A New Lens: The Lived Experiences of Interpreters with Disabilities

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Abstract

This study examines the experiences of ASL/English interpreters who self-identify as having a disability. Little is known about this group of professionals so the literature review begins by investigating various theories from the field of disability studies and their possible applications to the conceptualization of interpreting. Using grounded theory research methodology, quantitative demographic data was collected and combined with interviews from interpreters with disabilities to better understand their experiences from their own perspective. Patterns uncovered in the study include experiencing ableism and internalized ableism as common, the role of extralinguistic knowledge, and the challenges of performative neutrality when in the role of ASL/English interpreter. It is my hope that this work will usher in a future where we create a new, collaborative interpreting model and an interdependent, fully representative field of professional interpreters.

Keywords: disability, abled, interpreter, interpreting, ableism, deaf

Introduction

Access Intimacy

I remember one of the first interactions I had in the deaf community as a student of American Sign Language (ASL) in the fall of 2007. I was excited that my own knowledge of ASL had grown to the point where my classmates and I were beginning to attend local events, open to the public, where ASL would be the language in use. I arrived early, adjusted the button on my shirt that identified me as a student – a hearing person learning ASL who was attending to practice – and got out of my vehicle. I made my way to the little cinder-block building, the Center for Independent Living, where I intended to spend the evening playing a card game called Euchre and learning new signs for the different suits in the deck, for the left and right bowers, and hopefully making new friends. As I entered the building and followed the signs down the hallway to the lobby, I found a small group of people being welcomed by one of the organizers; a white, middle-aged, deaf man. The group had clearly been visiting because there were folding chairs scattered around the area. The deaf man motioned for the group to go ahead into the next room where the card tables were set up. He then turned to me and I nervously tried to smile as I looked away from the haphazard parking lot of chairs. I had been trying find a path to the fun and games beyond. I was a visitor, a student, so I knew I could not bulldoze my way through, using my wheelchair as a tool to clear a path. I figured the noise wouldn’t bother anyone, but there was the potential to get tangled in the chairs – folding chairs have skinny legs that can get caught in my spokes – meaning someone would have to awkwardly help me get untangled when the bulldozing was done. I could move each one by hand, but that meant a lot of back-and-forth pushing and pulling which would take longer. The deaf man followed my gaze, looked at me again, and started to move chairs himself. It took less than ten seconds and a path was cleared while I just stared, eyes wide. He then turned back to me and signed, “What else do you need? How can I help?” I had been a wheelchair user for less than a decade in 2007, but this was the first time that another person not only made space for my wheelchair, but asked me directly what other accommodations I might need. I hadn’t even needed to ask for help or communicate anything; it was just immediate and easy access provided by a stranger.

That night at the Euchre party illustrated part of what disability justice advocate Mia Mingus refers to as access intimacy on her blog, Leaving Evidence (https://leavingevidence.wordpress.com). Access intimacy is “that elusive, hard to describe feeling when someone else ‘gets’ your access needs” (2011). It was a great feeling, and years later I still remember that moment as one of many that led me to work with deaf people as an ASL/English interpreter. As a student I enjoyed the sense of interdependence, where I would eventually provide a service which made the world more accessible to someone else. However, the longer I work as an interpreter the more occasions I encounter where I wished I could talk to another interpreter who also used a wheelchair – I continue to have questions and I have often needed someone who understood my experiences. Later, as I became interested in social justice, advanced interpreting studies, and the role of disability as a critical lens through which we can analyze our world and my position in the world as a person with a disability, the more interested I have become in understanding what the field of ASL/English interpreting might look like through a critical disability studies lens.

St. Catherine University lists social justice as one of its Values, stating, “We create an environment of equity, fairness, and respect and we work for systemic change so Earth and all people can thrive” (retrieved 2020, https://www.stkate.edu/about/mission-and-vision). A social justice framework defines a path for activists and accomplices within the field of ASL/English interpreting to push the field towards a future we can only now imagine. By centering the stories and experiences of interpreters with disabilities, we can begin to uncover new ways of thinking about interpreter procedures, ethics, and education and perhaps move the field in a more equitable direction where all interpreters and the communities we serve can thrive.

Statement of Problem

Scholarship has documented the experiences of other groups of interpreters according to heritage status, sexuality, and race (Adam, Aro, Druetta, Dunne, & Klintberg, 2014; Donovan, 2019; Forestal, 2011; West Oyedele, 2015). Understanding the unique ways these groups navigate the interpreting profession has sparked interest and informed standard practices in the field, and documenting the experiences of interpreters with disabilities could help improve practices further.

When beginning an investigation into the experiences of people with disabilities, there are several points that must be acknowledged regarding positionality of our current body of disability knowledge, principles of social justice, and the possibilities and limitations of language to help us navigate these conversations. In the literature review, the complexity of finding a definition of “disability” will be investigated, followed by a brief history of disability from antiquity to modern theories, and the contradictions present in the ways in which the deaf community has become situated in the broader field of disability studies. The methodology section explains the study design, which relied on grounded theory and thematic analysis to locate new information about the way interpreters with disabilities perform our work. The results section reviews data collected from a national survey and series of interviews with interpreters who self-identified as disabled, which provides some insight to current practices while illuminating many areas in need of additional research. Throughout the following discussion I will illustrate the many failures of current binary paradigms which exist in the field of interpreting and ways we might embrace transformative practice and interdependence as principles to move the field into the future. All of these efforts are an attempt to answer one question, “What is the lived experience of ASL/English interpreters who self-identify as disabled?”.

Review of the Literature

To date, there has been little research conducted specifically about the experiences of interpreters with disabilities. Given this gap in the research, it is reasonable to begin by considering the factors which impact the experience of disability; what is the human experience if you have a disability? Because disability is impacted by and interwoven with various systems of oppression, it is necessary to recognize and name these systems. And, because disability is one of several marginalized identities a person can have, it is necessary to recognize that disability is complex and dynamic. Using Harding’s Standpoint theory, we begin by looking at several concepts from disability studies today. As these concepts are discussed, asking questions such as *whose knowledge is being produced? Who benefits from this perspective, and who bears the costs?* (Harding, 2016) allows us to appropriately frame the limits of our knowledge in 2020.

Perspectives from the global North

For the purposes of this research, one matter that must be recognized is the fact that much of current disability studies is highly Eurocentric. The stories we consider representative of the disabled experience are highly correlated with experiences of white people who live in Earth’s northern hemisphere – referred to as the global North – and the field of disability studies has maintained focus on the voices of activists and academics from the United States and United Kingdom (Grech, 2009). This hyper-focus on Northern perspectives means that experiences from the global South are overlooked or missing completely (Oliver, 1990). This is relevant for two reasons: our understanding of the disability experience is incomplete because half the world is missing from the discourse, and this incompleteness helps to maintain an ableist system which discriminates against people with disabilities. While those of us in the United States wait for this work to develop, it is important to recognize whose stories of disability make up the current narrative and who is missing from the discussion thus far.

Moving forward, the next section addresses one of the main concerns when designing this study – the question of how to define disability.

Defining Disability

Disability is experienced in a variety of ways, and the layers of complexity in this experience is one of the chief reasons that finding a satisfying definition of disability is so challenging. Disability can be an identity or a rallying call around which to organize a political or social movement. Disability can be a diagnosis around which an individual's life must orient itself. Disability can be a relationship to a space or to other individuals in a space. Disability can be a stigma or a marker which denotes group membership. So how can we begin to understand an idea with all of these twists and turns? The first step to untangling this knot is to understand from where our ideas about disability come, how our ideas are influenced by where we live, and that multiple views of disability can and do exist at the same time.

Goodley (2017) notes that disability is classically seen as a moral condition or a punishment from God for past sins – a failure of the individual for which they are being punished. This perspective from antiquity is contrasted with the contemporary medical model of disability where the condition is labeled with a medical diagnosis – a pathology of the body. What is more interesting is Goodley's assertion that disability as a moral condition is the "oldest of all disability models but, arguably, still the most prevalent worldwide" (Goodley, 2017, p. 7). Given Grech's 2015 observations about the limits of our current body of disability knowledge, this distinction between disability as a punishment from God or disability as a medical diagnosis points to a possible difference in the experiences of people living with disabilities in the northern or southern hemispheres. Framed against the medical model of disability, some have recognized systemic barriers for people with disabilities and have tried to write policies which grant better access to society. In order to produce disability access policies, a definition of disability is required.

One of the first countries to attempt disability policy was the United States, which passed a federal statute in 1990 that became a roadmap for disability rights around the world, called the Americans with Disabilities Act (ADA). Crossley (1999) wrote that the ADA contains distinctions between impairment, disability, and handicap. According to Crossley (1999) there were two disability frameworks which set the stage for current disability models. The first framework from the World Health Organization (WHO) stated

> impairment is any loss or abnormality of psychological, physiological, or anatomical structure or function; a disability is any restriction or lack, resulting from an impairment, of ability to perform an activity in the manner or within the range considered normal for a human being; and a handicap is a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal for that individual, depending on age, sex, and social and cultural factors (Crossley, 1999, p. 645)

In the WHO framework not every impairment will lead to a handicap, but a handicap is caused by a disability or impairment. It also acknowledges the influence of an individual's surroundings on disability and access (Crossley, 1999).

The second framework used by the authors of the ADA was developed by Nagi, and draws distinctions between pathology, impairment, functional lack, and disability. Crossley (1999) referenced Nagi's work which states

> Trauma to an individual's arm may cause the arm's muscles to become denervated; this response to the trauma would be deemed a pathology. As a result of the denervation, the muscle atrophies; this loss of physiological function at the level of an organ system would be considered an impairment. This impairment (muscle atrophy) may cause the individual to be unable to pull with her arm; functional limitation describes this lack of an individual's ability to perform an action. Finally, the individual might lose a job that requires pulling with her arm or be rendered unable to swim recreationally. These limitations on performing socially defined activities and roles could constitute disabilities. (cited in Crossley, 1999, p. 647)

Crossley (1999) goes on to observe that disability theory has not yet made its way into legal literature in the United States, and that the definition of disability in the ADA statute falls short in its failure to acknowledge the impact of the social environment on a person with a disability. The ADA defines disability as "a physical or mental impairment that substantially limits one or more major life activities of such individual; has a record of such an impairment; or being regarded as having such an impairment" (Americans with Disabilities Act of 1990). This failure in the legal definition means that Americans with disabilities cannot file for protection under the ADA for suffering a social disadvantage; meaning that a person with a disability who experiences unfair social treatment has almost no recourse under the law. One notable exception to this seems to be in the workplace, which is discussed further in the section titled Disability in the American Workplace.

Building upon the WHO and Nagi frameworks, disability theorists have created current models which address different aspects of life with a disability and tries to clarify the definition challenge. Goodley has outlined four systems, which he has dubbed "The Disability Studies

Matrix" (Goodley, 2017, p. 11). Each of these conceptualizations of disability is juxtaposed against the present-day medical model of disability.

The first is the social model of disability which came about in the 1990s and according to Goodley (2017) it is the predominant model used by scholars in Britain and has helped usher in a paradigm shift in sociology, social policy, and education. The social model adopts a distinction between impairment and disability, recommends the "eradication of disabling social, economic, political, cultural, relational, and psychological barriers" (Goodley, 2017, p. 11), and in part reflects the scrutiny in Britain on material inequity, class divides, and the growing distance between rich and poor. The major critique of the social model is that it does not allow for disability as a source of pride and belonging but instead blames society as the cause of disability which can be addressed with activism to lead to social changes (Goodley, 2017).

The second framework from Goodley (2017) is the minority model, which points to disability as a civil rights affair and gained a following in North American theory circles. Heavily influenced by the American Civil Rights Movement, the fight for lesbian, gay, bisexual, and transgender rights, and the return of veteran soldiers from the Vietnam War in the 1960s and 1970s (Goodley, 2017), the minority model calls out ableism and the biases created in this system which enables discrimination. One outcome is "the people-first language of *people with disabilities* [which was] coined to recognize humanity and diversity" (Goodley, 2017, p. 13). The minority model mixed critical views on capitalism, race and racial formation theory, adapted socio-cultural formations of disability, and activism from other marginalized groups (Goodley, 2017). One critique of the minority model comes from Davis (2019) and is the question of pain. Disabling conditions which cause or worsen pain are difficult to glorify, and the call for disabled pride and aligning the disability rights movement with the struggle for civil rights fails to address an aspect of disability that “does not fit into a celebratory mode” (Davis, 2019, 26:30).

Next is the cultural model which is unique amongst the frameworks in that its roots have, in Canada and the United States, come from the humanities in addition to the social sciences which inform the social and minority models (Goodley, 2017). In this model scholars cast aside the impairment/disability question and pivot to shine a light on the cross-influence of disability and culture and “have exposed the reliance of the normal body on the disabled body, the myth of the disabled/abnormal body” (Goodley, 2017, p. 15). The cultural model recognizes the function disability serves in pop culture, advertising, symbolism, and spends a lot of energy on the disabled person as metaphor for unwantedness (Goodley, 2017). A new viewpoint from Canadian theorists Michalko and Titchkosky have posited “that disability might be desired as an opportunity for thinking about our relationships with one another in the world” (Goodley, 2017, p.16). The cultural model has uncovered the possibility that disability is uniquely situated to teach humanity how to better relate to one another; meaning a person has value on their own, and outside of capitalist notions of productivity and worthiness.

The last framework is another interdisciplinary approach – the relational model. This perspective on disability comes from the Nordic countries and centers persons with intellectual disabilities – as opposed to communication or physical disabilities – more than the other frameworks and uses normalization as a process of making a space for disabled people in society (Goodley, 2017). The relational model puts forth the favorable impact of “services and professionals on the lives of disabled people” (Goodley, 2017, p. 16) and highlights the services provided for disabled persons in these countries as world-class. The impact of language on disability is discussed in the Language section, but the relational model is partially the result of the limitations of translation from one language to another. The conundrum of finding the difference between 'impairment' and 'disability' in other frameworks has encountered translation challenges into the variety Nordic languages, so the relational model uses "three main assumptions: (i) disability is a person-environment mis/match; (ii) disability is situational or contextual; and (iii) disability is relative" (Goodley, 2017, p. 17). In this framework, disability is located in the play between impairments and disabling social environments.

