Deaf Adjacency: Liminal Conditions of Not Hearing

Megan Marshall

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This chapter examines deafness as both a diagnosable biological condition and an embodied collection of experiences. By juxtaposing an autobiographical narrative alongside a discussion of historical, cultural, and theoretical perspectives, I provide a framework for identifying and acknowledging the range of Deaf, deaf, and hearing identities in order to demonstrate how the weight of cultural and contextual influence is more disabling than the actual audiological condition. This chapter concludes with a brief overview of Deaf Gain theory and my connection to it as a perspective that subverts the connotations of associated with deafness by highlighting its affordances.

Although this chapter will go into more depth in regard to deafness, Deaf Culture, and the identities and descriptions they contain, it should be noted here that:

- *Capital "D" Deaf* references people who identify and participate in most/all aspects of Deaf culture, who communicate primarily via signed language. It also applies when describing contexts in terms of Deaf Gain theory.

- *Lowercase "d" deaf* describes the general state and diagnoses of deafness; those who are partially deaf (*hard-of-hearing*) to the extent they require assistive technology to participate in the "hearing" world. People who are deaf likely do NOT use signed language or participate in Deaf culture.

Troubling Disability

In the fall of 2019, I was in the midst of a lesson that introduced basic tenets of disability theory for students in my Young Adult literature course. I framed this discussion against two texts we'd recently covered: a novel with a highly functioning autistic protagonist *Marcelo and the Real World* (Stork, 2010) and CeCe Bell's graphic novel *El Deafo* (2014) inspired by her

experiences grappling with sudden deafness caused by childhood meningitis. As the class began

dissecting the either/or notion of ability, I shared an excerpt from Robert McGruer's 2002 essay

"Compulsory Able-Bodiedness and Queer/Disabled Existence" where he applies Judith Butler's

theory of gender trouble to the idea of normative ability, proposing that

> Everyone is virtually disabled, both in the sense that able-bodied norms are "intrinsically
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> impossible to embody" fully, and in the sense that able-bodied status is always
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> temporary, disability being the one identity category that all people will embody if they
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> live long enough. (374)

McGruer's words prompted a strong response from many students who voiced opposition to his

claim. One raised an eyebrow before saying, *I don't buy that at all. Who's to say people need to*

become disabled before they die? Sometimes people are fine and then they just…die. Chatter

arose about scenarios involving robust men in their 70s who were killed in car accidents or who

lived long lives before succumbing to quiet death while sleeping. Students wielded these

hypothetical situations to neutralize the threat of disability, keeping it far away from them. This

maneuver was familiar to me, as it's something I'd practiced for a long time.

Disability in Disguise

At some point in my childhood, the tiny hair cells in the chambers of my ears' cochleae

began to deteriorate. There was no event to announce what was happening; I did not wake up one

day, suddenly unable to hear. This lack of defining incident means there was nothing specific to

point to and nothing specific to blame. Instead, I have spent years speculating. Was it firing rifles

at camp without ear protection? Did I clonk my head too hard, too often? Maybe my mother

picked up a virus in the place of my conception (Morocco) and it traveled through her

bloodstream and into my genetic code, biding time before settling into the task of chipping away at my audiological functions.

However, being unable to pinpoint the cause of my hearing loss does not mean that I can't enjoy placing blame, because I do. I fault my ears for my horrific math skills which have forever barred me from high-demand careers in biomedical engineering or software development. In fact, I'm certain my math scores on every college entrance exam I've taken are amongst the lowest of test-takers across the globe. Though one might point to other factors, such as my lack of aptitude and effort, there's an additional explanation:

As many public-school students can attest, math gets more complex once multiplying and dividing fractions enters the picture. For me, 5th grade was the point when terms like reciprocal, variable, and inverse entered the conversation, and it was a conversation led by a teacher who had his back to the class, dashing numbers upon a chalkboard. This was before projectors and smart boards were mainstream classroom tools, and it was common for most math teachers to deliver verbal instruction while actively engaging with the information they taught, turning their backs to the class while modeling math concepts on the board.

By the tail end of my elementary school career, I had already established myself as a mediocre student, but it was also true that I wanted to do well *enough*. Unfortunately, this is when I started to simultaneously notice and ignore the fact that I didn't always understand what teachers were saying. Imagine a pot of pasta being poured into a colander, with a some of the strands slipping through the holes and down the drain of a sink. This was math class. For a while I tried to catch those noodles by raising my hand and asking questions or muttering "what did she say" to someone sitting near me, grateful for anyone who would let me copy their notes. But my teachers were not always receptive to my questions, because they had *just explained this two*

minutes ago, and wasn't I listening? Whispering in class and copying from classmates was similarly discouraged, often noted on my report cards as "distracting others" and "talking too much." Eventually, it became easier to let those noodles slip down the drain, because there was enough pasta in the colander (or information jotted in my notebook) to get the gist and keep going. Until it got to the point that those long-gone noodles were actually pieces of a foundation for understanding the rising complexity of math…like algebra.

