

When I was younger, I knew that there were deaf kids because I went to school with them, but the larger Deaf Community? No. I had no idea. That's because deafness was largely hidden.

It still is, actually. – "Jerry"

Although hearing loss is ubiquitous, hearing-abled societies view hearing loss as a negative state. Approximately 48 million Americans, or 6.1% of American adults, have some degree of hearing loss (HLAA, 2018, Zhao et al., 2019). The term "hearing-abled" may be jarring for some who have never considered that their hearing status should be labeled and othered, even though millions of Americans are d/Deaf. Most d/Deaf Americans are born into hearing-abled families; around 95% of d/Deaf people have hearing-abled parents (Caselli et al., 2021). They are usually the only d/Deaf<sup>1</sup> family members, other than older relatives, whose hearing loss is viewed as a normal part of aging. Before the birth of their deaf child, hearing-abled parents may have had little to no experience with deafness except with people who lose their hearing due to advancing years and decreasing sensory acuity (Cheng et al., 2019). As this research suggests, growing up d/Deaf in a hearing-abled family is often uniquely challenging.

### **Deafness in America: Family of Origin**

d/Deaf people are among a small group of people who claim a different cultural birthright from their parents, which includes LGBT or gender non-conforming identities and people who identify with disability culture. Bauman and Murray (2013) note, "As Deaf individuals are born into a dispersion among hearing families, they are subject to a diasporic condition from the onset" (20). This is often the genesis of many struggles that most d/Deaf people face, like low self-esteem, language deprivation, and interpersonal problems. While hearing-abled parents

---

<sup>1</sup> In American Deaf culture, "little d" deaf signifies a severe to profound audiological hearing loss; "big D" Deaf means a person who has a hearing loss and identifies with the American Deaf community and uses American Sign Language (Bauman & Murray, 2013).

grieve the loss of their envisioned child, doctors and specialists often take over, guiding parents to approach their child's deafness from a medical perspective (Hall, 2017; Schmulian & Lind, 2019). Doctors and audiologists promote the medical model of disability and encourage parents to take steps to ensure that their child is as close to "normal" as possible, using tools like childhood cochlear implantation and speech therapy but discouraging using American Sign Language (ASL) (Hall et al., 2018). For many deaf children, spoken language is mainly inaccessible; therefore, a manual language like ASL is the most accessible language option for many deaf children. Unfortunately, less than 8% of d/Deaf children have regular access to fluent signed language, and about 81% of hearing parents cannot communicate effectively with their deaf child/children (Admire & Ramirez, 2021; Hall et al., 2018). As a result, d/Deaf children who grow up in homes without ASL miss out on information regularly. This inaccessibility has lasting repercussions.

It is essential to recognize that d/Deaf people exist in a hearing-abled world, which impacts all aspects of how d/Deaf people interact within our larger American society (Aldalur et al., 2021; Gault et al., 2023; Sherwood, 2023). As noted, medical and educational professionals who work with the d/Deaf tend to be hearing and have an unconscious auditory bias toward speaking and hearing as the gold standard for communication. This bias toward spoken and heard language for communication is the foundation for audism, or the systemic discrimination of d/Deaf people by hearing-abled individuals (Bauman, 2004; Eckert & Rowley, 2013). As this paper will outline, the lives of d/Deaf people are impacted daily by audism and its broader system of oppression, ableism.

**Deafness in America: Disability Justice**

Disability justice is a concept formalized by Sins Invalid that centers the lived experiences of people with disabilities (LaJoie, 2022; Sins Invalid, 2019). Its principles guided this analysis, namely the leadership of those most impacted, as the researcher is a member of the d/Deaf community and was raised in a hearing-abled family, intersectionality, and recognizing wholeness (Sins Invalid, 2019). Sins Invalid is a disability justice organization that centers the lives of disabled people, particularly those often marginalized within larger disability communities, like women, people of color, LGBTQIA+, and other oppressive intersectional identities. Disability justice, as outlined by Sins Invalid, is "a framework that goes beyond the traditional understanding of disability rights and advocacy. It is a holistic approach that seeks to address and rectify various forms of oppression and discrimination that intersect with disability" (2019).

In comparison, Critical Disability Theory consists of a paradigm shift that aligns with the social perspective or model of disability and borrows from established theories like Critical Race Theory (Connor et al., 2016). Critical Disability Theory is an activist and academic framework to analyze the multilayered impacts of disability on people, families, and humankind. It seeks to deconstruct the traditional assumptions and conceptualization of disability and reframe it as a sociocultural phenomenon instead of a medical issue needing mediation and curing (Connor et al., 2016).

### **Deafness in America: Trauma**

In addition to growing up in homes that are often inaccessible linguistically inaccessible, studies reveal that d/Deaf people are twice as likely as hearing-abled people to experience trauma (Admire & Ramirez, 2021; Anderson et al., 2016a; Johnson et al., 2018; Mastrocinque et al., 2017; Schenkel et al., 2014; Schild & Dalenberg, 2016). Many traumas stem from the fact that

d/Deaf people struggle to access language and communication during their formative childhood years, which can complicate or trigger a traumatic experience. When we are children, our primary means of support are family members, but hearing-abled family members frequently exclude their deaf relatives from communication (Meek, 2020). This exclusion is felt early and often. As a result of this linguistic isolation and complex traumas, Johnson et al. (2018) report, Deaf individuals are more likely to develop PTSD than hearing-abled people.

d/Deaf people also are more likely than hearing people to experience specific traumatic events. These traumatic events include physical abuse, sexual abuse, and trauma related to inaccessible information, such as the unexpected deaths of family and friends and natural disasters (Anderson et al., 2016a). Trauma connected to intimate partner violence and substance abuse are also problems in the Deaf Community (Anderson et al., 2016a). Due to their linguistic minority status, d/Deaf people struggle to access linguistically and culturally appropriate treatment.

