

## Chapter 8

# Engaging Families of Deaf and Hard of Hearing Children Through Asset- Based Approaches: Loaded Backpacks and Courageous Conversations

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### ABSTRACT

*This chapter was written by an interdisciplinary group of authors representing the disciplines of deaf education, speech-language pathology, marriage and family therapy, and educational leadership; and including parents of children with disabilities, including one parent of hard of hearing children. While*

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*the contents of the chapter are applicable to professionals working in any area of special education, the chapter specifically focuses on working with children who are deaf, hard of hearing, deaf-blind, or deaf-disabled, and their families. The authors take readers on a family engagement journey that begins with learning about one family's experience raising children who are hard of hearing, then moves to discussions about strengths-based counseling and intervention approaches, acknowledging the difficult conversations that may arise during family engagement, and culminates in readers' awareness that becoming a skilled family-engaged practitioner is a lifelong process.*

## **INTRODUCTION**

With mounting research on the unnecessary risks of language deprivation and the urgency with which many families make decisions around audiological care and language access choices, professionals working with deaf<sup>1</sup> children and their families must be prepared to provide unbiased family counseling and to engage families through a strengths-based approach. In recent years, the growing research into the developmental impacts deaf children experience when they don't have consistent language access has been referred to as language deprivation syndrome (Hall et al., 2017). Deaf children without consistent access to language often experience delays in cognitive, social, emotional, literacy, and academic development--the developmental domains that are dependent upon language development (Caselli et al., 2020). More than ninety percent of deaf children are born to hearing parents, parents who typically, and understandably, want their children to communicate through spoken language. Spoken language can be accessible to many deaf children through devices such as hearing aids and cochlear implants, but frequent, consistent, and *effortless* access to spoken language eludes many deaf children (Humphries et al., 2019). While "access to sound" is understandably prioritized by audiologists, speech pathologists, and physicians working with young deaf and hard of hearing children, parents must be counseled and advised that access to *sound* does not necessarily mean access to *language*. Sign language, on the other hand, is accessible to all sighted deaf children and can be a foundational first language that can serve as a bridge to acquiring spoken language while avoiding the unnecessary risk of language deprivation (Sanzo, 2021; Glickman, 2020; Humphries et al., 2014).

Unfortunately, families are often caught in a confusing storm of conflicting information and are frequently counseled that they must make a false choice of providing either spoken or signed language to their deaf child. As they try to make sense of this conflicting information, families are also processing their own grief, reconciling their own assumptions, beliefs and biases about their deaf child, and worrying about their child's potential and future. Parents understandably want their child to communicate in the family's primary language and hope for their child to experience a life with limited barriers. For this reason, when offered a choice between a binary "sign language approach" or "spoken language approach," most hearing parents would choose the spoken language approach, not knowing that their child may struggle to acquire spoken language. It is the responsibility of service providers to help families see through that storm to envision a successful future for their deaf child, and to make sense of the options and opportunities that can help their child thrive.

To do this, service providers arguably must approach early intervention from a strengths-based perspective, allowing them to view sign language, bilingualism, and development of a healthy deaf identity as assets, and guiding parents as they gradually come to see their child's deafness as a difference rather than a deficit. Following Gardner and Toope (2011), we hold that adopting a strengths-based approach to

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early intervention is a social justice issue that requires “recognizing students-in-context, critically engaging strengths and positivity, nurturing democratic relations, and enacting creative and flexible pedagogies” (p. 86). Our hope is that readers of this chapter will learn strategies for counseling families of deaf children in a way that emphasizes their strengths, avoids offering parents a binary “spoken language or signed language” false choice, and helps readers feel better equipped to have courageous conversations with families. We believe that bilingualism, American Sign Language fluency, and the development of a strong deaf identity are strengths that should be identified, supported and nurtured by service providers, not marginalized and diminished. Importantly, it is also our hope that readers recognize the need for lifelong learning in order to be truly effective at engaging families in a therapy process that leads to optimal outcomes for their deaf or hard of hearing children.

The inspiration for this chapter was a weekend seminar, led by the co-authors, as part of Iona University’s *Interdisciplinary Advanced Certificate in Working with Young Deaf and Hard of Hearing Children and their Families*. The title of the seminar was “Courageous Conversations,” and the focus was helping the participants—graduate students in Iona’s Early Childhood Special Education and Speech Language Pathology programs—learn how to engage effectively with families whose views on language access might be affected by the ableist notion that speaking bodies are better than signing ones. The Courageous Conversations seminar itself was informed by the experiences of so many SLPs who have worked with deaf children, including one of the co-authors, and seen the devastating results of language deprivation up close and been told by families over and over that they were counseled to “choose” spoken language *or* sign language for their deaf child. Conversations around the topic of language access can be uncomfortable for providers, especially if parents are resistant to recommendations that may be in conflict with what they previously learned from interactions with healthcare professionals, other parents, or the internet. It is therefore imperative that providers be prepared to be courageous yet compassionate and understand what life experiences, beliefs, and values inform their hopes, dreams, fears and concerns for their child.

We therefore begin this chapter as we began the seminar, with the unpacking of one “Invisible Backpack,” as told by Sarah Martin, a deaf woman who is the mother of six children, three of whom are hard of hearing. Sarah opened the seminar by inviting the students to consider all that parents of deaf children carry with them. The vignette that follows contains the authentic words of Sarah, who is also a certified teacher of the deaf, a college-level instructor of American Sign Language, and a program assistant for a graduate certificate program that prepares students to work with deaf and hard of hearing children and their families. Sarah’s vignette centers her “invisible backpack,” similar to the invisible backpack that all humans carry. The invisible backpack is each individual’s collection of experiences, such as traumas, pain, and grief, that we bring with us into various situations and that might impact the way we navigate different experiences: in this case, the early intervention process. The invisible backpack (sometimes called the invisible knapsack) (McIntosh, 1989; Watlington, 2016) as a way of understanding individual differences among clients, and between clinicians and clients, when approaching clinical work through a trauma-informed lens. In the following vignette, Sarah shares her personal backpack and the ways in which its contents emerge when she is in relationship with her children’s service providers.