So which conceptualization of disability is most relevant? I contend that the complexity of the disability experience is part of its richness. Disability can manifest in a variety of ways, which means that a top-down definition of the phenomenon is less useful than a bottom-up approach. For this, we have to center the experiences and stories of people with disabilities themselves. The field of ASL/English interpreting has not yet attempted a meaningful engagement with disability when disability is present in both the communities we serve and in the pool of professional interpreters who provide this service. Interpreters have a responsibility to learn about the impact of disability on our profession for the betterment of all.

Throughout these models of disability there is a common thread; a binary idea where disability is identified as a deviation from the able. While it can be useful for organizational purposes and introducing new ideas, there are limitations to the disabled/abled paradigm. One theory which addresses the black/white dichotomy popular in disability studies is that of dis/ability theory (Goodley, 2017). This framing investigates disability as a separate and unique experience from that of abledness. Part of the reason dis/ability theory is necessary is because of the prevalence of one very powerful concept – the norm, or normalcy. How can we identify the abnormal without knowing what the norm is? While we unpack this concept, Harding (2016) might encourage us to ask *who benefits from a society where the able body is normalized? Whose interests were served by applying norms to the human body?*

What is Normal?

Fundamentally, the field of disability studies gives us a fuller picture of the human condition by investigating the disability experience and how disability is perceived and interpreted by society. One of the foremost scholars in disability studies is Lennard J. Davis, who has published work on the myriad of ways 'the norm' has shaped our understanding of almost every aspect of life, specifically our conceptualization of the human body (Davis, 2006). The formation of normalcy is marked by the journey taken to arrive at a concept that is considered hegemonic today. However, our concept of the norm arrived with industrialization and is heavily influenced by Eurocentric notions from the eighteenth- and nineteenth- centuries of nationality, race, gender, sexuality, etc. Our understanding of disability is built upon a foundation that divides that which is considered "normal" and that which deviates from the norm for the purposes of comparison. As Davis (2006) explains, one astonishing feature of this history is that

> the constellation of words describing this concept "normal," "normalcy," "normality," "norm," "average," "abnormal"—all entered the European languages rather late in human history. The word "normal" as "constituting, conforming to, not deviating or different from, the common type or standard, regular, usual" only enters the English language around 1840. (Previously, the word had meant "perpendicular"; the carpenter's square, called a "norm," provided the root meaning.) Likewise, the word "norm," in the modern sense, has only been in use since around 1855, and "normality" and "normalcy" appeared in 1849 and 1857, respectively. If the lexicographical information is relevant, it is possible to date the coming into consciousness in English of an idea of "the norm" over the period 1840–1860 (p. 3)

The invention of these English words helped create our understanding of 'what is normal?' and the concept was born during the same time period when the California Gold Rush had started in 1948, Harriet Beecher Stowe published "Uncle Tom's Cabin" in 1852, and political and social tensions in the United States were moving steadily into the Civil War in 1861. Disability has always existed, but prior to this historical period it was not possible to measure disability against a *normal* body.

Today, the experience of disability is a constant comparison of the disabled body's capabilities measured against the expectations of what an average body is able to do, but research has shown that historical expectations of disability were very different than expectations today (Baynton, 2006; Rose, 2006; Schweik, 2011; Weaver, 2015). In antiquity, only the gods could have an ideal figure; by definition humans could not because they were not gods. As a counterpoint to the ideal heavenly body, sculptures on façades featured the grotesque which was a symbol for or representation of humanity, of everyday life and they had a "life-affirming transgressive quality in its inversion of the political hierarchy" (Davis, 2006, p. 4). If only the gods could have the ideal form, then by contrast all human bodies are imperfect. There was no concept of hierarchy for the human body – no average weight or height or shape.

Davis (2006) identifies the origin of "norm" and "average" in the field of statistics, and says that the purpose of statistics at the time was to track data for use by the governing class in creating policy. According to Davis (2006), French statistician Adolphe Quetelet had the greatest influence on the idea of the normal as essential. Quetelet realized that techniques used by astronomers of the time to plot the location of a star could be applied to human characteristics like height or speed, and individual plot points obtained for a society could be averaged together to conceptualize what he called the average man. According to Davis (2006), Quetelet believed in the norm as a means of progress, and the idea of the average was applied to wealth and production by Karl Marx in his work on the "labor theory of value" (Davis, 2006, p. 5). This ideology made way for the science that would justify the kind of middle-class ideology that celebrated the normal body, which began to emerge in the 1830's in England with the birth of statistical organizations. Many of the early members in these organizations also had an interest in eugenics including its founder, Sir Francis Galton. Davis (2006) reminds us that, "there is a real connection between figuring the statistical measure of humans and then hoping to improve humans so that deviations from the norm diminish" (Davis, 2006, p. 6). It was logical, perhaps, to expect that once the human body was measured that those measurements would be used to improve the population through selective breeding to replicate desirable human characteristics.

Interestingly, Galton also gives us a window into the human body as identity because, as Davis (2006) describes, Galton also created a system for fingerprinting as a way to prove familial ties. In the 1830's fingerprinting was understood as a kind of identification written into the body which, "pushes forward the idea that the human body is standardized and contains a serial number, as it were, embedded in its corporeality" (Davis, 2006, p. 7). If the physical body contained evidence of our identity, then variations in the physical body must reflect on the character of the person who inhabited the divergent physical body. Generations later, science would find that this serial number does indeed exist, but at the genetic level in our DNA code. At the time, this notion supported the thinking where physical difference, formed as part of the body, would "become synonymous with the identity of the person" (Davis, 2006, p. 7). The last connection Davis outlines for us is that Galton was a cousin to Charles Darwin, whose theory of evolution served to place disabled people as "evolutionary defectives" (Davis, 2006, p. 7) and theorized a natural process in which disabilities would eventually be eliminated because the theory of evolution implies that the body is perfectible. Galton's science of eugenics was the next rational step to decrease the frequency of defective human traits (Davis, 2006).

Hopefully, you have continued to ask Harding's (2016) questions about *whose knowledge is being produced? Who will benefit from this theory? Who will bear the costs of this theory?* while reading through these pages. The answers to these questions are embodied in one particularly complex and pervasive oppressive system called ableism. Ableism is explored in more detail in the next section, and it is important to understand that in addition to being a system of discrimination against people with disabilities, ableism is tightly entwined with other systems of oppression. When disability studies scholars started to explore the intersectionality of ableism and racism, a new theory was created called DisCrit (Annamma, Connor, & Ferri, 2007). The intersection of disabilities studies and queer theory is called Crip Theory (McRurer, 2006), and feminist theorists have looked at the crossroads of disability, gender, and queerness (Kafer, 2013) and disability, gender, and race (Schalk, 2018). Each of these theories could be applied to this research study individually, but the purpose of bringing them up now is to acknowledge, once again, the many ways disability can manifest in and interact with other identities to impact an individual's experience in the world.

Ableism

The system of oppression called ableism was created by a combination of society's ongoing preference for the non-disabled in body, mind, and communication with our tendency to focus on disability as a problem for that individual and their family to face. According to Merriam-Webster, "ableism" is defined as "discrimination or prejudice against individuals with disabilities" ("Ableism", 1981). Campbell (2009) observed that disability studies theorists have begun to "shift the gaze of contemporary scholarship away from the spotlight on disability to a more nuanced exploration of… ableism" (Campbell, 2009, p. 3). This shift in perspective might seem insignificant, but it is anything but. Rather than focus on disability as a problem for that individual, this shift in academic focus began to uncover societal barriers put up before people with disabilities. Disability was now being studied as a problem for society to address. One area of focus in disability studies is ableism. Campbell's 2008 work uses critical race theory and the study of internalized racism to explore the ways in which people with disabilities live with internalized ableism and how these phenomena are connected to and different from one another. Campbell (2008) claimed that "internalized ableism or disabled self-hatred" (p. 155) had not yet been given appropriate attention within the field of disability studies. Campbell stated "within ableism the existence of disability is tolerated rather than celebrated as a part of human diversification. I contend that internalized ableism utilizes a two-pronged strategy, the distancing of disabled people from each other and the emulation by disabled people of ableist norms" (2008, p.155). One explicit example of this social distancing of people with disabilities is the work of Wolf Wolfensberger who articulated Social Role Valorization Theory, "[which] explicitly discourages fellowship amongst persons with disabilities and other minorities" (cited in Campbell, 2008, p. 155). Campbell draws a line between this policy and the ways people with disabilities were signaled to avoid drawing attention to each other or their status by socializing. Expectations like this breed internalized ableism because the act of simply gathering, of being visible in groups with other people with disabilities is understood as bad, as negative, and unwanted by society (Campbell, 2008). People with disabilities were tolerated when on their own in society, but the abled majority were made uncomfortable when people with disabilities were in community together.

Campbell (2008) also touches on the fallacy of binary thinking between the abled and disabled, where she points at the question of disability permanence. Disability was identified as a protected class (with gender, sexuality, race, etc.) in legislation in the United States because impairments are viewed as permanent, medically diagnosed conditions of the body or mind, and because of this immutability has a stronger claim to civil rights protections (Campbell, 2008). However, "impairments exist in a state of constant deferral, being open to the interventions of psycho-medical regimes posting corrections, cures or indeed elimination" (Campbell 2001, 2005 cited in Campbell, 2008, p. 159). Disability legislation in the United States fails to address the question of temporary disability or changing disability (Campbell, 2008). How to address a disability which is made worse by cold weather? What about a temporary condition, such as the need for a scooter after knee surgery? What about someone who is considered disabled in one setting, but non-disabled in a different environment? Even a permanent disabling condition does not impact every setting. For example, in a relational model of disability, imagine a wheelchair user with a spinal cord injury who is paralyzed from the waist down. This individual is disabled by a flight of stairs with no ramp access. However, this person works as an ASL/English interpreter and is abled when providing interpreting services between two people who do not share a language. The new challenge facing disability scholars and society is how can we conceptualize disability in a different way to avoid this nearly-instinctual binary thinking?

One suggestion comes from Campbell (2018) and her work to encourage scholars, societies, and industries to consider turning away from the problematic binary conceptualization of abled/disabled and to embrace a more nuanced, accurate conceptualization she calls aporias (Campbell, 2018). An aporia is "a double-edged problem which cannot be solved because it pre-exists in the first place" (Campbell, 2018, p. 11). In this approach to theory, Campbell is encouraging scholars and researchers to conceptualize *both disability and ability* as processes, as a journey during which the individual encounters a variety of challenges, some disabling and others enabling. Rather than the medical model where a diagnosis or label is applied to indicate current conditions, embracing the aporia of *both disability and ability* as ever-evolving and dynamic and complex will yield different questions for research and theory.

In her attempt to understand and define ableism more precisely, “Nearly all disability studies research and recent works on ability have a predilection towards the comparative even if this aspect is not acknowledged” (Campbell, 2018, p. 3). Much of modern theorizing relies heavily on “abyssal thinking” (Santos 2014 cited in Campbell, 2018, p. 7) which posits two sides of an argument or paradigm, so much so that to consider another approach is nearly unthinkable.

Regardless whether or not scholars recognize and address the propensity to use comparison to discuss disability and ability, whether or not scholars move towards the precision of aporias as Campbell (2018) suggests, the complexity of the disability experience is another reason to support and focus on the stories, perspectives, and knowledge of interpreters with disabilities themselves. Allowing their stories to uncover gaps in interpreting scholarship is a vital and necessary endeavor.

Language Matters

Language is an important tool which allows ideas to be conveyed from one person to another. In order to embrace complexity and to challenge ableist notions, I will address language as the vehicle humans employ to transfer ideas like those already discussed – normalcy, the ideal body, and disability – from one generation to the next and from region to region. James Cherney (2011) offers a view of ableism as a rhetorical problem because ableist viewpoints sustain and spread themselves through rhetoric, which is the ability to argue one’s point satisfactorily. Therefore, examining the language used to identify and describe disability helps unveil the social systems that perpetuate ableism and the ways in which ableism might be dismantled. One example given is “Using physical deviance to render evil visible saturates the Western artistic tradition, and it plays a crucial role in such genres as horror stories and films about demonic possession" (Cherney, 2011, p. 6). His point is that disability – the body as deviation from the norm – as evidence of evil is a popular trope in Western popular culture. Other rhetorical examples when referring to disability such as 'suffers from their condition', 'struggles to overcome the disability', and 'thrives in spite of everything they have faced' help illustrate the point that the way we use language regarding disability helps in the continuation of ableism and further separates people with disabilities from society. Linton's (1998) work identified alternative language for disability such as 'handicapable' or 'the able disabled' as problematic, saying, "Although they may be considered well-meaning attempts to inflate the value of people with disabilities, they convey the boosterism and do-gooder mentality endemic to the paternalistic agencies that control many disabled people's lives" (Linton, 1998). This is an important point in disability studies, the discussion about language and who gets to decide what is appropriate. It is important to understand what language people with disabilities utilize when describing their own experiences, and this reasoning was used when crafting the questions used in both phases of this research study.

Although language is one tool used to keep ableism in place, rhetoric also has a role to play in the dismantling of ableism and other oppressive systems when new words are created to describe systemic functions and their outcomes. Cherney (2011) draws a parallel between the creation of the terms 'sexism' and 'ableism'. The process by which sexist practices were identified and taken apart, from passing Women's Suffrage in the United States to challenging workplace gender discrimination, Cherney (2011) shows how rhetoric functions in not only the creation of an idea but also serves as the tool with which to demolish systems of oppression. The recognition of ableism as an oppressive system is the first step in a long process to make positive changes for people with disabilities.

Community Knowledge

The complex knot of ideas, opinions, beliefs, and motivations which tie together our understanding of disability today is not without benefits for the interpreter with disabilities. These professionals may be singularly skilled at decoding ableist attitudes and their impact on the interpreted discourse. Daniel Gile (2009) wrote about methods of training interpreters and translators, and describes the function of extralinguistic knowledge (ELK) in the comprehension of specialized discourse. In comparison to linguistic knowledge, which levels off at a certain point in language acquisition, ELK does not – the more information an interpreter has about the topic of conversation, the participants including their motivations and use of language, the setting, and the relationships between these elements, the better an interpretation can be rendered (Gile, 2009). Additional knowledge connected to the interpreted setting "helps facilitate anticipation and Text comprehension not only as regards linguistic disambiguation, but also when reading between the lines" (Gile, 2009 p. 88). Given the intimate and extensive ways disability conceptualization manifests in the lives of people with impairments, having first-hand knowledge of disability can lend itself to the interpreted discourse in relevant settings. ELK also plays a major role in message reconfiguration in the target language (Gile, 2009).

