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On positioning, deafness, and educational research: an autoethnography on deafness and qualitative research

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ABSTRACT

Combining autoethnography and disability studies in education, this article is an autoethnographic study of the different ways the author was positioned as abled and disabled by her institution's review board when reviewing her qualitative research proposal. The author talks back to the prevailing understandings of disability and conceptions of research that emerged as she interacted with the review board. Through the article, the author problematizes the ableism that surfaced and seeks to redefine what it means to be a qualitative researcher in spite of and because of her deafness. She ends by arguing for a more inclusive understanding of what it means to be a researcher and a call for review boards to broaden their understandings of research methodologies for those who do not identify as able-bodied.

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Sitting in a second-grade classroom, 25 students swirl around me. Several are working in pairs at the various tables around the room; a few are sprawled on the carpet near the bookcases reading from books; others are standing near book baskets talking to their friends about which books they need to select; and others, still, are with the teacher at the reading table participating in guided reading. It is a boisterous, vibrant classroom. I am there conducting research and diligently taking field notes. However, I cannot hear a word of what is being said with the exception of the child sitting next to me, for I am deaf.

I lost my hearing at the age of 11 months old due to spinal meningitis. My loss is defined as a severely profound bilateral hearing loss, and since I lost it pre-language, I had to learn to communicate in a different manner than my hearing peers. My parents opted to try an oral method of communication with me over sign language and I primarily rely on oral communication and reading of facial and visual cues to communicate as I participate in the hearing world. This is also why I define myself as deaf, not Deaf, as I do not know American Sign Language and am not part of the Deaf community, since I live and participate solely in the hearing world. In addition, I identify my hearing loss as a disability in contrast to some members of the Deaf community who do not see their hearing loss as having a disability. As a result, I use the term disability quite intentionally within this paper not only because it is a term I use and a term included in the theoretical frameworks of this paper—Disability Studies—but also, by using the term disability, I am framing how society, the IRB, and potentially, the field of qualitative research views my deafness: as a disability. In conducting research, I have had to articulate that while I wear hearing aids my aids do not help me understand spoken language. They instead amplify noise and I

have to rely heavily on facial cues to lip read and make sense of my environment. While I can hear people talking around me, I often do not know what they are saying.

While my deafness was never a factor in my personal decisions as I became an elementary school teacher or when I enrolled in graduate school, I encountered experiences of marginalization regularly. In fact, during my graduate studies I had a professor question whether or not her class was right for me because “I would not be able to participate in the group discussions.” Another professor wanted a copy of my audiogram because my letter from the Office of Disability Services stating my accommodations was not enough for her, and another flat out asked “Where’s the deaf girl?” when taking attendance at the start of class. Yet, despite those examples of othering I did not realize, naively, what role it would play as I became a doctoral candidate, began the procedures for the Institutional Review Board: Ethics and Human Research (IRB), and started conducting my own research. It was when I was going through this IRB process and encountered resistance about my research design that I began to consider how my deafness factored into the IRB’s decisions regarding my proposal and ability to research.

There is a history of research critiquing the IRB process (Boser, 2007; Leisey, 2008; Sikes & Piper, 2010; Teachman, McDonough, Macarthur, & Gibson, 2018); mainly, critiquing the positivist view of research the board takes in evaluating scholars’ qualitative research proposals. Rooted in a biomedical model (Boser, 2007; Leisey, 2008), the IRB “assumes a distanced, objectivist research stance” (Boser, 2007, p. 1063). These assumptions preclude ideas of “who is able to participate in research and how they are able to participate” (Teachman et al., 2018, p. 37). As a result, scholars have argued the IRB does not take the realities of lived experience into account when evaluating qualitative research proposals. Adopting a “one-size-fits-all” approach could possibly explain the lack of understanding centering around research in the educational spheres (Sikes & Piper, 2010, p. 5). While researchers are bound to maintain high standards of integrity in their research methods, the IRB’s disconnect in not allowing researchers to make decisions that fit the context of their study potentially curbs researchers’ agency in responding to and adjusting to needs in the research he or she is conducting (Boser, 2007).

This “one size fills all” approach raises unexpected questions for me as I do qualitative research. Based on arguments against IRB procedures with qualitative research (Boser, 2007; Johnson, 2008; Leisey, 2008; Nelson, 2004; Sikes & Piper, 2010; Tierney & Corwin, 2007); I wondered if my own otherness would be problematic. I asked myself if I could even do high-quality qualitative research that maintained a level of integrity that other researchers in the field could not question. Therefore, as I went through and eventually attained IRB approval, I began to journal about my deafness, IRB procedures, and qualitative research. I want to use this paper as a means of “talking back” to dominant understandings of disability (Mintz, 2007), and challenging the positivist ideas of research as historically supported by the IRB. I asked, in what ways does the IRB and ideas surrounding qualitative research position my ability as a researcher within the frame of ableist ideologies? How do I position myself as agentive within this environment where my lived experiences as a woman who is deaf are not considered?

Using Disability Studies in Education (DSE) as a theoretical framework, along with theory on intersectionality, roots the positioning of both the researcher—me—and the research. Employing autoethnography as a methodology helped me write myself into this narrative about qualitative research. Furthermore, since I was scrutinizing the social norms around how the IRB attended to disability in qualitative research, Disability Studies was, in conjunction with autoethnography, a methodology in which to voice my perspective. Within these lenses I, as researcher, was able to recognize and sift through issues of ableism and marginalization that manifested through my qualitative research, forcing me to consider power and privilege, redefining what it means to be a researcher.