### **Deafness in America: Language Deprivation and Social Isolation**

As stated above, hearing-abled children pick up spoken language naturally through auditory input. In comparison, d/Deaf children born into Deaf families show no difficulty acquiring language since accessible and visual language exposure happens from birth (Hall, 2017). Accessible language is vital for a child's future success (Hall, 2017). Because d/Deaf children do not naturally overhear conversations and noises in their environment, they miss out on information that the rest of the family easily accesses. Due to the natural inaccessibility of this information in homes where spoken English is the only language, d/Deaf children often grow up with a smaller knowledge base than their hearing siblings (Admire & Ramirez, 2021; Hall et al., 2019). This limited access to knowledge impacts all parts of a d/Deaf person's life.

In hearing-abled families, members are surrounded by sound and spoken language. This language-rich environment provides opportunities for incidental learning, such as eavesdropping or overhearing a TV or radio report. Deaf children who grow up in these homes do not have easy access to incidental learning. As a result, widely known information, such as current events or what to do in the event of a fire, may not be known by d/Deaf adults raised in hearing families, especially if their only access to communication at home was in spoken English (Anderson et al., 2016; Sabrina et al., 2021).

Anderson et al. (2016) identified early language deprivation as a significant traumatic factor that increases d/Deaf people's vulnerability to trauma. Other factors include family conflict over educational methods, a preference to have children speak orally rather than use ASL, inadequate or insecure attachment to parents, and social isolation (Anderson et al., 2016; Meek, 2020). To aid hearing-abled parents' preference for their children to speak orally, doctors developed cochlear implantation to bypass damaged ears and fix their disability.

Cochlear implantation (CI), an invasive surgery wherein surgeons bypass damaged ear organs to connect electrodes directly to the auditory nerve, is a common intervention to treat hearing loss (Cheng et al., 2019). CI is a hot-button topic in the Deaf community since implantation runs contrary to the social and cultural lens of disability (Bauman & Murray, 2013). Many culturally Deaf people consider CI a threat to the community, mainly because hearing-abled parents often choose to implant their deaf children but opt not to learn ASL or participate in the American Deaf community. The reasons for implantation vary, but parents may feel pressure from doctors and hearing family members to implant their child because CIs are considered a "fix" for deafness (Cooper, 2019). As a result, most deaf children grow up in

hearing-abled families where ASL is often not a linguistic option (Hall et al., 2018; Hall et al., 2023).

In addition to being the only d/Deaf member in their hearing-abled family, many d/Deaf children are mainstreamed or placed in their local hearing-abled school, where they are sometimes the only child with hearing loss in the building. Typically, schools offer ASL as a foreign language in high schools, but their aim is not to teach ASL to d/Deaf students, but rather to teach ASL to hearing students (Sutterer, 2021). Alternatively, d/Deaf children attend school with supports like preferential seating in the front of the class for easier lipreading of the teacher or using an auditory setting that connects a student's CI or hearing-abled aids directly to a microphone worn by their teacher (Luft, 2016).

However, most d/Deaf people do not consider spoken English the best means of communication. Social and cultural models of disability state that d/Deaf people are not disabled in their inability to hear but instead by the environment and outside culture. Instead of being negative, d/Deaf people often find pride in identifying as d/Deaf as adults, usually after they leave their childhood homes (Bauman & Murray, 2013). When disability is seen through a social and cultural lens, the paradigm of disability shifts from isolation into a community of people who share a positive identity narrative and a sense of pride and kinship rather than as an inherently negative state of being. Culturally Deaf people consider themselves a linguistic and cultural minority who do not need fixing. Sadly, the larger hearing-abled world views a child's hearing loss as a disability that requires remediation. That remediation is often two-pronged: a) hearing-abled medical professionals help create amplified or artificial hearing in d/Deaf people, and b) educational and rehabilitation professionals help d/Deaf people learn to communicate verbally and minimize their auditory disability (Sherwood et al., 2023).

Since the passage of the Individuals with Disabilities Act (IDEA) in 1990, all American children have been guaranteed a free, accessible public education in the least restrictive environment possible (Dolmage, 2017). Nevertheless, what constitutes the least restrictive environment for a d/Deaf child is not always a class in a hearing-abled school, as d/Deaf students have limited opportunities to communicate with peers and teachers without using an ASL interpreter or attempting to speak orally (Ramirez-Stapleton & Duarte, 2021). The most standard educational settings for d/Deaf children in American schools are mainstreamed, in regular education classes, with or without supports like interpreters; self-contained oral courses or programs, where signing is discouraged or forbidden, and d/Deaf children have few opportunities to interact with their hearing-abled peers; residential schools for the Deaf, which may advocate simultaneous (ASL and Spoken English) communication in classrooms but provide barrier-free access to signed language. While there are choices for educational settings, hearing-abled parents typically choose to mainstream their d/Deaf children or place them in self-contained programs. Their educational choices, however, can trigger long-term trauma and self-esteem problems in d/Deaf children, especially if they are not with d/Deaf peers.

Hearing-abled parents and their deaf children all have unique stories. Still, many commonalities exist among people who grow up d/Deaf in hearing-abled families. These narratives have yet to be explored from a phenomenological lens. As such, this research seeks to share d/Deaf adults' experiences growing up in hearing-abled families, exploring feelings of difference and isolation as they grew up and their eventual reconciliation with their sensory differences. The following research question guided conversations between researcher and respondent: "How does being deaf in a hearing world affect a d/Deaf adult's self-esteem and self-views?"

## **Method**

Phenomenological analysis, rooted in the work of Edmund Husserl and Martin Heidegger, focuses on "deeper meanings achieved by prolonged immersion, that is, capturing the lived experience" (Padgett, 2017, p. 78). Phenomenological analysis allows researchers to examine the lived experience of the respondents and elicit commonalities and differences in their cumulative narratives.

The researcher conducted purposive sampling to recruit 14 respondents. The researcher interviewed respondents using HIPAA-compliant video call platforms rather than in person due to the COVID-19 pandemic and subsequent lockdowns. Participants ranged from 21 to 40 years old and had at least one hearing-abled parent. Due to the virtual nature of the research, the researcher was able to interview d/Deaf people from across the continental United States. All respondents in this study were either born deaf or acquired hearing loss in childhood. The Rutgers University Internal Review Board approved the research for human subjects (02/25/2021).