When in the role of interpreter, ELK can be divided into two categories according to Gile: a) pre-existing ELK, and b) knowledge derived from the context, the Text, and the situation (Gile, 2009). A minimum amount of pre-existing ELK is necessary to accept an interpreting assignment, but even seasoned interpreters run into message reformulation troubles while engaged in the task of translation (Gile, 2009). A principle reason for understanding the lived experiences of disabled interpreters is to better comprehend the ways in which relevant ELK can be distributed throughout the interpreting community and the impact disability ELK might have on the interpreter, the interpretation, and the setting.

Another view on the function of shared knowledge within a group is the role of ELK in various interpreting configurations. Marsh (2019) discusses the Acculturation Gap Model as a way to understand the role of deaf interpreters in the interpreted discourse. According to Marsh, there are two considerations when looking at interpreting through this lens; one is culture, and the other is communication (2019, 0:05-5:33), and a gap in knowledge in either area can lead to a miscommunication. Marsh (2019) states that acculturation is a process which takes place over time, and is shaped not only by the act of sharing cultural information, but by the breadth of topics covered. In today's interpreter education system, deaf cultural norms are often taught in a classroom and understanding of these cultural patterns and expectations is built in an academic setting prior to actual cultural exposure for many hearing interpreters. Hall, Holcomb and Elliot (2016) talk about challenges facing interpreter education and observe, "…the academic environment is not going to voluntarily become more collectivist and/or accommodate the presence (and cost) of large numbers of Deaf people as experts to enculturate interpreter students" (Hall et al, 2016, p. 9). For hearing students, the challenge of becoming culturally competent as an interpreter is an important consideration that needs to be addressed by the field. For deaf people, Marsh shares that learning about hearing culture is a life-long process and emphasizes the point by saying that one instance of cross-cultural contact typically takes place in one area of our lives (Marsh, 2019, 3:04) rather than touching on every aspect of our lives. This implies that the more cross-cultural contact a person can get over time, the more likely that their cultural competence is deepened and made richer.

The second consideration in the Acculturation Gap Model is communication, which says if a communication gap is present between a deaf person and a hearing person, common approaches to accessibility include gestures, writing back and forth, and the use of a hearing interpreter as tools to address the communication gap (Marsh, 2019). The problem with defaulting to the use of a hearing interpreter is that often miscommunications happen *because of* a deaf culture knowledge gap (Marsh, 2019, 5:51). As a deaf interpreter, Marsh pushes back on the viewpoint that deaf interpreters are best utilized in a limited capacity in high-risk, emergency interpreting scenarios – he says that deaf interpreters have a role to play in a wider range of interpreting work because they possess a breadth and depth of deaf cultural knowledge (2019) in addition to linguistic expertise. Marsh's work suggests that by engaging more often in work with deaf/hearing interpreting teams – sometimes referred to as tandem interpreting – gaps in cultural and linguistic knowledge can be addressed more smoothly and potentially result in a more accurately interpreted discourse.

The point above regarding interpreter education today and the lack of Deaf cultural exposure is indicative of a larger pattern in higher education where colleges and universities which offer instruction in ASL and interpreting have abdicated their responsibility to deaf communities. Responding to this, Robinson and Henner (2018) propose the concept of *cripping* the academy

> Cripping requires that higher education institutions consider authentic voices, faculty, and encounters when offering disability-related content. Explicit representation of disability among students, faculty, and academic discourse benefits everyone…Higher education institutions are profiting from ASL instruction without providing a return on those profits for deaf and disabled students and faculty by removing barriers to admission, matriculation, and academic careers, while engaging in exploitative relationships with local deaf and disabled communities (2018).

This call for institutions of higher learning to take an active role in dismantling ableist practices within their systems is important. Robinson and Henner's (2018) position informs this study in the selection of methodology and centering of the experiences of interpreters with disabilities.

These perspectives on the value of authentic voices brings up another important consideration for the field of ASL/English interpreting, which is the need to recognize and understand the outlook on disability within deaf communities around the country. The ways that disability is perceived in deaf communities could impact expectations of interpreter education, abilities, and practices.

Disability in the Deaf Community

Deaf communities around the United States are interestingly situated at a crossroads of disability and culture. Historically, deaf theorists have separated deafness from the rest of the disability spectrum as a means of survival, but this creates additional challenges. Davis (2019) acknowledges that deaf people feel disconnected from the disability studies orbit because "we are a cultural minority; we have a history, we have a language, we have a culture. The only problem is that most of you don't speak sign language" (2019, 27:40) and reminds us that deaf individuals are most often born to two hearing parents, so deafness as an identity and ownership of deaf cultural norms are concepts that have to be rediscovered by each new generation of deaf people at whatever stage of life they come into contact with other culturally Deaf[1] people.

Similar to Cherney's 2011 work on the ways in which a society's general rhetorical traditions impact the formulation of disability, Robinson (2010) provides a critical perspective on

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[1] A culturally-identified Deaf person is traditionally indicated by capitalization of "Deaf" in scholarship and signifies an association with Deaf culture and the use of American Sign Language. The individual with an audiological condition of not hearing is indicated in scholarship by the lower-case "deaf".

the ableist language used in the Deaf community at the end of the nineteenth century leading up to the first World War. “Internalized ableism has been and remains a comparatively invisible but potent ideological underpinning of deaf culture” (Robinson, 2010, p.18) and the ideas lodged in deaf activism of the time created for many deaf elites a feeling of superiority over other disabled people. Deaf leaders of the day extolled the virtues of English literacy, emphasizing commonalities between deaf and abled work habits, and “blamed individual deaf people for undermining the community’s ability to gain equal status with able-bodied citizens” (Fox, cited in Robinson, 2010, p. 10). Deaf people were intensely aware of discrimination from the hearing majority, but the fear of being cast as disabled continued to push deaf leaders to discriminate against and separate other marginalized groups within the deaf community. Robinson reminds us that membership in organizations like the National Fraternal Society of the Deaf required a “screening out [of] deaf individuals based on race, sex, and moral behavior, as well as by physical and mental ability, enabled NFSD members to shape an organization that especially mirrored a dominant, ableist model of white, patriarchal, nondisabled working citizens” (Robinson, 2010, p. 11-12). Throughout this period and continuing today, ableist beliefs have built the foundation upon which proud deaf identity has been built.

Residential schools for the deaf were likewise a locus for ableist rhetorical practices, and deaf leaders were concerned that deaf education – and thereby deaf people – were perceived as “an act of charity or viewed as a form of welfare, and schools for the deaf were classified along with asylums, prisons, and mental institutions” (Robinson, 2010, p. 13). The community called for schools to be re-named from asylums to institutions to realign with normative practices and raise the status of deaf graduates in public perception from charity case to independent contributors to society.

Today a popular refrain from the deaf community states that “deafness is NOT a disability” but this assertion fails to recognize the ableist historical influences on deaf identity construction, and ignores contemporary views in education, health care, public policy, service, and culture that identifies deafness as an impairment. This rigid dichotomy presents a problem when a deaf person applies for services for communication access (e.g. interpreters, hearing assistive technology) or protections under the law. To declare that deafness is not a disability yet having only the label of disability to leverage into access to public spaces is a catch-22 which allows internalized ableism to fester in the deaf community. In instances where the individual does not identify as disabled but registers for government assistance to access the services and spaces their impairment bars them from freely taking advantage, this act of “self-subversion” (Campbell, 2008, p. 159) reinforces the negative connection between impairment and self. These specific forms of internalized ableism are important to consider because they occur in the deaf community and could inform this study.

One important question is what influence does the ableist construction of deaf identity have on expectations for interpreter services and interpreter education? The lack of disability scholarship in the field of ASL/English interpreting could be caused by the influence of this negative view of disability in general.

Disability in the American Workplace

In stark contrast to the lack of research available regarding the experience of disabled interpreters, there is a mountain of data accessible regarding the wider experience of disabled people in the broader American workplace. After the passage of the ADA in 1990, countless studies have been completed to assess the effectiveness of the policies outlaid in the statute as well as the attitudes and perceptions of disabled workers, their employers, and their abled co-workers. One interesting point is that when discussing the complexities of defining disability above, and the fact that the legal definition of disability in the ADA fails to recognize the cost of social inequity, one exception Crossley (1999) notes is for protections in the workplace. An individual can ask for protection in the pursuit to "conform to societal expectations that she perform productive work" (Crossley, 1999, p. 649), which Harding (2016) might encourage us to ask *who benefits from this very limited recognition of the social costs of disability?* The answer is the American economy, and the interests of capitalism. Our perceptions of who is a valuable worker, how productive work can be performed, and who decides is heavily influenced by the economic structure in which we live and work. Next, let's take a look at the population which is counted as disabled in the United States. For this we turn to Brault's 2012 writing about the most recent U.S. census held in 2010.

Disabled Americans are the largest marginalized community in the United States, numbering 56.7 million in 2010, or 18.7 percent of the non-institutionalized civilian population (Brault, 2012). Interestingly, Brault (2012) writes that for the purposes of defining disability for the report, three domains have been created to understand the impact of different kinds of disability. The categories are a) communicative (e.g. blindness or vision loss, deafness or hearing loss, or have difficulty having their speech understood); b) cognitive (e.g. having a learning, intellectual, or developmental disability; Alzheimer's disease, senility, or dementia); and c) physical (e.g. used mobility equipment like a wheelchair, walker, crutches, or cane; had difficulty walking, standing, lifting, or grasping; or having arthritis or rheumatism, cancer, diabetes, missing limbs, paralysis) and it was possible for individuals to report difficulties in more than one category (Brault, 2012). These categories are relevant in other research regarding workplace attitudes about workers with disabilities and preference shown for certain kinds of disability. This indicates that the experience of living with disability is impacted by the type of disability present. “People with disabilities only in the communicative domain were more likely to be employed (73.4 percent) than people with disabilities in any other domain to combination thereof” (Brault, 2012, p. 10). In addition, “The combination of disabilities in the physical and mental domains was associated with a decrease in the likelihood of employment” (Brault, 2012, p. 10). There is a possibility that the experience of interpreters with disabilities are impacted by the type of disability they have as well as the type of assignment they are interpreting. Certain interpreting settings are inaccessible, or are made inaccessible because of these stigmatizing attitudes and it is vital that we have a better conceptualization of these influences on the interpreted discourse.

Hiring practices for workers with disabilities has been a focus of scholarship in the United States for decades. Kaye, Jans, & Jones, (2011) designed a study to look at hiring practices and discrimination faced by this population which found “More than half of respondents agreed that employers didn’t hire workers with disabilities because they feel that workers with disabilities cannot perform essential job functions, and that employers discriminate against applicants with disabilities” (p. 529). Among the top reasons for not hiring people with disabilities respondents reported concerns about additional costs of employing a worker with a disability, discomfort dealing with accommodation needs, and the potential to be left with no recourse if a disabled worker has poor work performance (Kaye et al, 2011). According to Kaye et al, these concerns were expressed by more than 80 percent of respondents, while the next tier of concerns were held by roughly 70 percent and included “difficulty assessing an applicant’s ability to perform job tasks, concerns over extra supervisory time, other cost worries, concern that the person with the disability won’t perform as well as non-disabled workers, and lack of job applicants with disabilities" (2011, p. 528-529). These undercurrents in the employment landscape have an impact not only on the hiring and earning potential for interpreters who have disabilities but also on the interpreted discourse. What is the difference in performance for employees who are concerned about these forces and their co-workers? If a professional feels this undercurrent of unwelcome in their workplace, how might that effect their job performance?

While Kaye et al (2011) focused on causes for not being hired in the first place, the issues do not stop if a worker with a disability manages to get past the job interview and gets the position. Vornholt, Uitdewilligen, & Nijhuis (2013) investigated literature about factors affecting disabled people interacting meaningfully while at work and discovered that a lack of acceptance from co-workers contributes to the failure of employees with disabilities sustaining employment for any length of time. The results pointed to three themes found which shape this lack of tolerance

> First, a part of the studies discussed antecedents of cognitive acceptance—factors that influence and form people's attitudes toward a person with a disability. Second, a number of studies investigated stigmatization attitudes, most often from colleagues at work toward employees with disabilities. Third, there was a group of studies concerning the attitudes and behavior patterns of employers with regard to their role in the process of accepting an employee with a disability (Vornholt et al, 2013, p. 466).

The formation of biases against disability are well-researched and evidenced in the earlier sections of this review; the factors that form people's attitudes run through historical narratives, cultural dispositions, and the influence of ableist beliefs. Other findings were that negative biases against the disabled worker were more common when their performance had consequences for the abled colleague, disabled workers tend to perceive stigmatization more frequently than was actually present, abled workers were disgruntled when accommodations were made for the disabled colleague which caused "fairness perceptions [to be] lowest when the person with a disability received an accommodation and excelled in performance" (Vornholt et al, 2013, p.

470). These findings point to the forces at work when a person with a disability is at their workplace and interacting with their surroundings. Many people in the general public believe that the passage of the ADA in 1990 has alleviated or eliminated these barriers for disabled people in the workplace, and the reality is very different.

This literature review was a survey of disability studies concepts, frameworks, and the ways these forces show themselves in the deaf community and the American workplace. Each of the theories could be applied to the practices in the field of sign language individually, and the most exciting aspect of this research is the possibilities which are opening up. The future of social justice work in the field of ASL/English interpreting presents countless options for future research. Though this study is the first attempt to understand the effects of disability on the practices of interpreting, it will hopefully lay groundwork for future studies.

Methodology

Goal of the Study

The research question for this study is, "What is the lived experience of ASL/English interpreters who self-identify as disabled?" Each part of this question was carefully considered in the proposal stages of this project. Because of the lack of research or any information about interpreters with disabilities, I did not want to limit this study to a particular disability experience or even a disability category as described by Brault's (2012) communicative, cognitive, and physical disabilities. The goal of this study was to be as inclusive of people and experiences as possible, which presented specific challenges. The biggest challenge was to decide on a definition of disability, a task for which the difficulty was made plain in the literature review.

