

**Access Intimacy: The Missing Piece**

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DISSERTATION

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This dissertation is dedicated to my Oma and Opa who passed recently. You two always believed in me. This is for you both!

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## SUMMARY

In 2011, writer and disability justice activist Mia Mingus, in her blog *Leaving Evidence*, described “access intimacy” as an “elusive, hard to describe feeling when someone else gets your access needs” and a sense of “comfort that your [entire] disabled self feels” (Mingus, 2011). To date, there is no other form of intimacy that speaks to the emotions involved in getting one’s access needs met. Since the coining of the term in 2011, various disabled bloggers have written about access intimacy, but academic writings on the term remain sparse. McNamara (2013) calls access intimacy the “missing piece” of the disability community. Due to the sparse amount of academic literature and the power behind the words used to describe access intimacy, this qualitative research study explored the defining features of access intimacy, its importance, and the relationship between access intimacy and community building within the disability community.

Utilizing blog posts and semi-structured interviews, I analyzed the experiences of access intimacy related by 13 disabled bloggers. During the various moments of access intimacy described by participants, they felt naturally attuned with another person which was based on full communication with that person. During these moments, disability was viewed as a natural part of the human experience which allowed participants to combat internalized stigma, be vulnerable, hold space for one another, and be in the moment. Some participants stated that access intimacy could happen with strangers, but all agreed that a deeper level of access intimacy came from longer, more in-depth relationships. Throughout their stories, participants mentioned that those with whom they experienced access intimacy had an awareness of others’ needs by having empathy through a compassionate connection. Participants stated that access intimacy was usually experienced with someone who belonged to one or more marginalized communities.



## **SUMMARY (continued)**

Access intimacy was important in the lives of all of my participants. They stated that access intimacy brought with it shared meanings through shared language, and as disabled people, they were able to define a form of intimacy for themselves. In all of the recounted experiences, participants described how access intimacy helped them function in their everyday lives, ranging from a friend waking a participant up for work to a community keeping a participant alive

## I. INTRODUCTION

In this dissertation research, I explored the term “Access Intimacy” through the blog posts and semi-structured interviews of 13 disabled bloggers. Although, there has been conversation around access intimacy in the blogosphere, academic literature around the term is sparse. In my initial experience of reading about access intimacy, bloggers described the term with such love and richness that I was immediately drawn to the term, and I wanted to find out how other people with disabilities viewed the term for themselves. I chose to ask those who were engaged in the conversation already: disabled bloggers. I did not want to have authority over how they told their experience. Therefore, I asked participants to submit a blog post of their choosing that they wrote before the start of my study. This allowed me to have an unprompted view of their experience and ponder aspects of the experience I may have had before the start of the interview.

Utilizing the blog posts and interviews, I set out to explore how disabled people defined access intimacy for themselves. I also wanted to see if access intimacy was important in their lives, and what role, if any, did access intimacy play in community building. Through this exploration, I was able to find a window into their varying and positively beautiful experiences. I did not find a concrete definition, but participants highlighted several defining features of both access intimacy and the people with whom they experienced the moment.

Through the stories of my participants, I was able to view the importance and positive effects that these moments had in their lives. Access intimacy was important in both interpersonal relationships and community building efforts. Access intimacy, as told through the stories of my participants, highlights the emotional side of access while advancing the need for an intersectional view on the disability experience. Most importantly, access intimacy shows us

interdependency in practice and the knowledge we can gain from one another through our everyday experiences.

## I. LITERATURE REVIEW

When I read Mia Mingus' blog post on access intimacy for the first time, tears began to roll down my face. At that moment, I felt like Mia understood a piece of me that no one has ever gotten before, or at the very least, named something that I did not have words for. The only word that came to mind was that I felt a sense of community in her words. Since then, whenever I feel access intimacy, I smile from the inside out. It makes me breathe a little, or maybe a lot, lighter. It comes in small and unexpected moments that make the biggest differences.

Access intimacy does not come in the moments when someone thinks that they are meeting my individual needs such as re-arranging space. Meeting a person's individual needs or putting accommodations in place often makes me feel like a burden. Rather, access intimacy recognizes and acknowledges how access affects one's emotional well-being. For example, when a person's access needs are not met, the person can experience an array of emotions such as frustration, stress, and sadness. Unlike accommodations, access intimacy is not something a person has to fight for or ask for; it is something that happens organically. Within instances of access intimacy, physical spaces may not change. Even though the physical space may not change, this form of intimacy can allow people the freedom and the space to develop meaningful relationships through a navigation process of learning from and with one another.

Access intimacy comes in the moments when I call my "best disabled friend," as she likes to call herself, to vent about my day or my personal care attendants, and I do not have to explain my feelings. More often than not, she has been in similar situations and, therefore, she can relate. Access intimacy comes when a friend plans out a trip for us, and I can relax because I know that she will make sure that all my needs, both my physical and mental needs, are met.

Access intimacy looks like my best friend, Tracey, coming up with creative ways for me to get my needs met, such as, looking up YouTube videos on how to best tie my boots in order to keep my ankles straight or learning how to lift me up a flight of stairs in order to give me a bath. These were not experiences of access intimacy because my physical needs were met, these were experiences of access intimacy because my friend took it upon herself to figure out the physical logistics because she understood the emotional effect that not getting my physical needs met would have. By figuring out how to get my needs met, my friend took on the emotional responsibility of sorting out the physical logistics that are oftentimes stressful for me. This gave me the space to focus on things aside from my disability-related needs. As shown in my examples, experiences of access intimacy can and do vary. However, within these experiences my access needs are not a burden but are part of the human experience. Tracey was not only caring for my access needs but she was also sharing space with me. With these experiences, my entire disabled self feels comfortable, trusting, and at ease. Due to my own experiences and the emotions that they elicit, I was drawn to explore the term further.

A. **Mia Mingus**

In 2011, Mia Mingus wrote about a form of intimacy that could not be categorized in terms of any other form of intimacy that was previously conceptualized in the literature. Access intimacy describes the intimate moments that Mia experiences, as a disabled, queer person of color, as an almost “magical” form of intimacy that can happen between two or more people based solely upon a person or more than one person’s access needs. As she describes, access intimacy is, an “elusive, hard to describe feeling when someone else ‘gets’ your access needs” and a sense of “comfort that your [entire] disabled self feels” (Mingus, 2011). Within these instances, disabled people have stated that they can be their authentic selves; while, at the same

time, gaining new insights and knowledge about their lived disability experience. Not only is knowledge fostered, but it has also been stated that access intimacy gives people the ability to embrace interdependence, resulting in an ability to care for ourselves and others (McNamara, 2013). Recently, in Mingus' remarks at the Paul K. Longmore Lecture on Disability Studies at San Francisco State University on April 11, 2017, she stated that access intimacy is interdependence in action, liberatory in nature, and it focuses on relationships rather than only the logistics of access, thus separating it from other definitions of both access and intimacy that are currently in the literature outlined below.

## B. **Intimacy**

Intimacy, in a broad sense, is an important aspect of human interaction, a central experience, and an activity when establishing and maintaining friendships, family relationships, and sexual and romantic encounters. Despite the centrality of intimacy to the human experience, operationalizing intimacy has proven difficult. Historically, psychological theorists were interested in understanding the role of intimacy within relationships. In pursuit of this goal, intimacy was studied and defined in several different ways, such as, self-disclosure (Altman & Taylor, 1973; Clark & Reis, 1988), emotional behavior (Montgomery, 1984), the role of sex and physical contact (Sullivan, 1953), and the role of support in a relationship (Newcomb, 1990). These studies focus on various components that need to exist in order for intimacy to occur within the context of a relationship. For example, Newcomb (1990) found that intimacy was strengthened if the person felt a sense of social support and connectedness with the other person. Current research on intimacy, however, is focused on what intimate relationships feel like, rather than defining what intimacy is. Furthermore, current research on intimacy is geared towards sex and sexuality, as well as friendship, which is oftentimes intertwined with physical contact and

emotional wellbeing (Impett, Peplau, & Gable, 2005; McCabe, 1997; Stephenson & Meston, 2015).

Recent literature on disability and intimacy has a similar focus as well (Gomez, 2012; Kattari, 2014; Rushbrooke, Murray, & Townsend, 2014). Kattari (2014), for instance, conducted phenomenological research about people with physical disabilities and the importance of negotiations around sexual intimacy with their partners. The study points out that open communication between partners is central to a satisfying sexual relationship between people with physical disabilities and their partners, resulting, in both parties getting their needs met and contributing to the positive emotional wellbeing of both people in the relationship. Rushbrooke, Murray, and Townsend (2014) found that people with intellectual disabilities had a desire for sexual intimacy that was similar to their able-bodied counterparts. However, unlike their counterparts, participants mentioned their caregivers in regard to access to sexual relationships. While both studies discuss the role that access needs can play in the context of intimate relationships, these studies treat access and intimacy as separate and lack language around the combination of these two terms.

#### 1. **Disability and intimacy within sexual relationships**

Recently, there have been entire anthologies dedicated to sexuality and disability which include stories and articles written by and for disabled people (Luczak, 2015; McRuer and Mollow, 2012; Wood, 2014). Within the stories that make up these anthologies, disabled authors have written about the complexities of intimate interactions within their lives. For instance, Jax Jacki Brown (2015) writes about physical intimacy and how it relates to identity when they<sup>1</sup> talk

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<sup>1</sup> I will use the pronouns of the authors and/or participants choice. Therefore, “they” may be used to refer to one individual.

about “pashing” or showing public displays of affection as a disabled person. Within this piece, they call pashing “acts of resistance” (p. 4). The public displays of affection they point out force the public to see them as sexual beings. Brown points out, “Until disability and sexual diversity become more visible...my kissing in public will never be a simple act” but an “act of resistance” (Brown, 2015, p. 5). Andrew Gurza (2015), on the other hand, writes that the mere question of “Can you feel that?” by a lover often makes him question as a disabled man whether he is a viable partner. While such a question may seem “sexy” to others, Andrew describes this question as taking away from the intimacy of the moment by triggering him to question his body’s desirability. Within these two stories alone, the authors write about the complexities of a sexual encounter as people with disabilities.

In these pieces, the authors both touch upon the intricacies of a sexual encounter with their partners. Gurza writes about how a question during a sexual encounter evokes negative thoughts and feelings while Brown’s (2015) public display of affection is associated with positive feeling for them. The act of pashing makes public their identities and the pride that they have within themselves. Along with pride, physical intimacy also helps people, specifically disabled people, understand themselves. As Andrew Freeman (2013) points out in *The Last Taboo*, a documentary on sex and disability, “...in order for you to really understand yourself, you have to be able to experience the touch of another person” (0:56) While physical touch can be important within some experiences of intimacy, it is important to note that not all forms of intimacy require physical touch which will be discussed in the next section on friendship.

## 2. **Disability and intimacy in friendships**

Sexual relationships are not the only forms of intimate relationships that are important to people with disabilities. Friendships are also central in the lives of disabled people. There have



been several articles written on friendships between disabled people (Knox & Hickson, 2001; Lafferty, McConkey & Taggart, 2013; McVilly et al., 2006). According to these studies mutual understanding, interdependence, and socialization were all pointed out by participants as important components of any friendship between disabled people. Lafferty, McConkey, and Taggart (2013) point out that their participants, when referring to intimacy within friendships, reported giving mutual support and reciprocity to one another. All of these components evoke positive feelings and emotions that lead to trust within friendships. Furthermore, McVilly et al. (2006) found that open communication, honesty, understanding, caring, reliability, being helpful, and common interests were all deemed as important qualities in any friendship by their participants. Knox and Hickson (2001) found that meaningful relationships included socialization, shared history, shared interests, and interdependence. Friendship for many people with disabilities brings with it the strongest bonds that they will have. Friendships between disabled people are unique and affected by the access needs of the people within the relationship.

Disabled people have diverse bodyminds and navigate the world differently based on their physical and psychological needs. Therefore, the ways in which disabled people experience intimacy may be different due to the way they navigate and live in the world. An important aspect of navigating the world as disabled people is access. As pointed out in the next section, access refers to a wide range of things and is not limited to physical access, such as elevators and doorways.

### C. Access

Access, like intimacy, is complex in nature. When access is mentioned, there are several images that commonly come to mind such as, ramps or “Handicapped Parking” signs and spaces. However, access goes much deeper to include a wide array of tangible and intangible things,

such as, Braille, voice over, and quiet spaces (ADA, 1990). More importantly, access is intertwined with whether or not disabled people can engage in a social activity or interact with their peers. Therefore, a person's relationship with access can be complex and must take both the social and physical world into consideration (Price, 2017). Access determines who is worthy of entering a particular situation and who is not (Titchkosky, 2011). In other words, access implicitly states who is valued and who is not valued by society. The original meaning of access, as pointed out by Williamson (2015), was "the power, opportunity, permission, or right to come near or into contact with someone or something" (p. 14). It is through its roots that we see that access can be more than a tangible thing but, rather, impacts all aspects of a disabled person's life--even their "rights" to be citizens. Shona, a 19-year-old disability and lifestyle blogger, writes that the lack of physical access on public transit "made me feel like a second-class citizen and as if able-bodied people are worthier of respect than me" (Sholl, 2017). Current definitions of both intimacy and access challenge society to think about how disabled people live in and navigate through a primarily able-bodied world and what that means to them. However, intimacy and access have not been analyzed in conjunction with one another until recently.

#### D. **Bridging the Gap between Access and Intimacy: Disability Studies Scholarship**

Before the creation of access intimacy, various disability scholars have written about intimate experiences between disabled people that have taken place in unstructured moments of being together, using a variety of terms. Chandler (2012) uncovers a sense of intimacy, without using the words, that is felt between disabled people within her conception of "Crip Community." She states that to engage in crip community means "to create...unstructured moments of being together, in which disability is welcomed rather than excluded or feared" (Chandler, 2012, 45). Within crip community, disabled people experience a level of comfort

from being together. Furthermore, Gill (1997) states that people with disabilities often describe feeling “at home” within the disability community or while engaging with others who have disabilities. Within these moments of being together, people with disabilities let their guard down, feel comfortable with one another, and, oftentimes, learn from one another. To reiterate this line of thinking, Garland-Thomson (2007) writes about how she feels “at home” with her academic disability community at the Society for Disability Studies Dance. As a way of illustrating her point, Garland-Thomson (2007) describes how a colleague of hers developed “tongue dancing” at one of these gatherings, and the bonds formed at the dance helped to create community between the conference attendees.

Recently, academics are joining the conversation about access intimacy, although the literature is sparse. Jay Dolmage (2017), in his book on academic ableism, writes that one way to combat what he terms “access fatigue” is by creating access intimacy within higher education. However, he notes that access intimacy can be hard to create because of its fleeting nature and that it can only be created under ideal circumstances. Although he mentions that these experiences are fleeting and require ideal circumstances, he does not offer insights into what these ideal circumstances are. Margaret Price (2016) states that sitting among other people with disabilities can foster access intimacy by giving people with disabilities the tools to intrinsically know a person’s access needs. The authors in both cases expressed the importance of access intimacy when it comes to taking the larger burden of responsibility off the person who needs their access needs met. Although scholarly discussions have begun to take place, the majority of dialog on access intimacy still resides in the blogosphere.

### E. **Blogging as a Platform for Stories of Access Intimacy**

Access intimacy was created and defined within the blogosphere. Since the creation of the term in 2011, disabled bloggers have discussed this term through the stories that they post in their blogs. In recent years, blogging has become a popular way that those within the disability community get their voices heard. As people with disabilities, our modes of communicating with one another have drastically changed. In the beginning, blogs were just shared links on the internet which can be dated back to 1994 when Justin Hall created “Links from the underground” (Stone, 2004). During the infancy of blogging, blogs were used to communicate information about issues such as politics and other newsworthy events to people across the world. Blogs are still used to disseminate information to the world. However, as blogs grew and continue to grow in popularity, their uses and meaning to people who use them grow as well. Personal blogs as we know them today did not grow in popularity until the early 2000s, and by 2007 there were over 112 million in circulation (Carvin, 2007).

Today, blogging has become a widely used tool for distributing counterstories, or alternative narratives, and facilitating connections between disabled people. One of the reasons that blogging has grown in popularity in the disability community is its accessible nature (Center for Disability Rights, 2018). Blogs allow freedom to create and take minimal time to set up, allowing people of diverse backgrounds to access them, either as readers or authors. One blogger writes that blogs “combine the expertise of academics, educators, and activists alongside the experiences and viewpoints of those who are less politicized” (The Goldfish, 2007). As a result, blogs do not hierarchize knowledge, and bloggers are on an equal playing field. By equalizing the playing field for disabled people, blogging invites disabled people to have the opportunity to get their voices heard, including those who might not have the opportunity otherwise which, in

turn, empowers both the reader and the blogger. For many people with disabilities who may not be able to access public spaces due to physical or mental limitations, blogs are an outlet to the outside world. As The Goldfish (2007) states, “blogging is a very personal lifeline; it is a way in which I stay in touch with the world during periods where I am otherwise very isolated by my ill health. But it has also given me a unique opportunity to allow my own voice to be heard on matters of disability.”

Along with giving visibility and equalizing knowledge, blogging has been used as a tool to share political views and disseminate information (Pole, 2010). As self-proclaimed disability bloggers, Harrigan (2007) and Kuusisto (2007) use blogging as a way to create a dialog around political issues, specifically, disability-related issues. For disabled bloggers, blogging is a political act even when not writing upon disability-related issues at all. Blogging about ordinary everyday lived experiences can be a political act by creating a new representation of what it means to have a disability. As Harrigan (2007) states, “I am the authority to my own story.” She later articulates that her blog may be the only other form of disability representation that the reader is exposed to. Aside from showing the reader counterstories or counter-representation of disability, the platform has also created a space to open up a crucial dialogue to critique disability representation within mainstream society. For instance, Villisa Thompson on her blog, “Ramp Your Voice,” frequently discusses the erasure and invisibility of disabled people of color through a lack of representation (Blahovec, 2017). Carrie Basas (2018) writes about how through the invisibility of disabled people of color, Basas learned to hide her disability because of handed down knowledge about ableism and racism, “I tried to overcome every stereotype about disability by being palatable—smiling, kind, smart, overachieving, conflict-avoidant, tidy, and funny. I was not the disabled person that we fear—angry, bitter, lazy, benefits-receiving,

argumentative, unkempt, and aggressive.” Blogging about the experiences of life as a disabled person allows people to read about the complexities of our lives that can involve both pride and pain.

Blogging has also been used as a way of forming bonds between people (Ko & Kuo, 2009; Moon, Jo, & Sanders, 2006), and as a way of empowering people (Hamill & Stein, 2011). Being connected to “something bigger” has been shown to have positive effects on people who experience loneliness (Lee, Noh, & Koo, 2013), enhances one’s well-being by providing social support (Baker & Moore, 2008; Schiffrin et al., 2010), and fosters intimate relationships (Bane et al., 2010; Detenber, Wijaya, & Goh, 2008). Within blog posts, the blogger and the readers are a small piece to a larger puzzle. For instance, TrailBlazing With CP (2018) states that blogging allowed him to, “become part of a community, connected with other people and families with disabilities, and found a place I belonged.” As pointed out blogging has been used by people with disabilities to get their voices heard, create new representation, and create community. For people with disabilities, this creates new meaning around what it means to have a disability. Access intimacy adds to the list of new meanings by describing a new form of intimacy.