### ***Data Collection***

After seeking basic demographic information, the researcher asked respondents to share their experiences growing up in hearing-abled families, with particular attention to communication methods, past and present, and the experiences of growing up d/Deaf in their families, with open-ended questions structured to highlight the respondent's feelings about themselves and their families of origin. This researcher conducted interviews using the respondent's preferred method of communication. Most respondents opted for American Sign Language (ASL), four preferred to communicate in spoken English, and all reported knowing some ASL.



### *Data Preparation*

Interviews were recorded for analysis. However, the software needed help to accurately capture what was being said because it is normed for people without strong/thick accents or speech impediments; “unlike a true accent, deaf speech is characterized by large variation in pronunciation both between individuals and within a single individual,” leading to inconsistent accuracy when using automatic captions (Bigham et al., 2017; Millett, 2022; Nelson & Reynolds, 2018). If the researcher and respondent talked, the automated transcription contained multiple errors, so revisions for accuracy were needed. For interviews conducted in ASL, the researcher analyzed the discussion for meaning and transcribed it in English. To ensure accuracy, transcripts were checked against the recording by another Deaf professional who signed the appropriate nondisclosure agreements with Rutgers' Institutional Review Board (IRB).

### *Data Analysis*

In addition to phenomenological analysis, the researcher's analysis of respondents' stories is what Smith and Osborn refer to as a double hermeneutic, wherein "participants are trying to make sense of their experiences, and the researcher is trying to make sense of their making sense" (2009, p. 53). To understand and analyze the experiences of people who grew up d/Deaf in hearing-abled families, the researcher used the tenets of disability justice and Critical Disability Theory (CDT) throughout the thematic analysis, as explained in detail in the discussion section.

Phenomenology, disability justice principles, and CDT primarily drove analysis, and components of CDT were applied as sensitizing concepts. Interviews were coded by the research researcher and analyzed for themes. Once the transcriptions were coded, a communal narrative

arc emerged, allowing the researcher to make connections. These connections reflected respondents' lived experiences; this standpoint epistemology adds richness to the data.

### **Results**

The 14 respondents spoke frankly about their lives growing up in hearing-abled families, and commonalities or themes quickly emerged. These themes included feelings of inferiority and frustration regarding their deafness, which Critical Disability Theory (CDT) terms as a conflict between the social and medical models of disability and struggles with language, both literally and metaphorically (Connor et al., 2016). All respondents reported that when they were children, they often felt different or lesser than hearing-abled people and knew that their hearing-abled family members had access to information that was not accessible to them. Most respondents were raised in homes where spoken English was the primary means of communication, resulting in frustration and missed information. Many respondents reported low self-esteem as children and teenagers, primarily due to their sensory differences. As they aged and were exposed to the Deaf community and the social model of disability, respondents often reported eventually viewing their sensory difference as a sense of pride and identity, reflecting CDT's rejection of abled-as-norm. All respondents reported knowing some American Sign Language (ASL) as adults.

#### ***Childhood: "The Family Deaf Story"***

Most respondents reported that they were either deaf from birth (congenitally) or lost their hearing due to illness or injury. While neonatal hearing screening is not required nationwide, laws mandate it in all but six states (National Center for Hearing Assessment and Management, 2021). The American Academy of Pediatrics strongly encourages pediatricians to screen all children for hearing loss shortly after birth (Grandori & Hayes, 2017). Of the

respondents who reported prelingual hearing loss, the only one who said their family learned of their deafness after a newborn hearing screening was Emma. Thirteen of the 14 respondents reported that their hearing-abled parents brought home what they thought were hearing children from the hospital. However, most respondents reported that they were either deaf from birth (congenitally) or lost their hearing in early childhood due to illness or injury.

Despite being deaf from birth or infancy, most respondents stated that their families did not realize they could not hear until they were two or three after hearing-abled children begin to speak orally. Anita, a fraternal twin, shared:

My parents were clueless about my hearing loss when I was a baby, but when I was 2, it was more obvious. When my sister and I were babies, we were like the same, but when it came time for us to become more independent and play and stuff, it was clear that I was not responding to sounds. My sister was playing with pots and pans, apparently making quite a racket. I was on the other side of the room, focused on what I was doing, not paying any attention to the noise. That made my parents skeptical, and then they realized I couldn't hear.

Erica is a notable outlier. She shared:

I wasn't diagnosed until I was 5. . . My mother noticed that I was starting to speak, but it was not clear at all; she knew that I wasn't picking up on sounds in the environment. My mom took me to several doctors, and they told her, "No, she's fine. She's fine." Finally, after two years of my mom trying to get help, she found an audiologist who specializes in children. The audiologist tested me for hours and [finally] told my mom, "She's deaf."

*Childhood: Being "Different"*

After they were diagnosed with hearing loss, most respondents reported that their parents struggled to reconcile parenting a child who cannot hear speech. Many respondents talked about their family's shock, grief, and fear upon learning that they were d/Deaf. Arturo reported, "When my parents found out I was deaf, my mother internalized a lot of it and considered herself cursed." Arturo stated that he does not consider himself cursed, but he wishes he were hearing since his life would be much easier.

This is kind of hard for me to admit to you, but I wish I were hearing. I mean, all my life, I faced abuse from the Deaf community and hearing people, but I almost expected it from hearing people. And the disregard for signs as a valid language by hearing people makes it hard to be deaf too. So, yes, I wish I had been born hearing and I wasn't Deaf, because all of the abuse and struggles simply are not worth it.

Despite his struggles as an oral student, including bullying by peers, staff, and teachers, Arturo states that he has achieved success beyond what anyone could have predicted for him. Still, he carries resentment about his childhood. "I think that I'm still going to school and getting all of these degrees because I need to do that in order to break down those barriers I've faced all my life," Arturo said, "People don't understand that."

