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Deaf in Her Own Way: The Role of Identity in Social Justice Leadership

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Abstract

The following fieldwork chronicles the personal and professional trajectory of Cindy Greenspun, a social justice leader at Yale University Library. At the age of eighteen months, Greenspun suffered an illness that resulted in the loss of her hearing and spent nearly the first half of her life fully immersed in the hearing world. Through significant self-reflection and perseverance, Greenspun evolved beyond the binary paradigm of oralism–the exclusive use of speech and lip reading–to ultimately embrace the essence of being both bilingual (speech and sign) and bicultural (hearing and non-hearing). These attributes not only enabled Greenspun to navigate between two distinctly disparate cultures, they also became effective tools for raising social awareness within her own family and professional life. While there is much work to be done in bridging the worlds between the deaf and the hearing, through her own exploration of self-identity, Greenspun has become *deaf in her own way*. As such, she serves as a catalyst at Yale in championing accessibility and equity initiatives for people with disabilities of all types.

Keywords: deaf, d/Deaf, audism, oralism, manualism, linguistic minority, identity

Deaf in Her Own Way: The Role of Identity in Social Justice Leadership

For well over a century there has been roiling controversy over the societal handling and education of deaf persons. The brunt of the argument lies between a clinical and societal interpretation vs. a cultural one. The medical profession, as well as the hearing world-at-large has historically considered deafness a disability, recommending hearing and speech-related interventions in order to *fix* the problem. Conversely, the Deaf community has vehemently objected to any such classification and declared it has neither a need nor desire to be *fixed*. Further, proponents of the latter viewpoint have consistently maintained their community is already representative of a fully intact culture, equipped with its own identity, language and support systems (Murray, 2018).

In order to more clearly distinguish which model of *deafness* was being addressed (medical or cultural), both sides adopted Woodward's 1972 upper- and lower-case usage of the word *deaf* in order to visually differentiate between the two (Ladd, 2003). In 2011, Mathews described Woodward's convention–collectively expressed as *d/Deaf*–as a *socio-cultural model of deafness* and defined them as follows: "*Big-D Deaf* is signified by the capitalization of the word Deaf, indicating membership to a cultural and linguistic minority group, as opposed to lowercase [*small* or *little d*] deaf which signifies an audiological deficiency." (p. 361).

Mathews (2011) reported that, once a person self-identified as a big D or a little d it would likely infer societal implications. The researcher posited the distinction of d/Deaf as not merely semantic and suggested most deaf people would be required to align themselves with one philosophy or the other at some point during their lifetime. Once determined, however, choosing either deaf or Deaf would socially translate into an inadvertent statement of a preferred cultural affiliation, which could result in exclusion by the non-preferred group. McIlroy and Storbeck

(2011) described this restrictive either/or scenario as a *disability-difference binary*: “The assumption has been that only two identities are possible for deaf persons, namely deaf or Deaf, and that all deaf persons fit into one category or the other.” (p. 495).

The societal aspects of d/Deaf have played a primary role in the ongoing controversy. In the United States, the Deaf community, or *culturally Deaf* is largely comprised of individuals that attended deaf schools and utilize American Sign Language (ASL), which is the language representative of the Deaf in this country (Ladd, 2003). Also identified as Sign Language Peoples (SLPs), Batterbury (2014) discussed the disparate geographic nature of the membership as well as the social ties that form its sense of culture: “SLPs are a territorially dispersed minority linguistic community with a shared sign-language, culture and experiences of exclusion and stigma.” (p. 547).

Conversely, small d individuals have generally been mainstreamed through standard education channels and for a variety of reasons that are largely societal, were not exposed to ASL (Ringo, 2018). According to the National Institute of Deafness and Other Communication Disorders (2016), 90% of deaf children are born to hearing parents. Antia (2013) stated likewise, 75% of deaf children are mainstreamed through the public education system in the United States. The culturally Deaf are highly attuned to the fact that ASL is not often presented as a viable alternative to invasive medical procedures such as the cochlear implant. Therefore, the community has been reluctant to acknowledge any midway position, for fear it would proffer a historical return to audism (a discriminatory attitude towards Deaf culture), which would pose a true threat to their established way of life (Lantos, 2012).