### **A PARENT’S INVISIBLE BACKPACK**

*I walk into the room lugging a dark blue North Face backpack. Four future speech language pathologists (SLPs) and four future early childhood special educators stare at me.*

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*I pull up a power point slide. The faces of my children fill the presentation screen—six young children ages twelve and under. Three kids diagnosed and labeled “hearing impaired,” two having “failed the hearing screening,” and one “late identified.”*

*Do you see them? Do you know their names? Are they just “cases” to you? Are we “that poor family with the deaf mom whose kids need hearing aids and speech services?”*

*I struggle with the backpack’s zipper. It’s hard to open up sometimes. It’s hard to even find the zipper at times.*

*Do you see all I am coming to the table with? This backpack is heavy. I carry it with me everywhere I go. Positive or negative, strength or deficit—I carry it with me. I don’t know you and you don’t know me.*

*I clunk my backpack down before this group of pre-professionals.*

*I tell them my children’s names.*

*I show them funny pictures of my children smearing white diaper cream all over their hair and faces.*

*I laugh as I point to the photograph while retelling how we found my beautiful flower girls decked out in frilly pink with the shock of added black permanent marker up and down their arms.*

*Do you see their humanity? My children are people too.*

*I push open my backpack.*

*I pull out my graduate school textbook. Do you know I went to school for this? I have two Master’s degrees. I’m smart and well-educated. I don’t want you to treat me like I don’t know what I’m doing.*

*See this clock from my living room? It represents the hours and hours of sleep deprivation I am experiencing. I just gave birth and I’m hurting physically. Plus, hormones. I haven’t slept through the night in months. I’m exhausted. My family’s schedule is all over the place. I need you to understand that this is all brand new for me—not just my kid being identified as hard of hearing but being a mom.*

*This red heart-shaped pillow represents pain. After giving birth, I had to get stitches. It took me weeks to be able to walk right. I experienced all of this while attempting to figure out breastfeeding plus why is my baby crying again?*

*This magnet? “Keep praying even if you only have a whisper left.” I’m late deafened. I passed this down. I can’t even look at my kid without choking up from the guilt. Will my baby be all right?*

*A random pair of scissors? It represents my maternal protective instincts. Feel free to come alongside me but don’t think for a second that you’re better than me or that you know my kid better than I do because I will cut you down.*

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*Tiny pastel pink baby hearing aids with glitter ear molds—I'm coming at this with a lot of "baggage" from my own personal beliefs and experiences with deafness, hearing aids, sign language, and the household in which I grew up. I panicked the first time my daughter wore these pink hearing aids in public. It was such an "out loud" statement to the world.*

*I pull out a magnet. I want to see my kids grow up connected yet independent, healthy, strong, loved, cared for. I want the best for my children. I don't want my babies to be made fun of or to have to experience some of the trauma I experienced. I just want to do the right thing and be the best parent I can be.*

*Logically, I know it's all going to be okay but emotionally and mentally, I'm scared and anxious.*

*I remove a rock from the backpack. On it are written the words "I am not afraid. I was born for this." I'm the fiercest mom you've ever met. It represents my determination to do what is best for my children, with or without the support of their service providers.*

*Either fight alongside me or get out of the way.*

*Not all parents have the same contents in their invisible backpacks as I do. But all parents have an invisible backpack that they bring to the intervention process. It is shaped by the plethora of life experience, language, culture, family, community, and economics that they bring to the table. Service providers must learn how to engage with families and support us in ways that honor, respect and recognize the numerous experiences that have brought them to this particular clinical relationship.*

*I turn to the group of pre-professionals in front of me. I distribute a picture of a backpack and ask them to fill it in with their own life experiences, cultural backgrounds and personality characteristics that theirs contain. I then ask them a series of questions: What do you bring to the table? What's in your invisible backpack? How did you pick the things you listed? Do you consider these to be assets? Why or why not? Are you comfortable sharing your backpack's contents with the group? Why or why not?*

The value of understanding the invisible backpack lies in our ability as clinicians to recognize the complexities of the individuals we work with in the relationship process. The children and families we work with have histories that may impact the way they see disability and the intervention process. Through a trauma-informed lens that recognizes the individual histories of our clients, practitioners can work with clients and families to "repack the backpack" with positive experiences, views, and beliefs (Watlington, 2016). Reframing what society typically identifies as a "deficit" as an asset is one part of this repacking. An asset or strengths-based approach focuses on what the child and family *can* do, not on what they cannot. This kind of approach takes into account the different funds of knowledge families bring to the table (Gonzalez et al., 2005). Consider, for example, a deaf child with cochlear implants who is not yet speaking. The family likely has hopes that the child will use spoken language, and at the moment the child communicates through sign language. A clinician describing this child's communication from a deficit approach might use language such as, "At the moment, the child only uses sign language, but I am hopeful that with a lot of hard work, she will learn to listen and speak." The same child could be discussed through a strengths-based view using language such as, "The child is an effective communicator in sign language, and may be able to use that strong language foundation in ASL as a bridge to become

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bilingual in both spoken language and sign language.” Importantly, practitioners must take the family’s invisible backpack into consideration at all times, as the family’s views of disability and language biases may be informed from their past experiences.

As practitioners, we must consider demographics, economics, family dynamics, attitudes, socioeconomics, beliefs about disability, feelings (fear, concern, optimism, etc.) about their child’s future, work and family obligations, education level, and perception of their role in their child’s development and therapy. We should also include race, religion, gender identity, sexual orientation, and other potentially marginalizing or privileging factors that might impact the family’s perception of the intervention process.