F. **Bridging the Gap between Access and Intimacy: Access Intimacy according to Bloggers**

Access intimacy brings both access and intimacy into conversation with one another. The term was created in the blogosphere and it is within the blogosphere that much of the conversations surrounding the term take place. Since Mingus coined this term in her blog in 2011, blogs and online avenues (i.e., FaceBook, Twitter, Tumblr, etc.) have been instrumental in the circulation of discussions and debates regarding this term within the disability community. Within these digital spaces, many bloggers such as, flowerprocess (2014) have found solace in

using access intimacy as an analytic tool that “validate(s) the complexities [and] idiosyncrasies of [their] existence”. Others, such as Piepzna-Samarasinha (2012), have deemed access intimacy a “place of love” that we should “continue to practice.” While both bloggers write about the creation of space, flowerprocess touches upon the internal space that these experiences allow by providing validation that the blogger is more than their disability. In contrast, Piepzna-Samarasinha touches upon the type of physical space that access intimacy can create--a space where love and understanding can take place. In their articulations of the term, disabled people have highlighted several possibilities that access intimacy offers for both community building and building solidarity between groups. McNamara (2013), for instance, calls access intimacy the “missing piece” to the community-building puzzle. McNamara (2013) suggests that access intimacy provides us [people with mental health disabilities] a “space to focus on how those of us who continue to experience madness, suicidality, post-traumatic stress, and other big emotional extremes deeply support each other.” It is within these experiences that we also “hold the complexities of pain, logistics, and needs for each other” (Erickson, 2015, 132). As pointed out by Erickson (2015) and McNamara (2013), experiences of access intimacy can bring with them a level of understanding and create a space where the complexity of life with a disability can be shared, recognized, and understood. Luna (2018) takes this one step further by stating that fostering access intimacy is a “survival skill” in their life. Access intimacy allows people such as, Luna, to be vulnerable to others and cared for in a way that does not make them feel like a burden, and therefore, allows them to form deeper connections.

Access intimacy allows us to look at access beyond physical logistics, such as, ramps or other assistive devices. Titchkosky (2011) begins to look at access in a deeper way by stating that access brings into question “who belongs?” in a place. However, past work on access tends

to leave out the emotional component of access that bloggers have articulated. The Uninspirational (2018) and Elizabeth (2017) suggest that access and accessibility embody a complex emotional component as well. For instance, The Uninspirational (2018) wrote about how access intimacy highlights the emotional dimensions of access. For people with access needs, not getting their needs met can take an emotional toll. For example, Elizabeth (2017) states, “I’ve devoted much of my energy and writing toward not just accessibility, but attempting to describe the emotions around inaccessibility, especially as a crazy person with severe abandonment issues.” According to these ideas, access intimacy acknowledges the emotions involved around access. Furthermore, these experiences provide a safe haven for people with disabilities to deal with their issues surrounding access as well as the everyday ableism that they have to deal with.

Within all of the above articulations, the concept of “holding space” (Plett, 2011) for one another through support and understanding is a constant. Holding space is a “willing[ness] to walk alongside another person in whatever journey they’re on without judging them, making them feel inadequate, trying to fix them, or trying to impact the outcome” (Plett, 2011). For this reason, people with various disabilities, as well as people from other communities (i.e., racial, ethnic, LGBTQIA+, and kink communities), have embraced access intimacy (Quirky Black Girls, 2011; Seale, Wade, & Alexander, 2014) as a way to explain feelings that result from holding space and providing mutual aid for one another.

However, access intimacy has also been critiqued. Tumblr user withasmoothroundstone (n.d), approaches access intimacy with reluctance due to the abstract nature of the term. He states, “there is not a single concrete definition.” Furthermore, Leah Lakshmi Piepzna-Samarsinha (2016) critiqued access intimacy as not addressing the labor of access or the



importance of building relationships. While these critiques of the term are valid, I would argue that the abstractness and lack of a concrete definition allows for the term to develop and flourish, as it is still nascent. However, the question of which factors (i.e., race, class, gender, type of access need, etc.) or conditions need to be present for an experience of access intimacy to occur needs to be addressed.

#### G. **The Importance of Access Intimacy**

Like intimacy itself, these experiences of access intimacy are oftentimes fleeting and difficult to put into words. These experiences have been described as liberating in nature, but often such experiences have gone unnamed and are not recognized until they are reflected upon. Due to these experiences being unstructured and hard to put into words, experiences of access intimacy have often been reported in unstructured spaces as well (i.e., verbal stories, blogs, social media, etc.). Yet, there has been no systematic, focused research done on access intimacy describing how disabled people define and experience access intimacy for themselves. Along with the lack of literature on how disabled people define access intimacy, there appears to be no literature on whether this construct is something that many disabled people can relate to, and furthermore, under what conditions experiences of access intimacy can take place. Historically, the disability community has been fragmented and our stories have been silenced; therefore, it is important to shed light on experiences that are meaningful to us and the ways that they may be unique. In that context, it is important to explore experiences of access intimacy because expanding understanding of such experiences may bring with it endless possibilities. However, we cannot begin to grasp these possibilities until we engage in a deeper exploration of the construct

### III. ADDRESSING THE PROBLEM

In the context of literature gaps identified in the preceding chapter, this chapter addresses the significance of this study to the field of Disability Studies, and most importantly, the disability community. This chapter will then delve into the research questions and the theoretical foundation that guided this study. In an effort to acknowledge how the researcher affects the research, the concluding section of the chapter will address the researcher's positionality.

#### A. Significance of the Study

As pointed out in the literature review, both intimacy and access play vital roles in the lives of people with disabilities. However, currently, there has been little academic literature written on the role that access plays in conversations on intimacy, more specifically, access intimacy. Yet, bloggers with disabilities have begun the conversation within the unstructured space of the blogosphere. Disability spaces often take shape in informal sites such as doctor's offices or kitchen tables, often lacking documentation and relying heavily on storytelling as is often the case in other marginalized communities. With this in mind, this study centers the voices of people with disabilities. This research brings the concepts of access and intimacy into conversation with one another, but also examines the experiences of access intimacy that disabled people have, explores what factors are necessary for access intimacy to occur, and seeks to understand how people define it for themselves.

#### B. Research Questions

When I researched the blogosphere, posts were filled with positive reflections of experiences of access intimacy. However, within these posts, I could not help but question what factors needed to be present for experiences of access intimacy to occur. An essential element of qualitative research is exploring the "what" and "how" of a phenomenon (Creswell, 2014). Due

to its exploratory nature, qualitative research was suited for this study because it allows for an open-ended, evolving, and nondirectional research process. In order to explore the gaps in the literature on access intimacy, I addressed the following research questions:

1. How do disabled people define access intimacy?
2. What is the importance, if any, of access intimacy to disabled people?
3. What is the relationship between access intimacy and community?

### C. **Theoretical Influences**

Several theoretical influences have guided my study which came out of my work as a scholar within the fields of Sociology, Women and Gender Studies, and Disability Studies. My study was influenced by four theories that will be discussed in this section: The social model of disability, the political relational model of disability, intersectionality, and cripistemology. My study, first and foremost, was influenced by the social model of disability which views disability as beyond pathology (Oliver, 1990) by locating the problem in the interaction between the body and the environment which is always predicated on a bodymind deemed not normal. The political relational model of disability further complicates the ideas that are embedded in the social model by articulating the complexities of the everyday lived-experiences of people with disabilities through the acknowledgement that disability is always experienced within relationships and disability is always political (Kafer, 2013). Within these complexities, we can learn about cripistemology or the knowledge that occurs in unstructured spaces by “doing and undoing” (Johnson & McRuer, 2014) what we think we know about disability. In order to understand the stories that are created in these unstructured spaces, a combination of cripistemology and an intersectionality (Crenshaw, 1989) approach was considered. These theories will be explored further below.

# 1. **Social model of disability**

Although, it has been argued that the activist group, Union of the Physically Impaired Against Segregation and activists such as, Vic Finkelstein, put forth ideals of the model before the coining of the term (Finkelstein, 2007), UK scholar Mike Oliver (1990) is often said to have coined the term, social model of disability. The social model of disability views the environment as being the disabling factor as opposed to the medical model that views disability as embodied deficits needing to be cured. Since the creation of this theoretical perspective, the social model of disability has become the defining framework of disability studies in both the UK and US. From this perspective, disability is caused by both structural and attitudinal barriers rather than the person's impairment. Recently, scholars have expanded how we view the social model by acknowledging the complexity of the disability experience, including how the disability experience is affected by such social distinctions as race, class, gender, etc. Connor and Ferri (2005), for instance, state that the social model of disability "interacts with social, cultural, historical, legal, and medical discourses, and further complicates factors such as race, ethnicity, gender, age, and class" (p. 110). Through acknowledging the impact that intersecting social factors can have on a person's lived-experience, the social model resists societal pressures of normalization in Western society such as able-bodiedness and whiteness (Gabel & Peters, 2004). By resisting standards of normalization, the social model calls for diverse disability experiences. Although the social model has many positive outcomes such as acknowledging environmental barriers and promoting disability pride, there are aspects of the disability experience that the model fails to sufficiently address, such as pain and other experiences of the body or mind that are often associated with disability.

## 2. **The political relational model of disability**

As a way to address the shortcomings of the social model, Allison Kafer developed the political relational model of disability to question the role that our lived-experiences and identity have on how we experience the world. The political relational model emphasizes that disability is not a fixed state of being. Rather, disability and our bodies are constantly changing and our thoughts and feelings around disability can change as well. Unlike the social model that states that disability is created by the environment, the political relational model takes into consideration that for some individuals, changes in the environment would not change their experience of disability. When it comes to pain, for instance, if the environment were changed, many people would not experience less pain. On the other hand, the same people can also experience moments of pride. From this perspective, both the desire to find a cure for their pain and pride can co-exist. As pointed out by Brownstein (2015), a Fat Studies scholar, “it is socially acceptable to express feelings of unhappiness one day, contentment the next, and resignation the day after that” which is at the essence of the political relational model of disability. By viewing and analyzing the complexity of the disability experience, a valuable perspective is added to our understanding of the human experience. As Kafer (2013) asserts, “To eliminate disability is to eliminate the possibility of discovering alternative ways of being in the world, to foreclose the possibility of recognizing and valuing our interdependence” (p. 83). Through both the written and verbal stories of access intimacy embedded within this study, alternative ways of being or navigating through the world were explored and uncovered.

In order to begin to understand the disability experience, we must take into account that, “disability is experienced in and through relationships; it does not occur in isolation” (Kafer, 2013, p. 8). From this perspective, how individuals experience their disability depends on their

relationship with others such as familial, romantic, and friend relationships. Due to this relationship and others gained throughout their lives, these people with disabilities experience their disability in very different ways. For my participants, their experiences of access intimacy, and their experiences with access in general, all occur within relationships with other people, whether those relationships were long-term or engaging with a stranger they just met. Lastly through the political relational model, we must acknowledge that the disability experience is always political, meaning that our existence as people with disabilities is tied to social structures that treat us unfairly. It is through this political lens that light can be shed on the discrimination and injustice experienced by many people with disabilities.

### 3. **Intersectionality**

On my exploration to understand access intimacy and its complexities, I utilized intersectionality as an analytic tool. Crenshaw (1989) points out that intersectionality acknowledges that by failing to address the complexities of one's social location we fail to think about "discrimination which structures politics so that struggles are categorized as singular issues (pp. 166-167) From this perspective, humans are understood as multidimensional beings whose lived-experiences are affected by the different factors that make up their social location intersecting all at once. In the last three decades, intersectionality has traveled from popular culture to diverse disciplines and has been used in various ways along with much debate. However, intersectionality was never meant to be a grand, one-size-fits all theory; rather, it was meant to give people the tools to analyze the consequences imposed on people with multiple marginalized identities. Intersectionality also exposes the need for many voices and helps marginalized groups articulate and develop alternative analyses and modes of oppositional consciousness, both individually and collectively (May, 2015). For example, as a disabled

woman with many intersecting identities, I cannot begin to unpack my experiences without first acknowledging how these identities affect my experience — an experience embedded in both privilege and oppression. Through an intersectional lens, people’s marginalization becomes a source of strength by giving context to the ways each of us experiences the world (hooks, 2000). Intersectionality was important to my research because it allowed me to do a multidimensional analysis of my participants’ experiences.

As people with disabilities, our stories and our histories get lost by not acknowledging intersectionality. As Chris Bell (2011) points out, “The stories of Harriet Tubman, Emmett Till, and James Byrd’s erasure of disability from their histories uncovers the misrepresentations of black, disabled bodies and the missed opportunities to think about how those bodies transform(ed) systems and culture” (p. 3). Oftentimes, people with multiple marginalized identities feel as if one or more of their identities are being ignored or that they cannot acknowledge more than one marginalized identity at a time. In 2016, Vilissa Thompson and Alice Wong, for instance, started a social media campaign, *#GetWokeADA26: Disabled people of color speak out*, in order to center the voices of disabled people of color. One of their respondents pointed out in the following quotation that he feels invisible or as if his race is the only one of his identity categories that gets noticed:

As a queer, black, autistic person, I feel that all these different intersecting identities impact the way these issues affect me. I feel as though I’m only allowed one marginalized identity, not several, so I might get treated as though I’m JUST black, rather than black and queer, or black and autistic, or all three of those things. It makes me feel pretty invisible at times. (Thompson & Wong, 2016)

Shoring up this sentiment, another participant notes that the disability community fails to address race and issues of racism, thus furthering one’s feelings of invisibility.

All issues are amplified because within most of the disability community, race is never addressed or acknowledged as a problem within the community. Many organizations and

advocates hold the same conservative/typically white views as others non-disabled folks...except when it comes to their personal interests. There are people extremely hostile to affirmative action (for example) for POC but who consistently advocate for policies which resembles affirmative action for middle/upper class people with disabilities. (Thompson & Wong, 2016)

In order to combat feelings of invisibility, the intersectional experiences of my participants were acknowledged throughout my study. This acknowledgement can be seen in probing interview questions such as, “Do you think race plays a role in access intimacy?” Also, for two of my respondents, having someone who understood how their race affected their disability experience allowed for a deeper level of access intimacy to develop which will be discussed in my analysis. Without this recognition, valuable pieces of our disability experience go unnoticed.

Within this uncovering of our unacknowledged experiences, diversity within the disability community can be recognized. Cole (2008) asserts that difference often gets ignored within community building among activists. However, she warns that by not acknowledging difference we miss opportunities to open ourselves up to new and innovative possibilities. However, it is in the differences that change and growth can occur. As a cancer survivor and a queer woman of color, Audre Lorde (2012) points out, “It is within...differences that we are both powerful and most vulnerable, and some of the most difficult tasks of our lives are the claiming of differences and learning to use those differences for bridges rather than as barriers between us” (p. 201).

#### 4. **Cripistemology and stories we tell**

As mentioned throughout this dissertation, lived experiences and informal sources of knowledge have been brought to the forefront when exploring access intimacy. In order to analyze the experiences of my participants, cripistemology (Johnson & McRuer, 2014) was utilized. Cripistemology challenges the concept of knowledge itself by calling out what we know



about disability but also what we do not know as well. Having a physical disability, for instance, I know firsthand what it feels like and looks like to experience my disability and I have read about disability for years. However, there is a lot about disability and the disability experience that I do not know and will never know. From a cripistemology perspective, knowledge comes in all forms and includes how “differing bodyminds moving through environments together, navigating barriers, and finding pathways, both materially and metaphorically” (McRuer & Johnson, 2014, 154). Whether my participants have physical, mental health, chronic pain or sensory disabilities, they all experience and navigate the world in very different ways. However, there is knowledge and a shared understanding that can be gained within and through their written and communicated experiences of access intimacy. The knowledge gained through these experiences includes an interplay of the physical and the emotional embedded within their access needs. As mentioned in the literature review, access can often be confined to physical barriers, but access also includes who belongs in a space and who does not (Titchkosky, 2011). Access intimacy, however, goes one step further and acknowledges the emotions surrounding access or lack thereof in any given situation. With that acknowledgement, there is knowledge that is gained through learning concrete skills and solutions or through a sense of comfort felt by a shared understanding.

As Johnson and McRuer (2014) point out, “knowledge about disability comes from both the lived-experience and being in situations with other disabled people as well as thinking about the sensations that are a direct result of these experiences” (p. 129). However, this experiential knowledge often is seen as invalid or goes unnoticed. As a key tenet of cripistemology, this epistemological approach acknowledges everyday-lived knowledges that are often not seen as credible within academia. Experiences of access intimacy and everyday-lived

knowledge are told through the use of various platforms (i.e., writing in blogs and anthologies, documentaries, or talking around the kitchen table) in order to unpack and talk about the complexities of various relationships people with disabilities have. The use of these various modalities allows disabled people to tell their stories in their own words. The ways in which we are represented or get our voices heard are important to note due to the fact that disabled bodies have historically been silenced and marginalized. As a way of uncovering these silenced voices, Michel Foucault urges the “return to knowledge” or the uncovering of those voices at the margins (Foucault, 1980). He states that these voices at the margins can be thought of as, “subjugated knowledges” which are the local, everyday, and often disqualified knowledges. Due to the diversity of the disability community, knowledge is often disseminated through stories that we tell about our everyday lived-experiences. Lorde reinforces the powerful nature of stories in the following quote:

Tell them about how you're never really a whole person if you remain silent because there's always that one little piece inside you that wants to be spoken out, and if you keep ignoring it, it gets madder and madder and hotter and hotter, and if you don't speak it, it will come out one day it will just up and punch you in the mouth from the inside. (Lorde, 2012, p. 42)

For disability scholars, stories have been said to provide a powerful means of survival and liberation by providing us a means to create or disseminate counterstories that dispute the claim that disability is all bad or negative and needs to be cured. Telling our stories creates new, positive meanings around disability. Along with the creation of new meanings, we also create a disability history. Rodriguez (2003) points out we learn from the shared stories and histories of the of the ones that came before us. As disabled people, we are often thought of as people belonging to a monolithic category, but this could not be further from the truth. Ellen Wu, a collaborator on *Disability Visibility Project* website states, “I do believe that through storytelling,

we are going to create an archive that one day people can use for, hopefully, historical purposes, or just educational purposes” (Wong, 2015). The history that can be created through storytelling is one that embodies intersectionality and includes various forms of knowledge, for purposes of this dissertation, specifically access intimacy.

#### D. **Positionality**

In this section, I will situate myself in the research and acknowledge my position within the research. Situating myself is an important component of my research project as, in many ways, I am an insider in the disability community. However, a person can never be completely an insider or an outsider to their research. I am a queer disabled Filipino woman with a working-class background from a small rural community in the southern U.S., and it is from this social location that I approach the research. It is from this position that I began to understand access and the importance of disability community, a community that was built largely within virtual spaces. Throughout my life I have had various access barriers, such as accessing my elementary school to getting the services I need to meet my daily basic needs.

Throughout my adolescence, I had an online journal on the platform, *Live Journal*. I wrote about everything from adventures that I had with my friends to other aspects of my disabilities that I felt I could not verbally express because the people around me would not understand. Everything was up for discussion, and it was through this online platform that I found people that I could relate to and who could relate to me. Since I was 16 years old, I have been a sporadic blogger; not writing every day but coming back to my blog when I need it the most. I had a blog before I had a disability identity or knew anything about the disability community. Blogging was my place of connection and outlet to people within the disability community in a place (my hometown) that often left me feeling isolated by its demographics

(able-bodied and predominantly White). As a result, the isolation I felt often left me feeling alone and misunderstood. However, within the blogosphere, I was free to be me; emotional outburst and all. Currently, along with being a blogger, I am a member of the FaceBook page entitled, *The Federation of Disabled Bloggers*. My experiences as both a blogger and a disabled woman gave me a partial insider's perspective. In approximately half of the interviews, my participants' level of comfortability with me and our rapport with one another can be heard through responses of "you know." Because my participants knew I had a disability, they assumed that we shared a common understanding or disability experience. While their assumptions helped me gain rapport, the "you know" responses prompted me to ask follow-up questions for clarification and more detailed explanations from participants in order to make sure that I understood what was being said. However, while my position as a physically disabled woman necessitated these careful follow-up questions, my "insidership" status also enhanced my ability to understand the participants' experiences and to make connections that I may not have made had I not had a disability.