My decline as a mathematician aligns with my development as a person who could not hear as well as people assumed. The signs of my hearing loss were usually interpreted throughout my adolescence as flakiness, daydreaming, attention deficit disorder, laziness, and the classic "Megan hears what she wants to hear." None of these assessments were off the mark, because I *was* an easily distracted daydreamer, who, like many kids, sometimes chose not to listen on purpose. Therefore, when I performed poorly on informal hearing tests -- such as those given by school nurses or aging pediatricians -- my parents easily believed that I was not taking things seriously, goofing off, and/or looking for attention. As I entered and progressed through high school, my identity solidified as a space-cadet bookworm who floundered academically, got in frequent trouble for not paying attention to her parents or teachers, and who could always get a laugh when after sliding my glasses on before saying: *okay, can you say that again now that I can see you?*

I have been asked how I managed to get through school without addressing the severity of "my problem." Part of this is because, for a long time, it was not clear that my level of hearing was that out of the ordinary. Growing up I wasn't the only one who got song lyrics wrong and ignored their parents, or who was baffled by the concept of dividing fractions. Also, I had long been constructing my coping mechanisms without being aware of what I was doing, relying on

speech-reading skills as well as an impressive ability to interpret body language and facial cues

to fill in blanks. For instance, as the sort of kid who always wanted to be in on the joke, I learned

to pinpoint the moment someone was on the cusp of delivering a punch line in order to be

amongst the first burst into laughter. While there were times when I hated putting effort into

participating in group conversation in a loud cafeteria or from the backseat of the car, it was as

easy to push those thoughts aside as it was to rely on the vague smile and nod combination, my

go-to method for navigating a social situation impeded by background noise.

  I also understood that asking questions someone had already asked was not scoring me

points with certain teachers, and in those cases, it was easier to say nothing and hope for the best.

Subjects where I could read for understanding (like English and history) came easily to me, and

so that's where I put my efforts. I chose individually focused sports where I didn't have to listen

for coaches or captains to call out plays or shout directions. Case in point: I joined the swim team

after one season playing high school basketball, where my defining moment on the court was the

day I careened into scoring an easy lay-up, forgetting that we'd switched sides after the half,

interpreting the hollering of my teammates and coach as cheers of encouragement rather than

entreaties to stop.

  My instincts (however indefinable) led me to forge a path filled with activities that

provided chances for success; I wanted to fit in, and this was how to do it. Yet my disability was

hiding in plain sight, disguised as a benign personality quirk. When members of my senior class

compiled the "Predictions for the Future" list, my entry read: *Megan Marshall will open*

Megan's Hearing Aid Shop, where she's not only the owner, she's also a client! As my hearing

issues had yet to be viewed as much more than an idiosyncrasy, what was essentially a

meanspirited jab at deafness was part of the joke; it was "funny" because I wasn't really deaf.

"You've been missing a lot"

At twenty-five, I worked in an office where part of my job required answering phones and taking detailed messages. My mistakes accumulated rapidly, and soon an observant co-worker pushed me to get formally assessed. The day of my diagnosis, the audiologist administering my exam expressed amazement that I'd managed to get by with this "severe degree" of loss. "You're way down here" she said, tapping a pencil along the slope of x-marks marching towards the bottom of an audiogram grid. "You've been missing a lot" before crediting me with "stellar speech-reading skills" when she noticed me trying not to cry.

Soon, I was fitted for hearing aids that I couldn't afford[1] and hated wearing. For the first few years, those plastic lumps of misery were constant reminders of my body's failure; they squealed amplified feedback into my brain on the regular, reminding me as they hurt me of my inadequacy. They made my ears itch and ache while doing little to help me at work, as phone calls were amplified, not clarified (plus, putting a phone anywhere near them contributed to more feedback). Plus, I was convinced that they stood out like beacons signaling my brokenness. These discomforts to my body and vanity meant that I often left them at home.

The improvement in technology and fit coincided with my career shift to education, and I began to wear them more regularly. I had to. It was similar to my experience getting glasses for nearsightedness in middle school: I didn't know how much I was missing until I saw it with my new-to-me eyes. Just as there was no going back to squinting in order to see across a room, once the volume dial of my world got turned up to 7, my natural condition of hearing at a measly 3 was not going to suffice.