An Evolution of Identity

Cindy Greenspun is a business systems analyst at Yale University Library. She holds a BS in Professional and Technical Communication from the Rochester Institute of Technology and an MBA from the University of New Haven. Greenspun is also deaf in both ears and has consistently described herself as a *little d.* In this context and for most of her life, Greenspun has largely been aligned both personally and professionally with the hearing world. Greenspun fits the aforementioned small d profile: she was mainstreamed in school and wore hearing aids as a child; worked extensively with speech therapists in her primary years in order to develop lip-reading techniques; and as an adult opted for a cochlear implant. During her freshman year in college, however, upon realizing her language skills were both lacking and holding her back, Greenspun opted to immerse herself in big D culture and subsequently acquired a fluency in American Sign Language (ASL). As a result, Greenspun is considered highly-functioning and able to navigate between the Deaf and the hearing world, as she not only has the ability to lip read, but also utilizes ASL, interpreting services and other assistive technologies in her professional life.

Ironically, it is the aforementioned social stratification that has at times kept Greenspun from being truly able to establish a foothold in either culture. During her interview, Greenspun was asked if her situation was perhaps comparable to a light-skinned black from an inter-racial union; the thought being that this person–no matter what–would never be quite *white* enough or *black* enough to be fully accepted by either group. Greenspun responded: “One of my biggest challenges is isolation. I chose to be in the hearing world (little d) but one of the drawbacks is not feeling included or being excluded at times.…I feel like I straddle between the deaf and the

hearing worlds, so I am that light skinned black person." (C. Greenspun, personal communication, October 10, 2018).

While feelings of exclusion and isolation are undisputed realities for Greenspun and others like her, studies have shown that a departure from the disability-difference binary to a more inclusive perspective are not only evidence of individualized growth, but also, represent a necessary transition in order to enact any meaningful societal change. Jambor and Elliot (2005) identified inherent practices, such as Greenspun's adoption of bilingual (speech and sign) and bicultural (hearing and non-hearing) strategies to be milestones of a highly functioning deaf person, as well as an indicator of personal confidence and future success:

> Deaf individuals who develop bicultural skills are able to function effectively in the dominant culture as well as in the culture of the minority group. They are often able to succeed professionally in the hearing world as well as identify with the Deaf community and fight for social change. Those who are able to find a balance between their involvement in the Deaf and the hearing world tend to have positive self-esteem. (pp. 67-68).

In an ethnographic study conducted on deaf identity, McIlroy and Storbeck (2011) defined these types of bilingual/bicultural behaviors as the culmination of becoming *DeaF* [capital D/capital F]. In this context, the uppercase *F* signifies a person's evolved sense of *fluidity,* defined as an ability to effectively operate between two cultural plains. The research suggested, however, once an individual chose to blur the line of d/Deafness, the emergence of identity could also result in unintended consequences, such as familial or cultural fallout. The study concluded that, once an individual fully transitions from binary to fluid, it was likely due to a substantial investment in critical self-reflection and cross-cultural dialog.

In 2004, Ohna published an article titled: *Deaf in my own way: Identity, learning and narratives*, which was an extensive qualitative study exploring the complexities of deaf identity and served as the cornerstone for McIlroy and Storbeck's 2011 research. Ohna's results suggested once a person made a conscious decision to cast aside the binary d/Deaf restrictions and opinions of others, they become *deaf in my own way*. Further, the research stated this transformation was likely achieved only after years of grappling with the juxtapositions of inclusion/exclusion, alienation/affiliation and acceptance/rejection from either or both sides: "*Deaf in my own way* means daring to risk something. It means recognizing that identification with hearing [and Deaf] persons can no longer be handled as it was in earlier [life] phases and that there might be significant consequences from that. (p. 34)."