As mentioned above, I am not completely an insider or outsider. I am a woman with a physical disability, and therefore, have an important but partial perspective into the disability experience. For instance, I am not aware of all the access barriers and other details that affect the lived experience of the Deaf community. Also, I am a Ph.D. candidate in Disability Studies which allows me access to disability terminology and knowledge that others may not have. However, my position as a blogger must be noted as well. The knowledge created within academia and the blogosphere are oftentimes a place of tension as the validity of the knowledge that is produced in the blogosphere is oftentimes called into question. The question of validity has popped up throughout this study, and bridging these two worlds has been a constant struggle.

I have also engaged in disability activism around a variety of issues giving me access to disability activists both nationwide and globally. Each piece of my identity affects how I view the world. As a result, my position as both an insider and an outsider affect how I analyze the data. Positioning or situating myself was an important part of reflexivity that will be discussed in the next chapter.

Lastly, before embarking on this project, I spoke with Mia Mingus. This term, access intimacy, does not belong to me. This term belongs to the people who experience these moments, and we are thankful to Mia for providing us with the language. In conclusion, the significance of the study, research questions, theoretical underpinnings, and positionality were addressed in this chapter and provide context for the methodological decisions discussed in the next chapter.

#### IV. METHODS

To explore components that reflect and define experiences of access intimacy for disabled people, I utilized qualitative research to conduct a constructivist grounded theory research study (Charmaz, 2014). Qualitative research is grounded in understanding experiences by looking in-depth at the details of the recounted experience to explore why a phenomenon takes place. When initially looking for a methodological approach to study my research questions, I was drawn to classical grounded theory, advanced by Glaser and Strauss (1967) as an exploratory research method that grounds the research findings directly from the data, and therefore, lends itself to the exploration of theories and concepts that are understudied. With no research done on the term access intimacy within academia, at first glance, grounded theory seemed like the perfect fit. However, classical grounded theory alone does not account for how both the researcher and participants' social location as well as the social context the research is being done in affect the research. As a result, I chose to conduct a constructivist grounded theory research study because it acknowledges the role of social interaction in one's lived experience while enabling an open-ended and flexible means of studying concepts (Morse et al., 2016). Using this approach, I was able to uncover ways that my participants made and created meaning around access intimacy. My positionality of the researcher needed to be accounted for. Specifically, I have used constructivist grounded theory research methods because I conducted an exploratory research study that investigated the social phenomenon of access intimacy.

##### A. **Study Design**

Due to the newly conceived nature of the term, the study had seemingly endless possibilities which were both daunting and exciting. Upon reading about the term, I found that while bloggers did not address the definition of access intimacy, specifically, recounted

experiences of access intimacy were out there. However, I also had a hunch that not every experience of access intimacy written about in the blogosphere was named as such. Still, I was aware that the term was created in the blogosphere and bloggers began the conversation.

Therefore, purposeful sampling was used to find individuals who could best offer information about access intimacy. In order to explore this phenomenon, I enlisted the participation of 13 disabled people who had written or commented on a blog post describing an experience of access intimacy in order to examine how they recount these experiences within their stories. Their written stories reflected how they experienced access intimacy, and as several participants reflected in their interviews, thinking around access intimacy often comes from “recognition in reflection.” However, understanding their experiences did not come from their written stories alone. I wanted a more in-depth look into how my participants defined the term for themselves and the lessons that they thought we could learn from access intimacy, specifically, in terms of community-building. Therefore, each participant engaged in a semi-structured interview.

#### **B. Sample Strategy**

For the study, I sought out a small diverse sample of disabled bloggers who had written about experiencing access intimacy. I wanted to understand the phenomenon through the perspectives of a range of individuals who had thought sufficiently about this experience to write about it. A small sample size allowed me to engage in a richer and more detailed analysis of the data (Creswell, 2014), giving me the opportunity to pick up on minute details that were important to the research. Participants were chosen using purposeful criterion sampling which involves selecting cases that meet some predetermined criterion of importance (Patton, 2002, p. 238). While not an exhaustive list, I must mention that there are several types of purposeful sampling strategies such as theory-based sampling, snowball sampling, and homogeneous

sampling, but due to my research question, purposeful criterion sampling was the best fit. Theory-based sampling, for example, is useful when examining a theory and its variations (Patton, 2002). However, due to the newness of the construct being studied, the theory is yet to be formulated, making this approach not suitable. Snowball sampling, on the other hand, is appropriate when trying to find people who are knowledgeable about a subject in a convenient way by identifying some possible participants and asking them to identify others (Patton, 2002). This strategy is useful and convenient; however, protecting the identity of my participants would have been compromised. Lastly, a homogeneous sample would have provided a narrow focus and, therefore, a simpler analysis (Patton, 2002). However, it would have eliminated diversity within my study. Through the use of criterion sampling, I was able to select participants who have knowledge and have had an experience of access intimacy.

#### 1. **Recruitment**

Before recruiting participants, this study was reviewed and approved by the IRB (Protocol #2017-1300) at the University of Illinois at Chicago<sup>2</sup>. I posted a call<sup>3</sup> on Facebook, Tumblr; and the *Disability Visibility Project*<sup>4</sup> website in order to recruit 15-20 participants. I chose those platforms for two reasons: 1) there is a disabled blogger presence on both Facebook and Tumblr and 2) the Disability Visibility Project acknowledges diversity within the disability community which can be seen and heard in the interviews and articles that are posted on the website.

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<sup>2</sup> For IRB approval see Appendix A.

<sup>3</sup> Call for participation is in Appendix B.

<sup>4</sup> The Disability Visibility Project (DVP) is an online community dedicated to recording, amplifying, and sharing disability stories and culture whose aim is to create disabled media that is intersectional, multi-modal, and accessible (Wong, 2015).



The call for participation asked potential participants to contact me by phone or e-mail. Once I received the call or e-mail, I sent the potential participant an e-mail describing the study in more detail. If the potential participant was interested, the person was asked to respond with a time/date that would work best for them to engage in a four-question eligibility screening by phone. Once a response was received, I contacted them at the specified time/date. During the telephone screener, I verified that each potential participant met the study's criterion. All but one potential participant was deemed eligible.

## 2. Sample

Fourteen people responded to recruitment efforts. After screening, 13 were deemed eligible. My inclusion criteria encompassed people who were: 1) 18 years of age or above and identified as having a disability (e.g., physical, mental health, sensory, learning, etc.); 2) capable of communicating in English; and 3) had written online about an experience that reflects access intimacy at least 30 days prior to the start date of recruitment (August 1, 2018). I wanted to recruit participants of diverse backgrounds (i.e., race/ethnicity, gender, class) in order to reflect the diversity within the disability community and to provide an in-depth picture or analysis of how social factors (i.e., race, class, and gender) can affect how a person experiences moments of access intimacy. However, my sample size was not as diverse as I would have liked, and a majority of my participants identified as White. My sample included people who self-identified as being one of the following races: White (9); Black (1); Black Indigenous (1); White/Hispanic (1); and East Asian (1). In terms of gender, the sample size primarily identified as female (9); male (1); other gender (1); genderqueer (1); and genderqueer femme (1). My participants were highly educated having a minimum of a Bachelor's degree. Within the course of our interview, a majority of my participants identified as being a part of the LGBTQIA+

community. Twelve of my 13 participants reside in various parts of the United States, and one participant resides in Canada.

Although my planned target sample size was 15-20, I was able to recruit only 13 participants. This discrepancy between target and actual sample size could have been the result of my choice to focus on disabled bloggers who had actually written about access intimacy rather than opening up my call to any disabled person who said they had experienced access intimacy. Furthermore, because I limited the study to bloggers, my call for participation was posted on only three online platforms. However, having a smaller sample allowed me to do a more in-depth analysis of the data.

#### C. **Procedures**

Once eligibility was verified, I scheduled the date and time of the interview and asked the participant to send me their blog post or comment before the completion of the phone call. I also asked the participant to pick a pseudonym (Creswell, 2014). After completing the phone call, I sent the participant a link to a demographic survey to be completed using Qualtrics. The informed consent form<sup>5</sup> was embedded at the beginning of the demographic survey. Participants could not move on to the demographic survey unless they agreed to the informed consent. If they had any questions, they were directed to a page with my e-mail address. However, none of the participants had questions beforehand. The demographic survey data was stored in electronic format on a password-protected computer in which I am the only person with access.<sup>6</sup>

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<sup>5</sup> See consent form in Appendix C.

<sup>6</sup> See Appendix D for demographic survey.

## D. **Data Collection**

### 1. **Demographic survey**

Participants were asked to complete an electronic demographic survey before the interview date using a Qualtrics link that they were provided by e-mail. The survey included questions about race/ethnicity, age, gender, education, employment, and who they experienced access intimacy with. The questions were intended to convey the social location of my participants which helped to analyze their diverse and intersectional experiences.

### 2. **Blog posts**

Both blog posts and interviews were used as data to be analyzed. Only two of the 13 participants submitted more than one blog post. Therefore, each blog post was analyzed. Upon receiving the demographic survey and blog post, a chart was created that included: the date; the pseudonym; disability; age; race; gender; and the link to the blog post. I read each blog post upon receiving it and took note of the aspects of the blog post that were relevant to the research questions. For example, Finn wrote about collecting a friend's skin flakes and using them in a collaborative art piece as an experience of access intimacy. However, I was still left wondering why the art project was an experience of access intimacy for her. So, during the interview I asked: "So, I really love your artwork with [name]. So, can you explain more about the importance of the skin flakes in terms of access intimacy, and why that was a big part of access intimacy for you?" The participants' blog posts served two purposes: 1) the posts served as a means of familiarizing me with the participant's experience so I could approach the subsequent interview with more information and conceptual sensitivity than I would have had in a typical first interview; and 2) the posts served as data to be analyzed through memoing,

open coding, and thematic analysis (Creswell, 2014). Blog posts, like interviews, were put into the qualitative analysis software program Atlas ti and coded based on relevance to my research questions (Creswell, 2014).

### 3. **Interviews**

Before the start of each interview, each participant was asked to provide me with their pseudonym. The name that was chosen was used to refer to the participant throughout the study in order to protect their anonymity throughout the research process. All interview participants were interviewed based on the interview guide (see Table I). The interview questions were crafted in order to elicit information pertaining to my research questions. The first six questions were created in order to jog my participants' memory about their experience of access intimacy by giving them an opportunity to reflect. The next four questions were created in order to encourage participants to think about how they would define access intimacy for themselves, and the last three questions were created to address the role, if any, that access intimacy could play in community building for people with disabilities.

When creating this study and its methods, including the interview questions, the social model, political relational model, intersectionality, and cripistemology were not thought about as separate, but rather, as four theories that expand and build upon one another in order to get to the heart of the experiences of access intimacy. Each theory was considered when creating the questions in order to draw out the complexities of the disability experience. For example, when asking participants, "What elements of your experience reflect access intimacy to you?," I thought about how their race, class, gender, environment, etc. might have affected their experience. Also, how did their relationship with the other person affect their experience?

**TABLE I**  
**ACCESS INTIMACY INTERVIEW GUIDE**

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If you heard about access intimacy, tell me about your first encounter.

If you were to tell a friend why the experience you wrote about reflects access intimacy, what would you say?

What elements of your experience reflect access intimacy to you?

What influenced you to choose to write about the experience?

What, if anything, made this experience that you wrote about unique?

In what ways, if any, has your understanding of access intimacy grown and/or changed since writing the blog post(s) or comment(s)?

According to Mingus, access intimacy is an, “elusive, hard to describe feeling when someone else “gets” your access needs” and a sense of “comfort that your disabled self feels”. What does this definition mean to you?

- Is there anything you think is missing? Is there anything that you would add to the definition?

Aside from the experience you wrote about within the blog post(s) or comment(s) you submitted, can you tell me about any other experiences of access intimacy that you may have had?

What characteristics do the people you have experienced access intimacy with have in common?

- For you, are these characteristics important or necessary for access intimacy to occur?

Describe a time, if any, where access intimacy did not place and you wanted it to.

- What was missing?

What role, if any, do you think access intimacy could play in bringing people together?

What can we learn from experiences of access intimacy?

What else do you think we need to know about access intimacy?

- What would you like to add?
-

Given the geographical scope of this study and the possible access needs of my participants due to their varying disabilities, interviews were conducted either by phone or Google Hangout based on the interviewee's preference. Interviews were approximately one hour in length, and the interviews were conducted from a private locked room either through the telephone or video chat. Interviews were audio-recorded using a digital recorder, and all files were stored on my password-protected computer.

#### E. **Ensuring Research Quality**

There are five components that ensure quality and trustworthiness of qualitative research (Korstjens & Moser, 2018; Patton, 2002). The five components are credibility, transferability, dependability, confirmability, and reflexivity. Credibility establishes that the findings are probable. The credibility of my study was ensured by stating my standpoint or position in the research throughout the dissertation. In my introduction, I described my relationship to access intimacy. I also utilized two forms of data (blogs and interviews) in my findings and analysis. Transferrability describes the degree to which the findings of a research can be transferred to other contexts or settings with other respondents. Transferability was ensured by giving the readers "thick descriptions" (Korstjens & Moser, 2018) of not only the participants' backgrounds, but I also gave details about their experience. Dependability involved having participants review the findings and analysis of the paper which was done through the member checking process. Confirmability is the process by which another researcher confirms how the findings were drawn. The confirmability of the study was done through the auditing process which is detailed in the auditing section. Lastly, reflexivity allowed me to do a critical examination on how I affected my research. Reflexivity is described in greater detail below.

#### F. **Member Checking**

At the completion of my study, participants were contacted via email and asked to engage in member checks to ensure that the participants are depicted throughout the study in an appropriate, consistent manner (Creswell, 2014). In this process, participants are given the opportunity to provide their input on the findings and analysis. This gave them the opportunity to ask me further questions about the research and to clarify what they said if they felt that it was taken out of context. In the member check email, participants were asked if they would like to participate in the member check process in one of the following ways: 1) I would not like to participate at this time; 2) I would like to review the findings section; and 3) I would like to review the entire analysis section of your dissertation. I used the information gained from the member checks as a way to validate that the participants had an opportunity to evaluate the findings and discussion. During this process, participants were able to give me feedback which was considered when completing the data analysis section of my dissertation.

#### G. **Reflexivity**

As a qualitative researcher, it is important to engage in reflexivity. Reflexivity is the process of examining both oneself as researcher, and the research relationship (Creswell, 2014). Reflexivity helps the researcher acknowledge the subjective nature of qualitative research, and encourages the researcher to be aware of how their own thoughts and beliefs affect the research. As a qualitative researcher, I shape my research and I am a research tool. My background and position potentially affected my entire research process from how I chose my research topic to how I came up with my findings and came to my conclusions (Malterud, 2001). Memoing and reflexive journaling were the two methods of reflexivity I used during the research process.

Memoing provides a space for researchers to think about their data and reflect on their ideas (Charmaz, 2014). My process and an example of my memos can be seen in the latter part of this chapter. My reflexive journal entries, on the other hand, were written after each interview to allow me to express my thoughts and feelings about my own experience of the interview as well as any assumptions I had prior to or during the interview (Patton, 2002). By engaging in reflexivity, I actively acknowledged how my social location (i.e. race, class, gender, disability, etc.) and how positionality play a role in my research. Through this process, I examined both myself as a researcher and the relationship I have with the research. Hsiung (2010) states that this can be done by self-searching or examining one's assumptions and preconceptions, and how these affect research decisions, particularly, the selection and wording of questions. I reflected on the research relationship and how the relationship dynamics between myself and the participants affected their responses to questions as well. Most importantly, reflexivity serves as a means to remain aware of and manage research bias.

#### H. **Auditing.**

Auditing refers to a systematic review of the decision-making process or actions involved in the research process (Creswell, 2014). I enlisted the help of a faculty member in the Department of Disability and Human Development at the University of Illinois at Chicago to audit my coding and analysis of the data. This was done to ensure that my dissertation maintains accuracy, credibility, and trustworthiness. I asked the faculty member to read the interviews, codes, memos, and blog posts associated with two random participants. I asked the auditor to examine the documentation with the following questions in mind: What is the degree of researcher bias? Can the auditor understand why the themes and subthemes were chosen? (Creswell & Miller, 2000). I communicated these questions to the auditor by e-mail. Once the



data were reviewed, the auditor responded with whether or not she felt I was biased and also if she understood how I came up with my themes and subthemes. For example, one of my subthemes was “vulnerability.” So, my auditor suggested that I do another look through the data to make sure that there were no more quotes I wanted to use in that section since it seemed so important. If the auditor thought that my data needed to be looked over in more depth to elaborate my coding, this was brought to my attention as well. Once this feedback was received, I reviewed the data accordingly and refined my analysis with the feedback in mind.

## I. **Data Analysis**

Memoing and coding were utilized when engaging in data analysis, and both of these methods will be discussed in the sections below.

### 1. **Memoing**

Memoing is vital to grounded theory research, and it is said to be where theoretical ideas and conceptual frameworks emerge (Charmaz, 2014). Memos are the written records, or notes, of the researcher’s thinking. I engaged in memoing throughout the entire research process. After I read each participant’s blog post, I took note of any important themes and questions that came to mind that were relevant to my research questions. Immediately following each interview, I memoed about my initial thoughts regarding important points and questions that still remained unanswered after each interview was completed. Memoing after the interview helped me take note of things I might have forgotten if I would have waited, such as, tone of voice, pauses, and important points. Memoing helped to inform my data analysis by helping to jog my thinking process and it was my first look at themes that stood out from the data. Memos were also used to help me think through the information that came out of the data.

Next, I transcribed the interview verbatim. After reading each interview twice in its entirety, I wrote down important quotes and other important points from the interview. Each memo looked a little different according to the information that was provided by each participant. Using this approach, I created a brief one-pager for each participant that gave me a synopsis of the interview and provided quick details for the data analysis. Along with these initial memos, I jotted down free-style memos. Free-style memos are those memos that a researcher writes spontaneously during any given moment (Charmaz, 2006). For example, if I was in the park and got an idea about the relationship between community and access intimacy, I jotted down my thoughts. All memos, aside from the one-pager, went into my reflexivity journal. This process helped me establish an overall picture of the data. In grounded theory, earlier memos are focused on describing the data or what is going on while, later memos are focused on the process in which the phenomenon takes place (Charmaz, 2014). For example: Under what conditions does access intimacy take place? How is access intimacy defined by the people who experience it? An example of one of my one-pager memos to summarize information from a particular participant is presented in Table II.

## 2. **Coding**

After receiving each blog post, I coded for salient themes before conducting each participant's interview. For example, I read each blog post with my research questions printed out next to me. While reading the posts, I was trying to understand what was going on throughout the experience described. The blog posts were used as data to get a first glimpse into the thoughts that participants had on access intimacy before the start of the interview. The two major themes that came out of the blog posts were connection and community.