This article discusses issues surrounding the acknowledgement and disclosure of disability in creating and establishing credibility in one particular qualitative research project. I will begin by describing the frameworks, DSE and intersectionality, that allowed me to see how I was enacted

and positioned within the research space. Then, I will discuss how I used Disability Studies as my methodology along with autoethnography. Lastly, I will explore my findings, using my research questions as the guiding posts, concluding with a discussion about my deafness and research practices.

Conceptual framework

Using the interdisciplinary, subdiscipline of Disability Studies approach of DSE as the lens to look at my data, I notice that I encountered positioning, by academia, in both model frameworks rooted in Disability Studies: the medical and social. In the medical model of disability, the focus is on one's limitations and depicts the individual's deafness as a problem that needs to be fixed (Ashby, 2012). In assigning medical constructs to disability, the condition must be intervened and "disabled people are to be acted on, shaped, and turned out as best as can be done" (Ashby, 2012; Linton, 2005, p. 518). The emphasis on "society's prioritization of normality," creates a divide between "disabled person" and non-disabled members of society, cultivating condescension and pity, and neutralizing the complete aspects of the individual (Ashby, 2012; Eyler, 2013, p. 320; Kunze, 2013; Linton, 2005). Conversely, in the social model of disability, the emphasis is on disability as a social construct. Disabilities are not one's impairments, but instead occur "when society restricts or impedes" the individual, limiting and excluding them from society (Eyler, 2013, p. 320). The meaning of disability, according to this model, is created through interactions with society (Ashby, 2012, p. 92). Disability is constituted within the politics of social relations—it is contingent upon the social relationship and how that situation becomes reconfigured when I enter its space. For example, my impairment is my hearing loss but my hearing only becomes a disability when I try to watch some movies and cannot due to lack of closed captions. Disability becomes a problem to be solved by society, while in the medical model, the disability is something to be treated and fixed by doctors (Wheeler, 2013, p. 339).

Understanding these models has important implications for the field of education. Reconciling the medical and social models, DSE emerged by questioning disability within a social and cultural context within education (Taylor, 2006). Baglieri, Valle, Connor, and Gallagher (2011) argue against the idea of disability as socially constructed since "It seems ridiculous because it appears to deny that some people cannot walk, see, or hear" (p. 271). They continue to clarify that DSE is not questioning the biology of some people being able to walk, see, or hear; "what is being questioned is the significance or meaning that we, as educators, place on those biological differences" (p. 271). Thus, as a subdiscipline of Disability Studies, DSE questioned constructions of disability at large and is not limited to issues and practices within special education (Gabel, 2005, p. 17). In DSE scholars engage in "the difficult questions about the educational practices surrounding the phenomenon of disability" (Baglieri et al., 2011, p. 268). Since most educational exclusion happens in general education settings like mine, DSE allowed me the framework to explore the exclusion I faced within my time as a doctoral candidate in the academy.

In Price and Kerschbaum (2016)'s study on two researchers with disabilities and their impact on conducting interviews with other faculty who identify as disabled, they commented, "Disability almost always changes the rules, and not always in ways that make people comfortable" (p. 34). With this in mind, I sought to see in what ways my disability changed the rules; how it reconfigured the space of research, when it comes to IRB's notions of qualitative research.

Intersections of disability, identity, and qualitative research

When I first began the process of autoethnography in studying my research and interactions with IRB, I only considered one aspect of myself—my deafness—and how it impacted the

process, for I had been questioned because of, identified by, and discriminated against precisely because of my deafness my whole life. When the queries came from IRB, I knew my deafness was at the root of what they were asking, for there is a long history in research of “those who are categorized as different/disabled, are constituted within the discourses and practices of normativity as disturbing the right and proper order of things” (De Schauwer, Van De Putte, & Davies, 2018, p. 8), as in my case, “the right and proper order” of qualitative research (p. 8). Up until the point of disclosure, I was just another researcher. But, as in my life outside of academia, as soon as my deafness became known, my disability within research became defined by societal parameters as well. It is because of this I realized that, if I am to work within my own disability, I needed to be aware of how the idea of normativity is prevalent within society, researchers, research, and the IRB.

Disability and qualitative research

In Young and Ackerman’s (2001) article on the working relations between Deaf and hearing professionals, they asked in understanding “how research is conducted and [how] knowledge is produced (Stanley & Wise, 1992) ... What is or should be the impact of an explicitly held value base on research production?” (p. 179). In my case, this value base is my deafness. While my research was not conducted through an emancipatory lens, how I and others quantified how I did research was shaped through predisposed ideas concerning how the research process should look and be executed.