It is vital that we position families as confident, knowledgeable, capable, and resourceful individuals and recognize them “in context.” Working from this place of honor enables practitioners to engage and support families and children equitably and effectively.

## **THE UNIQUE CASE OF DEAF AND HARD OF HEARING FAMILIES**

Children who are deaf or hard of hearing represent a group that, despite having a low-incidence disability—about 2-3 out of 1000 children are born with a detectable level of hearing loss (NIH, 2021)—is incredibly diverse. Deaf and hard of hearing children, as a group, include children with various etiologies of hearing loss; severities ranging from minimal to profound; a variety of types and outcomes related to listening device use; differences in language and communication modality preferences and use; differences in their age of hearing loss identification and subsequent intervention; and of course diversities related to socioeconomic status, racial, ethnic, cultural, linguistic and religious background, and additional disabilities. Because childhood hearing loss is a low-incidence disability, most early intervention practitioners lack knowledge and experience related to the population (Decker & Vallotton, 2016; Ingber & Dromi, 2010; Moeller et al., 2013). Furthermore, there is evidence that service providers across the professions struggle with engaging linguistically and culturally diverse families and fostering collaboration, particularly in the context of early intervention (Ghulamani, 2016; Hile et al., 2016; Murray & Mandell, 2006; Raver & Childress, 2014). Because the population of deaf children is so diverse, practitioners who work in this context need to engage in highly specialized and individualized evaluation, therapy, and family counseling processes in order to achieve optimal outcomes. It is a tall order, and while the learning curve for many practitioners is steep, failure to provide high-quality intervention can carry lifelong consequences for a deaf child and their family.

Family-centered early intervention is a practice used across disciplines (e.g., Education, SLP, OT, Medicine, etc.) that “involves adherence to help-giving principles and values that include treating families with dignity and respect, family engagement, collaboration, seeing families as partners and focusing on family strengths and needs” (Garcia-Ventura et al., 2021). According to the American Speech-Language-Hearing Association (ASHA), family-centered intervention should be centered on four core principles: respect and dignity, information-sharing, participation, and collaboration (ASHA, n.d.). Baas (2012) compares family-centered healthcare to a three-legged stool where one leg is the practitioner, one is the client, and one is the family. The legs all need to be balanced; if one dominates or is out of proportion to the other two, the stool won’t stand. We argue that it is essential to keep the child, family, and practitioner partnership balanced and mutually beneficial in order to ensure we achieve the best possible outcomes for our primary stakeholders: deaf children. For example, if practitioners withhold vital information from parents based on their own beliefs, biases or knowledge limitations, parents may be

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unable to make the best decisions for their child to optimize development. Likewise, if parents resist practitioner recommendations due to their own beliefs, biases, or knowledge limitations, the child's best interests may be compromised despite the practitioner's recommendations and the family's best intentions. Importantly, too, if practitioners focus solely on what they see as the best approach for the child but ignore the family's beliefs, biases, backgrounds or identities—in other words, the contents of their backpacks—outcomes will not be ideal.

In the sections that follow, we discuss the period of zero to six months in which parents of deaf/hh children are asked to make decisions about language and communication with their child that are often presented to them by medical professionals as both high stakes and binary (i.e., either spoken language or sign language). We also present evidence from the literature on the critical period(s) for language development and the associated risk of language deprivation for deaf children. Given this unique risk, we argue that it is critical for service providers to engage effectively with the diverse families of deaf children, meaning that the providers must not only understand the adjustment process many parents go through, but that they must also have the ability to discuss complex, and sometimes controversial, topics, including: the nature of language access; language deprivation and its impact on development; language, communication and educational opportunities available to deaf children; cochlear implant candidacy and outcomes; and the value and cultural wealth of the deaf community.

### **Rapid Intervention Timeline**

According to organizations that guide best practices for intervention with deaf and hard of hearing children and their families (e.g., ASHA, Joint Commission on Infant Hearing (JCIH), Early Hearing Detection and Intervention (EHDI)), children achieve optimal outcomes when they are enrolled in the early intervention system by six months of age. Families of children who do not pass their newborn hearing screening ideally begin a process of audiological evaluation and treatment, intervention, and decision-making that happens at a rapid pace, often before the end of the child's first year. After being referred for a full audiological evaluation, and after a child with permanent hearing loss is identified by an audiologist, the family is typically enrolled in early intervention. At this point, the parents begin to make numerous decisions, along with the support of service providers, about assistive technology, modalities of language and communication access and expression, and educational opportunities (Decker & Valloton, 2016).

While state-level Early Hearing Detection and Intervention (EHDI) programs advocate for a "1-3-6 timeline" (i.e., newborns are screened for hearing loss by 1 month, identified by 3 months and enrolled in early intervention by 6 months), policy-makers and state-level authorities are less involved in what happens once the family has begun early intervention. However, it is the conversations, interactions, and experiences that families have with service providers through early intervention (EI) that influence the decision-making process for parents who may know little to nothing about deafness, are unfamiliar with deaf individuals, and are feeling confused, isolated, and anxious about their child's future (Young, 1999). Ensuring that deaf children and families are enrolled in EI as early as possible is crucial (Yoshinaga-Itano, 2014), but it is not enough. Policy-makers and practitioners must aspire to provide the highest quality services at this time, which includes providing parents with complete and unbiased information about the benefits *and* limitations of listening technology and the importance of effortlessly accessible language (Humphries et al., 2012).