**TABLE II**  
**EXAMPLE OF ONE-PAGER MEMO**

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**1. Kit (28, White/Hispanic, Both disabled and non-disabled people, Employed (Full-time), Masters, CA, Member of LGBTQIA+ Community, Blind)**

Comfort  
 Needs being met  
 Connection  
 True authentic self  
 Holding space  
 intuitive

Access intimacy allows a person to be present in the moment and understand where someone else is coming from and at the same time allowed to be yourself and make mistakes.

Question about AI: What makes certain friendships so different and more connected?

There's just a broad community of this lived-experience....And even though it looks different for a lot of us, there is like this special closeness around us.

Access intimacy is not shying away from that fear of someone getting sicker or more disabled, and really looking at them and hearing like what kind of different support they need and how you can bend around that to still be there for them even if it's not something they used to need.

Characteristics of people who I experience AI with:

- Listen
  - Do not take things personally
  - Open heart and open mind
  - Willing to learn and change
  - Just be in the moment
-

After each interview was completed and transcribed, I engaged in a detailed process of open coding which involves “breaking down, examining, comparing, conceptualizing, and categorizing data” (Strauss & Corbin, 1990, p. 61). Codes allow for brief descriptions of the participants’ experiences, feelings, and actions (Creswell, 2014) as described by the participants. During this stage, I looked for chunks of data or actions within the data that could be meaningful and relevant to the research questions (Charmaz, 2006). All of the interviews were coded in Atlas ti. After my first read through, I engaged in line-by-line coding to get a more in-depth understanding of the interview data. Because I did a constructivist grounded theory research study, my codes changed as I got more and more enmeshed in the data (Charmaz, 2006). I engaged in this process three times: once after transcribing each interview, once after all interviews were transcribed and coded, and once in conjunction with the blog posts.

When this process was completed, I sorted the codes into themes and sub-themes using Atlas.ti. Themes and subthemes reflected important components within an experience of access intimacy, and the knowledge that we can learn from experiences of access intimacy. There were five major themes that came out of the interviews: Defining Access Intimacy: “Just getting it,” Levels and diversity of access intimacy, Characteristics of people with whom participants experience access intimacy, Importance of access intimacy, Limitations of access intimacy, and Sense of community within moments of access intimacy. Each theme had several subthemes. For example, under Defining Access Intimacy: “Just getting it,” there were the following six subthemes: full communication; disability as a natural part of the human experience; vulnerability; combating stigma and internalized shame; holding space; and being in the moment. The memos, themes and subthemes were used to write up the findings chapter of my

dissertation. The themes and subthemes, and the relationships among them, captured information that helped me construct answers to my research questions.

## V. RESEARCH FINDINGS

### A. Blogs

There were two primary sources of data that were collected for this dissertation: blog posts and semi-structured interviews. Therefore, my findings will be split into two sections. To begin this chapter, I will briefly discuss how and why blogs were used as one of the primary sources of data. Then, I will give illustrations of some of the questions that I had from reading the blog posts and how they related to my research questions. To conclude this section, I will discuss some initial findings found within the posts submitted by participants before delving into data from the interviews.

As noted in the methods chapter, blogging was used as a data collection tool to help me orient to access intimacy as a phenomenon and to help develop questions to explore in the subsequent interviews. The posts were my first glimpse into how my participants viewed and/or utilized the concept in their lives. As a disabled woman, I had my own vision of what access intimacy looked like in my life. Access intimacy, as pointed out in the introduction, made me feel a sense of comfort, ease, trust, and most importantly, within these moments my needs were viewed as part of the human experience. However, I wanted to be mindful that my thoughts and feelings did not overshadow their experiences. Hence, each participant was asked to begin telling their story in their own words before the start of the interview by submitting a blog post of their choosing that they wrote in the past about an experience of access intimacy. From their articulations, I was able to see first-hand how each participant came to view the concept. Participants described access intimacy in practice and within actions and feelings that were associated with the term. Whether in concrete examples or abstract thoughts and feelings associated with access intimacy, the word “connection” kept appearing across blog posts as I

read. Across posts, there was also a reiteration that access intimacy highlighted the emotional element within experiences of access.

Before each interview, I took note of anything that was pertinent to my research questions as well as highlighted and took note of anything that brought up further questions. I utilized my notes during the interview to ask follow-up or probing questions during each interview. My notes were next to me during the interview in case I had to refer back to them. The length, type of blog posts, and level of abstractness affected the kinds of follow-up questions that were asked. For each interview, the interview guide was used in its entirety and follow-up questions about each post were asked throughout the course of the interview. Below, I will illustrate some of the questions that were created from reading the blog post and how they were formulated.

#### **B. Questions from the Blog Posts**

Going into this dissertation, I thought I had a good understanding of what “access intimacy” meant, but I was just beginning to scratch the surface. Through the written accounts presented in the blog posts, access intimacy was so much more than a feeling. Access intimacy, while bringing participants positive feelings of comfort, safety, trust, and understanding, also helped participants connect with one another and embodied principles to create “radical access” (Erickson, 2016). Radical access involves building community across marginalized communities with the goal of striving for everyone to have access. Each post, whether one paragraph or 10-pages long, was spilling over with richness. Some pieces had a clear connection to access intimacy with the words “access intimacy” written throughout the post; others were more abstract and did not mention the words at all. However, each post left me with questions. It was my intention to let the answers to my questions come about naturally throughout the course of

the interview. However, if answers to my questions did not come up naturally, probing questions were asked.

For those participants who submitted abstract poems or an artist statement, I posed more direct questions about the correlation between the piece and access intimacy. For example, Finn submitted an artist statement with the following lines:

I decided to turn to sewing and made pods to hold [her friend]'s skin flakes as a way to document the intimate communications and the care relationships between Crip sisters. [name of art piece] is about preserving and sustaining the existence of my own kind.

From this snapshot, I could visualize the connection between access intimacy and connection/community within the art installation. However, I needed more detail and clarification. So, I asked, "Can you explain more about the importance of the skin flakes in terms of access intimacy? How did your installation embody access intimacy?" Anne's poem was abstract and needed more clarification as well. Within the poem submitted by Anne she wrote, "Do you have a voice? The way I have a gaze?" I was left wondering what the connection was between access intimacy and her piece of poetry. I thought she was trying to make a correlation between being deaf and being blind, but I could not assume that I had the answers. So, I asked, "So what made you submit those pieces as opposed to other pieces that you have written? What about them resonated with you to send that as part of the call for access intimacy?" Oftentimes, the more abstract the blog post were, the more participants engaged in-depth conversations about access intimacy and what the term meant in their lives.

For those who submitted concrete examples, I asked for more details about words and themes related to access intimacy that stood out. For example, after describing a moment of access intimacy with a friend in a psychiatrist's office, Jay wrote:

I am interested in how we expand the conversation to include people with serious chronic mental health challenges, whether or not we identify with diagnoses. I want to talk about



access intimacy on a day-to-day level, and also how it functions when folks go into extreme crisis.

Then, Jay stated that, “access intimacy gives us an opportunity to hold space for one another.”

When beginning to investigate access intimacy, it was my goal to recruit people with various disabilities, and I wanted to make the point that access intimacy is not just about attending to a person’s physical needs. Therefore, I was enthused when asking, “You wrote about access intimacy creating a space for people to be who they are and holding that space for people. So, can you explain a little bit more about what that means to you?” Through this question, I wanted to open up dialogue and explore how access intimacy is experienced within the psychiatric disability community.

Jane, who has a physical disability, recounted experiencing access intimacy with members of her travel group. As a result of this experience, she stated, “Looking back on this time, I see how these strangers that became more like family helped to shape my political disability identity. What they provided was radical and inclusive.” After reading this, I was interested in how access intimacy helped to shape her identity and helped her to find value within herself. So, I asked, “While reading your blog post, something stuck out to me. . .the part where you said access intimacy allowed you to internalize your own value. Can you explain to me a little bit more about what that meant to you?” Each post made me think about an aspect of access intimacy that I had not thought about before, and therefore, by having a glance into their experiences before the start of the interview I was given an opportunity to uncover new areas for exploration.

Through the experiences conveyed in these blog posts, the importance of language and common understanding was apparent in both Tesla’s and Cameron’s posts. Tesla, for instance, wrote about the importance of both language and common understanding. Tesla wrote:

noetisexual—being mentally attracted first and foremost, an attraction to the ways their mind works rather than a narrow aspect like “intelligence” (cuz then what kind?). Only consider being sexual if mentally connected, not attracted to you; it’s possible because I trust you, a physical expression of what’s going on in our minds; I’m attracted based on access intimacy, shared perspectives, and the ways your mind works or the ways you create and hold space for me or others, or to the shape of your mental landscape; my experience of attraction is different due to my neurodivergence.

This definition was in the introduction of Tesla’s post, and honestly, upon my first read I was confused by the importance and meaning of the term, “noetisexual.” Yet, the term seemed important in Tesla’s life and intertwined with their understanding of access intimacy. Therefore, I asked, “So, I was really interested in the term that you created in that blog post, and I wanted to hear you talk a little bit more about how that term that you created was different from access intimacy or inspired by the term.” Cameron described how invigorating having shared knowledge can be:

When I presented at [name of conference], I left feeling an exhilaration and energy that only comes from engagement with a community of people who experience misfitting in many of the same ways I do and, thus, share many of the same sorts of subjugated knowledges, in this case the crazies and mad.

I immediately thought about the connection between access intimacy, common understanding, and community. To my surprise, throughout the course of our interview, Cameron spoke in-depth about these connections unprompted. All of the questions posed were loosely worded in order to encourage an unbiased discussion.

Above, I briefly discussed the “how” and “why” questions that were created based on the blog posts that my participants submitted. Next, I will discuss the findings that came out of the posts that were submitted. As pointed out in the above examples, the submission of the blog posts before the start of the interview allowed for opportunities for an exploratory dialogue between myself and my participants and uncovered new aspects of the term, access intimacy.

Below, I will go over the themes of connection and community that I uncovered by reading the blog posts that were submitted.

### C. **Findings from Blogs**

#### 1. **Connection**

One term that stood out across blog posts was connection. No matter if the participant was talking about concrete or abstract examples or actions, whether in long-term relationships or small moments, a vital part of access intimacy was connection. Mary described how the smallest of actions can form connection in the following example:

I have fond memories of holding hands with friends at summer camp for disabled youth, where everyone seemed to perceive what the world outside could not—holding hands did not have to come with assumptions of romance. For us [people with disabilities], it was often a symbol of camaraderie when our mobility made it difficult to express support for each other through physical closeness.

For Mary, who cannot engage in physical touch easily, holding hands was more than a small gesture. Holding hands was a moment of access intimacy, a way to form true connection. As I learned through these posts, participants formed connections in a variety of ways. As Kit beautifully articulates through her poem, the connection formed through moments of access intimacy can happen “through our skins or souls.” She wrote:

Whether through our skins or souls, stories or songs or spirits, you and I are always connecting. You long ago intuited — and then memorized — what I do and do not need, where I might stumble, why I sometimes startle. You know that the smallest of touches can smooth roughness and fill emptiness.

For Kit, the connection between her friend and herself made her feel completely understood by another, seen, and loved. Shoring up these feelings, Claire wrote about her friend’s response to her needing to monitor her medication:

When I told my best friend and roommate about this [the possible side effects of the new medication] I had tears streaming down my face. He listened and when the time came for his response he said, “Here’s what we will do. We will check in every day, to see if your

mood feels different. We will actively talk about how our days were emotionally, and if things start to shift, we will recognize it's time to stop the medication.”

In this moment, Claire described a sense of relief that she felt by knowing that she did not have to manage her access needs. She was not in the situation alone. Mary, Kit, and Claire described actions that fostered connections in their interpersonal relationships which helped to fulfill their lives.

Kelly, on the other hand, wrote about the importance of connection on a larger scale. In her post, she described how computer-generated image descriptions take away from the potential connection that can happen through a person-generated image description. Kelly wrote:

In order to create a truly just world, we must challenge what she [Mia Mingus] calls the myth of independence. We should instead view access as “collective and interdependent.” In other words, creating an accessible world is everyone's responsibility.

For Kelly, person-generated image descriptions formed connection by putting the person's thoughts and feelings into the descriptions adding the emotional side to access. Across blog posts, these experiences touched on the emotions associated with getting access needs met.

Sylvia wrote poetically about the connection between emotion and access and its effects on people with disabilities:

The weight of inaccessibility is not logistical. It is not just about ramps, ASL interpreters, straws and elevators. It is a shifting, changing wall—an ocean—between you and I. It is just as much feeling and trauma as it is material and concrete. It is something felt, not just talked about. It is made up of isolation from another night at home while everyone else goes to the party. The fear of being left by the people you love and who are supposed to love you. The pain of staring or passing, the sting of disappointment, the exhaustion of having the same conversations over and over again.

## 2. **Community**

Community was another term that stood out across interviews. Tesla, Jay, and

Cameron mention the importance of community throughout their blog posts. Upon my first read, I was struck by Jay's words:

Identifying as disabled also allows me to acknowledge the recurrent and sometimes severe nature of my struggles, and to seek structural changes that wouldn't make it so hard to be in this world. Instead of trying to assimilate and "pass" as normal, it is so much more helpful for me to think about how to get support and get access needs met.

Community allowed Jay a space to be who they are. Within the demographic survey, a majority of participants responded that they experienced access intimacy with both disabled and non-disabled people. However, participants blog posts often stressed the importance of community, in particular, disability community. Jay also touched on the importance of access intimacy opening up opportunities for new dialogue in the mental health community. Jay wrote:

[A]ccess intimacy is one of the most powerful things support networks like [organization] can create for folks who participate. Sometimes I feel like it's missing in parts of the alternative mental health movement that focus so much on resistance to the prevailing medical models of mental illness and on promoting counter-narratives of full recovery that there isn't space to focus on how those of us who continue to experience madness, suicidality, post-traumatic stress, and other big emotional extremes deeply support each other.

Oftentimes, as stated by Jay, there is a focus on resistance, but there is not a space to talk about the struggles of having a mental health on a daily basis. Tesla reiterates that there is space and support given to a person with a disability within their disability community. She wrote:

For an autistic with chronic pain who can often miss a lot of social cues, it's always easier for me to spot my fellow awkward folks. It doesn't happen with every single neurodiverse person and/or those with chronic pain disabilities; we all have our own personalities after all. But with people I've developed deep friendships with, it often starts with that holy moment, that taste, that glimpse into a complimentary mental landscape.

Later, they further articulate, "Access intimacy, that sacred intimacy akin to the Black nodding of the head to another Black person." While Blackness and disability identity cannot be conflated with one another, Tesla wanted to acknowledge that there was some common knowledge or

understanding when belonging to the same identity group. Knowledge and understanding also gave participants a sense of value and validation as well. As Cameron pointed out:

Being part of the knowledge and praxis that such a community generates is intensely valuable to me and is something that I know many people in my life will never experience, namely my immediate family, my parents and my sister.

In her post, Jane reiterated the same sentiment. She wrote, “It [my experience] helped me internalize my own value as a member of our community. So thank you, once again, to all my Polska friends who demanded access.” As Alex articulated, access intimacy and community at its essence gave him strength by being part of a “we”:

Most importantly in all of this, I’m grateful for the community that I’ve found through Disability Pride. Without my own struggles I would never have found the people I call family. I think Nomi Marks said it best on Sense8: “Today I march to remember that I’m not just a me. I’m also a we and we march with pride.”

Community will be discussed further in the interview section of the findings as well as the discussion chapter. In the next section, I will outline and discuss the findings from the interviews and their relevance to my research questions.

#### D. **Interviews**

Initially, this study was designed to provide a concrete definition of access intimacy, but a majority of participants described it as an interactive concept that is always evolving. Although, definitions were similar in nature each participant’s definition differed slightly depending on their relationship with the person that they experienced access intimacy with. In the subsequent sections, defining features of access intimacy will be described to show how participants defined access intimacy, examples of these experiences will be given in order to show the importance that access intimacy has in the lives of participants as well as its limitations, and the ways in which access intimacy can be utilized in our everyday lives to build disability

community will be discussed in order to show the relationship between access intimacy and community. Below in Table III is a compiled list of my themes and subthemes.

**TABLE III**  
**THEMES AND SUBTHEMES FROM THE INTERVIEWS**

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- I. Defining Access Intimacy: “Just getting it”
    - A. Full communication
    - B. “Disability as a natural part of the human experience”
    - C. Vulnerability
    - D. Combating stigma and internalized shame
    - E. Holding space
    - F. “Being in the moment”
  
  - II. Levels and diversity of access intimacy
    - A. Depth and length of relationship
    - B. Racial understanding: Intersectionality
  
  - III. Characteristics of people with whom participants experience access intimacy
    - A. Awareness of the needs of others
    - B. Empathy through compassionate connection
    - C. Marginalization
    - D. Cultural and racial understanding
  
  - IV. Importance of access intimacy
    - A. Shared meanings from shared language and experiences
    - B. Defining intimacy for ourselves
  
  - V. Limitations of access intimacy
    - A. Can get confused for romantic intimacy
    - B. Too academic
  
  - VI. Sense of community within moments of access intimacy
    - A. Building community as a tool for survival
    - B. Sense of community in practice
-



### E. **Defining Access Intimacy: “Just Getting It”**

All participants resoundingly stated that “just getting it” was central to their experience of access intimacy which made the natural attunement participants felt with another possible. For participants, “just getting it” meant that those with whom they experienced access intimacy understood their access needs automatically without needing explanation or to be educated on what those needs are. Due to both parties “just getting it,” participants were able to experience the following: full communication, viewing disability as a natural part of the human experience, gaining power to combat internalized stigma through acceptance and validation, developing comfort with vulnerability, holding space for one another, and being in the moment. Each of these highlighted experiences will be described below.

“Just getting it” was associated with feelings that the person had when their access needs were met without explanation. T, a 40-year old Black female with a mental health disability, explained, “It is actually about having like a moment with somebody where they just get you and get your access needs whether it's like your mental health needs or physical disability needs.” Jay<sup>7</sup>, a 38-year old White genderqueer with a mental health disability and chronic pain, reiterates this idea. They stated, “access intimacy is a profound sense that someone else just gets it, in terms of what your needs or sensitivities or limitations are without having to do a lot of explaining and educating.”

For these participants, “just getting it” was important because they did not have to explain their needs to the other person. The constant expectation to educate others on their needs were often described by participants as “exhausting.” Jay, however, explained that when

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<sup>7</sup> Gender pronouns were chosen by participants through an open-ended question on the demographic survey.

experiencing access intimacy, there is no need to educate because the other person understands their access needs. Jay explained this in the following statement, “I think there’s a common level of understanding like not needing to educate the other person but they just share an understanding of access and how it works.”

The automatic nature of “just getting it” was important to some of my participants because the participants did not always know what their needs were at that particular moment or how to articulate those needs to others. Alex, a 29-year old white male with a mental health disability, described the importance of the automatic nature of access intimacy:

I think part of access intimacy is just like people know you, and they can kinda like just see what you need and just do it. You know, a lot of times I have a hard time asking for help. And I have a hard time especially when I’m in a really low place like vocalizing what’s going to get me to that functionality place or whatever.