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[1] The American Speech-Language-Hearing Association reported in 2019 that less than half of U.S. states require that health plans cover (even partially) the costs of hearing aids, and the majority of those limit coverage to children and young adults. The cost of hearing aids ranges from $1000-$6000 per ear and can be expected to last 4-7 years with proper care.

Definitions, Perceptions, and Performance

        In the years since that first diagnosis, I still struggle to articulate an easy term for what my audiologist recorded as "bilateral moderately severe to profound sensorineural hearing loss." I need hearing aids in order to continue teaching, to go to movies and catch at least ½ of the dialog, or to have a meaningful part in conversations that aren't one-on-one and face-to-face in a quiet environment (even so, those I'm speaking with should not have excessive facial hair, soft voices, or issues with how intensely I stare at their mouths). At night, once my ears are emptied of hearing aids, my family knows that attempting meaningful conversation with me is futile. But am I deaf if I can hear their voices or the faint sound of a door slamming, or am I deaf because of my inability to parse words out of the sounds they make? Or am I something else?

        Answers to questions like mine are varied, likely because of uncertainty about the best approach for categorizing people in terms of their deaf (or hearing) status. Part of this is due to disparities regarding how and when someone loses their hearing (National Association of the Deaf, 2020). There are also other considerations: is hearing loss relegated to one ear or is it bilateral? Is the loss symmetrical or is one ear worse than the other? How early or suddenly did it occur and how quickly was it addressed? How much linguistic ability does one have? (CDC, 2020). Even official definitions of deafness, such as this 2017 statement of the Individuals with Disabilities Education Act (IDEA) "a hearing impairment so severe that the child is impaired in processing linguistic information through hearing, with or without amplification" invites questions: What would be labeled a failure when it comes to processing information through hearing: missing ALL words, MOST words, or SOME words? If a child can process 20% of linguistic information without amplification but hears at 75% with amplification, are they more or less deaf than someone who can process 35% of words on her own, but averages only 60%

with an assistive device? Definitions like this fail to acknowledge the unique variances of what it means to be deaf.

Scholars in the field of deaf studies have framed deafness in terms of lived experiences. In *Deaf in America* (1990), Carol Paddon and Tom Humphries claim that

the lowercase deaf [refers] to the audiological condition of not hearing, and the uppercase Deaf [refers] to a particular group of deaf people who share a language – American Sign Language (ASL) – and a culture. The members…have inherited their sign language, use it as a primary means of communication among themselves, and hold a set of beliefs about themselves and their connection to the larger society. We distinguish them from…those who find themselves losing their hearing because of illness, trauma or age; [because] they do not have access to the knowledge, beliefs, and practices that make up the culture of Deaf people. (2)

They also maintain that while Deaf people may be both Deaf and deaf, the opposite is not true. Though deaf people may be accepted as part of the Deaf community through active use of ASL, participating in social and/or political activities, or otherwise demonstrating an authentic investment in allying with members of Deaf culture, their lived experiences remain significantly separate from those who are more intrinsically Deaf (Paddon & Humphries, 1990). This is why Deaf culture is sometimes viewed as "collectivist" (Mindess, 1999; Paddon & Humphries, 2005) and insular. Deaf Studies scholar Thomas Holcomb (2013) emphasizes this point, explaining "Deaf people are expected to be fiercely loyal to the Deaf community…and spend most of their social time with Deaf friends" (p. 24).

Ultimately, these explanations seek to show that deafness, capitalized or not, is a dynamic condition resisting easy categorization. Instead, one's deaf identity reflects the intersections

between a person's diagnosis and experiences, all of which are informed by historical, cultural, and social contexts.

Ancient History & After

Historically, deafness has been regarded as a condition that renders people socially and/or intellectually inadequate to the extent that they lack the capacity to interact "normally" with others. This view corresponds with the "traditional" medical model of disability, in which one's biological and/or neurological deficiencies require treatments, cures, or "fixes" that will correct or minimize impairments (Grover, 2021). In relation to deafness, this has long meant the use of hearing aids, cochlear implants, and/or targeted interventions via social services and special education programs (McAnally, Rose, & Quigley, 1987) that have often been bolstered by the use of audist[2] approaches that label deafness and markers of deaf culture, such as signed languages, as inferior (Markotic, 2001).