Anita is a twin. She is deaf, and her sister is hearing-abled. Growing up, Anita struggled with her identity as a deaf person, striving hard to pass as hearing-abled by speaking orally and viewing ASL as "for deaf people who were 'disabled,' not for smart deaf kids like me." Despite her pride in her ability to flourish in an oral-only classroom, Anita internalized shame related to her deafness, stating that she remembers going to bed and praying to God to make her hearing like the rest of her family. Anita also reported feeling ashamed of her "deaf voice" and said lipreading was not always easy. Anita developed an eating disorder in high school to cope with

these feelings. It was not until she went to the Rochester Institute of Technology (RIT), which is affiliated with the National Technical Institute for the Deaf (NTID), and surrounded herself with "people like [her]" that Anita's struggles with food and depression lifted. Anita reported that she still tries to make herself as hearing and oral as possible around hearing people so oral communication succeeds.

Among the respondents, Sam is an outlier. He grew up in a dysfunctional and abusive home, where his hearing-abled parents did not tolerate anything less than perfection from any family member. Sam's hearing loss, which the family saw as an imperfection, was neither recognized nor addressed by his family. Sam reports that he started losing his hearing around seven after surviving a bout with meningitis. However, Sam's parents refused to acknowledge that he was having problems hearing them, punishing him for not paying attention. Sam was raised to speak orally without special auditory or language support. As a result, Sam was not officially diagnosed with hearing loss until he left home at 17 and now identifies as late deafened. Sam stated that he is learning ASL and has connections with the local Deaf community. One of Sam's current goals is fluency in ASL.

***Family: "Dinner Table Syndrome"***

In addition to internalizing feelings of inferiority and frustrations related to language access, the CDT tenets of struggles related to voices and languages are also common in respondent stories. Several respondents used the term "dinner table syndrome," but all spoke about their struggles communicating with hearing people, especially family members. As Meek (2020) states, "The 'dinner table syndrome' is a metaphor for all of the conversations that are not completely accessible when deaf people are in situations with hearing groups." Emma stated:

My family would be all around, chatting and having fun, and I would have no idea what was going on. I would be struggling, trying to read lips, and failing. And sometimes, I would ask what was going on, what they were talking about, and my family would tell me, "Oh, don't worry about it, I'll tell you later." Later, later, it was always later, and then I would ask them to tell me what they were saying they would tell me later, and then they would say, "Oh, I forgot. It's not important."

Emma said that she took that to mean that she was not important enough to have the same access to information as her hearing-abled kin.

In interview after interview, respondents shared their communication struggles inherent in growing up deaf in their hearing-abled families. Meg's family learned ASL to communicate with her, but she felt like her language and problems were often overlooked. She shared:

Sometimes [my hearing-abled siblings] express their feelings and emotions, and my parents listen to them and empathize. It's harder to get them to understand my feelings and emotions—I share them, and my parents get defensive. And I'm just like \*shrugs\* I can't share my problems? About going to school or college? My parents really seemed to look at it like it was my fault that I'm deaf. Instead, if we replace it and substitute clear communication, there will be less miscommunications and misunderstanding. Most people grow up believing they can do anything and become anyone. For me to get there, I had to distance myself from my family and focus on myself, learn how to live my life. I was blocked from having information. I was different.

Respondents' status as the only d/Deaf child in their immediate family meant that feelings of isolation and shame related to their hearing loss were commonplace for most of them. For most d/Deaf people, oral language and lipreading are challenging, if not impossible. Therefore, many

respondents noted that they were failing at what their parents wanted them to do, making them feel bad about themselves. Sam notes:

So any effort that the hearing people in my life make to not make me have to ask for accommodation . . . it makes it feel like the burden isn't automatically on me, that I'm not the one that has to care more about being communicated with than anybody else cares about communicating with me, which is really the root of the lack of value that I feel when interacting with the majority hearing community is because I speak like you, but I don't hear like you and hearing loss is so broad that . . . I can understand what my husband is saying, but I don't understand what you're saying because I'm not used to your mannerisms, and I'm not used to the way your mouth moves.

As a result of this conflict between wanting their hearing-abled parents' approval and hunger for accessible communication, many felt a strong desire to fit into their families and make their parents proud by excelling at speech and school, especially when they were younger, even though oral communication is a daily struggle for d/Deaf people. Anita, the woman with a hearing twin, reported:

Well, I was often sad. I was very quiet and kept a lot of my feelings inside. I didn't really want to share what I was feeling to other people because I knew that I spoke in a "deaf voice," so there wasn't a lot of communication. I knew I was different, but why? I always felt like I was "broken" and not good enough. I isolated a lot. I would go to bed and write in my journal, "God, what can I do to feel better?" I was always crying or angry when I was younger because I knew my sister could understand what was going on, but I couldn't.

Several respondents shared stories when everyone else in their family knew information they did not. Emma, who identifies as deaf, stated that she would miss out on things sometimes at home and accidentally spilled the beans about a family surprise once because she did not realize it was not information for her to share. Emma said she finds the story funny now but reported being upset and ashamed about it.

Sometimes, missing out on information was tragic. Carrie reported that she was unaware that her father was dying:

I had no idea that his death was imminent. No one shared that with me. I remember that my whole family was there [at the hospital], maybe 8-10 people there, my father's side of the family, his sisters, his brothers, my grandparents, etc. I remember that they all knew he was dying, and I didn't know. I remember the doctor explaining what was going on, and it just went right over my head. The doctor was of Indian descent, and I couldn't understand his speech via lipreading because he had a really heavy accent, but I was included in the talk. I remember my mother sitting right next to me, asking me if I understood what was going on, and I told her no, I didn't understand, not really. I mean, it was an important and serious situation, and I remember that he was going to die really soon, they were going to take him off of life support, and the doctors were discussing when to "pull the plug." . . . And I thought about all of the information that I missed in the weeks leading up to his death, since he was on life support for a couple of weeks before he died . . . I remember thinking that he can wake up. I still didn't have the medical knowledge [that the rest of her family had] . . . I felt a little embarrassed, I felt stupid, and less than my hearing family. The fact that I was the only one who just found out THAT day, and it was because I was deaf, was awful.