For the purposes of this study, the definition of *disability* is "a physical or mental impairment that substantially limits one or more major life activity as defined by the ADA

(Americans with Disabilities Act, 1990), but also chronic illnesses, conditions, or injuries”. This definition was framed in the contemporary medical view of disability as diagnosis, but expanded to include chronic experiences as well. The reason for this decision is to recognize the impact a chronic illness can have on an individual’s ability to work. Given that this study was heavily focused on experiences during training for and professional provision of interpreting services, this was important to consider. Even if a chronic illness is not formally recognized as a disability by the laws of the United States, the lived experience of interpreting is impacted by chronic illness and other conditions.

Other goals of the study are to learn how interpreters with disabilities perceive themselves; is disability an identity? a diagnosis? ignored? How does the disability impact the way an interpreter advocates for themselves or consumers? How is disability addressed during the interpreter training process? What impact does deaf communities’ perspective on disability have on the way interpreters think about disability? What impact does ableism have on interpreter expectations? Whatever the findings of this study, the potential for ongoing and future research is expansive.

Theoretical Framework

Using Grounded Theory, analysis used a data first approach (Glaser & Strauss, 1967) where theme identification was generated from the data collected. The reason for using Grounded Theory is twofold; one is because of the current lack of research and the second is to emulate the values in disability studies scholarship in centering the experiences of the populations most affected by the research. First, there is so little information available about interpreters with disabilities that it would be difficult to draw any theories. Quantitative data was collected and analyzed to identify correlations between disability and other categories such as gender, sexuality, race, age, education, and regions of the United States. These numbers can also be compared to national trends from the Registry of Interpreters for the Deaf (RID, 2018) annual report to see if any correlations are discovered.

Secondly, research methods in disability studies works to center the experience of participants as valid and important, so encouraging participants to elaborate on their experiences is of the highest importance. Hale and Napier (2013) observed such methods were common in interpreting research, where popular methods seek to understand "behavior from the participant's own subjective frames of reference" (pg.14). Because of the complexities presented by the disability experience, Sommo & Chasks (2013) suggest that qualitative methodology will yield the most useful results, and the second phase of interviews with participants was designed to encourage interviewees to elaborate on their experiences, and this informed the composition of the interview questions.

Study Design

The data for this study was collected from February to May of 2020. The first phase was a questionnaire (see Appendix A) which was used to gather large-scale, anonymous data using a Qualtrics survey. This is a web-based survey to conduct research, specifically data collection and analysis of quantitative data. This survey was also used to recruit participants for the second phase of the study. There were a total of twenty-five questions on the survey, and estimated time for completion was fifteen minutes. To be eligible for this study, participants must be over the age of 18 years old, be an ASL/English interpreter, and to self-identify as having a disability. In the introduction to the survey (see Appendix A) I disclosed my own disability and the city and state where I live. The decision to disclose the disability was a deliberate decision so participants would be aware that whatever information they divulged on the survey or during the interview, they would know that the questions were coming from a member of the group being studied.

In the second phase, I utilized semi-structured interviews. Participants in the interview were contacted via email (see Appendix D) within 72 hours of submitting their contact information to the researcher with attachments of the Informed Consent (see Appendix E) and Video Recording Release (see Appendix F) forms in written English. Upon request of any participant, these documents will be translated into American Sign Language. After receiving completed consent documents, I worked with each participant to establish a meeting date and time. Participants were emailed a link to a Zoom meeting. The MAISCE program has a Zoom account, which is an online meeting software with the ability to record video meetings. Zoom videos were downloaded to my computer, which were then saved on an external hard drive following IRB standards to preserve confidentiality.

At the beginning of the interview, I began the recording and read a script in spoken English (see Appendix B) or signed a translation in American Sign Language. There were 6 interview questions (see Appendix B) which, following Grounded Theory standards, were designed to be open-ended and encourage the participant to tell stories about their experiences. After the interviews, I utilized constant comparison from Grounded Theory while analyzing the results. I began by reviewing the first video and creating a transcription of the conversation, making observations and coding the analysis, and then moving onto the next video and the next transcript. Each transcript was compared to the existing findings as the process advanced. Videos and transcripts were labeled with the participants chosen pseudonym, and combined with other responses. Analysis was then performed to identify themes and common experiences.

Recruitment took the form of contacting professional interpreting organizations via email and social media, specifically Facebook posts to these same professional organizations and the researcher's personal page. To make the announcement accessible to interpreters and the deaf community, I chose to create a video explaining the study and the language I chose to use was ASL for efficiency. An email (see Appendix C) with a link to the video was sent to seven different professional interpreting organizations, and shared on the Facebook page for three additional groups and organizations. Four organizations received an email and a Facebook request to post on their page. One of these organizations responded via email, National Association of Interpreters in Education, and communicated that the survey information would be sent to their members via email. Facebook members connected directly to the original February 19, 2020 post shared it 17 times (primary shares), which generated an additional five shares (secondary shares) by other Facebook members. Later on April 27, 2020 a follow-up post with the same recruitment video in ASL was posted again and generated 12 shares (primary shares), which generated one last share (secondary share) by another Facebook account.

Results and Discussion of Findings

Survey: Total Participation

A total of twenty-nine participants responded to the survey from all over the United States. National trends (RID, 2018) were mirrored in the self-reported demographic information of disabled respondents regarding gender with 80% identifying as cis women. Age distribution was varied with the top three responses 26-35 (31.03%), 56-65 (27.58%), and 36-45 (20.68%). Racial categorization showed a total thirty-two (110%) responses because participants were allowed to select all that apply regarding race (see Figure 1). Of the thirty-two total responses, twenty-five (78.13%) selected white which also matches historic trends of the field.

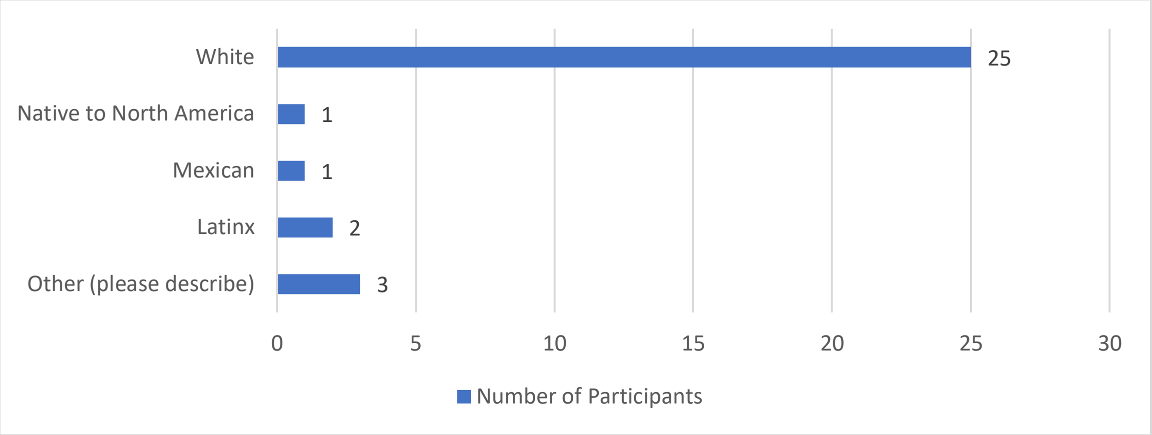

Figure 1 Interpreters with Disabilities: Racial Representation

Regarding educational levels and training experience, interpreters with disabilities reported high numbers of post-secondary degrees and interpreting credentials. Of twenty-nine total participants, six (20.68%) hold a 2-year degree, thirteen (44.82%) hold a 4-year degree, and seven (24.13%) hold a master's degree. When asked about formal interpreter training program attendance, the top three responses were completion of a 2-year training program with fourteen (48.27%) reports, seven (24.13%) respondents said they had attended no training program, and five (17.24%) participants said they had attended a 4-year training program. One additional question of interest would be to know how many of the degrees held by interpreters with disabilities showed an emphasis on interpreting or related studies.

Interpreting credentials (see Figure 2) held by interpreters with disabilities indicates the importance this group of interpreters places on professional credentialing. Of the twenty-nine participants, ten (34.48%) possess multiple interpreting credentials. The credentials most often held by interpreters with disabilities are the EIPA Elementary (eleven, 37.93%), RID's CI & CT (six, 20.68%), and EIPA Secondary (six, 20.68%).

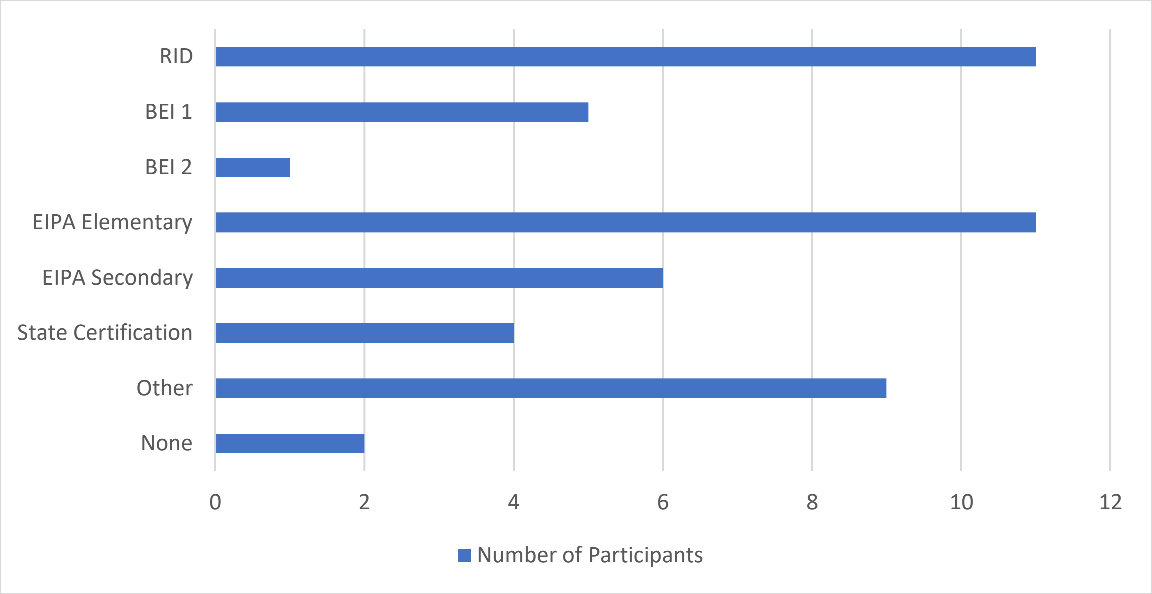

Figure 2 Interpreters with Disabilities: Interpreting Credentials Held

Other data was gathered regarding specific credentials held (e.g. which of RID's certifications, EIPA number and language modality) but there were no correlations found at the time of this work. Additional questions of interest include asking which participants were required by their work or state to hold interpreting credentials, and any accommodations requested while taking interpreter credentialing tests.

Separate from gender, age, and racial identity, one noticeable commonality in this study was the response to question #9 'In which region of the US do you live?' (see Figure 3). Of the twenty-nine participants, two people neglected to answer this question for unknown reasons leaving question #9 a total response rate of n=27 or 93.10%. Out of the remaining twenty-seven responses, the strongest representation was from the Midwest at nine (33.33%), the second-strongest showing was New England with seven (25.92%), while zero were recorded from the Upper Midwest or US Non-Mainland. The lack of participants in these regions could point to a gap in the distribution of the survey, potentially due to the limits of a digital format or circulation patterns on social media.

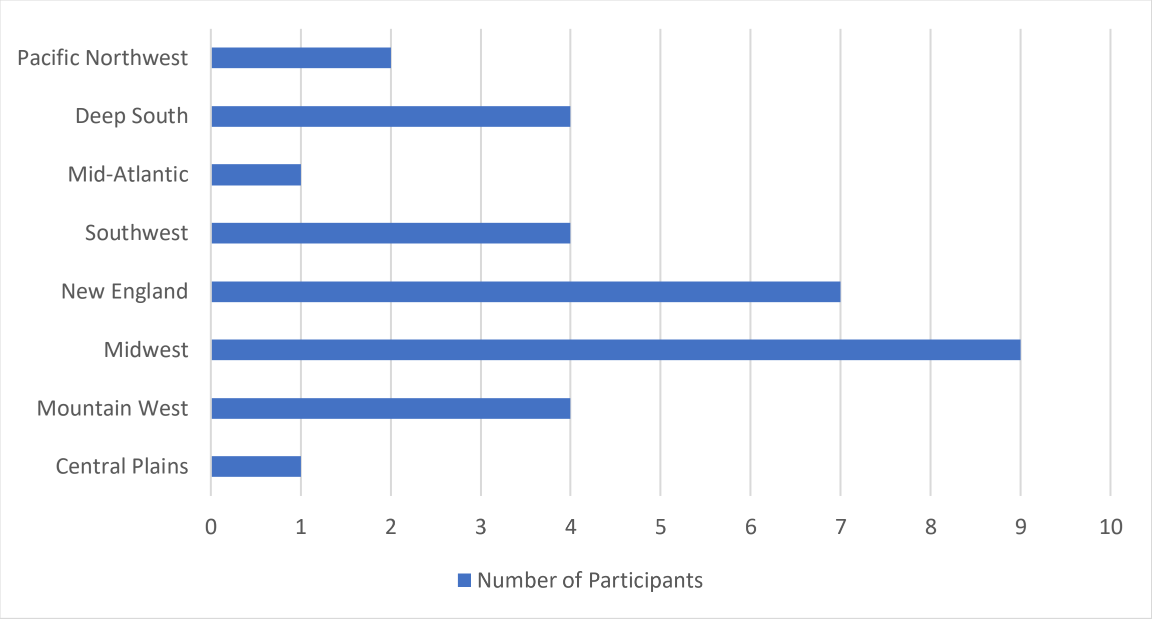

Figure 3 Interpreters with Disabilities: Where we live

Regarding the largest regional group reporting from the Midwest, and aside from the "Midwest polite" characteristic for which this part of the US is sometimes known, one possible reason for the 33.33% Midwestern response rate is that the researcher disclosed living in and attending school in this region. It is possible the survey was more widely circulated in this region.