The literature supports that in relation to her deafness, Greenspun exhibits many of the attributes associated with a highly evolved sense of identity. By being deaf in her own way, Greenspun has met the standard of bilingual, bicultural and DeaF. While that accomplishment on its own might be considered enough of an achievement, it is particularly remarkable given the fact that Greenspun had nearly *any* language skills prior to the age of five. Humphries et al., 2012 stated that by virtue of the impairment, young children with hearing deficiencies are in imminent danger of never fully acquiring their primary (or first) language and are therefore, at risk of being linguistically deprived: "The brain of a newborn is designed for early acquisition of language…A child who has not acquired a language by that time [the age of five] (often called the "critical period") runs the risk of not acquiring native-like fluency in any language." (p. 2). The following sections chronicle Greenspun's journey towards achieving her bilingual and bicultural freedom, as well as detail her background, education and career.

Background

Cindy Greenspun is the only deaf member in her family. She was born in Connecticut and has two brothers, one of which is a twin and an older sister. In 1969, at the age of eighteen months, Greenspun contracted spinal meningitis and as a result suffered a 65-70% hearing loss in both ears. Her mother, Ann Menze, sought advice regarding how to best handle the situation, but ultimately went against medical recommendations by deciding not to send her daughter away to a school for the Deaf. Moreover, Menze determined that she wanted Greenspun to have little, if any interaction with Deaf culture and became intent upon her functioning as a hearing person instead. Towards that end, Menze began working nights so she could tend to her daughter's needs during the day, ultimately embarking upon a strategy of utilizing hearing aids and prohibiting the use of ASL.

Thus, as a toddler, Greenspun's primary method of communication was largely non-verbal: "I did not speak until I was five years old, my mother would just let me grunt and point and try to appease me with lots of guesswork." (C. Greenspun, personal communication, October 30, 2018). This all or nothing linguistic scenario was consistent with the philosophy of the 1960's and beyond (Ladd, 2003). The literature of the day and medical advice strongly suggested once a child was introduced to ASL, it would only serve as a crutch and therefore, the child would not or could not become bilingual (attain verbal and sign acquisition). Since then, however, that assertion has been challenged across numerous studies (Thompson, Cotnoir-Bichelman, McKerchar, Tate, & Dancho, 2007; Mathews, 2011; Humphries et al., 2012) and will be discussed in a later section of this document.

Acculturation into Hearing Society

Once Menze discovered her daughter could learn to speak, she began searching for a public school that could accommodate her and found one nearby that had received a grant to host a kindergarten class for deaf children. It was there that Greenspun was first introduced to both speech therapy and Cued Speech, a visual communication method via the use of hand gestures, which is used in conjunction with lip reading in order to clarify any spoken words that may look alike, e.g., me, be, pea; mark, bark, park (Giese, 2018). Due to her lack of prior exposure, however, Greenspun's progress was slow and while therapy proved effective, she nevertheless ended up repeating the year.

In order to accelerate Greenspun's new-found awareness and assist in her learning, Menze hired a second speech therapist to work with her daughter at home during the evenings. Unfortunately, this approach proved to be too much therapy for a small child to endure. Greenspun stated that while that she was extremely fond of her both of her therapists and appreciated all they could offer, she was nevertheless miserable during that time and often threatened to run away. Ever mindful of the stress that induced these occasional outbursts, Menze nonetheless could see that real progress was being made and dealt with them in stride. Of paramount concern to her was the grant that provided Greenspun's critical accommodations was only applicable to kindergartners; this meant there would be no services available once she advanced into first grade and beyond. As such, Menze went on the hunt for a second time and ultimately discovered a school in a nearby state that had an established, long-term support system for mainstreamed deaf children. After careful consideration, Menze decided to uproot herself and her four children and relocate to Pennsylvania.

Over the course of the next four years, Greenspun developed her language skills to such an extent she was nearly fully functioning within the new educational environment. Her stability enabled the family to return to Connecticut, where she attended a public school without accommodations for the rest of her remaining years. While Greenspun acknowledged she no longer required speech therapy, the return to mainstream schooling presented new challenges. For example, in a typical classroom, Greenspun described she would frequently miss out on critical components of lecture, as the teacher's back would be to her while writing on the blackboard and speaking at the same time. Moreover, without accommodations, group discussions also proved nearly impossible to follow. Greenspun believes these were contributing factors as to why her grades ranged between C's and D's with only the occasional B. As such, her low GPA proved to be an additional obstacle when it came time to apply for colleges.