To date, Carrie's family does not sign, but her mother has recently asked Carrie to teach her some ASL.

Jerry, who emigrated from Colombia with his family and reported that his deafness was the primary catalyst for his family's immigration, said his parents were told not to sign with him. Jerry states:

We went to the doctor who told my parents that I should only learn English, not Spanish, and **definitely** not ASL. My deaf school had two separate classes, the oral class and the signing class. Because I was in the oral program, signing was forbidden. Based on that doctor's opinion, my parents decided that the only way they should communicate with me was in spoken English.

At the doctors' advice, Jerry's whole family learned English to speak with him despite the struggles of lipreading and oral education.

While Jerry is still fluent in English, he stated that his current preferred language is ASL, and he is the only one in his family who signs. He stated,

I prefer to speak in ASL now and use ASL with everyone [except my family]. Even hearing people. I don't accommodate them. If you're going to force me to read lips, you can read my signs. And after their initial shock, they are good at writing down what they want to communicate, and that's fine for me.

Many respondents shared frustration that their family's attitudes towards their hearing loss have not changed from the medical perspective and irritation that they are doing all the work to communicate with their families. "My mother always said to me if you want to learn ASL later on, go ahead," Jerry stated, "but my family doesn't have the interest in learning ASL to communicate with me."

***Higher Education and/or Adulthood: "Meet-Deaf Wow"***

In their research, Garberoglio et al., 2017 found that a little over half, or 51%, of d/Deaf Americans have some higher education. In this sample, most (11) reported attending some college. For most, higher learning opened unexpected doors. While several colleges and universities offer specialized postsecondary education for d/Deaf, the two famous universities for d/Deaf people are Gallaudet University and the National Technical Institute for the Deaf (NTID), the latter associated with Rochester Institute of Technology (RIT). Both schools provide instruction in ASL and attract d/Deaf students from around the world, regardless of language status and signing ability. Five of the 14 respondents stated they attended RIT, and each found their d/Deaf identity while attending.

After his application to join the Army was rejected due to his deafness, Edward's father suggested RIT but did not share that there would be other d/Deaf students. Edward recounted:

I had no idea whatsoever that there would be other deaf people there when I arrived. I was so lucky. I think my father had an inkling, because he did a lot of the research, but he obviously never told me that RIT was affiliated with NTID. He encouraged me to go to RIT, but never said why, specifically. When I arrived on campus, I was in shock! I'm not the only one! It was a very, VERY different kind of experience. For the first time in my life, I was meeting people who had walked in the same shoes as me.

Some members of the Deaf community call this experience Meet-Deaf Wow (Holt & Gavey, 2007). For many, it is their first real exposure to a social model of disability that values their sensory diversity, in line with CDT (Connor et al., 2016). After growing up in hearing-abled families, most d/Deaf people vividly recall the joy and relief of meeting people like them. This thrill of Meet-Deaf Wow sparks an interest in learning more about the Deaf community and

ASL and often guides a shift in how a d/Deaf person sees themselves. Though she did not know ASL and identified as hearing impaired, Jaime's Meet-Deaf Wow moment came at 17 when she attended camp for d/Deaf teens at NTID: "The [d/Deaf] staff showed me, for the first time Deaf culture and people who signed." Following the camp, Jamie's identity shifted. She decided to learn ASL and explore her d/Deaf identity. She reported:

I'm very proud of [my deafness now]. It's a big part of who I am. I love just being able to take out my cochlear. I can't imagine a life without it [my deafness] . . . it's really important to me . . . it's definitely a much bigger part of my identity and what I do in my life and how I interact with people. I don't want people to forget [that I'm deaf] now.

Jamie is learning ASL but does not think anyone in her family will learn with her. Jamie's career plans include focusing on mental health treatment in the Deaf community.

After Meet-Deaf Wow, respondents' perspectives about themselves changed. However, family dynamics did not reflect these changes since all respondents reported using oral language and some sign support with their hearing families. These contrasting perspectives indicate that hearing-abled families have not come to view their d/Deaf child's hearing difference in a positive light. However, several respondents remarked that their hearing family members asked them to teach them some ASL.

Several respondents noted a shift in their attitude towards ASL; many stated that they viewed spoken English as preferable as children since that was what their hearing-abled families used to communicate. As adults, all respondents have shifted their views about language preference. Arturo stated, "I feel like there's more deaf people who don't sign than Deaf people who do sign, and I do feel bad for people who don't sign at all because they're really limited."

In schools, where oralism reigned from 1880 to around 1990, oral students' sense of hearing-as-superior was reinforced since oral students were lauded as more intelligent and more "abled" than their ASL-signing manual peers (Aldalur, et al., 2021). As children, many respondents reported a feeling of pride in speaking orally like their hearing-abled families, of being less disabled (from a medical perspective) than their signing peers. Once respondents had an experience of Meet-Deaf Wow, they reported that their paradigm shifted, and they realized that ASL is equal to, if not better than, oral English for them in terms of access. The fellowship of belonging is crucial to all of us, and as respondents aged, their awareness of who constituted their fellowship increased. When it came to college, Tom reported:

I was given the opportunity to go to the University of Houston as well as RIT. I decided on RIT because of the Deaf community there because of the connection with NTID. I really wanted to be around my peers more often, and I wanted to be able to communicate with my friends using my preferred language. That's why I chose RIT. There was a connection there.

Following Meet-Deaf Wow, respondents reported they discarded the term "hearing impaired." Carrie stated, "Growing up, I identified as hearing impaired. I grew up thinking that word was okay. Now I think the opposite, and I hate that word now." Carrie says that "everyone thinks of their story as isolated, but then you talk about it later with peers, and everyone is like "Oh yeah, that happened to me too." That experience resonates deeply, especially after a childhood laden with feelings of being different or lesser than others.

Jerry reported a similar experience, stating that learning ASL has unlocked a part of his life that was missing when he was expected to speak orally. "My perspective of my hearing loss has definitely changed over time," he said. "Before I felt very negative about it because I was

told all my life that it was a negative thing." However, Jerry's family did not make that perspective shift with him. He said:

I still wish [my] family were d/Deaf or at least signed. We would be able to have more conversations . . . I think if we all had the same language and the same view of Deafness, we would have a deeper connection. Right now, I'm close to them, yes, but it's kind of superficial since we don't share the same language. I can't express myself how I want to in person with them.