In conducting qualitative research, whether through using grounded theory, case studies, ethnographies, narrative inquiry, or phenomenological studies, issues surrounding credibility and accuracy are important in establishing the credibility of the data. To maintain the integrity of the research project, questions pertaining to the soundness of research—especially in regards to the context of knowledge construction and/or one’s effect on the research process—are often raised by research committees such as the IRB (Glesne, 2011). In fact, in my research proposal, questions relating to how I was constructing knowledge and the effect of others on the accuracy of my data were raised. Yet, in making my methodological decisions pertaining to how I conducted my research, those same issues of epistemology and validity were key markers that shaped my research process. What differed was my deafness. Lester and Nusbaum (2018) argue “that critical qualitative research serves to challenge taken for granted social norms about doing research *with* or *by* (and not *about*) disabled individuals” (p. 3). My deafness challenged how research can look. Couser (2013) capitalized on the idea that modern culture wants to make decisions about others’ disability, stating,

Disability is an inescapable element of human existence and experience. Although it is as fundamental an aspect of human diversity as race, ethnicity, gender, and sexuality, it is rarely acknowledged as such. This is odd, because in practice disability often trumps other minority statuses. That is, for people who differ from the hegemonic identity in more than one way, certain impairments—such as blindness and deafness—may function as their primary defining characteristics, their ‘master status’” (p. 456).

Able-bodied people long have a history of making decisions about others because of their differences, but in doing so it stymies the ability for the person with a disability to be understood. Gill and Erevelles (2017) put a magnifying glass on this in their critique of the handling of the Elsie in the nonfiction novel *The Immortal Life of Henrietta Lacks* (Skloot, 2010). The events depicted in the book take place in the 1940s–1950s. Elsie, one of the protagonist Henrietta’s daughters, is briefly mentioned in the book; this absence would not be troubling if it were not for the fact that Elsie was described as having an unknown disability, one so severe she was institutionalized. Gill and Erevelles (2017) argue that Elsie, a real person, was dehumanized, with the emphasis on her violent actions that were, correctly or incorrectly, attributed to her disability. These violent actions were framed as a burden and therefore, a just cause to have Elsie removed

from her family and placed in an institution (Gill & Erevelles, 2017). With this focus and subsequent absence of Elsie from the story, the ableist ideology of able-bodied people making what they believe is the best decision for a person with a disability without understanding that person is perpetuated. Within Gill and Erevelles's (2017) critique, Elsie was positioned as a burden and someone to be fixed instead of understood.

This distrust of the disabled bodied has created a socially acceptable form of dismissiveness. Since the medical institutions did not know what to do with Elsie they removed her from society in order to fix her. Similarly, the IRB board did not know what to do with my deafness within the context of my proposed research and, as a result, put their own assumptions on me about what I could or could not do based on their ideas of disability as it pertains to society. While their response was not as extreme as placing me in an institution there is still an underlying current of others needing to make decisions about me precisely because of my differences. This affirms the positivist, ableist, and binary ways of doing research seemingly held by the IRB (Boser, 2007; Johnson, 2008; Leisey, 2008; Nelson, 2004; Sikes & Piper, 2010; Tierney & Corwin, 2007). De Schauwer et al. (2018) argue that within research there is commonly a "normal" way to do research wherein disability deconstructs this idea, potentially advancing ideas around both what it means to be disabled and to do research.

In another example, Michalko (2001) recounts his experiences as a university professor who happens to be blind; more pointedly he discusses how his blindness impacts the very environment, both physical and assumed, he walks into—a classroom. His blindness is not only different because most able-bodied people have not had experiences with disability but because his blindness is part of his role as a university professor teaching a classroom of students, causing students to ask "How can he know, if he doesn't see?" (Michalko, 2001, p. 356; Shakespeare, 1999). His blindness becomes cleaved to him as he is no longer just a person, he is a person with 'blindness' and his disability becomes theirs as he had to show his students he can do what his able-bodied colleagues can. Moreover, he has to confront students' perceptions that sight is connected to knowledge, and his blindness is not theirs but instead part of his identity, "and not one which is contingent and from which we must escape" (Michalko, 2001, p. 358). Michalko's (2001) difference, his disability, is now social aspect of the classroom and learning environment. He has a different set of criteria he has to function within because of his blindness. Social culture, according to Couser (2013), takes people's represented difference and "exposes affected individuals to inspection, interrogation, interpretation, and violation of privacy" (p. 458). Therefore, it is us, those with disabilities, who can continually peel away at the curtains in society that wants to "perfect the body" and instead reinstate identity into our conversations. Michalko's (2001) research, along with other scholars (see also Castrodale, 2018; Chaudhry, 2018; De Schauwer et al., 2018; Oliver, 1992; Teachman et al., 2018), center and reclaim disability in a way that opens up understandings of research—who can conduct and participate in research, how research can look, and create spaces where disability is essential to the research instead of on the periphery.

Intersectional categories of identity

However, as I began this autoethnographic research, I knew I needed to consider the intersectional (Crenshaw, 1989) aspects that complicated the larger picture of my marginalization. I had to unpack more than my feelings in being othered, I had to unpack all the social structures—being a woman, being deaf, being a graduate student—that were intersecting to complicate this notion of research and complicate how I had to approach research once those social structures became known. My history, my culture, and positionings lead me to realize my womanhood impacted the way I reacted to their questioning as well. Through this, I came to fully know "that female embodiment is a disabling condition in sexist culture" (Garland-Thomson, 2002, p. 6).