One interesting pattern in overall responses was illustrated in question #10 How long have you worked as an interpreter (see Figure 4), where almost half (n=14 or 48.27%) of the twenty-nine respondents were either at the very beginning of their careers with up to five years under their belt, or had been working interpreters with over thirty years' experience.

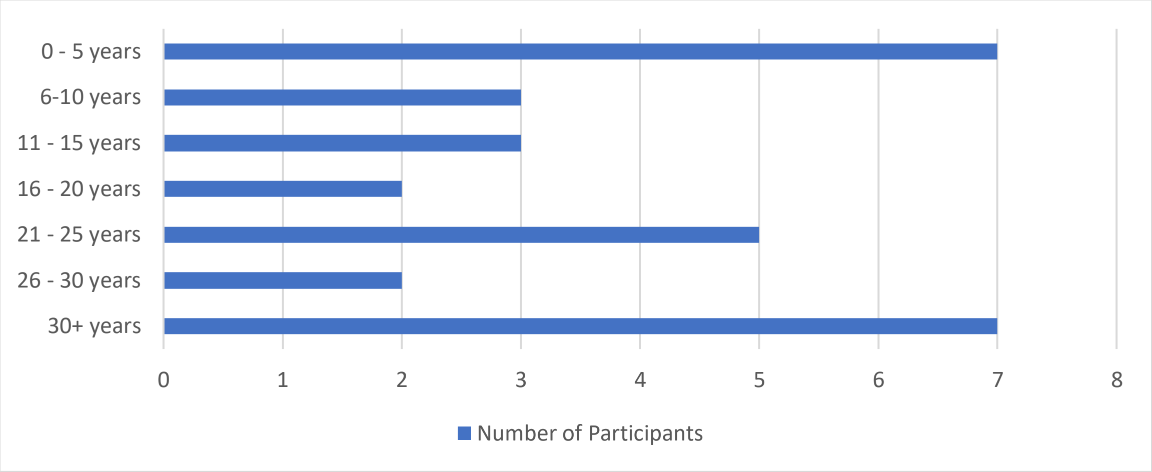

Figure 4 Interpreters with Disabilities: Years of experience

Work patterns reported by survey participants yielded some interesting results as well. Of the twenty-nine total respondents, fifteen people (51.72%) reported to working between 0 – 20 hours a week, nine people (31.03%) reported working between 20 – 40 hours a week, and five people (17.24%) reported that they work an astonishing 40+ hours every week.

Interpreters with disabilities reported working in a variety of settings on question #12, In which of these settings do you work as an interpreter? Select all that apply (see Figure 5). Twenty-five (86.20%) of the twenty-nine respondents reported working in multiple settings. Only four (13.79%) respondents claimed to work in a single setting.

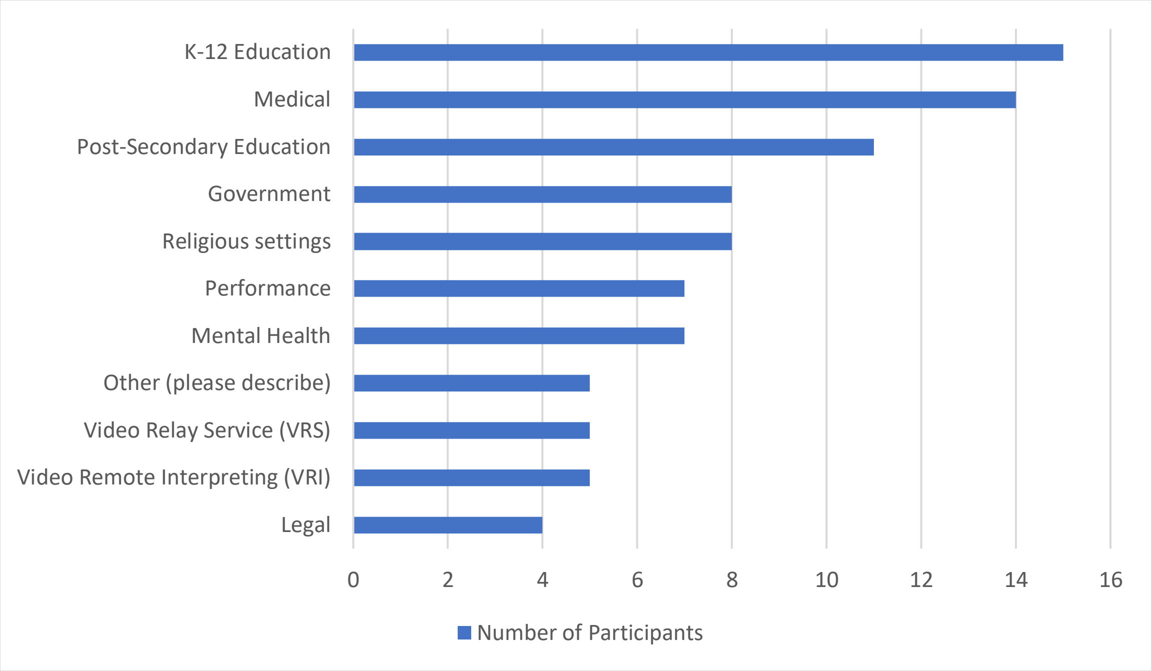

Figure 5 Interpreters with Disabilities: Where we work

Additionally, the survey would have benefitted from including a Community option for work settings those who selected 'Other (please describe)' then put entries such as,

- Various gatherings/events for a few different activist orgs and non-profits
- Community
- community (agency mtgs, SSA appts, community presentations)
- conference social work related

The last survey question regarding work asked if the disability had impacted access to opportunities, and the most common answer was "Sometimes" (13 or 44.82%). When asked if the disability had an impact on access to training opportunities, the most common response was "Never" (16 or 55.17%).

It is important to recognize that this research was conducted in part during the coronavirus pandemic and COVID-19 safety measures observed in early 2020. Many regions around the United States experienced full or complete lockdowns from March to June of 2020 and all but essential workers were ordered to stay home to slow the spread of the illness. Interpreters were considered essential only in some instances, and it is expected that life in lockdown most noticeably effected the number of hours worked by interpreters with disabilities, and the areas in which these professionals were performing their work. RID circulated a survey to interpreters in May of 2020 regarding work access, hours worked, and the ways in which coronavirus/COVID-19 impacted the work being done in our field. The results of that survey were not available at the time of this work, but should be considered when attempting to make connections between number of hours worked and the type of interpreting performed in 2020.

Disability Aggregation

Multiple or overlapping diagnoses was common in both survey (n=20 or 68.96%) and interview (n=10 or 90.90%) participants with some conditions occurring as secondary or tertiary symptoms of an original diagnosis; the most common were depression and anxiety being listed as symptoms of a primary diagnosis.

Among the twenty-nine participants, a total of 67 reports of disability were disclosed, and these 67 reports represented 37 different diagnoses, illnesses, and conditions. The most common diagnoses were depression (reported by six people) and anxiety (also reported by six people). The highest number of disabilities reported by a single individual was seven, and the lowest reported was one disability. Borrowing from Brault's (2012) work, reported disabilities were divided into three categories of communicative, cognitive, and physical disabilities for the purposes of comparison to the census data (see Figure 6). Of the 67 reports of disability, five (0.07%) were communicative disabilities, 32 (47.76%) were cognitive disabilities, and 30 (44.77%) were physical disabilities.

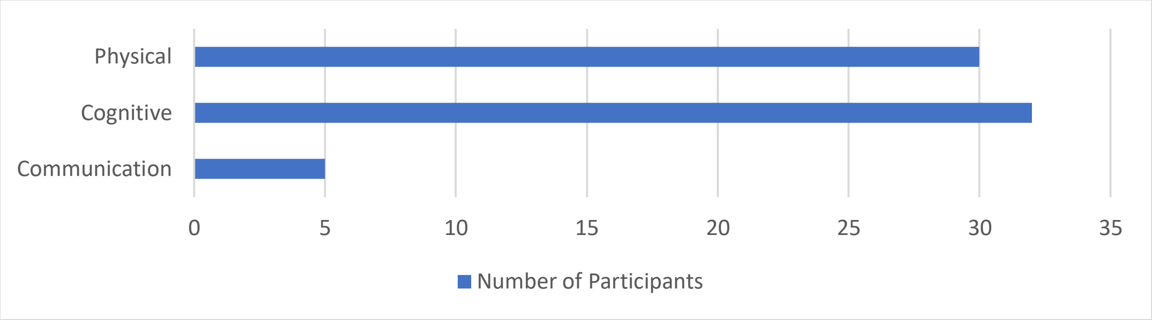

Figure 6 Interpreters with Disabilities: Disability Aggregation

Regarding the age of onset (see Figure 7) almost half of respondents (thirteen or 44.82%) reported that their disability occurred after they were an adult. The next largest group was 6-10 years old when their disability happened with five or 17.24% of responses. Age of onset is important to consider when discussing disability because it could potentially correlate to issues of identity, disability activism and/or awareness, and other issues impacted by the length of time an individual has been living with disability.

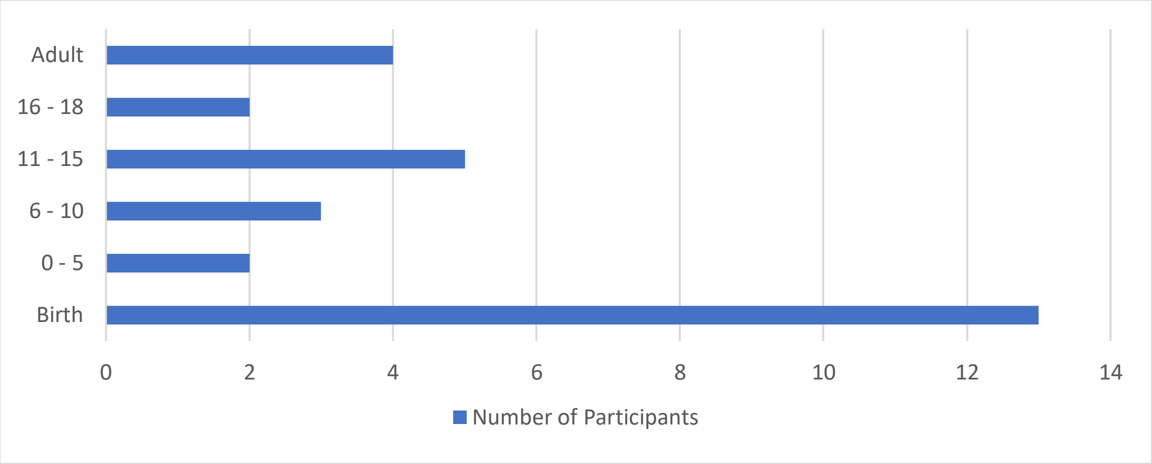

Figure 7 Interpreters with Disabilities: Age of Disability Onset in Years

Out of twenty-nine respondents, over half (sixteen or 55.17%) of survey participants reported requesting accessibility accommodations either most of the time, half the time, or sometimes. A total of thirteen (44.82%) respondents said they never requested accommodations while interpreting. Of the affirmative (n=16) responses to requesting accommodations, when asked if the accommodation requests were granted, the most common response was “sometimes” (see Figure 8).

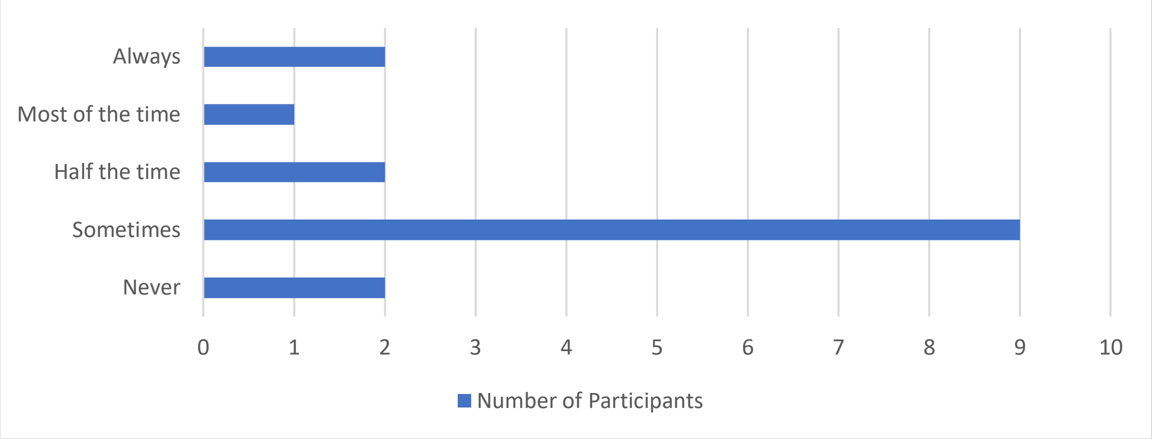

Figure 8 Interpreters with Disabilities: Accommodation Requests Granted while Interpreting

Several survey questions produced unexpected results. The first was in response to the question of whether or not the disability had ever benefitted the interpreter, and a clear majority (55.17%) of participants selected “Never” (see Figure 9). It seems unlikely that disability has so little use for the professional interpreter, so this data has sparked several additional questions. Were participants unable to identify any benefits? If this question had been formatted as short-answer, how different would the responses be? If interpreters were taught about disability theory and were able to apply those ideas to the task, how would responses differ? What impact, if any, does stigma or internalized ableism have on the response to this question? Upon final analysis of this question, several suggestions for future research were generated.