For Alex, moments of access intimacy took the burden or responsibility of asking for help away from him, and he did not feel the need to manage his access needs alone. The piece of not having to manage his access needs alone is of utmost importance because oftentimes people with disabilities feel isolated and alone in navigating their access needs. Access needs, when it comes to disability, often get deemed as a singular problem or issue that the person with the disability has to solve. Within these moments, all parties are un the moment together. Furthermore, when Alex does not fully understand what his access needs are, the person he experiences access intimacy with can help him navigate the situation at hand. The automatic nature of access intimacy occurs because of each person’s awareness of one another which can take place through listening and paying attention. The importance of listening and paying attention will be discussed in the theme addressing the characteristics of people with whom participants experience access intimacy under the subsection “awareness of the needs of others: Paying attention, listening, and being intuitive with another.”

For Mary, a 25-year old white female with a physical disability, these moments bring a “natural attunement” with another. She stated:

I know we don’t want people to assume our needs but when someone has good intuition like sometimes it’s refreshing when they just know to offer something for you. Like, I’m not saying I want people to assume that I need help with certain things all the time, but because I’m always explaining, and because it sometimes feels awkward to do so, it’s really nice sometimes when I’m sitting in a food situation and someone who I either know well or maybe don’t know well at all, it’s just like, “Hey, I’m gonna cut this for you.” And I’m like, “Oh my god, thank you for like, putting two and two together!”

For both Alex and Mary, having the weight lifted of describing their needs gives them a sense of relief and getting their access needs met was due to the full communication between both parties.

### 1. **Full communication**

Several participants mentioned the importance of full communication within experiences of access intimacy. Full communication referred to both verbal and nonverbal forms of communication. Claire, a 24-year old white female with chronic pain, also spoke about the importance of full communication within these moments. In the following quote, Claire pointed out that her friend with whom she experiences access intimacy knows her access needs entirely based on her facial expressions and her body movements:

[H]e pointed out to me that the reason he doesn’t always offer an elevator to me anymore is because he learned what my face looks like when I look at a flight of stairs- whether it’s going to be challenging or not challenging. And I was like man! I didn’t even know I made different faces depending on that! And he was like yeah, if you look at the stairs in one way, I can tell that you’re like “oh gosh, here we go” and if you look at it in another way, you’re like ‘mm, no not happening’ and if you look at it in another way you’re like “hm okay! Whatever let’s go!”

Sylvia, a White genderqueer femme, spoke of the non-verbal communication which they saw as a vital element within moments of access intimacy. They stated, “you know like Mia Mingus talks about how access intimacy is happening when your body relaxes about someone and I think that’s like communication. That implies communication.”

Sylvia goes on to say that full communication with another allowed her to trust and feel safe with them. For Alex, Mary, Claire, and Sylvia, non-verbal communication (body movements and facial expressions) was key to getting their access needs met both physically and emotionally. Another key point that was reiterated across interviews was that in these moments, their disability was viewed as a natural part of the human experience.

## 2. **“Disability as a natural part of the human experience”**

Across interviews, participants stated that within experiences of access intimacy their disability was seen as a natural part of the human experience. Participants who mentioned the naturalness of disability explained that they were “being seen as our whole selves” or their “true authentic selves,” indicating that the people they experienced access intimacy with not only saw their disability in a positive light, but they were seen as a “complete” person with multiple, complex identities. Jane, a 30-year old white female with a physical disability, described an instance when she needed to get her scooter on a bus while traveling. She stated that the way that they [her tour group] responded just made me realize like, “Oh, they see me as a full complete person just as I am. It’s not going to be an issue.” Being seen not just as a person with a disability was stressed as an important factor within access intimacy by several participants.

Sylvia stated:

Access intimacy is the kinds of closeness and moments of connection that come from having our whole selves and our access needs met. I think that AI for me involves connection and the meeting of our whole selves in a way that holds and recognizes our whole selves.

Mary described in more detail that during these moments of access intimacy, it was also important that people saw her disability as well:

It means to me that somebody has an understanding of your whole self and they are past that bullshit that your disability not being part of you. They recognize that it IS part of you and that so are all your access needs and if they’re going to really see you

Further, experiencing access intimacy allowed participants to let their guard down and as Kit stated show “your true authentic self.” In the following quote she stated:

It’s a special kind of comfort when all your needs are being met. And also, you’re able to able to connect on a deeper level. And there’s empathy and just being on the same plane. And just really just being able to be your full authentic self.

People with disabilities often have to manage their basic activities of daily living needs which range from physical to emotional needs. Therefore, for participants, it was a relief knowing that even if everything did not go as planned, everything would be okay. Knowing that everything would be okay and that she was seen as a complete, complex person allowed Kit, for instance, to be her true authentic self. Lastly, Mary pointed out that things often do not go as planned and that is also part of the human experience. She stated:

[People I experience access intimacy with don’t] make a big deal out of things, or if there’s something that they don’t know how to do, like they really listen and don’t get upset and don’t see it as a big things.

As a result of disability being viewed as a natural part of the human experience, participants were able to be vulnerable.

### 3. **Vulnerability**

When access intimacy was present, participants stated that they were able to feel vulnerable, safe, and they were able to trust the other person. In these moments, participants were able to let their guard down and let the other person in. When talking about vulnerability, Alex smiled and stated:

[I]t’s like a moment that lets me know that I can trust this person. And I can care about this person, if that makes sense. Yeah, and so, that’s someone I can be vulnerable with. You know, someone’s that’s not going to get scared or run away or not get it, you know.

For Alex, the vulnerability piece is important because he was ashamed of his access needs in the past. In this moment, he felt a sense of safety and security which allowed him to be himself.

Sylvia points out that vulnerability is reciprocal and both people participate in what they call, “an exchange of need meeting and care.”

I think about ways that we were both vulnerable with each other and we are BOTH vulnerable with each other. So it's not like this unidirectional help or care or unidirectional need-meeting but it's like an exchange of need meeting and care that we actually are able to connect in a more full way.

Kelly also described this shared vulnerability in the following quote:

[M]aybe, they feel vulnerable and they're like opening up. And they feel vulnerable and they see me being vulnerable through the process them telling me about the work and then me asking them questions. And then it brings the people closer together.

The vulnerability that occurs between people within these moments, as Kelly stated, brings people closer together by allowing them to share pieces of themselves with one another. A sense of access intimacy is enabled because each person within the experience feels comfortable with the other, allowing them to be vulnerable. Simultaneously, due to the comfort they experience within these moments, access intimacy allows them to be vulnerable in the presence of another as well.

#### 4. **Combating stigma and internalized shame**

Moments of access intimacy combatted negativity or stigma associated with my participants' disabilities through others viewing their disability as a natural part of the human experience and allowing them to be vulnerable. According to Goffman (1963) stigma is:

an attribute, behavior, or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one. (p. 3)

When Jane was traveling in another country, she was coming into her disability identity and battling internalized shame. However, her experience of access intimacy helped her gain a positive outlook on her disability. In the following example, Jane spoke about the positive effects

of having members of her tour group help her get her power chair onto the bus without having to ask. She explained:

[W]hen I reflect back on that time that was the time where I was becoming disabled. So, it was just so many emotions that recognizing that this group of people that did not know me well, like my family or friends that I had grown up with, still wanted me to be a part of that group without any sort of explanation was the first time where I realized, “Oh, I still have value.

Participants also spoke about how these experiences helped them feel accepted by others and validated. For example, Alex who is in “the process of identity formation” stated, “It’s an acceptance feeling. Like you accept what I need without judgment.” Within his process of identity formation, the acceptance he felt when experiencing access intimacy helped to shape how he internalized his disability experience.

Finn, a 37-year old East Asian female, explained that before experiencing access intimacy she did not feel as if she was a part of the disability community, and often her experiences were invalidated by others. However, when talking about how experiences of access intimacy made her feel and sharing her internalized views of herself as a disabled person, she stated:

I was like, “So, my experiences are true, right?” And it was like a huge validation. And also like, “Oh, I’m not just making it up.” like what other people would say. These are scholars, like smart people. They write in-sync about their experiences and they’re my experience, too. And then I had this like a huge validation. Like finally, having these feelings are valid.

Finn felt validated because others, often whom she viewed as “smart people,” understood and shared in aspects of her disability experience. Validation was also an essential piece of Jay’s experiences of access intimacy. In an example Jay provided, they explained:

[W]e both hate seeing psychiatrists and find them really triggering and generally invalidating and shitty most of the time and so whenever one of us has to go see one and then we’re really triggered we call each other, like I leave the psychiatrist’s office and I call him and I’m like oh my god can you believe what this person said?!

Finn and Jay both received validation through a common understanding from the people that they experienced access intimacy with.

## 5. **Holding space**

Across interviews, participants expressed feeling supported or holding space for one another within moments of access intimacy. For a majority of participants, holding space for one another did not mean sharing the same experience. Holding space meant being able to be in a moment with another without feeling judged or misunderstood. Heather Plett (2015) defined “holding space” as:

willing to walk alongside another person in whatever journey they’re on without judging them, making them feel inadequate, trying to fix them, or trying to impact the outcome. When we hold space for other people, we open our hearts, offer unconditional support, and let go of judgment and control.

Anne articulated the act of holding space beautifully when she stated, “Someone that can look through my window with me is someone that I can have access intimacy with.” For participants, the ability to look through another person’s window allows for people to engage in “holding space.”

Some participants explained that holding space for one another allowed them to support each other within moments of access intimacy. Tesla spoke about how she supports others through the act of holding space for them during experiences of access intimacy:

I know how painful or I know how difficult it is, and kind of letting each other know it’s okay, in a way, as well. Seeing that vulnerability and not attacking but being just like, “Okay, I’ll hold that space for you to feel that way.”

Others described moments of holding space for one another, but did not use the terminology. For instance, Claire stated:

It was an intimate moment! Because he said you know “I’m gonna be in this with you and it’s gonna be us together and we’re going to navigate all of these different



accessibility issues you're experiencing, together. Whether it's moments that you're afraid of your medication, or moments that your doctor's being rude to you, which is common, whatever it is, we're in it together."

In the moment described, "being in this together" allowed Claire to feel supported and less alone.

In the last section of features of access intimacy, the ability for people with disabilities to "be in the moment" within these moments will be described and highlighted. Due to the defining features of access intimacy described above, participants were allowed to be in the moment which for many people with disabilities is a rarity.

## 6. **"Being in the moment"**

Several participants mentioned throughout the course of their interviews that having moments when they did not have to think through or manage their access needs provided them with a sense of relief and allowed them to be in the moment. As Kit, a 28-year old female who is visually impaired, explained, "Access intimacy allows a person to be present in the moment and understand where someone else is coming from and at the same time allowed to be yourself and make mistakes." Kit described this feeling of being able to be in the moment in her blog post:

But when I'm close to you, life pauses. It's as though while struggling to swim against the tide, a chance wave tosses me into the path of your calmer current. I am swept towards you, propelled by a magnetic force I need not question or control. Leaning on my trust in you, I can break the surface and draw a long, cleansing breath.

In this situation, Kit felt a cathartic release from having to manage the ins and outs of her access needs, including the obligation to remain vigilant and on guard regarding any access problems that might crop up in the near future. In her interview, Mary expressed an instance where she was allowed to be in the moment. She stated that she limits her time at events due to her bathroom needs. However, in a moment of access intimacy, her worries were eliminated. Mary's

friend invited her over and told her that she would make sure she got to use the bathroom. To show Mary that she was serious:

she gifted me an entire box of peach ice tea Snapple and she said, “Listen you can drink as many of these as you want. We’re gonna have a f\*\*\*ing Snapple because you like the way it tastes.

For Mary, like many other people with disabilities that have to manage their access needs, this was more than just a Snapple but a promise between friends that she could be in the moment, breathe, and that everything would be okay.

#### F. **Levels and Diversity of Access Intimacy**

An important, and somewhat surprising, finding that came out of the research was that participants did not view access intimacy as an experience that was the same across relationships. Some participants felt that access intimacy could happen between strangers. While, others felt that a longer relationship was required. However, all agreed that a long-term relationship brought with it a deeper connection during moments of access intimacy. Also, participants mentioned the importance of racial understanding within moments of access intimacy, in turn, advocating for intersectionality.

##### 1. **Depth and length of relationship**

Several participants acknowledged that there are different levels of access intimacy. Claire explained that access intimacy can happen on two different levels. For Claire, access intimacy can happen in fleeting moments with a stranger or in a relationship where two people are “in this together” Alex, for example, described the long-term relational level of access intimacy:

I think there’s sort of a long-term development piece with it. Like when I think about when I’m talking about when I don’t know what my needs are sometimes and I don’t know what’s going on, that kind of relies on other people I build relationships with and

sort of um seeing how I am in different situations and seeing when I'm better and when I'm not and sort of figure that puzzle out with me.

For Alex, deeper levels of access intimacy required the long-term development of a relationship. In the above example, the “long-term development piece” allowed those he experienced access intimacy with to know him better and understand when he needed assistance with his access needs.

Reiterating the importance of the long-term development piece of access intimacy, Kelly stated, “Friendships, relationships, or the potential to have a relationship is central to a deeper level of AI.” While a majority of participants agreed that access intimacy can happen between strangers, several participants mentioned the importance of developing a relationship. Jane shores up this idea when speaking about her relationship with her boyfriend. She stated:

[W]e both do things for each other out of love and respect in our relationship which is access intimacy in a way. But it feels different because we've been together for so long now. Maybe, in the beginning, it felt more like those moments of relief and support. Now, that's just the way things are. I don't know.

In all the above examples, the longevity of the relationship allowed for a deeper form of access intimacy to occur.

## 2. **Racial understanding: Intersectionality**

T suggested that instead of looking at access intimacy as a concept that is experienced in the same manner by everyone, we should look at access intimacy being an umbrella term with many variations. She stated:

[M]aybe there being different types of AI just like different types of sexual intimacy or emotional intimacy. That just needs to be an umbrella and there needs to be distinctions between all the different ones for you know... that it looks different for people of color

T explained that the Black community may perceive disability differently than the White community due to cultural differences and a history of colonization. For instance, she mentioned

that in the Black community disability is not viewed as a defect, but rather, having a disability means that the person has to do things in a different way. Therefore, disability often goes unacknowledged. Disability Studies scholars trace the disconnection between race and disability back to a long history of disability being used as justification for committing injustices onto the bodies of people of color (Baynton, 2001; Erevelles and Minear, 2010). By looking at access intimacy as a concept that varies based on levels and racial background, we can begin to take an intersectional approach by acknowledging the variety of lived experiences that make up the disability community. From this viewpoint, we can then begin to unpack how these experiences that are based on the intersections of our race, class, gender, and disability affect our access needs in various aspects of our lives.

G. **Characteristics of People with whom Participants Experience Access Intimacy**

All of the participants were asked, “What characteristics do the people you have experienced access intimacy with have in common?” Awareness of others, empathy, marginalization, and cultural and racial understanding were the four characteristics that were mentioned. Below, each characteristic will be discussed as well as its importance to participants when they experienced moments of access intimacy. These characteristics helped participants feel comfortable and understood by another within moments of access intimacy which allowed for a deeper connection to form.

1. **Awareness of others’ needs**

Across interviews, participants spoke about those that they experience access intimacy with as having an awareness of other people’s needs. While Alex was the only participant to use the word awareness, others described the awareness that they felt that the other person possessed as “paying attention,” “listening,” or being “intuitive” with them. It was

through the characteristic of “being aware” that allowed the people that participants experienced access intimacy with to “just get it.” Being aware meant that all parties involved in a moment of access intimacy paid close attention to one’s actions through both verbal and non-verbal cues, or through what I called “full communication” which was described previously in this chapter. As earlier mentioned in Alex’s example, T said that her friend had an awareness of her needs even when she did not. T’s friend was aware of her needs because he was paying attention to her actions both in body and in mind. When recounting an experience of access intimacy, she stated how her friend’s awareness helped him come up with a solution to her needs:

they understood instinctively that like the morning is hard for me because I have night terrors and nightmares and so for a few months they would call me every single morning and tell me a very funny random joke to help me get out of bed in the morning.

These phone calls did not occur because T asked for help, but rather, her friend observed that she was struggling and came up with a helpful solution. As described in the following quote, Alex’s friend also came up with a helpful solution in order to hold space for him during a bout of depression. He stated:

[S]he just like showed up and spent time with me and we just watched music videos which I know she hates. And just had a laugh about the ridiculous situation of me laying on the floor with a blender on my chest just like drinking the milkshake. But I don’t know what would have been a pathetic situation maybe in my own head became like funny and light-hearted and like normalized in a way by having her there.

For both T and Alex, the awareness that their friends had of their needs allowed them to be there when they were in need. Further, both experiences allowed T and Alex to share in a that would have been stigmatized by society and make it into a humorous experience.

## 2. **Empathy through compassionate connection**

Empathy was another important characteristic mentioned by several participants. For participants, empathy was the ability to understand the needs of another, and it allowed for a sense of compassion and connection with another person or people. When describing a person that they experienced access intimacy with, Jay stated, “I think experiences of access intimacy just involve a lot of empathy, like people being able to have compassion.” Jay explained further that when they were not around someone that they experienced access intimacy with they often felt bad for having access needs or that they had to prove their disability to another. In order to experience access intimacy, participants expressed a need to be comfortable through a compassionate connection with the other person. Empathy, in Jay’s experience, was the catalyst that allowed the “sense of comfort” that Mingus (2011) wrote about to occur.

Empathy also allowed people to view situations from other people’s perspectives. Several participants mentioned that empathy gave people they experienced access intimacy with the ability to “put yourself in someone else’s shoes.” Kelly reiterated the importance of this when she stated, “I think that they’re empathic. I think they are willing to not take shortcuts, and they’re willing to go out of their way.” As a result, empathy also allowed for a deeper level of human connection to take place.

In order to describe the characteristics of people that she experienced access intimacy with, Cameron described an experience that she had on a recent trip to London where her friends understood her need to nap and limit herself to two alcoholic drinks per day. She stated that during this experience she noticed, “a stronger sense of human connection and empathy. And just a desire to connect with others” through the understanding she received. Above all, the

empathetic nature of the person or people that participants experienced access intimacy with allowed them to breathe a little easier.

### 3. **Marginalization**

A majority of my participants identified as part of the LGBTQIA+ community. However, both those who identified as part of the LGBTQIA+ community and those who did not stated that marginalization was a characteristic of those with whom they experienced access intimacy. Participants who spoke about marginalization as a defining characteristic used terms such as outsidership or queer to describe them. As Alex stated, those he has experienced the deepest level of access intimacy with experienced marginalization. He articulated this in the following quote: “I feel like there was some element of like they had gone through something. They had experienced that rejection or that otherness or that outsidership.” A majority of participants who mentioned marginalization as a characteristic of people they shared access intimacy did not state that the person had to experience the same type of marginalization, and in some cases, they did not. However, as pointed out by T and Tesla a shared racial background brought with it a deeper connection.

Claire reiterated this line of thinking when she spoke about why she thought she was able to experience access intimacy with her friend, “I think part of that is that he is a queer POC [person of color] and has needed people to pay attention to him in those ways too.” From Claire’s perspective, her friend was able to understand her and be more attentive to her needs because of his multiple stigmatized identities and because he knew what it was like to be stigmatized by society.

Sylvia stated that a majority of people that they experienced access intimacy with were queer or queer and disabled in the following quote:

I was gonna say the majority of the people that I've experienced access intimacy with, a lot of them have been queer or queer disabled people. Um I feel like access intimacy happens... not that it doesn't happen easier, more that it's just more mutually recognized when you're both working with the same sort of framework.