Young (1990) takes this idea further when she says, “Women in a sexist society are physically handicapped” (p. 153). Thus, as someone who is both female and has a disability, my disabilities are “ever present—explaining all, muting all” (Erevelles & Mutua, 2005, p. 254). I could not continue this autoethnographic work without considering both my identities as female and disabled. Garland-Thomson (2005) concludes,

Feminism challenges the belief that femaleness is a natural form of physical and mental deficiency or constitutional unruliness. Feminist disability studies similarly questions our assumptions that disability is a flaw, lack, or excess (p. 1557).

I never met any members of the board. All communication was done via the IRB portal or email. My name was on my application materials and later, in emails, I addressed each with my name which is decidedly feminine—Sara. Additionally, in conjunction with my last name, my name is fairly Anglo-Saxon, containing no clear cultural markers. While I cannot say for sure if IRB used that information to shape their transactions with me, I can say for sure that my femaleness is saturated with meaning within our culture, as is my race: Caucasian, and, that pervasiveness challenges my legitimacy on multiple levels. Womanhood, much like disability, brings with it negative connotations that affect the way culture views and interacts with us, for “culture inscribes narratives on [] bodies, willy nilly” (Couser, 2013, p. 458). Garland-Thomson (2002), in discussing the instability and social deviance of both women’s bodies and disabled bodies references Bordo describing the “too-muchness of women” that also “haunts disability and racial discourses, marking subjugated bodies as ungovernable, intemperate, or threatening” (as cited in Garland-Thomson, 2002, p. 8).

This intersectionality grounds how these identities—disability and female—inform each other. Crenshaw (1989) coined intersectionality as way of describing how the interwoven systems of power such as class, gender, race, and disability, among others, reciprocally construct each other and impact those marginalized by society. In considering these systems of power, one must consider the privileged identities as well as the marginalized ones. Intersectionality, then, provides a platform in which to describe my own lived experiences. It acknowledges I am not only disabled and not only a woman, but looks at the intersections of those social structures. Respectively, it achieves the “formidable task of mediating multiple differences” inherent in identity (Erevelles & Minear, 2013, p. 356). My experiences resulting from my identities collectively shape who I am, exposing commonalities with those that share some aspects of my identity and showing ways I am distinct and made exceptional (Linton, 2005, p. 518). But in looking at my other identities I recognize some support my privilege. For example, my role as a graduate student and my whiteness only play into this narrative as a privilege.

So, when I critique these able-bodied structures of power that challenged my legitimacy through the IRB process, I cannot do so without acknowledging my womanhood, my whiteness, my education, and, of course, my disability. Though the interactions with IRB were seemingly anonymous, their challenging of my authority of knowing what I am doing in regards to my research in a classroom revealed something “abnormal” about me (Siebers, 2013, p. 279). Suddenly, I was put in the new position of having to manage the IRB’s expectations of how disability and research can look. Before my disclosures, research was enacted in one way, but after, coming up against these social structures of disability, the standards for research shifted. Furthermore, as Siebers (2013) argues, “there supposedly exists no form of identity not linked ultimately to subjugation by others” (p. 282). My identity, and especially in the case of this study—my deafness—was brought under scrutiny. The IRB takes for granted that they view research with an ableist lens—research is how an abled-bodied researcher can enact it; when I come in, I alter it, changing the relationship between IRB and myself and between research and myself.

Methodology

Learning about myself as a deaf, female researcher happened as a result of my interactions with others. Thus, it was through the social process of designing a research plan, dialoguing with and eventually completing an IRB, and conducting research that I noticed the presence of disability where it had not existed for me before. As a result, I was, in this social context, positioned as a learner, “appropriating” knowledge of myself between the context of both IRB and my research site and my actions (Bodrova & Leong, 1996, p. 9).

This research is an autoethnography of my personal experiences in qualitative research, and is a result of a larger study encompassing the period between August 2014 and May 2015. I started the IRB process in mid 2014, began my research in a local public elementary school in January 2015, and ended in May of the same year. My research looked at how a second-grade teacher co-constructed an understanding of nonfiction as a genre with her students. All participants were hearing. I used pre-and-post interviews, video data of large and small group discussions, observational notes and conceptual memos as my data sources for that study. For the context of this autoethnographic paper, I used my IRB documents, emails from the IRB organization, personal narratives, and observational notes I kept through the aforementioned study as my sources of data. I triangulated my evidence as a participant-observer, a researcher with access to classroom data and lesson plans, and as a researcher with daily self-reflective memos and coded for areas where my deafness created a barrier between me and the research process. I did not seek to study my positioning as an outsider (deaf woman) studying an insider culture (hearing participants), as I approached the classroom study from the framework in which I was raised and still live my life: the hearing world. Instead, it was through that study that I began to notice my otherness and felt compelled to declare my disability, which resulted in this particular autoethnographic work acknowledging how I addressed my disability based on others’ perceptions of my deafness. Pulling from Disability Studies it seeks to assess whether there is a significant connection between disability and scholarly research and false ideologies that perpetuate assumptions about disability.