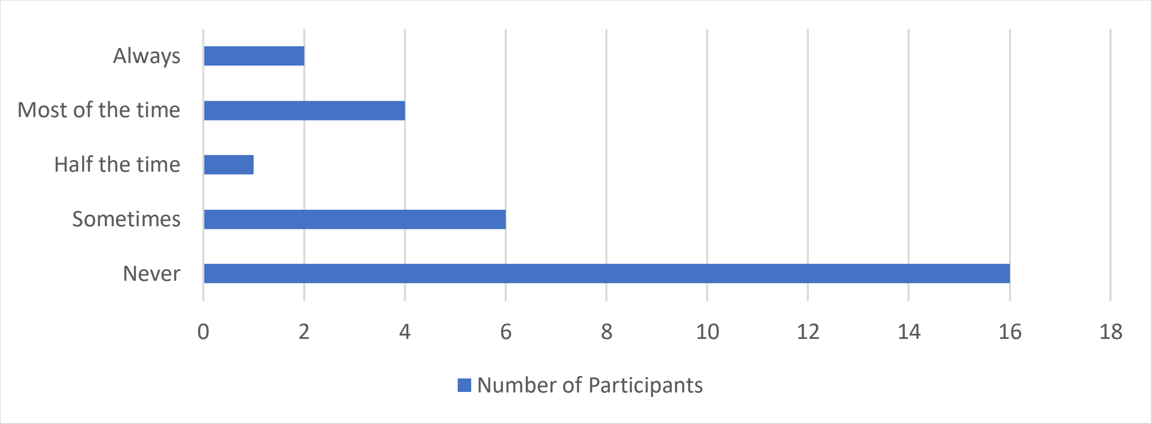

Figure 9 Interpreters with Disabilities: Has the disability ever benefitted you as an interpreter?

The next question which produced surprising results was whether the disability had ever impacted ethical decisions and again, almost half (48.27%) of respondents selected “Never”, but the next highest response was “Sometimes” (31.03%) (see Figure 10). As in the previous case, these results generated more questions and future investigation is necessary.

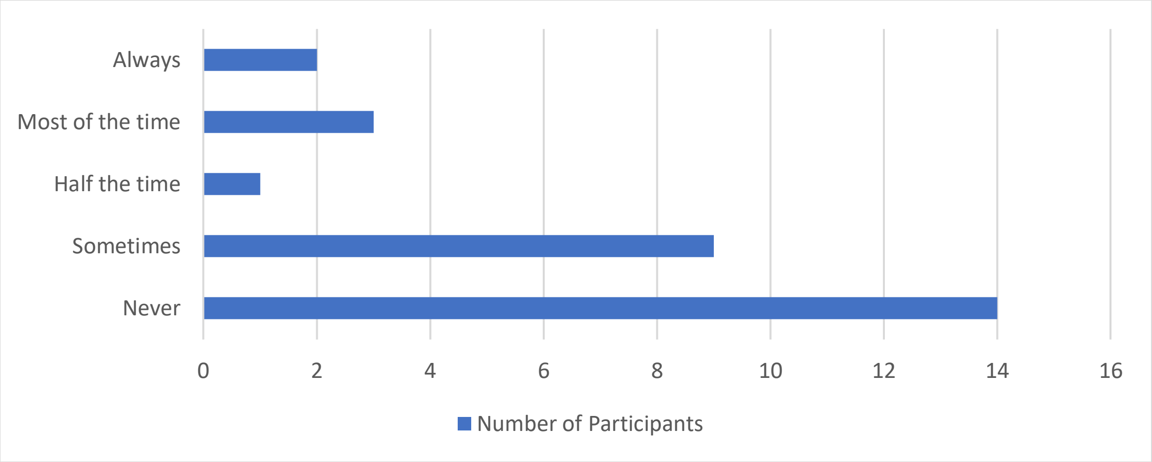

Figure 10 Interpreters with Disabilities: Has the disability impacted ethical decisions?

The last question on the survey which inspired questions for future research was regarding disclosure, and asking interpreters how often do they share information about their disability while at work. Over half of respondents selected “Never” (fifteen or 51.72%), but there were also six (20.68%) responses of “Depends” and in the space provided for elaboration, respondents listed concerns which included concerns about stigma, willingness to disclose only if it would set others at ease, and questions of team interpreter attitudes (see Figure 11).

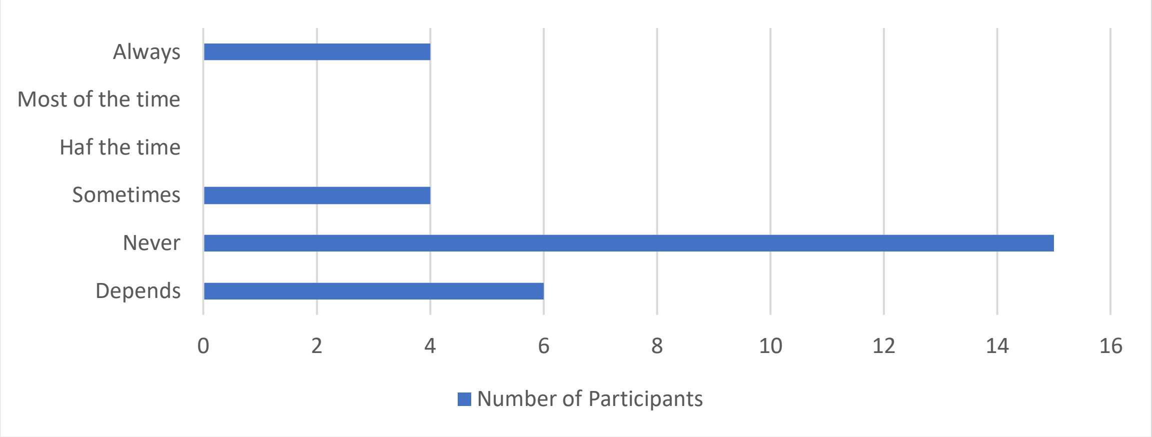

Figure 11 Interpreters with Disabilities: Do you disclose?

Interviews: Total Participation

Fourteen individuals volunteered for the interview phase of the study, of which eleven responded to my email with the consent forms. Eleven interviews were conducted, one of which experienced technical difficulties which were discovered too late to be fixed rendering that interview unusable. Of the ten interviews left, five were randomly selected (www.random.org) for analysis here. Due to time limitations, the remaining interviews will be saved and used in future publications. Basic demographic information about the interview participants is provided to give context for the comments shared in the next sections (see Table 1 Interview Participants).

Table 1 Interpreters with Disabilities: Interview Participants

Interview Participants

Name	**Gender**	**Age**	**Race**	**Age of onset (years)**	**Disability Category**	**Region**
Loreli	Cis Woman	36-45	White	Adult	Physical	Midwest
Marie	Cis Woman	36-45	White	Adult	Physical	Pacific Northwest
Gator	Cis Woman	36-45	White	Birth	Physical	Deep South
Emerson	Cis Man	26-35	White	6-10	Cognitive	Midwest
Hermione	Cis Woman	26-35	White	11-15	Physical	Deep South

Major Themes

The personal narratives collected in this study have uncovered an astounding wealth of data which will likely take years to fully analyze. Among the five interviews used here, several major themes have emerged as shared experiences for these interpreters including ableism and internalized ableism, the role of extralinguistic knowledge, and the performative nature of neutrality while in the interpreting role. Each of these first themes is investigated in greater detail below.

Ableism and Internalized Ableism

The first and most obvious theme that emerged from the interviews was the pervasive and varied experiences with ableism, both experienced personally and vicariously by this group of interpreters. Another related, but discrete experience was that of internalized ableism. These examples were present in all five interviews at varying degrees of severity and frequency, but none of the participants were free from ableist forces. Examples of ableism experienced by the interpreter often took the form of hostile work environments. As shared by Gator

> I'm the only employee in a wheelchair at the [LOCATION][2]; I've had comments made. I've had to report people for the way they've treated me in saying that I'm taking up too much space in the room and, but, yeah. I just go with the flow, basically.

Similarly, Loreli faced a hostile supervisor when trying to explain the accommodations her diagnosis required. Loreli stated

> it was very frustrating to have to have that kind of a conversation because it also meant that I can't just say, 'Look, this is what I need' I had to share with her far more than I was comfortable sharing. And even then, she fought me on it… I look back on it and I feel like much of it was her need

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[2] Information redacted for confidentiality purposes are indicated in text as all-caps inside of square brackets. Some participant responses have been edited for clarity.

> to feel like, 'I'm the boss and I'm in charge, I'm making the decisions and you're not gonna tell me what to do.'

Apart from workplace ableism, other participants shared stories about witnessing ableism directed at the deaf individual from hearing people. This may be similar or related to the phenomenon of vicarious trauma interpreters experience when we witness trauma in the course of providing interpreting services. Emerson and Hermione reported discriminatory comments made in classroom environments by hearing instructors toward the deaf student and/or the interpreting team. Specifically, Emerson shared

> I had one instructor who was very much, seemed to be dealing with his own baggage – can't identify that – but who was aggressive toward us. And the student was also someone who chose to speak for themselves, so the instructor seemed to think that we, as interpreters, had no place being there. And would do things like try to dictate what we could and couldn't interpret, actively – would announce that, 'I wish my friends would move so I could go over to the board' instead of talking to us directly. Which, again, that kind of interpersonal noise – I'm feeling that trauma response and so this grown man is shouting? Like, as loud as he could about us moving, and you just had a full-scale breakdown.

This interaction is interesting because one ableist action from the instructor traveled through the interpreter's body and triggered two simultaneous trauma responses in Emerson – one vicarious trauma response and one personal trauma response.

Marie told a story about an experience in the interpreting training program, and described systemic and volatile ableism throughout the entire institution. Marie gave several examples

> We had a CODA who was dyslexic, and still (SIGNS)[3] on fire, but couldn't spell for shit. Ok, so supports look like what? And they were all like, 'Don't be an interpreter. Get the fuck out of the field'

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[3] American Sign Language (ASL) has no written form. During some of the interviews, the participant would language-switch or engage in Simultaneous Communication (SimComming) where spoken English and ASL signs are used at the same time. While transcribing, spoken English was typed and any concepts which were signed are described here using their English glossed equivalent, indicated in text as all-caps inside of round brackets.

> I have ADHD, I'm trying to take notes while you talk. And they were like, 'I said no pens and paper in class'
>
> The interpreter training we got was in an inaccessible building, so if you had a physical issue you were fucked. And there was no, I don't know, (IT-ALL-WORKED-OUT) and there was no accommodation for background, for mental health, for ADHD or Autism or any of that. And so those people just dropped really early because they would get teased about being weird or socially awkward, or if you can't read… social cues then you can't be an interpreter.

One very interesting story of lateral ableism was observed by Hermione who provided interpreting services at a Cued Speech event.

> Yeah… there's such a culture divide in the communities, right? For so long it was a huge thing people… they couldn't co-mingle back in the day. Whereas now, there is a really big push for cuing and signing, and a lot of people don't know about that. So, it's really weird to just be an interpreter and a cuer, or cued language transliterator. I do have clients who are capital-D Deaf and then I go cue and it's really weird to see the divide and just see still how that impacts it.
>
> We ended up advocating for some of the students to get cued language transliterator services – we'd been fighting for that and some of them weren't able to get it because [EVENT] was like, 'No'. This person had tried to get cued language and [EVENT] had said they couldn't do it, it was kind of a whole thing, so then, because I have a lot of experience advocating, I said I would help, so we just sent a lot of emails to the important people and then finally got through! (laughing) We got a lot of people and we were like, 'Ok, well, let's all send emails' you know? It's about access, it's not about ASL or cue, it's about access.

This story shows the presence of lateral ableism in the deaf community, from users of ASL toward users of Cued Speech. For comparison, Loreli told a story about a situation where the ableist action was directed at the interpreter, but had implications for the deaf consumer. When a question is presented that means prioritizing disabled people's experience, how to decide who gets the access this time? And what is right when access for one person with a disability creates access for another person with a different disability? Loreli recalled

> When I first started working as an interpreter I can remember a conversation with somebody who told me that she'd broken her leg and

> she was in a wheelchair and trying to go to her classes, she was working in a school, and she went into a woodshop class and the teacher said, ‘You can’t be in here’ and it’s like, ‘Um… dude, I gotta be in here – I’m interpreting for this kid’ and he was like, ‘I can’t have you in here with that, you’re a liability’ because if somebody, she was in a wheelchair with a leg extension, and he’s like, ‘You know, I’ve got kids using ban saws, I’ve got kids using all these tools and things, if somebody turns around and doesn’t see you there or they’re looking ahead and they’re tripping on you and they’re gonna get inj – I can’t have you in here’ and at that time it kind of sparked this, like, what do you do? If that’s the only interpreter here, what are you going to do? Are you gonna tell the kid you can’t be in shop?!

The ableist action from the instructor was intended to bar access for the interpreter who was using a wheelchair temporarily, but that act of ableism created a ripple ableist action which barred access for the student who will not have an interpreter for class. All of these examples are ableism from the outside, directed toward a person with a disability. However, internalized ableism is directed from an individual to themselves and there were just as many examples of internalized ableism in the interviews. One example from Loreli illustrates this idea simply, when she stated, “Like I’ve lived my diagnoses very openly, and *without shame as much as possible*” (emphasis added). Internalized ableism is sometimes as easy to understand as feeling shame over a diagnosis. Even in trying to overcome and live openly, Loreli’s statement implies that shame is pervasive and hard to escape at times. That a person feels shame over a disabling condition also points to the universality of our society’s preference for the abled body, abled mind, and abled communication.

Another example of internalized ableism is the struggle some people with disabilities experience when deciding whether to discuss or disclose their experiences. There are various motivating factors behind this decision, as illustrated in the survey response to the disclosure question (see Figure 11). Hermione elaborated on this point by saying

> So I don’t really talk about it. I was a little bit nervous to do your study, not that I hide it, I just don’t, it’s not something that comes up a lot of

> times… I just sometimes feel like I don't want to have that conversation and I think that will change and I think it is changing already. And I do talk about it with my, the interpreter and the team and the mentors I've had in the past and they know. But yeah, I don't really talk about it that much

Gaining a level of comfort with conversations around disclosure and disability is an internal process which can be impacted by various factors, and many people with disabilities are familiar with the struggle of when to disclose and when to avoid it. The most extreme example of internalized ableism was revealed in conversation with Gator, who described her experience with disability as an ongoing process of disabusing abled people of their mistaken assumptions about people with disabilities. Gator stated

> I'm fortunate that people don't see me as "disabled" (quote fingers). They see me as [NAME] who uses a wheelchair to get around. I'm not the typical user, like, person with a disability. I'm just not. I'm very independent, I'm very go-getter, very like, "Ok, so my feet don't work as well as yours – I can still flail my arms around and they can still understand me"-type person.

This short passage illustrates ideas which are often synonymous with disability including dependence, laziness, and disability as a universal experience without much variation.

These are just a few examples from the conversations which illustrate various forms of ableism which were described by the participants. Ableism comes in various forms and directionalities, and Emerson's story in particular, indicates that ableism may multiply inside the bodies of people with disabilities who are in a service-provider role.