### **Discussion**

This study centered on d/Deaf adults talking about their experiences advances our understanding of the inner lives of d/Deaf children raised in hearing-abled families. Most respondents stated that their parents decided to raise them using oral methods. As adults, all respondents reported they have come to accept or love their d/Deafness. The d/Deaf person's hearing-abled family seldom shares this shift in perspective.

Critical Disability Theory (CDT) is an emerging theoretical perspective that draws from other critical theories, like Critical Race Theory (CRT), to provide "a theoretical approach to the concept of disability" and compare American norms and values towards people with disabilities (Block, 2016; Connor et al., 2016). The social model or social perspective of disability, as mentioned earlier in this paper, states that disabilities are essentially a social construct that misplaces the disability within the individual (as does the medical model) rather than with their environment (Block, 2016). All the respondents in this study reported knowledge of different perspectives on their hearing loss. Everyone noted that they knew that society preferred hearing people and that their parents listened to doctors when making language and educational

decisions. Additionally, most reported that their perspective on their d/Deafness shifted over time to align closely with the social model.

Multidimensionality or intersectionality, a developing concept that has long focused on race, gender, and sexuality but not disability, is another facet of CDT and disability justice (Block, 2016; Sins Invalid, 2019). Awareness of the unique needs of people with disabilities is increasing, but disability is often left out of conversations about diversity. Most respondents talked about their multidimensional identification and how important it was for them to be valued for the different aspects of their personhood. Valuing diversity within our social spheres and our conceptualization of the world, is another component of CDT and the tenets of disability justice (Block, 2016; Sins Invalid, 2019). When we view ability and disability as polarized, we miss the gradient variations that are the reality of human experience; we all fall somewhere on the spectrum between both poles.

CDT and disability justice frameworks highlight the failure of current liberal rights theory to respond to the unique needs and diversity of the disabled community by illuminating the ableist tendency to devalue disability and instead amplifying disabled voices (Block, 2016; Sins Invalid, 2019). An example of ableist tendencies is the hearing-abled parental preference to raise their d/Deaf children with a primary oral language of English instead of ASL. Many respondents also talked about the language disconnect between them and their families now that they know and prefer using ASL.

To counteract the dominant ableist narrative, CDT and disability justice value the voices of people with disabilities, providing standpoint epistemology (Block, 2016; Sins Invalid, 2019). d/Deaf voices have been largely overlooked-- we have our language and voice, neither

normalized nor valued in hearing-abled America. Often, d/Deaf people internalize these perceptions of voices and value spoken word over signed language.

Another component of CDT focuses on language since disabled people have been viewed as objects of pity and difference or as being cursed (Block, 2016; Connor et al., 2016). This is reflected in how we speak and think about disabilities. For d/Deaf children born into hearing-abled families, the ideal is access to fully inclusive family language and communication modalities, preferably ASL, since it is the language most accessible for d/Deaf people. Once a d/Deaf person has a solid language base, other languages like English are more accessible since they are studied as second languages to be built upon the foundations of ASL (Hall et al., 2018; Hall, 2017; Hall et al., 2017a; Hall et al., 2017b; Meek, 2020). Every respondent talked about language modalities and how they correlated to their acceptance of themselves as a d/Deaf person. Several respondents remarked on the terminology "hearing impaired" and how that conflicted with their shifting views about themselves. This finding fits the CDT view of language, as respondents talked about the terms used to describe d/Deaf people and the inaccessibility and frustrations of trying to communicate orally with others.

Disability justice principles mandate recognizing the wholeness of people with disabilities. When we look at people with disabilities through a socially constructed and devalued paradigm, we diminish the voices and experiences of those most impacted (Sins Invalid, 2019). Through open-ended questions, the researcher captured each respondent's unique experiences and perceptions of themselves as d/Deaf people. Most respondents reported that being deaf and raised in a hearing-abled family directly affected their self-esteem as children because they had internalized their parents' medical perspective of their deafness and viewed

themselves as people needing fixing. Their stories of struggle and isolation, regardless of communication access, highlight the lifeworld of many d/Deaf Americans.

ASL is gaining recognition in America, but many Americans still do not know that ASL is not English. Additional implications for practice include increasing the general public's awareness of the experience of growing up d/Deaf in hearing-abled families and providing professionals who work with hearing-abled parents of d/Deaf children with another perspective on their child's sensory difference. Social workers who work with d/Deaf children and their families in schools and programs like Birth to Three should consider their own biases regarding language and ability. Suggested interventions for families with d/Deaf children should include an examination of parents' biases and linguistic preferences, as well as psychoeducation regarding social models and cultural models of disability.

Like all studies, this one has limitations. The virtual nature allowed the researcher to connect with d/Deaf Americans regardless of geography, which became a limitation because recruitment had to be accomplished virtually. This skewed the sample more toward respondents who were financially able to access the Internet, which meant that respondents tended toward relative affluence. As a result, most respondents reported that their parents had the means and knowledge about current hearing technologies and opted to raise their d/Deaf child using oral methods.

Another area for improvement was the study size of 14 respondents since such a small sample size means that generalizability cannot be guaranteed. The response from the d/Deaf community was overwhelming, and many people wanted to participate. Though much work is needed in this marginalized community, d/Deaf people want to tell their stories. Suggestions for additional research include:



- Exploring additional narratives and subgroups within the larger American Deaf community;
- Highlighting different age groups, communication styles, and educational backgrounds; and
- Exploring how d/Deafness is shaped by current systems of oppression other than ableism, such as racism, sexism, and sexuality.

Many of the respondents of this study were White, so further research is also essential to fully understand the d/Deaf perspective of growing up deaf in their hearing-abled families from a racial and intersectional perspective.