Disability studies as methodology

Using Disability Studies (DS) as a methodology, I am analyzing the social norms—in this case, qualitative research practices as seen by the IRB—that “define particular attributes as impairments, as well as the social conditions that concentrate stigmatized attributes in particular populations” (Minich, 2016, n.p.). Furthermore, I use DS as a way to process, identify, and analyze not my deafness but, instead, the social conditions around the structures in qualitative research that seek to exclude my non-normative ways of being. Linton (2005) argues in using a DS lens the focus “is turned toward the representational and institutional structures” that people with disabilities people must supposedly be fit into (p. 518). Focusing on these structures shifts the impetus away from fixing the individual and towards looking at the macro-level structures disabling people with disabilities and assigning more value to others (Baglieri, Valle, Connor, & Gallagher, 2011; Minich, 2016; Taylor, 2006). It helps disrupt notions of what counts as quality, ethical research and challenges notions about accessibility and research practices that are rooted in the ways that ability informs research.

Historically, qualitative research falls along a binary, dividing “abled from disabled, and normal from abnormal” in which boundaries are created and the disabled and abnormal are separated as other (De Schauwer et al., 2018, p. 9). In this manner, while I intrinsically knew how my deafness impacted my methodologies in conducting research, the questions posed to me by the IRB went further than asking how I accommodated my deafness within my research, it raised questions about my ability to even conduct research. I was not only being held up to able-bodied standards but being questioned precisely because of my supposed lack of an “able” body.

Compounding this dilemma, I have a 'hidden disability' in that I am deaf, wear hearing aids, and communicate orally, so when my hair is down, covering my ears, I can easily be mistaken, and have, as hearing or as someone with a minor speech impediment. I am frequently asked what country I am from, as people assume I have an accent from somewhere other than the United States. My supposed accent, notwithstanding, I present myself as in possession of a normal body and thus, because of this front of abled-ness, people have been offended when I peel that veil away to reveal a need or accommodation; people are taken aback that I no longer fit their ideas of normalness. Because I do not fit able-bodied definitions of how deafness "should" be perceived, the harder it can be to expect accommodations surrounding my research process. All people with disability, regardless of visibility, are socially pressured to emphasize their normality and meeting the standards of the dominant society (Gill, 1997). This is where Minich's (2016) assertion that disability studies is also a teaching methodology, allows others, including myself, to reflect and challenge the reductionist thoughts and actions prevalent in society, or in my case, the IRB's perception of qualitative research. In order to effect change, to assert a voice where I am commonly erased (Teachman et al., 2018), I needed to challenge the social norms and structures that positioned me in ways I did not want, nor did not need (Rinaldi, 2013). Thus, my inclusion of autoethnography in my methodology allowed me to disturb and problematize both conceptions of disability and my perspectives as a researcher who happens to be deaf (De Schauwer et al., 2018, p. 17).

Autoethnography as social action

In using DS as a methodology, I looked outward to acknowledge and complicate the social norms that stigmatize the IRB's potential conceptions of accurate research and research practices. However, I also needed to look at myself and examine my own identity and power, or lack thereof, within the cultural context of the conduction of qualitative research. In order to do this, I also employed autoethnography as a methodology. I positioned myself as the researcher and the research subject, being critically reflexive of not only the problems I perceived in my research, but also of my own complicity in the issues surrounding research, understanding my own educative history that shaped how I approached and conducted research, and acknowledging the oppression that I felt while being aware of the privilege I did bring to the research process (Hughes & Pennington, 2017). Additionally, when applying autoethnography as a methodology, I sought to consider and analyze this emerging awareness of deafness and qualitative research, the effect it had on me, and how it does/could impact research.

This "performative act" (DeLeon, 2010, p. 399) of autoethnography required me to situate myself in the framework of something I had done before—qualitative research—but instead think about the experience in new ways, contesting, and resisting what I was seeing, holding it up to current epistemologies (Hamilton, Smith, & Worthington, 2008). Challenging the idea that research can be done from a solely objective stance, autoethnography allowed me to acknowledge the differences I saw emerging from my research methods (Hughes, Pennington, & Makris, 2012). Using the vulnerability of reflexive self-exploration and explaining exactly how I was othered by the "ordinary fabric" of educational contexts (Chavez, 2012, p. 339) I was positioning myself as a "major character" in the over-arching story of qualitative research and, hopefully, will create a sense of connection and empathy with other researchers (Holt, 2003, p. 2). Moreover, with the lens of Disability Studies in Education, I became aware of how I was shifting between privileged and marginalized status, giving voice to the experiences that are often ignored or invisible in academia (Laubscher & Powell, 2003, p. 210). By opening up my work to a wider audience, I hope to bring people to new ways of inquiring, thinking, and critiquing issues surrounding evidence and research (Cheek, 2008; DeLeon, 2010).

My deafness, IRB procedures, and qualitative research

Since I had seen and positioned myself in a hearing world for my entire life, when writing my research plan I did not consider the ways my hearing loss would impact my research precisely because I had lived my life in a way that automatically accommodated my needs. When I did not hear or misheard something, I would ask a person to repeat what they had said; I sat close to speakers and ensured I had an unobstructed view of their face; I used my keen sense of observation to study behavioral mannerisms as ways to fill in the gaps that my ears could not. I used all of those strategies to make certain I could participate in the hearing world as best as I could. Thus, in drafting my IRB proposal, my hearing was not mentioned and I did not give much thought to my own access needs. When I stated that part of my daily conceptual memos would be checked by the teacher I was studying, I unknowingly opened myself up to criticism. Since I did not see my hearing as a vital part of the study, I did not consider any issues around validity or whether or not the teacher would sway or change my opinions or data because I was only using her as a means of clarifying what I did not hear much in the same way I have used hearing people my whole life. Additionally, having conducted and completed research before without having to disclose my deafness, it did not occur to me that the everyday things I do to fully participate in a hearing society would challenge ideas of research.