Extralinguistic Knowledge

The body of knowledge around disability norms has to be taught from one person to the next. All five of the interview participants shared stories about extralinguistic knowledge (ELK) from a variety of perspectives as well. Marie told a story about her experience acquiring disability ELK from a more knowledgeable member of the disability community. It is perhaps important to note that Marie’s circumstances are uniquely situated in that Marie has a disability, is a caregiver for other people with disabilities, and a service provider for the deaf community. Marie talked about being corrected by her client when she said

> And so I would say things that you don’t say, like ‘wheelchair bound’ and she would very kindly explain why those are not what we say. So my brother had no more understanding of it than I did, like the disabled world. But I was working with someone who was, like, she works for Centers for Independent Living. I would go over there and she would pay me but she would also teach me how not to be a dick? Which I didn’t know I was doing

Another example of ELK was shared by Emerson and Hermione when they expressed the ways in which their disabilities helped them tune in to the needs of a consumer. Hermione explained

> I feel it really quick. I’m like, ‘Nope, this is not going to work’ but I also do feel like I can notice if that’s happening or if somebody’s placement is weird then I’ll very quickly go and I’ll shadow or I’ll copy sign or I’ll do something. I do feel like I pick up on that very quickly and I notice things like that whereas a lot of other interpreters might not notice that. Because I’m always looking at like, ‘Oh, that’s not gonna be comfortable for your head all day long, so how can I fix this?’

Hermione’s disability fell into the physical category, and manifests in body aches and pain. A coping mechanism which Hermione has acquired for her own use in adjusting the environment to work for her was used to benefit not only the consumer but the team of interpreters as well. Emerson’s disability fell into the cognitive category, and his condition has primary and secondary characteristics. When connecting to the needs of consumer, Emerson described

> the benefit, I think, as someone with a disability and someone who has experienced a lot of trauma, I get a lot of empathy for people and it allows me to, I think more quickly identify people’s needs when I’m interpreting. Whether that be linguistically or emotionally, I feel that I have a really good handle on how I should present myself as the interpreter and how to build appropriate relationships with consumers.

Through the experience of trauma, Emerson was able to use the experience to empathize with and facilitate the needs of the consumer. Gator talked about recognizing the space between a person who has ELK and when that knowledge is missing, particularly around the question of access. Gator's disability fell into the physical category, coupled with the use of mobility equipment. When requesting access information, Gator remembered

> oftentimes I would contact the Contact Person and hope that they knew what they were talking about. But a lot of times I really never… they figured it out. When I would show up in a wheelchair, they'd be like, "Oh!" and they'd figure it out… most people's perspective of 'is it handicapped accessible?' and my perspective of handicapped accessible – totally two different things. Like, even a bathroom stall. The smaller ones that have the side rails, ok, well, is my chair gonna fit in there? No, it's not. So that is not accessible. The big ones that people change their clothes in because they can't use the 15 other ones that are open? That's the one I'm gonna need. (laughing)

Because of the variety of ways disability can be experienced it is rare that standardized disability recommendations are adequate, but it is even more rare that abled members of the community are familiar with disability accommodations or measures, even when working in positions connected to accommodation requests. This reinforces the idea that proximity to disability accommodation requests does not produce awareness of access standards and indicates that community knowledge is not only taught from person to person but also the product of a group (Harding, 2016).

Another perspective on knowledge formation and creating community knowledge as an educational interpreter was a decision Loreli made when she committed to living openly with the visual symptoms of a former diagnosis. Loreli remembered

> I'm open to talk about it, like, I don't have any secrets when I got my [DIAGNOSIS] I made the decision at that time that I can't show up at work with a bald head and expect a deaf kid to understand what's going on. Like, no, we're going to talk about this and I'm going to talk about this very openly because they have… (long pause) a lack of opportunity compared to most of their hearing peers to understand things like that. You know, do they have the opportunities at home to talk about what is [DIAGNOSIS]? What does it look like?

This is one example where disability was used as a vehicle to create a better understanding of the human experience for students in a classroom. This created not only a learning opportunity for deaf children, but helped create an environment in the classroom where the staff and students created a shared body of knowledge because of equitable exposure to information.

Performing Neutrality

The last pattern identified in the interviews is the performative nature of neutrality as an interpreter, and the ways that this performance is influenced by disability. Loreli talked about the differences between the way she was trained and expectations in the field today, saying

> You know, how do you manage these things? And then thinking about well, you know, I was trained – I was taught – I think now we've kind of gotten past the, 'Act like I'm not even here' part of the interpreting role, like, 'I'm here, and I have influence on the discourse because I am here and I'm a person'. But, if I come in and I'm not 100% 'normal' how does my disability bare on the deaf person? We really aren't having those types of conversations.

This illustrates the tension felt between different models of interpreting – the previously endorsed machine model and other current models being taught in training programs today. What was interesting was the different perspectives I heard from Emerson and Hermione, both of whom are in the beginning of their careers (0-5 years experience) and both mentioned being taught about neutrality. First, Hermione shared about the complications of disclosing her diagnosis, and stated

> I feel like sometimes, well we're taught not to draw attention to ourselves, right? We're taught to not be the center of attention, so I feel like sometimes I say [DIAGNOSIS] people will say, 'What's that?' and I don't really have any answers. I'm like, 'I don't know. People don't know' so then I don't really have any answers either, so I just sometimes feel like I don't want to have that conversation

While there is plenty of evidence from disability studies which explains the unwillingness that people with disabilities feel when forced to disclose more than we intended in order to satisfy voyeuristic interests or questions from abled peers, but Hermione framed the complexity of this conversation against interpreter training which emphasizes a minimization of the self while in service to the deaf community, while in the role of the interpreter. Trying to balance the performance of neutrality against when it becomes necessary or appropriate to disclose a disability. However, their training, more recent than Loreli, still placed a primary value on neutrality as subjugation of the self. Emerson commented

> And I had a call that had not even connected yet but the hearing person, I don't know if it was the cadence of my voice or whatever, immediately flipped the script and started calling me some pretty homophobic stuff, and it – the con of interpreting for me is feeling a little bit of disempowerment because, you know, the appropriate interpreter boundary. We're not neutral but we're 'neutral', you know? When I can't act as my full self, responding to injustice that's going on, I find myself actively triggered and so in that time, the person made their remarks and then the deaf person video mail pops up. So I can't stop it and, like, respond, so I'm just stuck in this, like, "How do I respond appropriately but also do the professional thing?" so the con of that is kind of crossing over appropriate boundaries and figuring out how to exist as an interpreter and a person.

Emerson's training also included confusion around the boundary between interpreter role and person when expected to maintain an interpreter's neutral role. This may indicate a more complex conceptualization of neutrality, and raises questions about how this expectation can be taught in a way that does not compound trauma later on. It should also be acknowledged that this conversation cannot happen without members of the deaf community involved, because the Code of Professional Conduct, which requires neutrality when in the role of the interpreter, was originally conceived as representation of values from the community and practices all interpreters should embrace. Does the deaf community expect interpreters to experience personal trauma in the interests of neutrality? Is neutrality in its most extreme form a harkening to the older machine model, and these exchanges indicate the need for interpreter education to shake off the cob webs of this outdated and harmful practice? I contend that neither of these are true, but rather the way we teach about neutrality is the culprit. These interviews point to interpreter instruction regarding neutrality seemingly undergoing a shift from the days when interpreters came from the community to now when most interpreters come from formal training programs. Neutrality is a difficult concept for instructors to relay because it is highly contextual, and our interpreter training classrooms are not currently able to deliver the variety of applications for neutrality which exist in the community. This instructional gap needs to be addressed.

Limitations and Suggestions for the future

Although the implications of this study point to exciting new areas of inquiry for the field of ASL/English interpreting, there were some limitations present which could not be mitigated in at the time of this work. One limiting factor is the question of whether the twenty-nine participants in this study are representative of interpreters with disabilities in the field at large. Answering this question is difficult because we lack an understanding of how many people in the United States are engaged in ASL/English interpreting as part- or full-time employment, so it is not possible to extrapolate a number of interpreters we might expect to have a disability. The RID (2018) Annual Report is the closest thing we have to a head-count, but many interpreters are not RID members and many states do not have interpreter credentialing requirements or oversight of any kind. According to Brault's (2012) work, we know that people with disabilities numbered 56.7 million or 18.7% of the United States population in 2010, but we do not have corresponding data for the total number of professional interpreters.

Another limitation of this study was time and recruitment options. The window of time where responses were collected was during an exceptionally challenging time in the early months of 2020, partially during lockdown periods for the coronavirus/COVID-19 pandemic. Future studies on this topic would be well advised to leave additional time in the data collection portion. Recruitment options available at the time of this work were limited to digital contacts and the use of social media, and while useful are still not accessible for everyone and not available to everyone. Consideration for expanded recruitment efforts would potentially yield a more representative pool of study participants. As mentioned in the Results and Discussion of Findings section, this study was potentially skewed toward the Midwest region, and efforts to include a wider range of interpreters should be given consideration for future research.

Race was another area which needs further investigation. According to RID's (2018) Annual Report, Hispanic/Latino and African-American/Black interpreters are the second and third largest racial groups in RID's membership, yet these groups are not represented at corresponding levels in this study. Recruitment materials were sent to professional interpreting organizations Mano a Mano and National Alliance of Black Interpreters, but additional efforts need to be made to collect the stories of and understand the experiences of BIPOC interpreters with disabilities.

The last area which begs more consideration is the fact that none of the twenty-nine participants in this study self-identified as Deaf or deaf. The definition of disability used clearly includes deafness, but none of the data collected here represents the experiences of deaf interpreters, which are a vital and influential group of professionals in the field of ASL/English interpreting. Other studies have looked specifically at the experiences of deaf interpreters (Adam et al, 2014; Forestal, 2011) but not in the context of disability in general. It is possible that the ableist construction of deaf identity discussed in the Disability in the Deaf Community section, and the lack of deaf involvement on this study may indicate the pervasiveness of this ableist ideology. Future research which investigates the relationship between deafness and disability in the field of ASL/English interpreting is highly recommended. This may be one of the most important findings of the study, and merits more attention from academics and community members.

Additional suggestions for future research include investigations into interpreter education to root out systemic ableism and other oppressive practices, and begin efforts to dismantle them. Recent work published on this topic from Moutinho (2019) recognizes the need for interpreter education to make some changes. Moutinho states

> If interpreting education adopts an approach similar to Inclusive Deaf Studies' proactive endeavor to understanding d/Deafness, then they must prioritize d/Deafness and interpreting with intersectional topics of race, class, gender, disability, sexuality, and others as central to understanding instead of compartmentalizing it as extraneous to a binary Deaf/hearing, signing/speaking conceptualization of sign language interpreting (2019, p. 82).

Moutinho's work was a critical look at one program's interpreter training curriculum, and the implications of her work support the claim in this study that the application of critical disability frameworks to the conceptualization of interpreting could help to move the field in a more equitable direction to create a body of professional interpreters which more closely reflects the deaf communities we serve.

The last suggestions I will make, in addition to applying critical disability theory, reflect my curiosity on the impact disability has on three current concepts within the field of interpreting. The first is the Llewellyn-Jones & Lee (2014) role-space concept put forward in their reframing of the responsibilities of the community interpreter. The next is Roy's (2000) work on interpreting as a discourse process. Finally, Dean & Pollard's (2013) work on demand-control schema and interpreting as a practice profession. I believe that introducing disability as a consideration in each of these discussions could lead to breakthroughs in our understanding of the way interpreting services can be provided, the role of the interpreter, and unique ethical and decision-making requirements of interpreters.

Conclusion

This study represents the first collection of stories from interpreters who self-identified as disabled and their experiences in the field of ASL/English interpreting. The importance of this lens as a step towards transformative praxis was explored, along with the ways in which disability frameworks could inform the way interpreters approach our work.

Using the principles of Grounded Theory and centering the stories and experiences shared by disabled participants, the methodology used in this study served to uncover patterns which until now had not been sought out. Allowing the data to shape theories has benefits in the way academia and the community can come together and establish a more inclusive and interdependent praxis through establishing improved standards of practice and influencing interpreter education delivered by institutions and organizations.

The field of ASL/English interpreting is still young, and this study will hopefully usher in new areas of inquiry, leading to a more collaborative model of interpreting where we ask, “Who are you as a person and what can you bring to this work?” There is much difficult work ahead, but good work is currently being done on ways to move into the future of this profession where the field of interpreting more closely reflects the communities we serve, where interpreters are more adept at identifying equity gaps and have the tools to address and remedy those instances. I am looking forward to continuing the work of this research and sharing what insights the remaining interviews may uncover. Mostly, I look forward to a future where we collaboratively create a new, interdependent, and fully representative field of professional interpreters.

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Appendix A: Survey Introduction and Questions

Survey Introduction

Hello interpreters! My name is Lindsey Williams and I'm an interpreter in Lansing, MI. I'm also a graduate student in the Master of Arts in Interpreting Studies and Communication Equity program at St. Catherine University. I'm conducting my master's thesis on the lived experiences of sign language interpreters who self-identify as disabled. My experiences as an interpreter with a disability have inspired this research. For the purposes of this study, the definition of "disability" is a physical or mental impairment that substantially limits one or more major life activity as defined by the ADA, but also chronic illnesses, conditions, or injuries. If this describes your experience, I am requesting your participation in the study. Taking the survey will require around 15 minutes. Survey responses will be anonymous. All information shared during this research will remain strictly confidential per St. Catherine University Institutional Review Board approval (#1340).

There is an interview component to the study as well. If you would be willing to be interviewed and discuss your experiences in the field of interpreting in more depth, please contact me at llwilliams788@stkate.edu and provide your contact information. The interview will take about an hour, via Zoom.

If you have questions, you may contact the Chair of the board, Dr. John Schmitt, at (651) 690-7739 or jsschmitt@stkate.edu. You may also contact my thesis supervisor, Dr. Erica Alley, at (651) 690-6018, (612) 255-3386 (VP) or elalley@stkate.edu.