This pathologizing has deep roots. Reviews of Greco-Roman literature suggest that deaf people were banished from social life and considered "on a par with idiots" (Ferreri, 1906, p. 463). Aristotle is said to have claimed the deaf to be incapable of learning and of no use to rational society, while Plato went so far as to suggest they -- along with all those who were visibly disabled -- be put to death (Eleweke, 2011; Schmale & Eirksson, 1993). Centuries later, Saint Augustine is said to have described deafness more pragmatically, deeming deaf children manifestations of God's anger sent to punish parents. However, unlike Plato and Aristotle, there is evidence that Augustine was receptive to the notion that the deaf could communicate; he analyzed the significance of gestured exchanges he observed between deaf people, noting

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[2] Audism is the belief that the ability to hear gives one privilege over those who cannot. The term was first used by Tom L. Humphries in 1975. Source: https://www.britannica.com/topic/audism

similarities between spoken language and signed interactions which he felt indicated the potential for the deaf to "hear" God's word (Bragg, 1997).

This interest in signed vs. oral communication highlights the religious origins of formalized sign language, which was viewed as a means of bringing deaf people closer to God. In fact, although historians have pointed out that communication based on signed gestures likely extends to the beginning of mankind (Stokoe, 2001), the first public school focused on educating the deaf was founded in France by Catholic priest Charles-Michel de l'Épée in the mid-18th century. He wanted to ensure the deaf were able to learn their way into heaven and developed a system of methodical signs (combining French grammar with the already-established rudimentary signed language of the deaf) to teach students to understand the word of God (Sacks, 1990).

Deaf Culture in the U.S.A.

In the early 19th century, Dr. Thomas Hopkins Gallaudet traveled from Connecticut to France to study with one of de l'Epee's successors, Abbe Sicard. There he met and took lessons with Laurent Clerc, a former student of Sicard's and a prominent deaf educator. Clerc accompanied Gallaudet back to the United States, and in 1817 they founded the American School for the Deaf in Hartford, Connecticut (Burch, 2002). Graduates of this school went on to form similar institutions in other states, providing deaf students with instruction in what eventually became American Sign Language (ASL). The establishment of ASL helped lead to the founding of what is now known as Gallaudet University in 1864[3], the world's first post-secondary institution for deaf students.

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[3] The "History and Traditions" page in Gallaudet University's website provides a timeline of institutional name changes. Though established in 1864, Gallaudet University was initially called the National College for the Deaf and Dumb, changing to the National Deaf-Mute College in 1865, to Gallaudet College in 1896, and then to Gallaudet University in 1986. (https://www.gallaudet.edu/about/history-and-traditions/whats-in-a-name)

For some, the proliferation of ASL was alarming. In 1884, Alexander Graham Bell issued warnings about the rise of Deaf culture, claiming that ASL encouraged the formation of a "defective race of human beings [that] would be a great calamity to the world" (Bell, 1884). Bell was no stranger to deafness: his father was a teacher for the deaf (using oralist methods); his mother was partially deaf, and his wife Mary Hubbard Bell, was profoundly so. Despite this connection to deafness (or perhaps because of it) he fought to keep deaf people from forming communities, and actively encouraged lip reading and oral communication over ASL (Bell, 1884; Wiles, 2015).

This practice, known as oralism, signaled a shift in the education of the deaf, perpetuating the idea that the best way for deaf people to integrate into mainstream society was to communicate in the same manner of the hearing. Oralists advocated speech training, teaching deaf children "to generate sounds, to mimic the mouth shapes and breathing patterns of speech" (PBS, 2007). Accounts from the 2007 PBS documentary, "Through Deaf Eyes," show that the rise of oralism was widely considered to be the "ideal mainstream" approach for the education of deaf children; yet the use of ASL was not erased. Deaf schools, whether they embraced ASL or oralism, ensured that deaf people were brought together, thereby solidifying the presence of Deaf culture in the United States.

Other than Hearing

The growth of Deaf culture is at least partially due to the very structure that scaffolds the social model of disability. This view posits that rather than limitations being the "fault" of the person with the disability, the failure exists with mainstream institutional and social structures that are not accessible or accommodating (Grover, 2021). In other words, the physical body doesn't disable someone, but a non-accessible society does. Within this society, deafness is able

to swiftly reduce one's capital, be it educational, cultural, or economic. For although arcane views like Aristotle's have been invalidated by the formalization of worldwide signed languages and expansion of Deaf Culture, they have also been reinforced. While deaf people have the same intellectual capacity as hearing people, mainstream education is still designed to serve (and privilege) the hearing (NCD, 2018), which hampers access to the cultural and economic capital necessary for obtaining social status (Bourdieu, 1984).