As a self-identified queer disabled femme, Sylvia felt that a majority of people with whom they experienced access intimacy shared in one or more of their marginalized identities. As pointed out in the literature review, people of color with disabilities, for example, felt that they could only acknowledge one identity at a time. Therefore, the only identity that is often acknowledged within the disability community is their disability identity. However, the disability experience is not a homogenous experience. Rather, as mentioned previously, how someone experiences disability is based on the intersections that make each person who they are. Without this understanding, we are missing out on a large part of someone's story. For participants who mentioned the importance of marginalization, access intimacy was the missing piece that allowed all of their identities to be acknowledged through the other person or people seeing them as more than just a person with a disability.

Sylvia also mentioned that the person or people they experienced access intimacy with had the same underlying values as well. Some of the values they mentioned were collective access and community building. For participants, shared values allowed for a deeper connection through common goals and shared understanding or perceptions of the world. As discussed in the next section, cultural and racial understanding was important to participants when it came to developing a deeper level of access intimacy because the people involved in these moments had a better understanding of how one another experienced the world.



#### 4. **Cultural and racial understanding**

T and Tesla mentioned cultural and racial understanding as a characteristic of those with whom they experience access intimacy. T stressed the importance of understanding someone's racial background in the following quote:

I do think the definition needs to be hammered out in terms of what that means in terms of race. And that can mean, you know, somebody just understanding my mental health needs also requires them to understand me racially. So if you do one but not the other, then I don't feel a warm magical thing.

As mentioned earlier in this chapter, T stated in the course of her interview that people of color experience the world and disability differently than White people. Although people of color may experience the world differently, Tesla stated that the intersection of race and disability often goes unacknowledged. Both T and Tesla stated that the lack of acknowledgment around race and disability erases a long history of colonialism and enslavement that often created disability and silences people's experiences. T went deeper and stated that in order to fully engage in access intimacy, the person or people must be willing to engage in decolonization. She stated:

I think people who acknowledge that they're doing it and either benefit from it or have an internalized version of it, people who tackle that and who do something about it are people that are able to have AI and are able to develop that.

For T, the decolonization process begins with acknowledging how race affects people's lived-experiences while simultaneously acknowledging the privileges of others. However, as Tesla pointed out, this is a rare experience:

"Oh yes, I know in particular what you're going through. I know how your race can make that experience worse in many ways." I think that's a really huge thing, and I wish it was talked about a lot more.

However, both T and Tesla have experienced access intimacy with people outside of their race.

## H. **The Importance of Access Intimacy**

As outlined throughout this chapter, there were several defining features of moments of access intimacy as well as levels of access intimacy, and within these moments there were characteristics of people with whom participants experience access intimacy. However, the heart of access intimacy was conveyed when participants spoke of its importance. Throughout the course of their interviews, participants expressed several reasons why access intimacy is important to them. Participants pointed out that access intimacy shined light on shared meanings through shared experiences, disabled people were able to define a unique form of intimacy for themselves, and these moments often gave them a sense of community.

### 1. **Shared meanings from shared language and experiences**

Several participants expressed the feeling that some moments of access intimacy included shared meanings which derived from shared language and experiences. Access intimacy was important in these moments because it helped several participants realize the camaraderie created through connection. Anne expressed the importance of having shared meanings through her discussion of “shared language.” She discussed the comfort that she gets knowing that the other person or people share in the same type of experiences. In the following quote, Anne recounted discussing transportation with fellow blind people:

If I'm with fellow blind people or with fellow people with disabilities I kind of like the shared language. Again, if I do say transportation and I just laugh and we laugh together because it's different when you have two or three people who don't drive saying something, rather than, if I say it to my husband or my daughter who do drive well. Their response is, “Let me offer you something or let's figure it out.” Whereas, with my friends we just laugh about it bitterly and say, “ugh transportation.” So, it's a shared understanding at times.

Because of the shared language between Anne and her friends, Anne was able to look at a stressful situation with humor. Cameron, a 38-year old white female with a mental health disability, also spoke about the importance of shared language and humor when asked to define

access intimacy for herself. She stated, “Access intimacy is an unspoken connection based on shared experiences shared sense of humor, and shared vulnerabilities.” For Cameron, access intimacy and shared language allow a “kinship” to develop between people as well. She explained, “There’s only certain people that I can say, ‘Oh I’m tapped. I can’t do it,’ and they completely understand. And there’s like no pressure like, ‘Oh, you’ll have fun. It’ll relax you, or you should be more social.’” Because of the shared understanding that she feels during moments of access intimacy, Cameron did not feel like she has to make up excuses or have negative feelings concerning her access needs which is an important aspect of access intimacy.

## 2. **Defining intimacy for ourselves**

Along with developing a deeper connection, access intimacy can offer people with disabilities an opportunity to redefine intimacy for themselves. Access intimacy was important to participants because oftentimes others define and impose things upon people with disabilities without their consent, and therefore, other people become the authority of the disability experience. For Jay, their organization had a shared language and redefined terms used to describe their disabilities for themselves that did not include clinical definitions:

Everyone in the project would not use the word mental illness, for example, it was not a word that any of us identified with we found it really pathologizing and clinical and it was language that came from the medical establishment and not language that we would use to talk about ourselves, erm, and so we came up with different terms like having dangerous gifts, um, or being highly sensitive.

Alex reiterated the sentiment of “Nothing About Us Without Us” (Charlton, 1998) when he stated:

Intimacy is a part of need. Like the level of intimacy and types of intimacy, and I think that disabled people have a unique opportunity to redefine that and reconstruct it in a way that makes sense for each of us.

Oftentimes, the stories of people with disabilities are clinicalized by healthcare professionals and/or their loved ones, rather than by people with disabilities themselves. For both Jay and Alex, the concept of access intimacy gave them the language to define a unique form of intimacy for themselves since the term was coined by another person with a disability. By having the language to define intimacy for themselves, people with disabilities gain power and authority over how their stories are told.

### I. **Limitations of Access Intimacy**

A couple of participants mentioned that there are limitations or issues that can occur in the context of access intimacy. These limitations or issues are that the experiences can be confused for romantic intimacy and that the term can be seen as too academic. Anne, for instance, thought that access intimacy was an important term to have. However, she thought that it was important to acknowledge that some people with disabilities may mistake access intimacy for romantic intimacy. Anne stated:

I particularly know blind people who would confuse access intimacy with love. And they think because someone is good to them and they don't have to ask that that person really cares about them. And at times, it does. But at times, that person is just a really good professional or a nice person that's glad to help when they're there but that doesn't mean that they're romantically interested or involved.

She went further to state that this misconception can be from the lack of a concrete definition of the term, access intimacy. Claire, on the other hand, thought the term was useful. However, they both agreed that the term was too academic. When speaking about this, Claire stated:

[People] wouldn't just hear the phrase and just be like "I know what that means!" and to me that's like a level of inaccessibility in and of itself. If you can't define something without reading a scholar's definition of it, then it's probably too academic. So, I think giving it... living it out as an example is one way. But also like talking about it using like really really simple words.

Claire worried that the term would not be accessible to a broad spectrum of people with disabilities, and therefore, worried about its outreach to the broader disability community.

## J. Sense of Community

All participants were asked, “What role, if any, do you think access intimacy could play in bringing people together?” However, a majority of participants spoke about this topic before being asked. A sense of community resonated with participants across interviews when they spoke about the importance of access intimacy in their lives. For participants, having a sense of community allowed for positive self-reflection, closeness, the ability to build sustaining organizations, and as a tool for survival. Under this theme, “sense of community within moments of access intimacy,” the ways in which a sense of community can be found through moments of access intimacy will be explored within interpersonal relationships. This section will conclude with examples of how the sense of community as a result of access intimacy can be transformed into guiding work at the organizational level.

When participants spoke about the sense of community that they felt in moments of access intimacy, they acknowledged the diversity of lived-experiences. As Kit explained, “There’s just a broad community of this lived-experience...and even though it looks different for a lot of us, there is like this special closeness around us.” Along with closeness, Alex stated that his willingness and ability to build community with someone was a result of his ability to feel a sense of acceptance and experience of access intimacy:

Even though that’s not always easy for me because like existing as queer, existing as someone with a disability is hard in the world. And when I find people who accept who I am and want to build community with me like that’s really important to me.

For Alex, having a sense of community helped him navigate the world as a queer, disabled man.

Related to this acceptance and sense of community, there was also a common understanding that disabled people navigate the world differently. As Mary explained:

In my article about how people with disabilities, you know, holding hands has a different meaning often in our community. That too is something that reveals access intimacy to

kind of this inherent understanding that we can't move or typically be with each other in the same way all the time as people without disabilities can.

Within the disability community, people adapt in order to get their needs met, and sometimes their needs get met in unconventional ways.

When speaking about an experience of access intimacy she had had at a conference, Cameron stated, “[S]ense of community can teach us to find joy in imperfection and vulnerability.” Finding the joy in imperfection and vulnerability was important to many of my participants. Throughout the course of their interviews, participants often spoke of laughable moments in which their access needs are not always met perfectly. For example, Kelly said that moments of access intimacy are “very chilled and [the other person is] not worried about doing something wrong and like if they mess something up we can laugh about it and it’s not like the awkward stilted interactions that I’ve had with some people.” Although, she was speaking about a two-person interaction, she stated later that she utilized principles that she learned from experiences of access intimacy in the student accessibility group that she helped to organize.

Due to a long history of being a separated and fragmented community, we often do not recognize the support that we give to one another or, in many cases, we do not have any other disabled people in our lives. Therefore, Finn articulated the importance of recognizing that we, disabled people, are a part of a community and acknowledging when we have experiences of access intimacy in the following quote:

I think having this concept helps us to recognize who we are as a community and the things that are happening within our community beyond just like this person cannot do it, you know, and we’re helping. And also highlighting the complex care relationship that we actually do have.

Oftentimes when others speak about disability, they speak about it in terms of limitations and defects. However, for participants such as Finn, acknowledging or recognizing the existence of

access intimacy allowed them to take pride in the complex relationships that they have with one another as people with disabilities. As Sylvia stated, “Access intimacy shows up how to be in a respectful relationship with one another.” Along with showing us how to engage in “respectful relationships,” Alex stated, “Access intimacy shows us who we can care about and trust,” which Sylvia and Alex stated were both important components to their community-building efforts.

### 1. **Building community as a tool for survival**

Building community within these moments not only teaches us about the beauty of everyday life, but, for many, access intimacy and the community that results from it is also a survival tool. Tesla described these moments and the community that resulted as a survival tool in the following quote:

Just the support of online community like, I think that was something that helped keep me alive when I was homeless and, you know, and going through everything. It was these connections with access intimacy the other people online, and they used that. They leveraged that. They were like, “Okay, we’re gonna, I’m gonna talk to- I know you don’t have any resources there but I have resources here that I’m going to point in your direction,” and things like that.

Being connected to others kept Tesla alive through allowing her to feel loved and supported and in her words it also “helped keep me alive.” Several participants also gave examples of experiences of access intimacy helping them manage crises. For example, Claire and Alex’s friends helped them through bouts of depression and T’s friend helped her get to work in the mornings. Experiences of access intimacy may, at times, be short-lived but they have had long-term positive effects for participants.

### 2. **Sense of community in practice**

As discussed in the previous section, some participants focused on how access

intimacy brings us together on the inter-personal level, but Jane, Kelly, and Sylvia spoke about how principles of access intimacy can bring us together towards “collective access.” Mingus (2010) wrote that collective access is:

about imagining something more and knowing that we had to do it for ourselves because it is so rare for movement spaces to ever consider disability and access in ways that go beyond logistics; in ways that challenge the ableist culture of our work. This was about being very clear that we wanted to shift the individualized and independent understanding of access and queer it and color it interdependent. This was about building crip solidarity.

Jane spoke about utilizing principles of access intimacy to create collective access in a student group focused on access. She stated:

I’ve certainly learned that it’s not just physical access and having ASL interpretation. There’s a lot that goes into this collective access that you need a group to do it. Like no one person can ensure access, I think is what we’ve learned. So, it’s like you’re stronger together because you have more perspectives and resources

For Jane, access intimacy taught her how to build and maintain community through her experiences with others.

Kelly also spoke about how principles of access intimacy were utilized in a class project. When Kelly was pursuing her Master's degrees, she created a project that paired a sighted person with a visually impaired person at an art museum and the sighted person was asked to describe the painting. Below Kelly described what she viewed as the most important outcome of the project:

[W]hen they say, “ this painting is really striking for me, you know, because x y and z is going on to even being like I don't know how to describe this.” And then me like watching their process of struggling with how to describe something. And then also because I’m like congenital totally blind and I don't understand like a lot of visual things. Hey, it's like me asking certain questions, and having it be like a dialogue like Is it this kind of purple or that kind of purple like. And then maybe like them sharing with me and frustration and pain that it’s not something that I could ever fully appreciate. and then them like sharing in frustration.



Kelly stated in the interview that the beauty of these moments were that she was able to experience the painting through the other person's eyes or perspective. Although the moment was brief, they were building a relationship and deeper connection with one another through their open dialogue and communication with each other.

Sylvia reiterated the importance of building relationships that develop during moments of access intimacy. Sylvia built a care collective to get their care needs met after state-funded services could not provide for her needs. They stated that moments of access intimacy were important to the sustainability of their care collective because, "it was so much about relationship building, and keeping people in the care collective is also about relationship building and keeping enough people in is also about relationship building." Sylvia explained that many of their experiences of access intimacy and relationship building developed in the bathroom while their care needs were being met. For example, while their attendant was helping them onto the toilet, they may be helping their attendant figure out solutions to a problem. Sylvia stressed the importance of the multi-directional relationship that forms:

[W]e're both sort of in it to collaborate. We're both in it because we care about each other and we want to support each other. I think that's what I mean by mutual. So it's not just like here's this independent person helping this dependent person.

For Sylvia, these moments were not one-sided but shared experiences. For participants, moments of access intimacy were life changing experiences.

## VI. DISCUSSION

Access intimacy was described in the context of a variety of experiences; however, they all put connection and community between two or more people into practice. The connections formed by the research participants included people with disabilities as well as people from various marginalized communities. Within these moments, there was full communication between all parties that included both verbal and non-verbal cues, such as, body language and facial expressions. Others' ability to fully communicate and "just get it" allowed participants to view their disability as a natural part of the human experience, be vulnerable with another person or people and combat internalized stigma and shame. As a result, all parties were holding space for one another, and they could be in the moment.

While participants viewed access intimacy as a connection that was deeper within longer, more in-depth relationships, participants never verbally asked for their access needs to be met. T, Alex, and Claire all described moments in which they did not know how to communicate what they needed verbally. However, their friends knew from their body language how to help them get their access needs met. In each of these instances, a long-term relationship was involved and these cues were learned instinctively. The instinctive nature of these moments was due to the fact that the person or people participants experienced access intimacy with had an awareness of their needs which oftentimes included cultural and racial understanding. Price (2016) advocated for people with disabilities to be around each other in order to instinctively learn what one another's access needs are. However, I would go one step further. Access intimacy can teach people with and without disabilities to instinctively care for one another.

By instinctively learning to care for one another and recognizing our interdependency through moments of access intimacy, we learn how to support each other in order to function in

our everyday lives. Access intimacy helped participants get through crises, assisted in organizing community, created connection, and kept a participant alive. Access intimacy answered the call to look for the knowledge that occurs in unstructured spaces by “doing and undoing” (Johnson and McRuer, 2014) what we know about ourselves and our disability.

A. **How Do People with Disabilities Define Access Intimacy?**

When setting out to explore how my participants define access intimacy, I initially thought I would find a concrete definition. I was wrong. I did not find a definitive definition, but rather, participants mentioned several defining features of the concept. Participants stated that during moments of access intimacy, disability was viewed as a natural part of the human experience which allowed them to combat internalized stigma and to be vulnerable with one another by holding space and being in the moment. For my participants, holding space and being in the moment meant that the other person shared in the experience of getting their access needs met and they did not have to worry. In order to make moments of access intimacy possible, the people with whom participants experienced access intimacy had an awareness of others’ needs, conveyed empathy through compassionate connection, belonged to one or more marginalized communities, and had cultural and racial understanding or understood the participant’s intersectionality. However, it must be noted that all of these characteristics were not mentioned by all of the participants, and therefore, all of the characteristics were not necessary for access intimacy to occur. For my participants possessing these characteristics made moments of access intimacy and the connections formed stronger.

Throughout these discussions, viewing disability as a natural part of the human experience was central to the experience of access intimacy. From this viewpoint, there is an understanding that disability is not intrinsically negative or seen as lesser. Family members, for

instance, may know how to care for a disabled person's access needs. However, if the person does not understand how access affects the participant, they will not have experiences of access intimacy. Alex, for instance, described a moment that might have been looked at with pity. However, in his experience of access intimacy, his disability experience was viewed as normal and with a sense of humor. Access intimacy is more than knowing physical or verbal cues. Access intimacy is acknowledging that we do things differently and understanding one's emotions surrounding navigating an inaccessible world as well. In each experience of access intimacy, participants felt comfortable. In each instance, participants did not experience negative emotions about their bodies.

While the literature review highlighted various forms of intimacy, whether physical or emotional, other forms of intimacy did not address the emotional toll that access needs can and do have on a person with a disability. Because people with disabilities are often under the care or gaze of others, they often do not feel that they have the space (e.g., time, energy, or support) to be emotionally vulnerable. However, access intimacy allows us the privilege to let our guard down and be in the moment. Within the experiences that were recounted by participants, physical spaces were not discussed when defining access intimacy. Jay Dolmage (2017) stated that access intimacy requires ideal circumstances. However, as pointed out by my participants, the disability experience is an experience in which the unideal is embraced. These experiences were about how participants reacted to having access or the lack thereof, rather than the space itself.

Although spaces can and do get set up with access intimacy in mind, interpersonal connections during these moments had more to do with the person or people involved. The characteristics of the person or people that participants experienced access intimacy with allowed them to be comfortable even in unideal spaces. Within access intimacy, there are no apologies

needed because the other person had unpatronizing compassion and an unspoken understanding of their needs. Within the disability community, people are often in unstructured spaces together, such as, elevators, kitchen tables, disability pride events, and physical therapy appointments (Chandler, 2012). Participants experienced access intimacy in such places as on a bus, in the bathroom, or on an elevator. The spaces mentioned by participants were not ideal but that did not take away from the moment.

B. **What Is the Importance, If Any, of Access Intimacy to Disabled People?**

Participants reiterated that the importance of access intimacy was the experience of having shared language with another, and that access intimacy allowed participants to define intimacy for themselves. The disability experience often gets pathologized or stigmatized by medical professionals and nondisabled individuals. Having a shared language, however, allowed participants a space where they did not have to explain what they needed. As people with disabilities, our care is often in the hands of others, but far too often there is not a space to talk about how we help and care for one another. As Mary pointed out:

[W]e [her friends with disabilities] all like very naturally take to helping each other get dressed and brush teeth and it's like everybody sort of found their niche and, "Okay I'm going to take what I'm not able to do and another person who's disabled in this group can help me with that, and then I'm sure there's something they're not able to do on their own and that I can do for them." And we just kind of made it we're a special little team

As pointed out in the above quote, access intimacy gives us the opportunity to acknowledge the support that we give one another within the disability community. Stella Young (2014) gave several examples of concrete support that we offer each other every day in a Ted Talk:

I learn from other disabled people all the time. I'm learning not that I am luckier than them, though I am learning that it's a genius idea to use a pair of barbecue tongs to pick up things that you dropped.