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The team of professionals working with families of deaf and hard of hearing children includes a medical provider (e.g., pediatrician, otolaryngologist, otologist), an audiologist, a speech-language pathologist (SLP), and often a special educator or other service providers depending on the needs of the child. While the SLP serves as the language expert on this multidisciplinary team, parents often first receive information from the physician and/or audiologist about language access and development that is guided by a medical model of deafness, aimed primarily at fixing the biological problem rather than ensuring the child's optimal linguistic, cognitive, and social-emotional development. It is at this point that many parents are compelled to make a false choice that inadvertently may lead to language deprivation and its many consequences

#### **False Choice: Speech vs. Sign**

The debate about deaf children's language and education is centuries long and has centered primarily on the notion that families of deaf children have two communication options: speaking or signing. Parents are typically presented with this false choice very early in their infant's life, often only weeks or months after they have just begun to learn about what deafness is, and while they are still learning to understand what it means that their child is deaf or hard of hearing (DesGeorges, 2016). The process begins when a child does not pass the newborn hearing screening and is then referred for an audiological evaluation. If the child is identified as having a hearing loss at this evaluation, a series of events is "triggered" (Mauldin, 2019) that involves the child receiving hearing aids, the family being enrolled in EI, and numerous meetings and appointments with service coordinators, speech-language pathologists, physicians, social workers, and follow-up audiological visits.

If the intervention team determines that the child does not benefit from hearing aids sufficiently to acquire spoken language, cochlear implants are often the next consideration, triggering a process that involves more meetings, appointments, brain-imaging, and developmental evaluations in several domains. It is during this period of time—very early in the child's life and amidst a whirlwind of information that parents must take in while adjusting to their child's hearing loss—that practitioners often present parents with a false choice; they must choose, very soon, how they want their child to communicate: through sign language or through spoken language (Madell, 2016).

Many parents are led to believe that if they want their child to learn to speak, they must avoid the use of sign language because—even though the use of sign language will help stimulate their child's linguistic development and foster parent-child attachment and bonding—it will also put their child's spoken language development at risk (Humphries et al., 2015, 2016, 2017; Humphries, Kushalnagar, Mathur, et al., 2014a). Despite the fact that there is no empirical evidence suggesting that use of a sign language prevents acquisition of spoken language—to the contrary, there is growing evidence to suggest that the development of sign language *supports* the development of spoken language and literacy (Allen, 2015; Allen et al., 2014; Chamberlain & Mayberry, 2008; Dammeyer, 2014; Freel et al., 2011; Harris et al., 2017; Harris & Beech, 1998; Hermans et al., 2010; Hrastinski & Wilbur, 2016; Humphries, 2013; Humphries et al., 2017; Humphries, Kushalnagar, Napoli, et al., 2014; Jasińska & Petitto, 2014; Knoors & Marschark, 2012; Kovelman et al., 2009; Padden & Ransley, 2000; Petitto et al., 2001, 2016; Scott & Hoffmeister, 2017; Strong & Prinz, 1997; Tomblin et al., 2018)—and despite the fact that parents of hearing children are actually *encouraged* to use sign language to stimulate language development in their infants and toddlers, parents of deaf and hard of hearing children are told by the experts they turn



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to these early months that they must decide between speech and sign, and that the choice they make will have significant consequences for their child's future.

### **Critical Period(s) for Language Development**

Prior to the most recent advances in listening technology, deaf children educated in “oral/aural” environments were often required to use their residual hearing and speechreading skills to receive spoken language. For many deaf children, this was difficult and tedious, and it prioritized learning to produce and receive auditorily inaccessible speech sounds over the acquisition of a full language. Due to technological advances, such as newborn hearing screening technology, digital hearing aids, and cochlear implants, deaf and hard of hearing children can be identified within the first months of life, receive amplification that provides access to all or most speech sounds, and be enrolled in early intervention before they begin to exhibit any language delays. With appropriate listening technology, many deaf children have the tools they need to access speech sounds and learn to make sense of them for the acquisition of spoken language. That access, however, is dependent on numerous factors, including background noise present and distance between speaker and listener, and not every deaf child learns to use these listening tools for fast and efficient acquisition of spoken language within the critical period(s) of language development (see Bley-Vroman, 2018; Lenneberg, 1967).

Although linguists and cognitive psychologists continue to debate the precise nature of the critical period(s) for language development—including arguments around how many critical periods there are (e.g., phonological, morphological, syntactic) and how long they last—there is general agreement in the scientific community that language is effortlessly acquired in a child's early years in a way that is not demonstrated by older children and adults, indicating that the brain is most receptive to acquiring language in the early years of a child's life. A significant research literature substantiates the relevance of the critical period to deaf children's cognitive and linguistic development (Berk & Lillo-Martin, 2012; Boudreault & Mayberry, 2006; Ferjan Ramirez et al., 2013, 2014; Mayberry, 1993; Mayberry et al., 2011, 2018; Mayberry & Eichen, 1991; Mayberry & Lock, 2003; Morford & Carlson, 2012; Woll, 2018).

Many turn to advances in cochlear implant (CI) technology as a solution to the language access problem. Importantly, however, simply having a CI implanted is not sufficient for spoken language acquisition in children if that is the goal; long-term aural habilitation is required to learn to use it and be able to communicate using spoken language. This is comprised of a set of techniques, referred to broadly here as auditory training (AT), that focus on optimizing sound recognition and perception, particularly for the purposes of developing spoken language, and speech therapy to improve speech production. In a multipronged approach, AT is typically paired with the expectation to provide near constant amplification (i.e., wearing the CI at all times) and often to avoid exposure to sign language (Clark, 2003; Geers et al., 2017; Humphries et al., 2015). Professionals set “expectations of persistence” for families and advise them to stick with it even if child's progress is slow. Professionals often convey a sense of “infallibility” of the CI, leaving slow progress or “soft” failures to go unacknowledged or unnoticed (Mauldin, 2019). This faith in CI technology is unwarranted given the body of research demonstrating significant variation in the outcomes associated with cochlear implantation (M. L. Hall et al., 2019; Humphries, Kushalnagar, Mathur, et al., 2014b; Mayer & Trezek, 2018; Pisoni et al., 2008; Spellun & Kushalnagar, 2018).

