication needs of their children or provide adequate support to both the children and their families. On the other hand, there are concerns that families lack the necessary knowledge to support their children. They need support and resources to effectively advocate for their children. These issues impact the quality of collaboration between families and schools. This

results in not meeting the language and communication needs of deaf and hard of hearing students and, thus, their language development. This includes inadequate accessible environments, socialization opportunities, and early language acquisition.

Examples of responses related to the impact of language and communication on schooling and family involvement:

*“... Families do not understand language development, and do not participate often enough in their child’s learning, and do not have a relationship with the school team ....”*

*“In our situation, the topics selected all go together. We are moving to another state for our child to go to deaf school because the district we are in will not provide interpretation to our profoundly Deaf child. They have a Deaf/Hard of Hearing class but because our daughter has other disabilities and a trauma history, they refuse to put her in it; in the long term they focus on voicing, not signing. For a child who cannot hear, this is ridiculous. Policy had a huge hand in this, and the school does not want parent involvement and their education is all about voicing not signing. It’s isolating and ignorant. (Parent)”*

*“It has been difficult to help parents see the need for early language acquisition. There seems to be a reluctance on their part to reach out to other parents and support one another. Collaboration for parents and educators is so important. Getting resources into parents hands is the easy part. Getting them to utilize those resources is a whole different ball game.”*

*“For ‘other,’ some schools do not provide the support that families need. Public schools only accept students from kindergarten-12. One school accepts deaf students in mainstream preschool with an interpreter, which does not help if that student does not have a language. They refuse to put the student in a deaf education classroom until he is in kindergarten. One deaf school cut the age 0-3 program. Deaf kids again cannot enter school till preschool. There is no acceptable daycare that can work with the deaf students with their language development. Parents need a place to drop their kid off while they work.”*

*“Where do I start ... It is slowly getting better with school districts understanding the need for accessibility more and more, but you still have gaps, either small or huge, in these above areas. A lot of families are told don’t sign ... you will hurt their chances in working in the hearing world ... It is so easy to miss communication, language, and literacy when you cannot read lips or understand what a hearing person is saying since less than 70% is understood. A lot of our students and teachers are isolated from other people and don’t get a chance to practice their language as much at school unless it is with interpreters or at home if they are the only person who is deaf or hard of hearing.”*

*“... Lack of understanding - Adults who work as caregivers, teachers, and/or professionals in other roles working with children do not fully understand the needs of a deaf/hoh child or what hearing loss really means. If the child has some ability to speak or communicate orally, many adults ignore that the child is deaf/hoh and try to talk to the child as that adult would talk to any hearing child. Thus, the deaf/hoh child’s communication needs are not met, and there are miscommunications leading to frustration in both the adult and child. Just because a child with hearing loss can speak well doesn’t mean [they] can hear well. It just means that someone has put in the time to work with that child on speech development. The child should still be given special consideration to the fact that [they are] deaf/hoh ....”*

*“At the heart of the concern for deaf/hard of hearing students, who struggle in school, are language delays and often language deprivation—which has the strongest impact on preventing D/HH students from achieving their full potential. Many hearing parents, overwhelmed with having a child who is D/HH, do not all fully understand the gravity of the impact that this can have on a child’s achievement long term ....”*

*“Many hard of hearing children are forced into mainstream schools and labelled as slow or incompetent. Many times deaf and hard of hearing students and parents don’t know what they need or resources available to them, and because of lack of knowledge and resources they spend many years frustrated and sometimes act out behaviorally because they have not received the appropriate resources. When they get the right resources and ASL training for parents and students, the students begin to flourish and do great things.”*

### **Overlaps Between Language and Communication and HAT Impacting Family Involvement**

In the Lack of Understanding model, the Language and Communication and HAT categories are interrelated in that HAT is ideally provided to meet the language and communication needs of deaf and hard of hearing students. The overlap between these two categories impacts how families support their deaf and hard of hearing children.

As shared by respondents, there is a tendency for families to be provided with biased information about language and communication options or opportunities. As a result, deaf and hard of hearing children often are provided with HAT, such as a hearing aid or cochlear implant, and are prevented or not encouraged to learn ASL.

Examples of responses related to overlaps between language and communication and HAT impacting family involvement:

*“Way too many deaf and hard of hearing infants, toddlers, and children are fitted with hearing aids or implanted with cochlear implants, and are expected to learn to speak and hear without any access to ASL or any opportunity to acquire a language (typically ASL) that is natural, barrier-free for an early fluent communication with parents, family, peers, caregivers, teachers, and other service providers ....”*

*“Parents are misinformed. Babies/young children are not being taught or exposed to ASL in the hope that they will “learn to listen and talk.” Parents are often given the oral/medical view of deafness by the medical and audiology community first and told that if their child learns ASL they will not learn to talk. YES! It is STILL happening. Parents are then referred to private LSL programs or AVTs that reinforce this belief. They believe cochlear implants are like glasses and will ‘fix’ their child.”*

## **Conclusion**

This model was developed based on the feedback received from parents and caregivers of deaf and hard of hearing children as well as professionals who work with those children and families when asked to share their views on the obstacles that hinder deaf and hard of hearing children from reaching their academic, linguistic, and socio-emotional potential. Lack of Understanding emerged as a significant barrier.

Limited awareness and lack of clear understanding regarding deaf and hard of hearing children’s unique needs may result in inadequate support for language acquisition, socio-emotional growth, academic progress, and postsecondary skills, leading to delays in key developmental areas. This demonstrates the need for training and education from a societal level to families and educational professionals themselves. Without a better understanding, deaf and hard of hearing children may face challenges in communication, integration into learning environments, and accessing appropriate resources, ultimately hindering their ability to reach their full potential.