Imposing positions through ableist ideologies

In creating my research plan, the two biggest areas of concern addressed by IRB concerned reflexivity and external validity (Creswell, 2007) as it related to the relationship between the teacher I was studying and myself, and transcription. While both of these are common research concerns able-bodied people confront and address, due to my disclosures of disability, these issues were challenged, problematized, and required explanation and defense.

Within qualitative research, the normative frame of interviewing, observation, and video/audio recording is challenged within the aspect of disability since disability is seen as changing this normative part of the research process, affirming what Kerschbaum (2014) means when she states, "The reality is that disability to many still signals disqualification" (p. 69). This questioning and positioning is problematic, because being seen as different is, essentially, marginalization. In Kerschbaum's (2014) article on disclosing disability in academic writing, she comments "questions about my disability can feel ancillary to my scholarship, rather than integral to it" (p 58). By asking about my disability status, and challenging the needs I have in order to conduct qualitative research, scholars are marginalizing my position as a researcher and consequently revealing ableist ideas surrounding research and how it is done. In asking about one's disability status, Davis (1995) states "there is a powerful policing mechanism" in as much, as there is a perception about my ability or inability to do research (pp. xvi–xvii). While I acknowledge my deafness does reshape how research is done; I question if conceptions of research are aligned and held up to standards of able-bodiedness that, in effect, constrain what counts as trustworthy and valid research?

The IRB and disclosures of deafness

I have had to rely on captioning and subtitles my entire life, and so it was logical for me to request outside transcription for my audio and video data. In fact, many hearing scholars I know outsource their transcription, and if they could, why couldn't I? When I wrote in my proposal that ODS transcribers would be transcribing my video and audio data, rightly or wrongly, I was positioning myself agentive, recognizing my disability hinders one aspect of me being in the world—hearing video—and finding a way to fix the issue. There was no consideration of whether this would affect my research process because I was not seeing my disability as a problem to be

fixed or something to overcome, instead it was a natural extension of how I lived my life outside of academia. I was already achieving authority, confidentiality, and accuracy in my work simply by conducting it the way I already knew how.

However, my disclosures of disability had effects. In disclosing not only my disability but how my disability was going to shape my research, I had to acknowledge that others understand my deafness differently than I do. When the IRB found issue with my disclosure of talking with the teacher about my study and my explanation about my video and audio data being transcribed by others, I had to amend my research plan two more times. The IRB requested I clarify information in order to establish whether the people in my study—the students and teacher—were being treated with fidelity. There could not be any question about whether or not the students or teacher saw, interacted with, or influenced my data, otherwise, per IRB, they would be co-researchers instead of the people being studied. This disclosure of disability is a disclosure of the positivist views commonly prevalent in IRB. For example, in disclosing that the second-grade teacher whom I was researching was privy to my daily conceptual memos only in order to ensure the memos I was creating matched up with the actuality of what was happening in her classroom, I opened up myself to questions about whether or not the research subject could influence my conceptual memos, and thus, change the trajectory of the study. Again, I struggled with this. Could these behaviors which were only in place to ensure that I was hearing the data that I did miss through no fault of my own cause others to question the credibility of my data? In some qualitative research studies, participants are allowed to co-construct or participate in data collection; however, the collegiate review board follows stricter protocols about participants' roles in the research process.

The IRB was concerned about changes in behavior, issues surrounding internal and external validity, and threats to my (researcher) bias. I recognized these as positivistic views surrounding research, where events within a research setting are observable and interact in a precise, regular manner. Within a positivistic perspective, there is distance between the researcher and the research, creating a neutral lens in which research is viewed and conducted, rendering it, according to positivists, purely objective. Therefore, my checking to make sure specific students said the things I thought they did was challenged by the IRB and did, in fact, challenge my agency as a researcher. I was essentially closing the gap between the researcher and research. What I saw as a way of using my agency to ensure the credibility of my study, others saw as a way for me to manipulate the data to desirable outcomes.

In each of my two amendments for IRB, I noticed varying degrees of disclosure on my part. When the board challenged why the teacher was privy to my data on a daily basis, I originally tried to position it as member-checking, but the IRB spoke about breaking confidentiality, asking "What will [the teacher] pull off of the recordings that the ODS transcriber will miss?" implying that the transcribers would be able to capture all the information I needed, negating the need for the teacher to answer any questions I had about the classroom lessons. The board also spoke about confidentiality when challenging my transcription protocols, asking that my transcribers, employed by the University's Office of Disability Services (ODS) and who have to adhere to their own confidentiality contract, be added in as co-researchers. This is when I felt I needed to disclose exactly why my research was being structured in this way and discussed my hearing loss, writing "I have a hearing loss and need help with transcribing. ODS has helped with transcribing for me in the past and they are bound by their own confidentiality agreements." Thinking this would clarify things, instead, it caused more issues. IRB began to push for me to only share portions of my video data that included information needed for my research, revealing they did not fully understand what it meant for me to not hear nor understand any of the video data and thus unable to divide up the data without it first being transcribed. It was here, as Schalk (2017) states, that "the marginalized space of disability exists around, and helps define the limits of, the centered, privileged space of ability" (n.p.). In seeking to reframe my work around their idea of confidential, ethical qualitative research, the board was revealed to be leaning into its own

ableist privilege, not acknowledging or recognizing that it was pushing against and pushing out a space for conducting research that was outside its norm. After several revisions and emails back and forth, where nothing was getting resolved and my explanations about why I felt what I was doing was still adhering to structures around data collection in qualitative research, I finally sent an email explaining the degree of my hearing loss, my history, what I could and could not hear, and why I needed ODS to transcribe my data for me and wanted to be able to discuss with the teacher in my study what had happened in the classroom that day. I wrote:

The ODS transcriber will not be seeing the video information at that moment. It'll be given to her several days later; hence I will also have to use my notes to make sure I know what is going on in terms of visual cues, etc. I will miss some information due to my hearing, which is why I was hoping I could have the teacher help me if I do... The transcriber will only write down what she hears in that particular video and won't make comments on pauses and visual cues as I would if I could do my own transcribing.

That section of my research proposal was immediately approved. Looking back, I question whether what I did was correct or agentive, but I know I was reacting from a place of marginalization. I needed to disrupt what they saw as what "counts" as quality, confidential, and ethical research. Did they let their own assumptions about what they thought deafness meant, looks like, or operates influence their definition of research? Did they, as Shakespeare (2011) says when writing about disability, "already think they know how it will end?" (Section 2, para. 1). My overt disclosure was a way of negotiating access and inclusion to the research process. Since I had been defined and perceived by their biases of disability I felt I needed to speak to my disability in ways that they could come to terms with, that seemed tangible, and palatable to able-bodied conceptions of what I could and could not do.

Agentive positionings within research

Once I began my research, I noticed in situations where I previously would have been unfazed that I had begun tailoring how I saw or gathered research based on the comments I had received from IRB. For example, in observing a small group lesson in a vibrant, noisy second-grade classroom, I knew I was not going to be able to hear some of the young children's voices as well as I could hear the teacher and the children closest to me. I began to question whether or not I was really getting a "true picture" of the conversations happening in the lesson. I began to move the audio recorders several times because "I needed to get everything" but ended up distracting and disrupting the lesson. I would stop the students' natural conversations and ask them to tell me what was being said or even repeat conversations. After that lesson, I asked myself if I was erecting roadblocks because I was viewing the scene through IRB's lens and not mine. On asking myself what would have I done had I not received any questioning from IRB, I realized I would have placed the audio recorders in the best possible place at the start of the lesson and left them alone, would have collected data based on what the teacher was saying and would have done the best I could to establish what the children closer to me were saying in response, and I would have taken extensive notes on the visual behaviors of the children further away. Instead, by trying to manipulate the classroom to get the so-called "true picture" I was doing the very thing I did not want to be doing—shaping the students' construction of knowledge by my position in the classroom. Did the IRB, with its positivist leanings, view note-taking as existing in a vacuum where in the researcher captures every word as it was uttered and every moment as it was done? Even hearing researchers do not catch everything that is being said. I decided to share my frustrations with the teacher in my study and she offered some ideas on how to best accommodate my needs in an organic way for her classroom. Upon realizing that the other students in the class probably have trouble hearing their quieter classmates during both large and small group discussions, she decided to start repeating what a student said to ensure not only that I heard everyone, but that the other students heard each

other. By voicing my concern, I opened up a space for everyone in the room to hear, not just me and not just for my research purposes.

Since Davis (1995), has famously said that the idea of “normal” is inextricably tied to disability: to be not normal is to not have a disability, I wondered if my idea of research, with the accommodations I needed to make, was “not normal.” Since my “normal” did involve, very heavily, different degrees of signaling my deafness within the research, how could I define my research and its process as “normal” or not? I began to redefine what “normal” research looked like, and began to redefine how I maintained standards around confidentiality and accuracy in my data. When going over my observation notes with the teacher, I did not show her my notes but instead communicated verbally about what I had heard or had missed. I did not ask her about her interpretations and instead focused solely on factual accounts of what happened or did not. If she was not able to confirm or negate any questions I had about dialogue, I noted that as well. I took notes on these discussions and later triangulated them with my field notes and my daily conceptual memos.

I refused to subscribe to the notion that my research was different because I, a deaf woman, outsourced my transcription, in comparison to able-bodied researchers outsourcing theirs. I took something that was a “normal” practice but was seen as abnormal due to my deafness and reclaimed it. Focusing instead on what I could do, observe visual behaviors, meaning “that what is being listened to can often be perceived off of the listener’s body” (Price & Kerschbaum, 2016, p. 40), empowered me as a qualitative researcher. My “normal” research meant having others transcribe my work but I still went through every line of transcripts cataloging, coding, and organizing my data. I had to “engage[] in the ongoing process of situating [myself] and [acknowledge], even making use of, [my] own filters. [I had to] be open to negotiation, for ‘defining a research role for oneself is not entirely in one’s hands’ (Reinharz, 2010, p. 33)” (Rinaldi, 2013). When I received all of my transcripts, I read through every line of the transcripts while playing my video data, in way, triangulating all of my different experiences to get a fuller, more accurate picture of what transpired in the classroom. I redefined the culture of researcher.