Deaf and hard of hearing children enrolled in early intervention by six months of age have the opportunity to develop age-appropriate language (spoken and signed), and with it, age-appropriate functioning in the many other domains that are dependent upon language and communication development: parental

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attachment, cognition, literacy, socio-emotional and psychological development. The research shows, however, that many deaf and hard of hearing children demonstrate avoidable delays in these areas due to language deprivation (Boudreault & Mayberry, 2006; Ferjan Ramirez et al., 2014; M. L. Hall et al., 2019; Humphries et al., 2016; Humphries, Kushalnagar, Mathur, et al., 2014a; Mayberry, 1993; Mayberry et al., 2018; Mayberry & Eichen, 1991; Mayberry & Fischer, 1989; Mayberry & Lock, 2003; Petitto, n.d.; Wong et al., 2018; Yuen et al., 2022).

In recent years, some researchers and practitioners have increased their attention to language deprivation and its devastating consequences. Language deprivation uniquely affects deaf and hard of hearing children, who without sufficient auditory access, can be cut off from spoken language and communication. Language deprivation occurs when children are deprived of full and consistent access to language, particularly during the highly sensitive critical period for language development (W. C. Hall, 2017; W. C. Hall et al., 2017).

### **Language Deprivation Syndrome**

Hall (W. C. Hall et al., 2017) and his research team proposed the term “language deprivation syndrome” to describe the effects of language deprivation, which had long-been referred to in the research and among service providers and deaf educators by terms such as “low-functioning deaf,” “traditionally-underserved person who is deaf,” and “problem behaviors of deafness.” For much of history, the causes of the disabilities described by these terms were attributed to deafness itself. More recently, however, researchers have discovered that it is lack of accessible language, not lack of auditory stimulation or spoken language in particular, that leads to language deprivation syndrome and its accompanying disabilities, delays and deficits (Goodwin et al., 2022; W. C. Hall et al., 2017).

Individuals with language deprivation syndrome have been described as exhibiting all of the following: language delays and disfluencies; deficits in funds of knowledge; disruptions in thinking, mood and behavior; impaired executive functioning and cognition; impaired psychosocial functioning, including difficulty with self-regulation; and literacy delays (Glickman & Hall, 2019; M. L. Hall et al., 2017; W. C. Hall, 2017; W. C. Hall et al., 2017). For many deaf children, these impairments could be avoided by the child having consistent and fully accessible language from early childhood, when the brain is expanding at its most rapid rate and establishing a foundation for the child to achieve developmental milestones in a variety of domains.

Unfortunately, awareness of the critical period of language development has also been used by many practitioners working with families involved in early intervention, including some cochlear implant surgeons, speech-language pathologists and audiologists, to advise parents to focus solely on the development of auditory skills and spoken language as early as possible, ‘bombarding’ the brain with as much auditory linguistic input as possible while the child is young enough to acquire spoken language ‘naturally’. This emphasis on auditory skills and spoken language and the false choice of ‘sign *or* speech’ can lead families to the erroneous belief that they have to make a time-sensitive decision about how to communicate with their deaf child. When parents understandably choose a spoken language path, they are typically coached to provide near-constant language and auditory stimulation to their implanted children and are told that they--and their participation and involvement in the EI process--are the essential and most important factor in their child’s development and well-being (Decker & Valloton, 2016). These parental expectations place a large amount of pressure on parents and can result in guilt, confusion, and a sense of failure if the child’s progress does not reach spoken language benchmarks. This, in turn, often

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creates a situation in which parents unknowingly put their child at risk of language deprivation by not offering them a fully accessible visual language during the critical period.

There is a growing community of practitioners who prioritize language access and recommend that parents sign with their deaf children, as evidenced by organizations such as *Language First*, legislative initiatives such as the Language Equality and Acquisition for Deaf Kids (Lead-K) campaign, and curricula such as *ASL at Home*. However, it is the experience of the authors that some families may resist the recommendation to use sign language with their infant for a number of reasons. One reason is that they may have already been given contradictory advice by medical professionals. In addition, parents may fear the social stigma they believe is associated with the use of sign language, or they may worry about their child's potential for success as a signing deaf person in a predominately hearing world. For these reasons, EI providers must also be willing to draw on the rich cultural resources available in the deaf community, including collaboration with deaf mentors. For example, Chapman and Dammeyer (2017), in their study of the association between deaf identity and psychological well-being, surveyed 742 deaf and hard of hearing adults in Denmark and found that "those with a deaf, hearing or bicultural identity had significantly higher levels of psychological well-being than those with a marginal (neither deaf or hearing) identity" (p. 187). They found no significant differences between those with deaf and hearing identities in terms of psychological well-being. It is the responsibility of EI service providers to help parents of deaf/hh children understand the full complexity of developmental issues at stake when they make decisions about language and communication. In order to do so, they need to be able to understand and address parents' concerns with respect and empathy so that they can enter into truly collaborative partnerships with families in the best interests of their children.

## **REVISITING THE "INVISIBLE BACKPACK"**

Early childhood service providers and educators who work with school-age deaf children have insight and a first-hand view into the challenges children and families face each day. It is important to guide families through the processes necessary to ensure their children receive fair and equitable opportunities to develop linguistic, cognitive, social and literacy skills in order to thrive. A meaningful relationship with children and their families is paramount for this guidance. Connection with children and their families serves as a foundation for not only the support provided, but also for compassion, belonging, learning, and critical love. Critical love is defined by Sealey-Ruiz (Jackson et al., 2014; Naputi et al., 2022; Ohito et al., 2019b, 2019a; Reid & Sealey-Ruiz, 2022) as a profound ethical commitment to caring for the communities with which we work. This includes relationship-building and creating a culture where children know they are loved and cared for, and also that their teachers, service providers, and families expect the best they can give. Dr. Sealey-Ruiz argues that without transparent and critical love for children, their families, and their communities, change will not occur. When we choose to lead with critical love, we make a commitment to removing barriers that impede growth and successful outcomes.