Thank you for your consideration,

Lindsey Williams, BEI 2, EIPA 4.2, RID Ed:K-12
Graduate student, MAISCE program
St. Catherine University
llwilliams788@stkate.edu

Survey Questions

1. How old are you?
    a. 18-25, 26-35, 36-45, 46-55, 56-65, 66-75
2. What is your gender identity? Select all that apply.
    a. Cis Man, Cis Woman, Transman, Transwoman, Gender Non-Conforming, Non-Binary, Agender, Gender Queer, Other (please describe)
3. What is your race? Select all that apply.
    a. White, Black, African American, Native to North America, Native to Alaska, Native Hawaiian, Pacific Islander, Mexican, Latinx, Central American, South Asian, Central Asian, East Asian, Prefer Not to Say, Other (please describe)
4. What is your sexuality? Select all that apply.

    a. Straight, Gay/Lesbian, Bisexual, Asexual, Pansexual, Graysexual, Sapiosexual, Demisexual, Prefer Not to Say, Other (please describe)
5. What is your highest level of education?
    a. High school, GED, some college, 2 year degree, 4 year degree, Masters, Doctorate
6. How did you get interested in interpreting? (please explain)
7. Did you attend an undergraduate Interpreter Training Program?
    a. Yes, 2 years
    b. Yes, 4 years
    c. Other (please describe)
    d. No
8. What interpreting certification(s) do you hold? Select all that apply:
    a. EIPA (please describe numerical level and indicate whether elementary or secondary)
    b. RID (please include specific certifications)
    c. BEI (please describe level)
    d. State certification (please describe and indicate which state)
    e. Other (please describe)
    f. None
9. In which region of the US do you live?
    a. Pacific Northwest, Deep South, Mid-Atlantic, Southwest, New England, Midwest, Mountain West, Upper Midwest, Central Plains, Non-US Mainland (Alaska, Hawaii, Territories)
10. How long have you been working as an interpreter?
    a. 0-5 years, 6-10 years, 11-15 years, 16-20 years, 21-25 years, 26-30 years, 30+ years
11. How many hours a week do you work as an interpreter?
    a. 0-10, 11-20, 21-30, 31-40, 40+
12. In which of these settings do you work as an interpreter? Select all that apply:
    a. K-12 Education, Post-Secondary Education, Medical, Mental Health, Legal, Government, Performance/Entertainment, Video Relay Service (VRS), Video Remote Interpreting (VRI), Other (please describe)
13. Which of these descriptions best fits your employment position? Select all that apply:
    a. Part-time Staff Interpreter, Full-time Staff Interpreter, Part-time Freelance Interpreter, Full-time Freelance Interpreter, Other (please describe)
14. Please describe your disability
15. Please indicate the age of onset
    a. birth, 0-5 years old, 6-10 years old, 11-18 years old, I was an adult
16. Did you ever request accommodation for your disability as a student?
    a. Always, Mostly, Sometimes, Rarely, Never
17. Has your disability been accommodated as a student?
    a. Always, Sometimes, Rarely, Never, NA
18. Did you ever request accommodation for your disability as an interpreter?
    a. Always, Mostly, Sometimes, Rarely, Never
19. Has your disability been accommodated as an interpreter?
    a. Always, Sometimes, Rarely, Never, NA

20. Has your disability benefitted you as an interpreter?
    a. Always, Mostly, Sometimes, Rarely, Never
21. Has your disability impacted ethical decisions while interpreting?
    a. Always, Mostly, Sometimes, Rarely, Never
22. Has your disability impacted access to work opportunities?
    a. Always, Mostly, Sometimes, Rarely, Never
23. Has your disability impacted access to training opportunities?
    a. Always, Mostly, Sometimes, Rarely, Never
24. Do you disclose your disability prior to interpreting?
    a. Always, Sometimes, Rarely, Never, Depends (please explain)
25. Additional comments?

Many thanks for your participation in the study! Results of the study and final thesis will be available at https://sophia.stkate.edu/maisce/ after June 2020.

Appendix B: Interview Script and Questions

Interview Introduction

I have started recording, and to ensure that all participants receive the same information I have to read from this script, ok? My name is Lindsey and I'm a graduate student in the MAISCE program at St. Catherine University. Thank you for agreeing to participate in this study on the lived experiences of ASL/English interpreters who self-identify as disabled. I'm a member of this group; I'm an interpreter and I've used a wheelchair since I was 17 years old. I want you to know that our conversation will be filmed and the video will be viewed by the researcher in this study for transcription purposes. As you noticed in the forms that you recently completed, I may include English text of your responses in scholarly articles or scholarly presentations. All references to you will be only by the pseudonym you choose. Demographic information, including your age, gender, and years of experience may be shared to describe the source of data generated from this conversation.

Your participation in this interview should take around one hour. If you feel you need a break at any time, please let me know. Also, if you become uncomfortable at any time and prefer to end our meeting, please let me know. Ready to begin?

Great! Let's begin.

Interview Questions

1. What has been your experience related to disability?
2. How was the topic of disability discussed while you were in training?
3. What has been your experience with accommodation requests?
4. As an interpreter, has the work environment itself stood out as friendly or do you have to fight to be present?
5. Has your disability ever impacted your work setting/interpretation/team?
6. You may be familiar with the Deaf community perspective that deafness is not a disability – does this perspective ever impact your work? If yes, how so?

Appendix C: Recruitment Email

Hello,

I am writing to request that ORGANIZATION consider sharing the message below with your membership. As I prepare to present my thesis later this year, my goal is to include participants from as broad a range of our field as possible. Please let me know if this is possible, or if you have questions about my research!

Respectfully,

Lindsey Williams, BEI 2, EIPA 4.2, RID Ed:K-12
Graduate Student, MAISCE Program
ASL and Interpreting Department
St. Catherine University
text/voice: 989-400-3998

Dear Interpreter,

Hello! My name is Lindsey Williams and I'm an interpreter in Lansing, MI. I'm also a graduate student in the Master of Arts in Interpreting Studies and Communication Equity program at St. Catherine University. I'm conducting my master's thesis on the lived experiences of ASL/English interpreters who self-identify as disabled. My experiences as an interpreter with a disability have inspired this research. For the purposes of this study, the definition of "disability" is a physical or mental impairment that substantially limits one or more major life activity as defined by the ADA, but also chronic illnesses, conditions, or injuries. If this describes your experience, I am requesting your participation in the study! Taking the survey will require around 15 minutes. Survey responses will be anonymous. All information shared during this research will remain strictly confidential.

There is an interview component to the study as well. If you would be willing to be interviewed and discuss your experiences in the field of interpreting in more depth, please follow the link at the end of this survey and provide your contact information. The interview will take about an hour, via Zoom.

Link to ASL video explaining the study:
https://youtu.be/PXn2RJAGLN4

Link to the Research Survey:
http://stkate.az1.qualtrics.com/jfe/form/SV_5pfg3SeLqIaQzk1

This study has been approved by the St. Catherine Institutional Review Board (#1340). If you have questions, you may contact the Chair of the board, Dr. John Schmitt, at (651) 690-7739 or jsschmitt@stkate.edu. You may also contact my thesis supervisor, Dr. Erica Alley, at

(651) 690-6018, (612) 255-3386 (VP) or elalley@stkate.edu.

Thank you for your consideration,

Lindsey Williams, BEI 2, EIPA 4.2, RID Ed:K-12
llwilliams788@stkate.edu
Graduate student, MAISCE program
St. Catherine University

Appendix D: Interview Participant Welcome Message

Dear PARTICIPANT,

My name is Lindsey and I'm a graduate student in the Master of Arts in Interpreting Studies and Communication Equity program at St. Catherine University. Thank you for your interest in participating in my research!

If you agree to be in this study, you will be asked to do these things:

- Read, sign, and return the attached Informed Consent form.
- Read, sign, and return the attached Video Recording Release form.
- Schedule a one-hour meeting, which will be video recorded.

In total, this study will take approximately one hour in a single session.

We will select a date and time for an interview over Zoom. You will need access to a computer and the internet. It is possible that I may contact you at a later date with follow up questions; however, you are not required to participate after our initial interview. All information shared during this research will remain strictly confidential per Institutional Review Board approval (# 1340).

If you are interested in participating, please address the following in your response:

- Approximately how many hours a week do you work as an interpreter?
- In what settings do you interpret (e.g., VRS, educational, legal, medical)?
- Please provide a description of your disability.
- Please provide a description of any accommodations required for the interview.

I will follow up with you via email within two weeks to find a date and time for participation in this study.

This study has been approved by the St. Catherine Institutional Review Board (# 1340). If you have questions, you may contact the Chair of the board, Dr. John Schmitt, at (651) 690-7739 or jsschmitt@stkate.edu. You may also contact my thesis supervisor, Dr. Erica Alley, at (651) 690-6018, (612) 255-3386 (VP) or elalley@stkate.edu.

Thank you for your consideration and I look forward to hearing from you.

Lindsey Williams, BEI 2, EIPA 4.2, RID Ed:K-12
Graduate Student, MAISCE Program
ASL and Interpreting Department
St. Catherine University
text/voice: 989-400-3998

Attachments:
Informed Consent
Video Recording Release

Appendix E: Informed Consent for Interviews

ST CATHERINE UNIVERSITY
Informed Consent for a Research Study

Study Title: A New Lens: The Lived Experience of Interpreters with Disabilities
Researcher: Lindsey Williams

You are invited to participate in a research study. The study is being done by Lindsey Williams, a Masters' candidate student at St. Catherine University in St. Paul, MN. The faculty advisor for this study is Erica Alley, PhD, Program Director for the Master of Arts in Interpreting Studies and Communication Equity in the ASL & Interpreting Department at St. Catherine University. The purpose of this study is to seek to understand the experiences of interpreters who have a disability. This study is important because at present not much is known about this group of professionals and how their experiences inform what we know about the field of interpreting. Approximately 20 people are expected to participate in this part of the research. Below, you will find answers to the most commonly asked questions about participating in a research study. Please read this entire document and ask questions you have before you agree to be in the study.

Why have I been asked to be in this study?

You work as a professional ASL/English interpreter, and you have self-identified as having a disability. You have volunteered to be interviewed about your experiences related to disability in the field of interpreting.

If I decide to participate, what will I be asked to do?

If you meet the criteria and agree to be in this study, you will be asked to do these things:

- Read, sign, and return this Informed Consent form.
- Read, sign, and return the Video Recording Release form.
- Schedule a one-hour meeting, which will be video recorded.

In total, this study will take approximately one hour in a single session.

What if I decide I don't want to be in this study?

Participation in this study is completely voluntary. If you decide you do not want to participate in this study, please feel free to say so, and do not sign this form. If you decide to participate in this study, but later change your mind and want to withdraw, simply notify me and you will be removed immediately. You may withdraw up until participation, after which time withdrawal will no longer be possible. Your decision of whether or not to participate will have no negative or positive impact on your relationship with St. Catherine University, nor with any of the students or faculty involved in the research.

What are the risks (dangers or harms) to me if I am in this study?

There are no anticipated risks to your health or welfare if you participate in this study; however, you will be sharing information regarding your experience as an interpreter who self-identifies as disabled. Because you are sharing potentially sensitive information, there is risk associated with this study. However, strict protocols will be in place to maintain the anonymity of each participant and the confidentiality of all information shared.

What are the benefits (good things) that may happen if I am in this study?
Participants will benefit in an indirect way because results will benefit the interpreting profession at large and the ways that interpreters with a disability navigate the field. Information collected about the contributions of interpreters with disabilities will add to our well of knowledge about interpreting.

Will I receive any compensation for participating in this study?
You will not be compensated for participating in this study.

What will you do with the information you get from me and how will you protect my privacy?
The information that you provide in this study will be translated and/or transcribed into English. Your personal identifying information will be removed and replaced with a pseudonym that you select. Each participant's information will be combined for analysis. The researcher will keep the research data on an external hard drive in the researcher's home, and only the researcher and their faculty advisor will have access to the records while they work on this project. The researcher will finish analyzing the data by June 1, 2020 and will then destroy all original reports and identifying information that can be linked back to you. Your name will not be used in any presentation or publication that comes from this research. Instead, your chosen pseudonym will be used. All video recordings will also be labeled with that pseudonym so that your real name and any other personal information (e.g., where you live) will not be known by others.
The transcribed data resulting from this study may be made available to other researchers in the future for research purposes not detailed within this consent form. In these cases, the data will contain no identifying information that could associate you with it, or with your participation in any study. Any information that you provide will be kept confidential, which means that you will not be identified or identifiable in any written reports or publications.

Are there possible changes to the study once it gets started?
If during the course of this research study the researcher team learns about new findings that might influence your willingness to continue participating in the study, they will inform you of these findings.

How can I get more information?
If you have any questions, you can ask them before you sign this form. You can also feel free to contact me at (989) 400-3998 or llwilliams788@stkate.edu. If you have any additional questions later and would like to talk to the faculty advisor, please contact Dr. Erica Alley at (651) 690-6018, (612) 255-3386 (VP) or elalley@stkate.edu. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739 or jsschmitt@stkate.edu.

You may keep a copy of this form for your records.

Statement of Consent:
I consent to participate in the study and agree to be video recorded.

My signature indicates that I have read this information and my questions have been answered. I also know that even after signing this form, I may withdraw from the study by informing the researcher(s).

____

Signature of Participant Date

____

Signature of Researcher Date

Appendix F: Video Recording Release for Interviews

I ________________________________ agree to be video recorded as part of my participation in the study “The Lived Experience of Interpreters with Disabilities” conducted by Lindsey Williams. I understand that the video recording will be labeled using a chosen pseudonym and kept secure on an external hard-drive stored in the researcher’s home. I understand that the video will be kept by the researcher and used for research purposes. The video will not be shown to others without my written permission.

Please read the following and check those for which you give consent. Please note: you cannot participate in the research if you are unwilling to be video-recorded.

Video Recording Release:

☐ YES, I give permission for my video recorded data to be used in scholarly presentations and publications for with the public. The researcher will contact me and show me the clip(s) to be used, and I will approve the clip(s) I am willing to share.

☐ NO, I DO NOT give permission for my video recorded data to be used in scholarly presentations or publications for the public. The researcher will only use my video recorded data for research purposes.

Future Contact Release:

☐ YES, I give permission to be contacted by email about future research. My

e-mail address is: ____

☐ NO, I DO NOT give permission to be contacted by email about future research.

____

Signature of Participant Date

____

Signature of Researcher Date