Participants also spoke about terms, such as, “tapped out” and not having enough spoons, to describe their energy levels. Due to their shared language and shared experience of disability, participants did not have to explain or come up with excuses. As Finn pointed out we often do not see this support and the importance of shared language without reflection. Access intimacy, however, gives us the language to reflect on these moments:

I think having this concept helps us to recognize who we are as a community and the things that are happening within our community beyond just like this person cannot do it, you know, and we're helping. And also highlighting the complex care relationship that we actually do have.

Having language to describe their feelings as well as the experiences that they shared with others offered participants a sense of power and control over their lives. It is in this recognition that we can begin to realize that we are in community with one another.

#### C. **What Is the Relationship between Access Intimacy and Community?**

As a result of these moments, access intimacy helped to build community through interpersonal relationships and relationships with groups of people and organizations. Some community building efforts that were mentioned were student organizations, an art project, and a care collective. While organizations are important, interpersonal connections formed helped participants function and navigate their everyday lives. Tesla stated that the community they formed “kept me alive.”

A point reiterated across interviews was that without access intimacy participants often felt isolated and alone due to stigma and ableism. Jay suggested that access intimacy can help in acknowledging people's varying abilities. Jay stated, “Rather than feeling alienated and alone, just acknowledge that everyone's at a different level of ability at different times of their lives.” However, our society often stigmatizes people with disabilities due to their access needs. Recent literature suggests that people with disabilities often feel they are alone in managing their access

needs, and therefore, feel as though their needs are burdensome. They internalize the ableism (Kattari, Olzman, & Hanna, 2018) that they feel in society—a sense that was reiterated throughout my dissertation research. From this standpoint, value and privilege flows to able-bodied and neurotypical people, and therefore, not to disabled people and their needs. Mingus (2017), in her keynote at the Paul Longmore Institute, addressed this issue by stating:

Understanding disability and ableism is the work of every revolutionary, activist and organizer—*of every human being*. Disability is one of the most organic and human experiences on the planet. We are all aging, we are all living in polluted and toxic conditions and the level of violence currently in the world should be enough for all of us to care more about disability and ableism.

The reason connection and community are at the heart of access intimacy is because the experience teaches us, as a society, that we are all in the struggle together. Access intimacy helped my participants to combat ableism and its effects by allowing them to relax, be in the moment, and think positively about themselves and their disability. Through the positive lens created by access intimacy, participants were able to build meaningful authentic interpersonal relationships and community.

Being able to relax and be in the moment is a privilege that many nondisabled people have. However, people with various disabilities have to constantly think about the future. Mary, for example, thinks about her bathroom needs before going out and oftentimes limits the amount of liquid she drinks. Jay, on the other hand, thinks about whether or not an event or a space will be conducive to their mental health needs. However, within moments of access intimacy and the connections formed, participants did not have to worry about navigating their access needs alone. Access intimacy validates both the Social Model and the Political Relational Model by putting into practice that disability is not an individual problem (Finkelstein, 2007; Oliver, 1990) and the fact that the disability experience takes place in relationship with others (Kafer, 2013). Access

needs in moments of access intimacy are not individual problems, rather, they are viewed as a puzzle we are going to work on together.

For these reasons, participants spoke about access intimacy not as a one-sided interaction but as being a reciprocal interaction in which they were in the moment together with the other person or people, whether it was a moment of crisis or a moment of happiness. The reciprocal nature of access intimacy allowed all parties in the interaction to hold space and be vulnerable with one another. Kathy Weingarten (1991) theorizes that intimate interactions are interactions that embody moments of co-creating and mutual meaning making which involves knowing someone and being known. The reciprocal nature of access intimacy allowed participants to know another and be known in return. These experiences of access intimacy varied from a long-term relationship to spontaneous interactions with strangers. However, when participants spoke about their experiences, they spoke about how they felt rather than how the other person or people felt. Access intimacy was spoken in terms of how it made the participant feel and the characteristics that the other person had. From their perspectives, the characteristics of the other person made access intimacy and the intrapersonal experience possible. However, this study did gather the perspective of the other persons who are involved in experiences of access intimacy.

Oftentimes, helping or assisting people with disabilities is associated with negative connotations. However, the beauty of access intimacy is that it draws attention to our interdependency on one another. Within the disability community, interdependence acknowledges the fact that *all humans* need one another. Mingus further stated:

Access intimacy is interdependence in action. It is an acknowledgement that what is most important is not whether or not things are perfectly accessible, or whether or not there is ableism; but rather what the impact of inaccessibility and ableism is on disabled people and our lives.



The impact of inaccessibility and ableism on disabled people occurs due to the complexity of access. As Price (2017) and Titchkosky (2011) state, access is much more than the physical and encompasses complexities of the social and material world, in turn, telling us who does and does not belong. When it comes to belonging, participants felt that their access needs related to their disability made them not worthy because they felt like a burden. However, unlike any other form of intimacy, access intimacy acknowledges these emotions while making participants feel valid, trusting that the other person will not abandon them, and they felt like a complete person. Forming connections and feeling supported allowed participants to function in their everyday lives.

Access intimacy is the place where we can feel like we belong and are validated and accepted. However, access intimacy goes beyond validation and acceptance by allowing us to live in and with disability (Kafer, 2013). Through living in and with disability, we create counterstories of disability. For example, during her experience of access intimacy, T's friend did not say, "She will never be on-time due to her disability." Rather, her friend thought, "What can I do to help her wake up in the morning?" Access intimacy creates positive counterstories about difference and how we navigate in our everyday lives.

Several participants mentioned that access intimacy allowed them to develop a positive disability identity, and it was from this positive self-identity that they began their organizing work. When writing about the effects of access intimacy and community organizing on his life, for instance, Alex wrote:

Disability Pride isn't about the things you've lost, or the things you can't do. Disability Pride is about the things we've been given and the community that supports us. Still, I admit that it's hard. Hard to accept Disability as part of my identity, and even harder to celebrate it. But every day I'm learning more and more who I am and what I need.

Alex described finding disability community as helping him to develop a positive self-identity and present this positive identity to the world (Gill 1997). However, as pointed out by Alex, having a positive self-identity is not a linear process. Positive self-identity is something he works at every day. Access intimacy helped my participants acknowledge all the complexities of the disability experience that includes pride, shame, and frustration (Chandler, 2012). For Alex, it is within those moments when he experiences panic attacks and isolation that he needs access intimacy the most. Whether big or small, within moments of access intimacy, participants learned to value and accept themselves. It was from this place of value and acceptance that both Alex and Jane were able to join in community with others. Jane wrote:

Looking back on this time, I see how these strangers that became more like family helped to shape my political disability identity. What they provided was radical and inclusive. It helped me internalize my own value as a member of our community.

As disabled people, we live in a world that is not structured with us in mind. Both the structural environment and public policies operate by practices that exclude disabled people which leads disabled people to feel they do not belong in society or humanity. Access intimacy signals that they are fully human as they are (“unideal”) and that they have an equal right to belong in the world. At the same time, access intimacy acknowledges that “equality” does not always mean “the same.” During experiences of access intimacy, there is an acknowledgement that we navigate the world differently. However, different does not mean lesser.

#### D. **Intersectionality Helping to Build a Stronger Community**

Intersectionality served as both an important analytic tool and also as an important factor that helped participants feel understood. Kimberlé Crenshaw defined intersectionality as, “the rejection of one-dimensional analysis [in order to] analyze the various ways in which race and gender interact to shape Black women’s experiences” (Crenshaw, 1991, p. 1244). In the original

articulation, Crenshaw wanted to highlight the need for looking at all the identities that make a person who they are in order to understand the effects of these factors on the person's life experiences. However, oftentimes people with disabilities are not recognized as having multiple identities.

Disability often gets discussed as a monolithic category. However, as disabled people, we are complex human beings. Access intimacy allows us to engage in interpersonal relationships that acknowledge intersectionality. Acknowledging intersectionality can help us build a more diverse community. Kendrick Kemp Sr., a Black man dedicated to Black liberation and living with a disability, stressed the importance of being viewed as an intersectional being:

I have a multiplicity of oppressions because of my dark skin color and the effects of my double stroke which has me to walk with a cane and limited use of my right hand. Disability Rights is more than getting a ramp or an accessible door. It's about respecting me as a human, not looking beyond my race and cane, but including them in my humanity. (Thompson & Wong, 2016)

Access intimacy is a tool that can help us respect and be in a healthy relationship with one another, because in these moments we acknowledge all parties involved as complete and complex human beings. It is from the acknowledgement within these moments that we can build coalitions and solidarity between groups to fight injustices. For instance, African Americans and American Indians have the highest rate of experiencing disability in the United States (Artiles, 2013). With this considered, disabled Americans also experience high rates of preventable health disparities (Goode et al., 2014; Gulley & Altman, 2008), and they disproportionately experience hate crimes and police brutality (Bagenstos 2016; Sherry 2016). If we do not view disabled people as intersectional beings, we cannot begin to tackle the various challenges that people with disabilities face.

Although there were only three people of color in my sample, they all mentioned the importance of racial and cultural understanding. However, T and Tesla were the two participants who particularly stressed this idea. T and Tesla felt that the key to experiencing access intimacy on a deeper level was that the other person was able to understand them racially or culturally, and therefore, within these moments their intersectionality was acknowledged. T, for example, felt that without racial understanding people could not understand an important aspect of her lived experiences. She felt that without this understanding a person could not understand how she navigated or experienced the world as a disabled person.

Both T and Tesla advocated for people to look back into our colonial history. Oftentimes, the voices of people of color, specifically people of color with disabilities, get silenced or ignored. Grech (2015) and Smith (2013) attribute the hidden histories and unequal treatment experienced by people of color, particularly people with disabilities, to our history of colonialism. Colonialism involved colonizers taking full control of a country from its people. The key component that made colonialism possible was the colonizers' strategy of dividing the population by privileging one segment of the population over another (i.e. whiteness holds privilege in Western society). Once the population was divided, the people could be easily conquered and controlled through both practices and the body. Both Spillers (1987) and Wynters (2003) suggest that when tracing inequality we need to begin by analyzing what it means to be human in western society which can be used as a way of looking at the creation of the docile body (Foucault, 1980) or a body that can easily be controlled. For example, Wynters (2003) states that colonizers tried to divide people based on religion. However, when that did not work race became the marker of the defective other. Baynton (2001) reiterates the ways in which the body was used as a way to normalize and control society by showing us that disability was used

as the justification of slavery, restrictions on immigration, and women's suffrage. Proponents who believed in the restriction on the rights of people of color and women did so under the guise that they were disabled; therefore, by restricting their rights society was protecting them. For example, it was argued that African Americans lacked the intelligence to fully participate in society, and in regard to women's suffrage, it was argued that women were not emotionally stable enough to fully participate in society (Baynton, 2001). The disabled body was and still is the marker of what the normalized body is not, and in turn, the disabled body helps to shore up the bodies that are deemed normal.

With this taken into consideration, Lukin (2013) reflected on the repercussions of using disability as a marker to impose injustices on Black bodies through his discussion of the disconnect between the Black community and the disability community. He recollected a comment by Johnnie Lacy:

I believe that African Americans see disability in the same way that everybody else sees it—[perceiving people with disabilities as] worthless, mindless—without realizing that this is the same attitude held by others toward African Americans. This belief in effect cancels out the black identity they share with a disabled black person, both socially and culturally, because the disability experience is not viewed in the same context as if one were only black, and not disabled. (Lukin, 2013, p. 309)

Lacy's comment put into words the effects that the disconnect between the Black community and the disability community has on a Black disabled woman. Her statement brought up several conversations that I have had throughout my life with my friends of color in which I've been repeatedly told, "I cannot be disabled and Black. I already have too much stacked up against me." T reiterated the disconnection between her black and disability identities. However, T saw access intimacy as creating a connection between these two identities. She stated:

Having a word that we can maybe take and be like this is what it feels like when someone recognizes me with my disability, because it's almost like you gotta pick like you either

gotta be black and disabled or disabled and Black because the reality is we are all POC then disabled. So, I think having language is important for us.

For T, access intimacy created a space in which to acknowledge all of her identities. Tesla calls the term “sacred” and compares it to unspoken understanding by people in the Black community in the following quote:

In his soft and lyrical voice he asked to see what the doctors had done. I lifted my shirt and he reached out to the incision in my belly button, eyes glistening with admiration, sorrow, and something else. Access intimacy, that sacred intimacy akin to the Black nodding of the head to another Black person.

Intersectionality was also discussed when participants spoke about the characteristics that people they experienced access intimacy with had in common. When experiencing access intimacy, participants mentioned the importance of the other person belonging to a marginalized community. However, the person did not have to belong to the same marginalized community. For instance, Sylvia stated that most of the people they experienced access intimacy with belonged to the LGBTQIA+ community. Claire, on the other hand, stated that the person she experiences access intimacy with is a person of color and belongs to the LGBTQIA+ community and she does not. The connections formed during these moments can be seen as opportunities for people from different marginalized communities to join together. Cohen and Cole (2004, as cited in Cole, 2008, p. 447) point out that if we can show people how we fight under the same system of oppression, we can begin to build community which can start during moments of access intimacy:

If you can find those places where people may not agree in terms of racial identification or sexual identification, but where they in fact suffer from state regulation or some “system of oppression,” where they share that experience, it seems to me if we can find those spaces, those are also the spaces for shared mobilization.

From this perspective, we see not only where our interests converge, but we also see how we can support one another.

Access intimacy allows us the opportunity to forge community between different marginalized groups and between people with different disabilities. As Mingus (2010) pointed out:

Every time I attempt to move through the world with other disabled folks, I am always so astounded at how hard it is for disabled people to stay together, literally. I watch how the world separates, isolates and divides us, so that we cannot move together. I watch how it is constructed for us to move with non-disabled people, instead of each other; and how it discourages folks with different disabilities from moving together. (n.p.)

Due to a society that is not set up for us, it is often hard for people with disabilities to join together due to our varying access needs that are sometimes at odds with another. Access intimacy can provide us the tools needed to work through the difficulties of our access needs that are sometimes competing and gives us the patience and respect that is needed in order to be in true community with one another.

#### E. **Limitations**

This study had several limitations. My sample primarily self-identified as White and as members of the LGBTQIA+ community. These demographics were not intentional, and future research needs to be done to explore the relationship between the LGBTQIA+ community and access intimacy. Alex mentioned that his community organizing within the LGBTQIA+ community assisted in his abilities to organize around disability, and therefore, experience access intimacy. In further research, I would like to study the correlation between access intimacy and queer identity. For example, is there a relationship between access intimacy and identifying as part of the LGBTQIA+ community? In order to do this study, I would do a qualitative study and

enlist the help of Centers for Independent Living and LGBT centers nationwide in order to find participants to understand the possible connection.

Men and people of color were underrepresented in my current study. There was one self-identified male in my sample and three people of color. In follow-up studies, I would open up recruitment to include anyone with a disability that has had an experience of access intimacy through my local disability organizations and centers of independent living. When researching bloggers with disabilities, women were disproportionately represented. Therefore, opening up the study would create new opportunities for participation. However, I may find out that access intimacy does not resonate for men.

People of color were also not equally represented in my dissertation. In order to recruit more participants of color, I would not only recruit using disability organizations, I would also recruit at events and spaces for people of color. My participants of color had strong feelings when it came to the relationship between race and access intimacy. Therefore, I would like to qualitatively study this relationship, if any, between marginalization and access intimacy. For instance, how does race affect one's experience of access intimacy?

In terms of relationships and access intimacy, there is an immense amount of work that still needs to be done. While participants described access intimacy with a variety of relationships, they did not discuss the role of access intimacy in the personal care relationship. A major finding of the current research was the factor of full communication. For participants this meant communicating their access needs through both verbal cues and body language. However, when someone is in a personal care relationship they are often in-sync with one another. The in-sync nature of this relationship, from personal experience, does not necessarily mean that I am experiencing access intimacy. Therefore, I would like to explore the role of access intimacy and



personal care. I would recruit through personal care attendant agencies and state fiscal agents. I want to interview both attendants and people with disabilities to explore access intimacy in their relationships, or lack thereof. Through this exploration, we could learn more of the nuances of the term and how, if at all, access intimacy could be learned or taught. There is still much to be learned about access intimacy, and we are just beginning to scratch the surface.

## VII. CONCLUSION

Access intimacy was more than moments for my participants. During access intimacy, participants found acceptance, validation, and support. Access intimacy allowed participants to learn and grow in their disability identity. During these moments, disability was viewed as a natural part of the human experience which allowed participants to combat internalized stigma, be vulnerable, hold space for one another, and be in the moment. Access intimacy helped them acknowledge the messiness of the disability experience. In order to embrace the messiness of disability, we must acknowledge that we may love our disability and our disabled body one day and hate it the next. Through this process, we learn from one another often in unstructured spaces or crip community (Chandler, 2012).

Throughout the course of this dissertation, I have described the complexity of access intimacy and the joy that participants feel due to these experiences. At the heart of access intimacy is true connection based on a complete understanding of someone's access needs. Participants described both experiences of access intimacy that occurred immediately as well as moments that happened in long-term relationships. In both cases, I would argue that access intimacy is intuitive because these experiences did not involve a verbal conversation, rather, the person that participants experienced access intimacy with was intuitively aware of their needs. These moments allowed participants to be their true authentic selves, access needs and all. By allowing participants to be who they are, they were able to see their disability in a positive light and accept their disability as a natural part of the human experience, in turn, allowing them to be vulnerable and safe in another's presence. It is from this outlook on disability and the sense of comfort felt that participants were able to form deeper connections with others. Kit described these moments eloquently when she wrote:

Whether through our skins or souls, stories or songs or spirits, you and I are always connecting. You long ago intuited — and then memorized — what I do and do not need, where I might stumble, why I sometimes startle. You know that the smallest of touches can smooth roughness and fill emptiness.

When thinking about the term, I am reminded of late-night conversations with a friend who said, “I didn’t fully see myself as a person with a disability until I started visualizing myself as disabled within my dreams.” By broadening our understanding of access intimacy, we can continue to deepen our interpersonal relationships and learn to love ourselves and build community.

As Disability Studies scholars, we value all people with disabilities and their varying knowledges. In order to uphold this value, we must incorporate a critical disability praxis (Nishida, 2016). Nishida (2016), in her keynote address entitled, “Critical Disability Praxis,” urges that, “recursive encounters and continuous socializing are ways for people to share in each other’s struggles, frustration, tears, laugh, and love. It is through these moments that we build knowledge” which can and does occur through moments of access intimacy. Therefore, I urge scholars to explore what a critical disability praxis would look like if we incorporated lessons learned from moments of access intimacy. To incorporate a critical disability praxis, we must also “make Interdependence a central tenet in DS, focused on care, commitment, and acting with others in mutually-dependent relationships” (Price and Kerschbaum, 2016, p. 27).

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## **APPENDICES**

## APPENDIX A

### Approval Notice Initial Review (Response To Modifications)

May 14, 2018

Ashley Volion, MA  
Disability and Human Development  
Phone: (504) 259-2176

**RE: Protocol # 2017-1300**  
**“Access Intimacy: The missing piece”**

Dear Ms. Volion:

Your Initial Review (Response To Modifications) was reviewed and approved by the Expedited review process on May 13, 2018. You may now begin your research

Please note the following information about your approved research protocol:

**Protocol Approval Period:** May 13, 2018 - May 12, 2021

**Approved Subject Enrollment #:** 20

**Additional Determinations for Research Involving Minors:** These determinations have not been made for this study since it has not been approved for enrollment of minors.