## **Acknowledging our Backpacks**

It is critical for educators and service providers to address unjust issues in order to uncover personal and institutional biases that prevent all children, and especially children born into marginalizing circumstances such as poverty and systemic racism, from reaching their fullest potential (Spencer et al., 2019). Working

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with others to achieve this goal requires a deeper understanding of the communities we serve, as well as a deeper understanding of oneself as an educator or service provider. No service provider or educator shows up as a blank slate. We liken this to an invisible backpack of the beliefs, biases, backgrounds and identities that we carry around with us each day. It is important to remember that when we engage with the world, we don't see things as they are. We see things as *we* are. Our internal beliefs and biases guide how we make meaning of internal and external events. They guide how we interact with others. Knowing that everyone brings a different lens to the table can help us deal with the complexity that is dismantling the barriers in our early intervention and educational systems. This is why we invite all practitioners to do the internal work of unpacking the identities we bring into learning spaces.

Why does this matter in EI? If we don't fully comprehend what impedes our ability to understand the ways power and privilege exist in our personal lives, it becomes much more difficult to teach children and their families about systemic oppression with the complexity and knowledge required. We bring all of our identities—and the experiences that informed them—into our clinical work. Therefore, we have to interrogate the ways in which these experiences have shaped our practices and our relationships with families. It is difficult work, but these experiences of internal reflection become opportunities to be educated ourselves.

Supporting families who are navigating the medical, EI and educational systems is a challenge. It requires a shift of our mindsets or beliefs to find solutions. Taking on tasks such as dismantling an ableist school system or implementing culturally relevant learning practices can seem vague and ambiguous to a practitioner who is uncertain. Although some are eager to facilitate these critical conversations, many others are skeptical, resistant, or indifferent. Many take a neutral approach and avoid conversations about prejudice and inequities. They may not understand the “why” behind changing their ideas, which can cause them to resort back to practices of comfort. Yet these familiar ways of doing things may be harmful and damaging to families. As an educator or service provider, it is imperative to encourage yourself to grow beyond self-imposed limitations. An examination of your own identity helps you gain empathy towards students and their families to help support them from a genuine place. Being explicit about the ways power and privilege show up in our lives can educate children and their families in profound ways that will help them gain independence as informed, active advocates.

## **Examining Our Backpacks**

As a guide to examining your own backpack, we invite readers to ask themselves three key questions: What positions of power do I hold?; What positions of power do I uphold?; and How can I use these positions of power to create safe spaces for families?

### **What Positions of Power Do I Hold? (Backgrounds, Identities)**

In today's society, no issues are tougher or more contentious than those involving inequalities, whether rooted in race, ethnicity, gender, disability, sexual orientation, socioeconomic class, religion or cultural stereotypes. When we examine our backpack, we take a close and hard look at which of our identities fall within categories of privilege. All of us, no matter our racial or ethnic background, financial status, gender, or physical disability, hold positions of power and privilege.

Examine where your privilege may show up in intervention or educational spaces.

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What beliefs do you hold regarding parent-practitioner relationships? Do you feel the practitioner is always right and the parent must follow the advice of the practitioner?

What beliefs do you hold about health and who is considered healthy? Do you think certain groups of people are healthier than others? Do you believe certain body types are less healthy? How do attitudes towards health affect how you interact with families?

What are your beliefs about visual language? Do you place equal value on signing well and speaking well? Do you believe that signing individuals and speaking individuals can be equally successful? Do you focus on the development of speech and listening skills at the expense of linguistic, cognitive, and social-emotional development?

What are your views on childhood? Were you raised in a way that outlined strict guidelines for how children behave? Do you believe time spent in audiology appointments and speech therapy sessions is equally or more valuable than time spent in self-directed play?

When answering these questions for yourself, notice where you hold an idea or belief that may put you in a position of superiority over a student or their family. Who does it benefit for you to hold this idea? If the answer is not the families you serve - and even more crucial, if the answer is not the *child* you serve - you may want to shift your perspective. Recognize that all families bring a backpack with themselves, as well. In it are many strengths, skills, and talents. Utilize them to form genuine connections and see where these talents can be used to advocate for their child.

### **What Positions of Power do I Uphold? (Beliefs, Biases)**

Though it may appear when examining one's own identity that there aren't many areas of privilege, we all uphold the systems of power and privilege in the system we work within. There are often policies that can leave families of marginalized groups at a disadvantage. How can we utilize our positions to level the playing field? Our first step is to always start with ourselves. Notice where there is language that is normalized within your educational and intervention spaces that sets children up at a disadvantage. For example, phrases like *impaired*, *these kids*, and *low functioning* imply that a child is other, or that they are broken in some way. When interacting with families, be mindful of using a strengths-based approach. Be very intentional with language so as not to place blame or guilt or shame on children and families. Consider using a strengths-based approach that utilizes a child's success as their foundation for learning. A child who decides to take off their listening devices during speech therapy or the school day, for example, can be seen as non-compliant, or as in tune with their need for a listening/sensory break. A child who benefits from sign language in noisy environments can be seen as using visual language as a "crutch", or can be praised for being bilingual.

Build up your health literacy. There are many groups and organizations that have a justice focus. Stay aware of positive shifts in deaf education and share the knowledge with your colleagues by lovingly calling them in when you hear labeling of a child that could be harmful.