As hearing-abled practitioners increase their awareness of working with d/Deaf people, the narratives of growing up deaf in a hearing-abled family are critically important for understanding the d/Deaf experience in America. We know that deafness impacts family dynamics, self-esteem, and self-perception. As clinicians, we know the long-lasting residue developmental trauma leaves. Hearing-able clinicians must address any ableist tendencies of their own when working with hearing people who have d/Deaf loved ones and with d/Deaf people who are, as Jerry stated, "hidden."

### References

- Admire, A., & Ramirez, B. (2021). Violence and Disability: Experiences and Perceptions of Victimization Among Deaf People. *Journal of Interpersonal Violence, 36*, 088626051773056. <https://doi.org/10.1177/0886260517730564>
- Aldalur, A., Pick, L. H., & Schooler, D. (2021). Navigating Deaf and Hearing Cultures: An Exploration of Deaf Acculturative Stress. *Journal of deaf studies and deaf education, 26*(3), 299–313. <https://doi.org/10.1093/deafed/enab014>
- Anderson, M., Wolf Craig, K., Hall, W., & Ziedonis, D. (2016). A pilot study of Deaf trauma survivors' experiences: Early traumas unique to being Deaf in a hearing world. *Journal of Child & Adolescent Trauma, 9*(4), 353-358  
<https://doi.org/10.1007/s40653-016-0111-2>
- Bauman, H.L., & Murray, J.J. (2013). Deaf Studies in the 21st Century: “Deaf-Gain” and the Future of Human Diversity. In LD. Davis (Editor), *The Disability Studies Reader, 4th ed.* (pp. 246-262). Taylor & Francis.
- Berke, J., & Carew, J. (2020). *Self-Identification in the Deaf Community*. Hearing Loss/Deafness. <https://www.verywellhealth.com/deaf-culture-big-d-small-d-1046233>.
- Bigham, J. P., Kushalnagar, R., Huang, T.-H. K., Flores, J. P., & Savage, S. (2017). On How Deaf People Might Use Speech to Control Devices. *Proceedings of the 19th International ACM SIGACCESS Conference on Computers and Accessibility*.  
<https://doi.org/10.1145/3132525.3134821>
- Block, P. (Ed.). (2016). *Occupying disability: critical approaches to community, justice, and decolonizing disability*. Springer.

- Caselli, N., Pyers, J., & Lieberman, A. M. (2021). Deaf Children of Hearing Parents Have Age-Level Vocabulary Growth When Exposed to ASL by Six-Months. *The Journal of Pediatrics*, 232. <https://doi.org/10.1016/j.jpeds.2021.01.029>
- Cheng, Q., Roth, A., Halgren, E., & Mayberry, R. (2019). Effects of Early Language Deprivation on Brain Connectivity: Language Pathways in Deaf Native and Late First-Language Learners of American Sign Language. *Frontiers in Human Neuroscience*, 13, 320–320. <https://doi.org/10.3389/fnhum.2019.00320>
- Dolmage, J. T. (2017). *Academic Ableism*. United States, University of Michigan Press.
- Connor, D. J., Ferri, B. A., & Annamma, S. A. (2016). *DisCrit : disability studies and critical race theory in education*. Teachers College Press.
- Cooper A. (2019). Hear Me Out: Hearing Each Other for the First Time: The Implications of Cochlear Implant Activation. *Missouri medicine*, 116(6), 469–471. Gallaudet Research Institute. (2011). Regional and national summary report of data from the 2009–10 annual survey of deaf and hard of hearing children and youth. Retrieved from: [https://research.gallaudet.edu/Demographics/2010\\_National\\_Summary.pdf](https://research.gallaudet.edu/Demographics/2010_National_Summary.pdf)
- Engelland, C. (2020). *Phenomenology*. MIT Press.
- Eckert, R. C., & Rowley, A. J. (2013). Audism: a theory and practice of audiocentric privilege. *Humanity & Society*, 37(2), 101–130. <https://doi.org/10.1177/0160597613481731>
- Garberoglio, C. L., Cawthon, S., & Sales, A. (2017). *Deaf People and Educational Attainment in the United States: 2017*. Washington, DC: U.S. Department of Education, Office of Special Education Programs, National Deaf Center on Postsecondary Outcomes. Retrieved from: [https://www.nationaldeafcenter.org/sites/default/files/DeafPeopleand\\_Educational\\_Attainment\\_white\\_paper.pdf](https://www.nationaldeafcenter.org/sites/default/files/DeafPeopleand_Educational_Attainment_white_paper.pdf).

- Gault, G., Wetmur, A., Plummer, S., & Findley, P. (2023). Violence against people with disabilities: Implications for practice. In E. Slayter & L. Johnson (Eds.), *pressbooks.pub*. PressBooks. <https://pressbooks.pub/disabilitysocialwork/>
- Grandori, F., & Hayes, D. (2017). Reflections on Lake Como Conferences (2000–2016). *American Journal of Audiology*, 26(3S). [https://doi.org/10.1044/2017\\_aja-17-0062](https://doi.org/10.1044/2017_aja-17-0062)
- Hall, M. L., Eigsti, I. M., Bortfeld, H., & Lillo-Martin, D. (2017a). Auditory Deprivation Does Not Impair Executive Function, But Language Deprivation Might: Evidence From a Parent-Report Measure in Deaf Native Signing Children. *Journal of Deaf studies and Deaf education*, 22(1), 9–21. <https://doi.org/10.1093/Deafed/enw054>
- Hall, M. L., Hall, W. C., & Caselli, N. K. (2019). Deaf children need language, not (just) speech. *First Language*, 39(4), 367-395. 10.1177/014272371983410
- Hall, W. C., Smith, S. R., Sutter, E. J., Dewindt, L. A., & Dye, T. D. V (2018). Considering parental hearing status as a social determinant of Deaf population health: Insights from experiences of the "dinner table syndrome". *PloS One*, 13(9), e0202169. <https://doi.org/10.1371/journal.pone.0202169>
- Hall, W. C. (2017). What You Don't Know Can Hurt You: The Risk of Language Deprivation by Impairing Sign Language Development in Deaf Children. *Maternal and Child Health Journal*, 21(5), 961-965. <https://doi.org/10.1007/s10995-017-2287-y>
- Hall, W. C., Dye, T. D., & Siddiqi, S. (2023). Associations of childhood hearing loss and adverse childhood experiences in deaf adults. *PLOS ONE*, 18(6), e0287024–e0287024. <https://doi.org/10.1371/journal.pone.0287024>
- Hall, W. C., Levin, L. L., & Anderson, M. L. (2017b). Language deprivation syndrome: a