Concluding remarks

My deafness matters. I resented this implication at first because not only had I lived my life trying to prove my able-bodiedness, but when starting the research process, I did not initially recognize a place for my deafness inside the framework of research as proposed by the IRB. By coming face-to-face with my deafness, I recognized how I had continually, unintentionally and intentionally, negotiated my deafness in hearing environments, enabling my understandings of how I fit in lived spaces of research. The questions that arose about my research process, and consequently my deafness, are indicative of greater questions overall. I began to wonder whether qualitative research is still seen as a sterile process where the outside researcher must observe in a way that does not contaminate the environment or disrupt the “natural” behavior of the participants. Yet, these assumptions about this purity in research leads to assumptions about the people conducting the research. Research and research subjects are social, and since researchers and subjects are jointly part of the setting, we all impact our research in some manner.

Qualitative research is still an emerging, growing field, yet it may never catch up to the cultures and worldviews, and specifically, in my particular experience, societies that privilege the ability, of their members. For while I acknowledge and support that the IRB board exists to ensure ethical research practices and that its earlier questioning of my research proposal was rooted in the framework of qualitative research ethics, not in stigmatizing my ability to do or not do research, I still recognized the members’ comments, while potentially well-intentioned,

stemmed from an ableist worldview. That positioning marks their assumptions of the relevance of my deafness and assumptions about me and my deafness (Kerschbaum, 2014, p. 67).

While these critiques of the IRB are not new, as explained earlier, the IRB needs to allow for accommodations within research or, even more, recognition that the methods in place have been chosen by the researcher as the best means to collect data and he/she has considered all avenues. Does the research need to be protected from the researcher, regardless of ability? If I had had to reveal my deafness at the start of writing my research plan would I have run into more obstacles? Did my deafness “limit the imaginations of those who think of themselves as nondisabled?” (Garland-Thomson, 2005, p. 1567). Research is messy, hence why we have the IRB to begin with, yet the lack of acknowledgment around the messiness of the researchers—who we are, what we bring to the study, and how we become an additional means to the study (Smagorinsky, 1995)—has effects. Within the realm of disability, this effect is even more, the questions around my practices move beyond conceptions of research and encroach into conceptions of people. At what point am I considered qualified to make decisions about research? Will it be when I reach a higher rank within the academy? Or, when my deafness has become so minimized within my research as not to seem offensive? This is precisely why I became more nervous each time I had to respond to IRB with disclosures around my deafness. Because of my disclosures I had to decide to announce personal information about myself which made me feel more vulnerable precisely because my study was not autobiographical, in order to be seen as agentic. These disclosures, however, do not signal disqualification. As someone who has wanted to be seen as legitimate within the academy, I had to confront that my lack of hearing is part of that very legitimacy. By reclaiming my story, I changed the idea of othering from someone about whom assumptions have been made to reshaping the limitations I was originally unaware of but impacted all stages of the research process.

My deafness changes how I conduct research. For example, I recognize that if subjects talk at once, interrupting, and overlapping each other, I will miss what is being said. Consequently, I rely on one-on-one interviews throughout the research process. This does not diminish my data corpus, instead it shifts it, taking into account the social setting and me, as a social being. It takes into account that I may, and do, rely heavily on other forms of data collection, using observational notes, interviews, and written data in order to capture a full picture of my study. In enacting agency, I subscribe to the idea that researchers will be open to discussing how qualitative research can look outside of the stringent framework of how it is conducted, instead seeing disability as a natural influence on the process.

Yet, even while writing this, being aware of those limitations still causes me to ask, “Am I qualified to do qualitative research?” While I know the answer is, “Yes,” the question becomes: How can the IRB open the boundaries of what qualifies as ethical research so I can question myself in the same way other researchers do? My disclosures of disability are actually an important piece in productive conversations around inclusion in research, and they help problematize “unexamined attitudes, beliefs, and assumptions” (Ware, 2001, p. 108) held by research boards and/or individuals confronted with definitions of research outside their own. All of these experiences, personally and professionally, have shaped my identity as an academic scholar. And, I would like to contribute to encouraging more stories by faculty members who identify as not having an abled-body, promoting diversity and justice within the realm of research. Most research that has asked these questions have been on research conducted with and on marginalized populations, with the main researcher(s) being from an outside group. Here, this lens is flipped, as I was the marginalized population conducting research on able-bodied persons with a potentially able-bodied review board.

I believe we owe it to our colleagues and students to see and dialogue about research that is different than the able-bodied dominant narratives within the academy. Such conversations foster empathy, honor subjectivity, and extends understandings; they also help researchers confront and, hopefully, begin to eliminate boundaries in relation to qualitative research. These

conversations, while underpinned by connectivity, can be riddled with unpredictability. Some may dismiss my wonderings, and even my research, asking why I do not do research that does not include the situations in which I cannot fully participate. Some may even ask what my deafness even has to do with research in literacy related fields. I cannot control what people will say about my research, and even acknowledge that there may be questionings and dismissals but these disclosures are, as Kerschbaum (2014) states, “assert[ions] of myself as a certain type of person: competent, assured, capable” (p. 68). I can continue to acknowledge and discuss how my deafness has shaped me, refusing to let it be silenced, and allowing it to be a foundation on which discussions around equity and social justice in qualitative research must be had.

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