### **How Can I Use these Positions of Power to Create Safe Spaces for Families? (Power, Privilege)**

Where do we find safe spaces for marginalized families when they are dealing with other hardships? Again, this starts with the service provider. Become a safe harbor for families. Are you being flexible in ways that families can approach you? Are you asking for feedback to evaluate your current systems of

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communication and education? Are you open to families giving you feedback? Communicate to families how much you honor their trust and let them know that you are here to support without judgment. This takes constant communication and bravery. Creating safety for others may include some discomfort within ourselves. When advocating for families, we have to challenge some of the systems in which we work. We have to be willing to change, grow, and try new things.

Dr. Jodi L. Falk, executive director of St. Francis de Sales School for the Deaf in Brooklyn, NY, has found that creating a safe space for families begins with clearly articulating the organization's mission, values, and vision, as these three pillars impact the culture of care one creates. Some ideas to ensure a sense of family belonging is integrated into service provision with the families of deaf and hard of hearing children are these:

**Representation Matters.** One key aspect of representation is ensuring that the diversity of an organization reflects the families it serves. This includes historically marginalized people, such as Black, Indigenous, and People Of Color (BIPOC) and people with disabilities, whose lived experiences provide a valuable contribution to your organization's mission, values, and vision. Their voices need to be heard. To truly ensure that these voices are heard, it's important to look beyond just the organization's leadership teams. Take a closer look at the organization's employees and ensure that they, too, are representative of the communities they serve. This can be achieved by advocating for diverse hiring practices, equitable opportunities for career advancement, and an inclusive workplace culture that values and supports all employees.

**Accessible and Inclusive Practices.** It is helpful to conduct a comprehensive audit of physical spaces and work practices to determine their accessibility from an ADA perspective. Document areas that are accessible, including entrances, restrooms, water fountains, braille signs, and interpreters. If any areas are not accessible, take the necessary steps to correct them. However, the real work of inclusivity goes beyond just meeting basic accessibility standards. It involves designing spaces and practices using principles of universal design, a set of principles that guide design of spaces and environments to ensure inclusivity, flexibility, equity, easy and intuitive use of space by people of all abilities (Edyburn, 2020). In essence, inclusion means that disabled and non-disabled peers work together side-by-side without any sense of segregation. By adopting the principles of Universal Design in our spaces and practices, practitioners can ensure that everyone feels welcome and included.

**DIY Makeovers.** A run-down environment can be demoralizing for families. To create a more positive and uplifting space, it is essential to assess the condition of physical space and make any necessary improvements. Take a walk around and pay particular attention to where families sit and wait. Make note of any areas that need attention, such as carpets that need shampooing, floors that require waxing, exteriors that need power washing, or areas that could benefit from new, bright LED lighting. A fresh coat of paint and bright lighting can help to lift everyone's spirits and promote a sense of well-being.

**Supporting the Whole Family.** If families are worried about housing, immigration and food then they may not have the bandwidth to focus on the linguistic needs of their deaf or hard of hearing child. Consider advocating for an on-site clothing and food pantry or locating nearby options for families; connect with peer-to-peer family support groups; and work with a social worker to aid with communication with outside agencies.

**Engaging Families of Deaf, HOH Children With Asset-Based Approach****Reflection and Call to Action**

Self-questioning can eventually lead to activism. If we care about the communities we serve (emphasis on serve), we are mindful of the education we offer them. We are mindful of the way we talk to them. We respect their decisions and reserve judgment. We utilize their funds of knowledge. We empower. We are not here to save.

Some families may have contents in their backpacks in common with your own. Use those connections to establish a foundation of trust and rapport. Some things in our backpacks may differ from those of the families we work with, and that's all right: It's the awareness of those differences that is an important prerequisite for engaging with families, having trust-filled conversations with them, and establishing the culture of critical love.

**COURAGEOUS CONVERSATIONS**

One of the ways that practitioners can practice and integrate courageous conversations in their work with deaf children and their families in order to create a connection of care and trust, while putting in context the “invisible backpacks” of all the participants (Client, Family and Practitioner) in the relationship, is the use of the Multicultural Relational Perspective (Hardy, 2016).

The Multicultural Relational Perspective (MCP) is a way of thinking and being in relationship with self and others. It is “a worldview, an epistemology or way of thinking about the world and where we place ourselves in it” (Hardy & Laszloffy, 2002, p. 569). MCP is a philosophical stance and approach to being in relationship and engaging in difficult and courageous conversations that allows one to locate oneself in the world and in relationship to others. This is particularly important when there are differences within the relationship that are connected to power and privilege. According to Hardy (2016), one of the assumptions of MCP is that culture is a multidimensional concept that consists of race, class, sexual orientation, gender, family of origin, ethnicity, age, ability, regionality, etc. In other words, culture does not only refer to one's ethnicity or heritage, but culture can also be connected to the values and practices in one's family of origin, and the ways that one relates to other members within one's community such as one's care team, school or play group. Culture can also refer to the ways in which deaf children relate to their own family members, as well as the ways in which health care providers engage deaf children and their families. MCP posits that all interactions and encounters are cross-cultural relationships. In other words, even in one family, a cross-cultural relationship is occurring between a deaf or hard of hearing child and a hearing parent, in which, given their hearing abilities, the child and the parent live in two different contexts and therefore have two different realities in terms of how they experience the world and how others in the world experience them. Similarly, there is a cross-cultural relationship between the health care provider and a deaf child in terms of age, race, gender, hearing abilities, etc.