Othering is structured upon "set of dynamics, processes, and structures that engender marginality and persistent inequality across any of the full range of human differences*"* (Powell & Menendian, 2017). Putting this concept into conversation with the concept of performativity clarifies how degrees of deafness are interpreted, especially in terms of how society labels those who are either unable or unwilling to perform according to societal norms and expectations. In "Arguing with the Real," Butler (1993) examines "performativity as a specific modality of power as discourse" asking readers to consider how it is that those who designed and maintained societal expectations have accumulated the discursive authority to do so (p. 187). Therefore, even with assistive technology that helps one to "perform" as hearing or the benefits afforded by Deaf culture, most D/deaf people face systems, practices, and infrastructure established by the hearing *for* the hearing, reducing their power to fully reject marginalization.

Pathologizing Otherness. What many see as inborn "rights" does not necessarily extend to those with disabilities. In his article "Disability as Diversity" Couser (2005) calls this a "natural form of human inequality" (p. 98) that supports the paternalistic management of disabled bodies. Often, a person with disabilities must be modified with assistive (and costly) devices and/or rely on others to provide accommodations for access to participate in society.

Once afforded this assistance, they become "privileged" with access to experiences, spaces, and opportunities that others generally take for granted.

Conventional wisdom posits that D/deaf people should seek medical interventions in order to correct the "body-gone-wrong" (Michalko, 2002) such as cochlear implants or hearing aids. On the surface, these interventions are seen as "gifts" that afford the experience of listening to voices of loved ones, to birdsong, to music. This gift also has a capitalistic function, in that it provides deaf people with the means of achieving the mainstream educational and economic success for contributing to society (Marx, 2013), and granting the opportunity to maintain relationships with hearing people. To that end, the focus on successful integrations into mainstream spaces is what drives much of the research focused on deaf subjects' experiences in school, the workplace, and within relationships (Kamil & Lin, 2015; Vas, Ackroyd, & Hall, 2017).

Given the value society places on sustaining normalcy, the "fix it" approach makes sense. In *Discipline & Punish*, Foucault (1995) suggests that mainstream constructs are upheld in any given culture by the power of social discourse, and threats of punitive action from the majority have conditioned us to behave in normative (and nondisabled) ways. In this system, both implicit and explicit surveillance ensures that most people can be policed into an acceptable state rather than risk being ostracized for deviating from the social contract. The result is a population that functions beneath a Foucauldian "panoptic lens," mindful of surveillance and adjusting behavior to avoid unwanted attention, intervention, and/or isolation. Successfully concealing otherness allows access to the collective, where one can contribute to the very constructs that punish difference and ensure mainstream power remains intact.

My Loss, My Gain

Helping to push against the assumption that there is a "normal" way for a body to perform is the theory of Deaf Gain, which defines deafness as "less biological dead end…than evolutionary adaptation" (Bauman & Murray, 2014, xix) and a phenomenon that has long contributed to the world's biocultural diversity and D/deaf people occupy minority position in a society largely constructed for the able-bodied (Barnes, 2016). Moreover, empirical findings show the deaf brain as not just shaped by its loss in audiological capacity, but also by enhancements to visual and manual systems (Sutherland & Rogers, 2014). In other words, hearing loss is offset by additional benefits, which contributes to our sociocultural ecology.

I personalize this concept to argue there is no "natural" way to function in hearing (or Deaf) cultures except for the way/s that I construct for myself. In other words, instead of mourning what was lost, I build on what has been gained, such as the heightened ability to "read" people's facial expressions and body language and accepting as a gift a world that will go mute when I need it to, thereby increasing my focus and alleviating stress. This gain also means I'm engaged as a teacher, always alert for visual cues. Also, my own experiences as someone who slid through the cracks has made me more perceptive to those who try to hide that they are struggling.

Certainly, participating in hearing society is exhausting, and it's easy to feel like a part-time citizen in an able-bodied realm, struggling to maintain probationary status. In new situations, my disclosures still lean self-deprecating. "My ears are terrible at hearing" seems easier than telling someone that I'm deaf, partially because I'm still conditioned to avoid appearing disabled, but also because to many, deaf = Deaf, which I'm not. In fact, the Deaf community is apt to view me as "more" disabled than Deaf people, as I lack ASL skills and require accommodation to participate in hearing society. It is a strange place to occupy, identity-

wise. Yet, perpetual adjacency to both spaces has led me to accept that while I will always have to work harder to live as I want to, the boundaries of this world are flexible, and I can push against those edges to change its shape.

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