- possible neurodevelopmental disorder with sociocultural origins. *Social Psychiatry and Psychiatric Epidemiology*, 52(6), 761-776. <https://doi.org/10.1007/s00127-017-1351-7>
- Hearing Loss Association of America (HLAA). 2018. Hearing Loss: Facts and Statistics [https://www.hearingloss.org/wpcontent/uploads/HLAA\\_HearingLoss\\_Facts\\_Statistics.pdf?f?pdf=FactStats](https://www.hearingloss.org/wpcontent/uploads/HLAA_HearingLoss_Facts_Statistics.pdf?f?pdf=FactStats)
- Hott, L. & Gavey, D. (Directors). (2007). *Through Deaf Eyes* [Film]. WETA Public Television, Washington, D.C., Florentine Films, & Hott Productions, Inc.
- Invalid, S. (2017). Skin, Tooth, and Bone – The Basis of Movement is Our People: A Disability Justice Primer. *Reproductive Health Matters*, 25(50), 149–150. <https://doi.org/10.1080/09688080.2017.1335999>
- Johnson, P., Cawthon, S., Fink, B., Wendel, E., Schoffstall, S., & Johnson, P. (2018). Trauma and resilience among Deaf individuals. *Journal of Deaf Studies and Deaf Education*, 23(4), 317-330. <https://doi.org/10.1093/Deafed/eny024>
- Lajoie, C. (2022). The Problems of Access: A Crip Rejoinder via the Phenomenology of Spatial Belonging. *Journal of the American Philosophical Association*, 8(2), 318-337. [doi:10.1017/apa.2021.6](https://doi.org/10.1017/apa.2021.6)
- Limb, S. J., McManus, M. A., Fox, H. B., White, K. R., & Forsman, I. (2010). Ensuring financial access to hearing aids for infants and young children. *Pediatrics*, 126(1), S43–S51. <https://doi.org/10.1542/peds.2010-0354I>
- Luft, P. (2017). What Is Different About Deaf Education? The Effects of Child and Family Factors on Educational Services. *The Journal of Special Education*, 51(1), 27–37. <https://doi.org/10.1177/0022466916660546>

- Mastrocinque, J. M., Thew, D., Cerulli, C., Raimondi, C., Pollard, R. Q., & Chin, N. P. (2017). Deaf Victims' Experiences with Intimate Partner Violence: The Need for Integration and Innovation. *Journal of Interpersonal Violence, 32*(24), 3753–3777.  
<https://doi.org/10.1177/0886260515602896>
- Meek, D. R. (2020). Dinner Table Syndrome: A Phenomenological Study of Deaf Individuals' Experiences with Inaccessible Communication. *Qualitative Report, 25*(6), 1676-1694.
- Millett, P. (2022). Accuracy of Speech-to-Text Captioning for Students Who are Deaf or Hard of Hearing. *Journal of Educational, Pediatric & (Re)Habilitative Audiology Vol. 25, 2021-2022, 25*(2021-2022). <https://www.edaud.org/journal/2021/1-article-21.pdf>
- Padgett, D. K. (2017). *Qualitative Methods in Social Work Research, 3<sup>rd</sup> ed.* Los Angeles, CA: SAGE Publications, Inc.
- Ramirez-Stapleton, L. D., & Duarte, D. L. (2021). When you think you know: Restorative justice between a hearing faculty member and a Deaf+ student. *New Directions for Student Services, 2021*(173), 11–26. <https://doi.org/10.1002/ss.20374>
- Schenkel, L. S., Rothman-Marshall, G., Schlehofer, D. A., Towne, T. L., Burnash, D. L., & Priddy, B. M. (2014). Child maltreatment and trauma exposure among Deaf and hard of hearing young adults. *Child Abuse and Neglect, 38*(10), 1581-1589.  
<https://doi.org/10.1016/j.chiabu.2014.04.010>
- Schild, S., & Dalenberg, C. J. (2016). Information Deprivation Trauma: Definition, Assessment, and Interventions. *Journal of Aggression, Maltreatment & Trauma, 25*(8), 873–889.  
<https://doi.org/10.1080/10926771.2016.1145162>

- Schmulian, D., & Lind, C. (2019). Parental experiences of the diagnosis of permanent childhood hearing loss: a phenomenological study. *International Journal of Audiology, 59*(1), 54–60. <https://doi.org/10.1080/14992027.2019.1670364>
- Sherwood, K. L., Katz Kattari, S., & Wetmur, A. (2023). Sexuality, hearing loss, and d/Deaf individuals. In S. Katz Kattari (Ed.), *Exploring Sexuality and disability: a Guide for Human Service Professionals*. Taylor & Francis.
- Siebers, T. (2008). *Disability Theory*. Ann Arbor, MI: The University of Michigan Press.
- Smith, J.A., & Osborn, M. (2009). Interpretive phenomenological analysis. In J.A. Smith, P. Flowers, & M. Larkin (eds.) *Interpretive phenomenological analysis: Theory, method, and research*. (pp. 53-80). London, UK: SAGE Publications, Inc.
- Sutterer, Claire, "Signing to Success: Developing Effective ASL Curricula in Secondary Public Education" (2021). Undergraduate Research Symposium. 66. Available at: <https://irl.umsl.edu/urs/66>
- Zhao, G., Okoro, C. A., Hsia, J., Garvin, W. S., & Town, M. (2019). Prevalence of Disability and Disability Types by Urban–Rural County Classification—U.S., 2016. *American Journal of Preventive Medicine, 57*(6), 749–756. <https://doi.org/10.1016/j.amepre.2019.07.022>