A principle of MCP that connects to the multidimensional concept of culture is the notion of multidimensional view of self. The author of MCP asserts that there are multiple views of self and an understanding of the stance of the multiple views of self allows for a complex view of self, which then allows one to view and understand others from a complex view of self as well. According to Hardy (2016), “the development of a multidimensional view of the self, changes the notion that what is typically thought of as *the self* is actually comprised of many *selves*” (p. 17). Often, the belief that one is an individual creates the notion and practice of only seeing one dimension of one's self – “I am a female...he is a

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deaf child...she is a speaking body.” However, MCP implores us to see the individual as more than one dimension. The individual—*the self*—has multiple *selves*: There is a gendered self, an ability self, a racial self, a sexual orientation self, a family of origin self, etc. All these *selves* often show up in our encounters with the multiple *selves* of those we are in relationships with. Consequently, any encounter is not only a cross-cultural relationship, it is also a relationship that places emphasis on the importance of “Self in relationship to Other”. Taking a relational stance when we engage with others allows the opportunity for one to be curious about the ways in which one shows up in relationship and how others experience one in relationship with them.

Such curiosity not only focuses one’s thoughts on the other person’s thoughts, behaviors, or emotions, but it requires a critical self-awareness, self-interrogation, and self-reflection with regards to how one relates to others. And even more specifically, self-interrogation regarding one’s own thoughts, beliefs, biases, actions, and emotions in relation to others is essential in all cross-cultural encounters. To effectively embrace a relational stance of “Self in relationship Other” in all cross-cultural relationships, one must also pay attention to power and privilege in all relational encounters. According to Hardy (2016) “power and privilege are often unacknowledged but influential properties of virtually all relationships” (p. 12). Engaging in cross-cultural encounters and relationships requires the need to recognize and acknowledge the power and privilege that one possesses in relationship to others. Such self-awareness of one’s power helps in cultivating a space within the relationship to pay attention to contextual differences (e.g., disability, gender, race, sexual orientation, social economic status, gender identity, religion, nationality, etc.) between one’s multiple selves and the multiple selves of the other person. The aim is that self-awareness of one’s power will then expand to one’s ability to self-interrogate the ways in which power may be unequally distributed in the cross-cultural relationship. Such intentional acts of self-awareness and self-interrogation, we hope, will bring about self-reflection and thus, behavioral relational changes that would allow one to examine how one uses their power and privilege in the relationship to foster a space of respect and dignity, information-sharing, participation, and collaboration, where the humanity of each person in the relationship is seen and centered.

According to Hardy (2016), “differentials in possession of power are common in relationships. Those who possess greater degrees of power must also assume greater responsibility in relationships” (p.12). Assuming the greater responsibility in a cross-cultural relationship in which one has the power and privilege requires one to take intentional actions to initiate conversations about power differentials. This calls for the need to have difficult and courageous conversations, that would bring about authentic connection and trust in cross-cultural relationships. As practitioners working with deaf and hard of hearing children and their families, it is important to remember that your services are being sought at what is potentially a very stressful and painful time, when parents are informed that their child might have different hearing and speaking abilities from their own. It is critical that we realize that we hold power in our relationship to the client and the family, given that as professionals we are not experiencing similar life-changing levels of stress and emotions to those that the child and the parents are experiencing. And it is essential for us to pay attention to how we engage, and that we enter difficult and courageous conversations with the child and parent in ways that benefit the health and well-being of the child.

Within the MCP, Hardy provides the Validate, Curiosity, and Request (VCR) approach to engage in difficult and courageous conversations, particularly conversations in which the practitioner may want to invite the parents to shift their perspective in some way. The VCR approach can be used by practitioners to engage in trust-filled, caring connection and courageous conversation with a parent of a deaf or hard of hearing child for the benefit of the child. Often when parents engage a practitioner, they are stressed



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and worried about their child and thus, it is critical for the practitioner to validate the parent. “V” stands for “validation”. First, validating allows for the practitioner to slow down the pace of the conversation, creating space for calmness in the conversation. Validation does not mean that the practitioner agrees with the stance of the parent; it just allows the practitioner to communicate that they see and hear the concerns and point of view of the parent. Validation also allows the practitioner to check in with their multiple selves regarding which part of the point of view or concerns of the parent they might be responding and/or reacting to and how such a response/reaction might facilitate and/or impede the clinical relationship and work with the child and parent. The practitioner also must pay close attention to how the parent is responding and/or reacting to their expression of validation. This emphasizes the importance of “Self in relationship to other”, in which the practitioner is focusing on their own self-awareness, self-interrogation and self-reflection while still focusing on and attuning to the subtleties of communication and connection with the parent.

Once the parent communicates verbally and/or non-verbally that the validation is enough, the practitioner then moves on to the next step, “C”, which is “Curiosity”. It’s important that the practitioner be curious and express that curiosity about the concerns and viewpoint of the parent before challenging, dismissing, or providing an alternative viewpoint to the parent. The hope is that this action will further build trust and a collaborative stance in the relationship. The final step is, “R”, is “Request”. This is the point at which the practitioner requests that the parent think about or do something differently than they have in the past. After validating the parent and expressing curiosity, the practitioner has created a trusting and caring space for making the request, allowing the parent and child to respond in ways that indicate that they are respected, seen, and heard. As such, the use of VCR approach can foster a family-centered intervention that will allow for the centering of the child’s needs and well-being.

## **NEVER STOP LEARNING**

While we hope the insights and resources presented in this chapter will help service providers to engage more authentically and effectively with families in the best interests of deaf children, we believe that lifelong learning, risk-taking, sitting with moments of discomfort and learning from them, and self-interrogation are needed in order to continuously hone our family engagement practices. In addition to the citations in our reference list, we recommend the following resources to assist readers on their family engagement journeys:

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**ENDNOTE**

- <sup>1</sup> The term “deaf” will be used as an all-inclusive term referring to children with all audiological severities and those who are deaf-blind and deaf-disabled. It also includes children from culturally Deaf families, as well as those who identify as audiological deaf, hard of hearing, or “hearing-impaired.”