**Performance Sites:** UIC

**Sponsor:** None

**Research Protocol(s):**

- a) Access intimacy: The missing piece; Version 3; 04/23/2018

**Recruitment Material(s):**

- a) Telephone Screener; Version 3; 03/23/2018
- b) Follow up email; Version 3; 03/23/2018
- c) Call for Participation; Version 4.0; 04/23/2018

**Informed Consent(s):**

- a) Informed Consent; Version 4.1; 04/23/2018
- b) A waiver of documentation of informed consent and alteration of consent have been granted under 45 CFR 46.117(c)(2) and 45 CFR 46.116(d), respectively, for eligibility screening; minimal risk;
- c) A waiver of documentation of consent has been granted under 45 CFR 46.117 for all of the research (online and telephone interviews); minimal risk; subjects will be provided with an information sheet containing all of the elements of consent.

## APPENDIX A (continued)

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific category(ies):

- (5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for non-research purposes (such as medical treatment or diagnosis).
- (6) Collection of data from voice, video, digital, or image recordings made for research purposes.
- (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

**Please note the Review History of this submission:**

Receipt Date	Submission Type	Review Process	Review Date	Review Action
12/01/2017	Initial Review	Expedited	12/05/2017	Modifications Required
02/02/2018	Response To Modifications	Expedited	02/16/2018	Modifications Required
03/29/2018	Response To Modifications	Expedited	04/17/2018	Modifications Required
05/01/2018	Response To Modifications	Expedited	05/13/2018	Approved

Please remember to:

→ Use your **research protocol number** (2017-1300) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the guidance:

**"UIC Investigator Responsibilities, Protection of Human Research Subjects"**

(<http://research.uic.edu/irb/investigators-research-staff/investigator-responsibilities>)

**Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.**

**Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.**

**APPENDIX A (continued)**

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-9299. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Allison Brown, PhD  
IRB Coordinator, IRB # 2  
Office for the Protection of Research Subjects

**Please note that OPRS/IRB no longer issues paper documents. Stamped approved recruitment and consent documents have been uploaded to OPRSLive, and you must access and use only those approved documents to recruit and enroll subjects into this research project.**

Enclosure(s): Approved and stamped documents are available via OPRSLive.

- 1. UIC Investigator Responsibilities, Protection of Human Research Subjects**
- 2. Informed Consent Document(s):**
  - a) Informed Consent; Version 4.1; 04/23/2018
- 3. Recruiting Material(s):**
  - a) Telephone Screener; Version 3; 03/23/2018
  - b) Follow up email; Version 3; 03/23/2018
  - c) Call for Participation; Version 4.0; 04/23/2018

cc: Tamar Heller, Disability and Human Development, M/C 626

Carol J. Gill (Faculty Sponsor), Disability and Human

## APPENDIX B

### Call for Participation Post

I am conducting a research study through the University of Illinois at Chicago on “access intimacy,” and I am looking for participants with disabilities who believe they have experienced access intimacy. In 2011, Mia Mingus, in her blog *Leaving Evidence*, describes access intimacy as an experience that is an almost “magical” form of intimacy that can happen between two or more people based upon access needs. As Mingus describes, access intimacy is an “elusive, hard to describe feeling when someone else ‘gets’ your access needs” and a sense of “comfort that your [entire] disabled self feels” (Mingus, 2011).

My research study seeks to uncover the ways in which access intimacy is experienced and understood by disabled people. This study seeks the stories and input of those who identify as having a disability (e.g. physical, mental health, sensory, learning, etc.) and who have written online about experiences related to access intimacy. Participants in this study will be asked to submit a blog post that was written a minimum of 30 days prior to [insert date] that they feel reflects access intimacy. After submitting the blog post, participants will be asked to complete an interview that will take approximately one hour of their time. As a token of appreciation each participant enrolled in the study will receive a \$10 Amazon gift card. Participants may be asked to participate in a second follow-up interview in order to clarify prior interview data.

Please remember that while Google Hangout and Skype may not share the specific data collected during this research, it does collect information regarding your online activities, as per the usage agreement you accepted to use Google Hangout or Skype, and will share this information with others, including advertisers

#### How to participate?

You may be eligible if you have blogged or commented on another person’s blog about an experience that reflects access intimacy, would be willing to share your blog post or comment, and meet the following eligibility criteria:

- 18 years of age or above and identifies as having a disability (e.g. physical, mental health, sensory, learning, etc.)
- Can communicate in English
- Have written online about an experience that reflects access intimacy at least 30 days prior to [insert date].

Please, contact me, Ashley Volion, by e-mail at avolio2@uic.edu or by phone at (504) 259-2176.

Faculty sponsor: Carol J. Gill, PhD; email: cg16@uic.edu  
Institutional Review Board # 2017-1300



## APPENDIX C

### University of Illinois at Chicago Research Information and Consent for Participation in Social Behavioral Research Access intimacy: The missing piece

Principal Investigator Name and Title: Ashley Volion, Ph.D. Candidate  
Department and Institution: Department of Disability and Human Development  
Address and Contact Information: 2851 Maurepas Street, Unit A, New Orleans, LA 70119

#### **Why am I being asked?**

You have been asked to participate in the research because you are a person that is 18 years of age or above who identifies as having a disability (e.g. physical, mental health, sensory, learning, etc.). You can communicate in English, and you have written about an experience that reflects access intimacy at least 30 days prior to the date of recruitment.

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future dealings with the University of Illinois at Chicago. **If you decide to participate, you are free to withdraw at any time without affecting that relationship.**

#### **What is the purpose of this research?**

The researcher will be exploring the following questions:

1. What is the importance of access intimacy to disabled people?
2. How do disabled people define access intimacy?
3. What is the relationship between access intimacy and community?

#### **What procedures are involved?**

In order to take part in this study, you are required to submit a self-selected publicly accessible blog post or comment. Based on the blog post or comment, you will be interviewed based on a semi-structured interview guide. The interview will take an hour to an hour and a half to complete, and interviews will take place via telephone, Skype, or Google Hangout based on your access needs. Interviews will be audio recorded. You will be asked to participate in one

interview. However, if further clarification is needed, you may be asked to participate in a second interview.

#### **What are the potential risks and discomforts?**

To the best of my knowledge, responding to my interview questions or sharing your blog post(s) and/or comments will pose no more risk of harm than you would experience in everyday life.

## **APPENDIX C (continued)**

However, there is a risk that a breach of privacy (others will know you are participating in research) and confidentiality (accidental disclosure of identifiable data) may occur.

Please remember that while Google Hangout and Skype may not share the specific data collected during this research, it does collect information regarding your online activities, as per the usage agreement you accepted to use Google Hangout or Skype, and will share this information with others, including advertisers

### **Are there benefits to taking part in the research?**

There are no direct benefits to this research. However, the knowledge gained from this study may empower you by providing a space to get your voice heard. Furthermore, this study may also empower the readers by providing them the terminology to describe an experience they may have had. By pinpointing these experiences, ideas and knowledge may be gained in regards to ways in which we can facilitate disability community

### **What about privacy and confidentiality?**

To protect confidentiality, before the start of each interview, you will be asked to select a name off of a list that I have created using the current 50 most common names. The name that you have chosen will be used to refer to you throughout the study. Your pseudonym will be used to protect your confidentiality throughout the research process.

There will be no hardcopies of the interviews, blog posts, or comments. Transcript files will be labeled using a coding system that will link the data (transcripts and audio files) to you (the participant). The laptop and storage device will be kept in a locked room when I am not using them. You will be asked to participate in one interview. However, if further clarification is needed, you may be asked to participate in a second interview. All identifiable data will be destroyed six months after member checking. In order to engage in member checks, you will be contacted via e-mail after the completion of the analysis section of the study. To engage in member checking, participants will be asked to review a summary of the findings and/or discussion sections of the dissertation and asked to provide feedback in regards to what is written. Member checking is done to ensure that data accurately captures the experiences of the participants. Your participation in member checking is completely voluntary.

### **What are the costs for participating in this research?**

There are no costs to you for participating in this research.

### **Will I be reimbursed for any of my expenses or paid for my participation in this research?**

There are not any expenses associated with this study. You will to complete one interview. However, if further clarification is need, you may be asked to participate in a second interview. You will receive a \$10 Amazon gift card for each completed interview as a token of appreciation

## APPENDIX C (continued)

for your time and participation. You will have to complete at least five interview questions to be eligible for the \$10 Amazon gift card. If you decide to withdraw from the study after the interview has been completed, you will still receive the compensation.

### **Can I withdraw or be removed from the study?**

This study is completely voluntary, and you can withdraw or be removed from the study at any time.

### **Who should I contact if I have questions?**

Contact the researcher Ashley Volion, Ph.D. Candidate in Disability Studies at (504) 259-2176 or by email at: [avolio2@uic.edu](mailto:avolio2@uic.edu) or her academic advisor Dr. Carol Gill, Professor Emerita, Department of Disability & Human Development at [\(630\) 920-0924](tel:6309200924) or by email at: [cg16@uic.edu](mailto:cg16@uic.edu)

### **What are my rights as a research subject?**

If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at [uicirb@uic.edu](mailto:uicirb@uic.edu).

### **Remember:**

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

Participants should print out and save a copy of the consent information sheet for their records.

## APPENDIX D

### Demographic Survey

#### Consent

1. Have you read and do you agree to everything on the informed consent sheet?
  - a.) Yes
  - b.) No (If no, the participant will not be allowed to proceed)
2. Do you have any questions?
  - a.) Yes (If yes, participant will be directed to the researcher's e-mail address and cannot proceed)
  - b.) No

#### Demographic Survey

1. What is your age?
2. What is your racial/ethnic background?
3. What is gender?
4. Who have you experienced access intimacy with?
  - a.) Disabled people
  - b.) Non-disabled people
  - c.) Both disabled and non-disabled people
5. What is your employment status?
  - a.) Employed (Full-time)
  - b.) Employed (Part-time)
  - c.) Unemployed
  - d.) Other
6. What is the highest level of education you completed?
  - a.) Less than a high school diploma or GED
  - b.) High school diploma or GED
  - c.) Associate's degree
  - d.) Bachelor's degree
  - e.) Master's degree
  - f.) Doctoral degree
  - g.) Professional advanced degree (P.T., O.T., etc.)

## VITA

### ASHLEY M. VOLION

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New Orleans, LA 70119  
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## EDUCATION

DOCTOR OF PHILOSOPHY, Disability Studies (Exp. August 2020)  
Department of Disability and Human Development  
University of Illinois at Chicago, Chicago, IL

MASTER OF ARTS, Sociology (May 2010)  
University of New Orleans, New Orleans, LA

BACHELOR OF ARTS, Sociology (December 2006)  
University of New Orleans, New Orleans, LA

## WORK EXPERIENCE

### TEACHING

**UNIVERSITY OF IL AT CHICAGO**, Chicago, IL

**2016 – 2019**

**Teaching Assistant – Disability Studies**

DHD 101 – Introduction to Disability Studies

DHD 102 – Disability and American Film

DHD 205 – Disability, Race, Class and Gender

- Served as the coordinator of disability accommodations
- Assisted in the creation of class materials
- Graded exams and assignments
- Assisted students in achieving

**TEXAS A&M UNIVERSITY CENTRAL TEXAS**, Killeen, TX

**2010 – 2012**

**Adjunct Instructor Online - Sociology**

SOC 320. 110 – Social Stratification and Inequalities (online)

SOC 312. 120 – Environmental Sociology (online)

Develop lesson plans and reading list for each course. Teach concepts and provide constructive feedback to students.

- Designed the final exam in which each student picked a community institution and demonstrated how social stratification operated within the context of their specific institution.
- Provided ongoing technical support to those students who had never utilized Blackboard 9.1 previously resulting in their ability to navigate the software and perform in an online class with comfort and ease.
- Helped students gain appreciation and understanding of cultural diversity by providing them with activities using everyday scenarios with which to grasp difficult concepts.

## RESEARCH

**ADVOCACY CENTER**, New Orleans, LA

**2015 – Present**

### **Policy Assistant**

Assistant to the policy director. Primary duties include:

- Researching and analyzing pieces of state legislation
- Editing short videos on issues affecting the Louisiana disability community
- Attending meetings and visiting legislators
- Creating and presenting voter accessibility trainings to disability organizations throughout the state of Louisiana

**University OF IL AT CHICAGO**, Chicago, IL

**2013 – Present**

### **Research Assistant**

Primary research assistant on a project studying the effects of interstate variation of Medicaid Home and Community-Based Services policy on the experiences of opportunity on people with disabilities. Primary duties include:

- Helped in obtaining consent from the Institutional Review Board (IRB)
- Helped in the recruitment of participants
- Created demographic survey and gathered demographic information
- Conducting semi-structured in-depth interviews
- Coding and analyzing data

**UNIVERSITY OF NEW ORLEANS WOMEN’S CENTER**, New Orleans, LA

**2007 – 2010**

### **Graduate Assistant**

Plan, organize and promote activities at UNO. Develop and maintain contacts, keep resources up-to-date and input data.

- Organized and facilitated a ‘coffee talk’ series that provided professionals the opportunity to present their academic research.
- Created an easily accessible database for women that included updated community resource and scholarship information replacing data that was obsolete and outdated.
- Provided backup when the Director was unavailable by overseeing that shift workers arrived and left on schedule, that they knew what they were to do and that all tasks were completed correctly.
- Partnered with reps from other University Women’s Centers around the city to plan and support a two day event commemorating “The Vagina Monologues” resulting in recognition for the center.

**UNIVERSITY OF NEW ORLEANS**, New Orleans, LA

**2008 – 2010**

**Center for Hazards Assessment, Research and Technology**

### **Graduate Research Assistant**

Chart hurricane indicators for the UNO-CHART. Provide and distribute information for projects involving the Jean Lafitte, LA area, as well as, maintain the history of the Manila Village in Jean Lafitte.

- Developed a hurricane tool guide that can be used by coastal communities in the aftermath of natural disaster through the use of Participant Action Research with the Town of Jean Lafitte.
- Assembled a meeting of 13 Louisiana Coastal Communities in order to provide resident the opportunity to network and obtain resources from one another.
- Provided the CHART Team conducting research in Jean Lafitte with local contacts, updates on local events and coached them on how to engage with community members resulting in their acquiring additional research data.
- Conducted in-depth qualitative interview with residents after research showed a high resilience in the Jean Lafitte population after Hurricane Katrina but not the reason why. Determined that their community bond and sharing of resources was a large part of the reason.

- Utilized research results to host and organize an event including 13 additional coastal communities in LA which helped residents share knowledge and led to the creation of a hurricane resiliency tool and resulted in Jean Lafitte receiving government funding for hurricane preparation tools.

## PUBLICATIONS

- Volion, A. (2015). An incomplete story. In R. Luczak (Ed.), *QDA: Queer Disability Anthology* (p. 44). Minneapolis, MN: Squares & Rebels.
- Laska, S., Peterson, K., Alcina, M.E., West, J., Volion, A., Tranchina, B., and Krajeski, R. (2010). Enhancing gulf of Mexico coastal communities' resiliency through participatory community engagement." Center for Hazards Awareness, Research, and Technology (CHART) Publications, Paper 21. New Orleans: University of New Orleans. Retrieved April 29, 2016 from [http://scholarworks.uno.edu/chart\\_pubs/21](http://scholarworks.uno.edu/chart_pubs/21).

## AWARDS

Ethel Louise Memorial Fellowship, 2015-2017  
 Frederick J. Krause Scholarship on Health and Disability, 2014 – 2015  
 Anne Hopkins Memorial Scholarship, 2013  
 Jack Taylor Memorial Scholarship, 2013  
 Outstanding Contribution Award, UNO's Women's Center, 2008 – 2009  
 Recipient, Town of Lafitte Scholarship, 2002  
 Recipient, Cox Cable Hero, 2002

## PRESENTATIONS

### Disability Advocacy

Volion, A. (2018, March). From accommodations to accessibility. Powerpoint presentation presented at Advocacy Center of Louisiana, New Orleans, LA.

Volion, A. (2018, March). Words count: engaging with people with disabilities Part 2. Powerpoint presentation presented at Advocacy Center of Louisiana, New Orleans, LA.

Volion, A. (2018, February). Words count: Engaging with People with Disabilities. Powerpoint presentation presented at Advocacy Center of Louisiana, New Orleans, LA.

Volion, A. (2017, November). Pity parties and charity cases. Powerpoint presentation presented in DHD 102: Disability and american film at the University of Illinois at Chicago, Chicago, IL.

Volion, A (2017, August). Community Conflict within the Disability Community Creating Social Change: Possibilities within Moments of Access Intimacy. Powerpoint Presentation presented at The Society for the Study of Social Problems, Montreal, Canada.

Volion, A. (2016, December). The importance of collaborative advocacy to the disability community. Powerpoint presentation presented at Families Helping Families of SELA, Belle Chasse, LA

Volion, A. (2016, August). Finding your voice: Becoming empowered. Powerpoint presentation presented at the Empowerment Academy, New Orleans, LA

Volion, A. (2016, July). Community living. Powerpoint presentation presented at the Empowerment Academy, New Orleans, LA

Gallegos, D., Pasquantonio, V., and Volion, A. (2016, July). LEP beyond spoken language. Panel discussion at the Louisiana Language Access Coalition, New Orleans, LA

Volion, A. (2016, June). Living a fulfilling life as a person with a disability. Powerpoint presentation presented at Families Helping Families of SELA, Chalmette, LA

Volion, A. (2015, October). Living a fulfilling life as a person with a disability. Powerpoint presentation presented at Families Helping Families of SELA, Chalmette, LA

Volion, A. (2013, March). Being a disability advocate. Powerpoint presentation presented at LSU Human Development Center – LEND, New Orleans, LA

#### Medicaid Home and Community-based Services

Grossman, B.R. and Volion, A (2017, August). Family, Friends, Peers, and Volunteers: Exploring Their Role in Cross-State Move Success for Medicaid HCBS Users. Powerpoint Presentation presented at the The Society for the Study of Social Problems, Montreal, Canada.

Grossman, B.R. and Volion, A (2016, May). Disability, mobility, and opportunity: State policymaker perspectives. Powerpoint Presentation presented at the Congress of Qualitative Inquiry, University of Illinois at Urbana-Champaign.

Grossman, B.R. and Volion, A. (2015, August). Locked in or busting out: Comparing the experiences of Medicaid HCBS users who successfully moved out of state with those who did not. Powerpoint Presentation present at the Society for the Study of Social Problems, Chicago, IL.

Grossman, B.R. and Volion, A (2015, May). Opportunity deferred: Disability and intrastate confinement in Medicaid Home and Community-based Services. Powerpoint Presentation presented at the Congress of Qualitative Inquiry, University of Illinois at Urbana-Champaign.

Grossman, B.R. and Volion, A. (2015, April). Living at home and in the community: Personal opportunities, structural challenges. Powerpoint Presentation presented in Disability and Human Development 202, University of Illinois at Chicago.

Volion, A. (2014, June). Trapped: A first person narrative account of lack of portability in the personal care attendant system. Powerpoint Presentation presented at the Society for Disability Studies, Minneapolis, MN.

Grossman, B.R. and Volion, A. (2014, August). Intrastate confinement as a barrier to economic opportunity for people with disabilities. Powerpoint Presentation presented at the Society for the Study of Social Problems, San Francisco, CA.

#### Disability and Sexuality

Blanco, M.T. and Volion, A. (2014, April). Sexuality and disability: What health professionals need to know. Powerpoint presentation presented at LSU Human Development Center, New Orleans, LA

Blanco, M.T. and Volion, A. (2013, November). Sexuality and disability: What health professionals need to know. Powerpoint presentation presented at LSU Human Development Center, New Orleans, LA