Menze's impact on her daughter's life, particularly during those formative years cannot be understated. Throughout the interview, Greenspun attributed both her strength and resilience to her mother's continuous dedication and pragmatic support:

> My mother is a very strong and strong-willed woman and I believe that she shaped who I am this day. She had every belief that I could do anything I want. I remember a conversation with her when I turned 16 and was exploring what types of jobs I could go for. When waitressing was suggested, my immediate answer was that I couldn't do it – and at first, she said I could. When I insisted I couldn't, she then said, okay – you're right, you can't do it. I remember feeling shocked that she would say that and to prove her wrong, I went out and got a waitressing job. I waitressed the rest of the year in high school, and throughout college. (C. Greenspun, personal communication, October 10, 2018).

It is also necessary not to underestimate the extent to which Menze's firm stance regarding oralism–speech and lip reading vs. manualism–the use of sign language (Lantos, 2012) influenced Greenspun's own philosophy of cultural affiliation. Throughout her young life, Menze had instilled in her daughter a strong sense of allegiance to the hearing world. More importantly, restricting Greenspun's exposure to Deaf culture as well as discouraging any use of ASL also resulted in her holding a negative attitude towards Deaf society. Greenspun described herself during this time as being almost *anti-deaf* and for that reason, had never even considered any big D options when applying for colleges, which is what made the likelihood of what happened during the next stage of her life all the more remarkable.

The Turning Point

Due to the diligent efforts and sage advice of a family friend who was also a counselor, despite Greenspun's limited choices (largely due to her GPA) she was encouraged to apply to the Rochester Institute of Technology (RIT), which also happened to be the home of the National Technical Institute for the Deaf (NTID). Because of her reluctance to explore big D options, however, Greenspun attended her freshman year at RIT without the use of accommodations, thus, her trend of poor grade performance continued. By the end of the year, Greenspun was warned that unless her grades improved, she would be in danger of flunking out. Greenspun described how strongly she relished her new-found freedom and being away at college. She believed the experience significantly improved her level of confidence and for the first time, she had even begun to date. It was only when faced with the likelihood of losing it all that her epiphany struck: "I struggled in my first year until I realized that if I learned sign language, I just might be able to keep up." (C. Greenspun, personal communication, October 30, 2018). This single leap of faith served as the impetus for Greenspun to break away from the paradigm of

oralism. Once she opened her mind to what NTID had to offer, Greenspun not only received accommodations and training in ASL, but also, for the first time gained exposure to the richness and complexity of Deaf culture:

> I learned a little bit of sign during my first year but not enough to be able to use a sign interpreter. I felt that I needed to immerse myself with the Deaf culture. The summer between my freshman and sophomore year, I applied for, and got a job as a summer camp counselor at NTID. I plunged myself into the world of deafness and became a sponge, learning as much sign as possible. I also realized that there was more to just learning signs - I needed to learn the syntax of American Sign Language (ASL), and that there is more to just being deaf (the Deaf culture). I started my Sophomore year with determination. I knew I could do well if I could just hear what was going on. In the fall, I requested and used sign language interpreters. That semester was the first time I got A's, but here's the icing on the cake -- I got A's in *all* of my classes and for the rest of my years at RIT I remained on the dean's list, only pulling in A's... (C. Greenspun, personal communication, October 30, 2018).

After obtaining her bachelor's degree from RIT, Greenspun continued her career in the food and beverage sector. Her felicitous start as a waitress eventually led to a director's position in a prominent hotel chain, but after a while she found the long hours taxing and began to consider switching careers. In 1998, Greenspun applied for a circulation position at Yale University Library. From there, she continued to move up the ranks and now works in the library's information technology (IT) department and currently holds the title of Project Manager / Business Analyst.

DiversAbility at Yale

During her twenty-year tenure at Yale University, Greenspun spent nearly half of it serving on the Provost's *Advisory Committee on Resources for Students and Employees with Disabilities.* The committee's charge was to ensure the University addressed any accessibility needs of disabled groups from an environmental and scholarly perspective. In 2015, Greenspun was approached by the Office of Diversity and Inclusion to chair a new affinity group focused on disability; thus, *DiversAbility@Yale* (2018) was launched. Also known as DAY, during its first year Greenspun focused her efforts on attracting membership and forming a cohesive community representative of multiple disabilities. Today, the group has over 100 subscribers on its listserv and a fifteen to twenty-member steering committee of dedicated stakeholders. In October 2017, in recognition of Disability Awareness Month DAY launched a series of disability related events (e.g., speakers, panels, training sessions) that proved so successful it became an annual event.

The Cochlear Implant

While in her mid-forties, in 2009 Greenspun underwent surgery to receive a cochlear implant. Fully expecting it to yield positive outcomes, she spoke about how surprised she was to discover instead that she instantly hated it. After living within a calming (albeit often frustrating and excluding) cocoon of silence, Greenspun described the sudden and intrusive introduction into a world of cacophonous noise as highly disturbing. Prior to the operation, Greenspun had 30-35% hearing in both ears, but was warned the implant could (ironically) result in permanent hearing loss. This proved to be the case; as a result of the procedure Greenspun now retains only 30% of hearing in her right ear and none in her left. Intended as a permanent solution, cochlear procedures are not easily reversible. As such and particularly while in the presence of large groups, Greenspun has frequently opted to turn the device off by disconnecting its external aid.

There is a large body of evidence that challenges the positive outcomes of cochlear implants that are ethically, socially and developmentally grounded. First, there is the risky nature of the procedure itself. Humphries et al., 2012 discussed the physical harms from surgery (as experienced by Greenspun) and questions why such an invasive procedure is even deemed as necessary: “ethically speaking, a standard for success should be cochlear implants measured against hearing aids which are less invasive and do not cause permanent damage to the cochlea” (p. 2). Lantos (2012) concurred, stating there is not enough long-term data to determine the implant’s effects, particularly when performed on children at an early age. Moreover, Lantos’ review revealed that during the mid-eighties, the procedure was performed upon children well before receiving its FDA approval in 1990. Lastly, Lund’s 2016 meta-analysis reported mixed empirical findings that questioned whether or not children that receive cochlear implants would be able to *catch-up* to their hearing counterparts in the development of a full vocabulary. These findings underscore the Deaf community’s concerns over the rising popularity of cochlear surgery, which has been opted for in 80% of deaf children in the developed world over less invasive options (Humphries et al., 2012).

Conclusion

Today, Greenspun continues to excel in her work at Yale University. In 2018, she began serving on an international steering committee related to her job in library systems, which allows her to travel domestically and abroad. Greenspun is also the mother of two active (hearing) boys, Garrett, age eleven and Nicolas, nine. While her immediate family never opted to acquire either Cued Speech or ASL, Greenspun taught her boys those techniques and proudly shared they both began speaking [signing] to her in as early as six months old. This is consistent with the literature that suggests ASL is not disruptive to a child’s verbal acquisition in later years. Thompson et al.,

2007 posited both deaf *and* hearing children can potentially benefit from an early introduction to sign language. The study further indicated that any non-verbal conduit established prior to an infant being able to articulate sounds could later be either discontinued or employed as a second language. For her sons, Greenspun opted for the latter approach and today, both are bilingual and able to freely converse with their mother by utilizing either method.

Greenspun acknowledged that personally, academically and professionally, the acquisition of ASL was a transformative game-changer in her life. Moreover, ASL introduced Greenspun to an entire culture she never believed she was even a part of–despite the fact she was deaf–as well as to an array of beneficial services she didn't realize she was entitled to. Today, Greenspun remains optimistic about the future, and while all roads are not clear and new linguistic challenges abound–namely, lip reading an array of foreign accents as part of her steering committee work–there is little doubt that Greenspun will prevail by assiduously invoking her strength of character and by being deaf in her own way.

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