## Disability, Blackness, and Online Community: Black Twitter as Self-Narrative

by

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#### **ABSTRACT**

Black disabled people, especially those with invisible disabilities, are often not included or welcomed by all in the disabled community. In addition, Black disabled individuals also face discrimination and exclusion within the Black community due to ableism. This project will be an investigation of Black disabled community and health culture in online spaces, specifically using Twitter hashtags as a starting point. This research project is about helping to write the whole story, an opportunity that my Black ancestors did not have but still demand, for our generation and those who will come after us. For this project, I conducted an inductive textual analysis, narrative analysis, and observation of Twitter. In comparison to previous research, my findings confirm the exclusion of Black disabled people and need for disabled individuals to create selfnarratives of their own. The self-narratives of Black people with disabilities on Black Twitter are reflective of their life experiences and personal struggles. These self-narratives are not specific to just one or two people on Twitter, but a large community of people who share common experiences. Spaces like #BlackandDisabled and #ActuallyAutistic have allowed Black disabled people to empower themselves and others. It also gives them space to speak up about racism and exclusion within the disabled community at large and reframe their identity as Black and disabled people who belong, and always have belonged, within the disabled community.

#### **CHAPTER ONE: INTRODUCTION**

Black disabled people, especially those with invisible disabilities, are often not included or welcomed by all in the disabled community. In addition, Black disabled individuals also face discrimination and exclusion within the Black community due to ableism (Bell, 2011). When people think of a person who is disabled, they tend to automatically think that they are white (Bell, 2010; Berghs and Dyson, 2022). This is because of exclusion in the disabled community at large, discrimination, hyper able-ness stigma, and lack of representation in the "mainstream" (Brock Jr., 2020; Nolan 2020; Bailey and Mobley, 2018). They also face personal attacks and racism from white people within and outside of the disabled community (Miles et. al., 2017). This means that they must look elsewhere for safer spaces. These are some of the reasons why Black disabled people go to online spaces, such as Twitter, to create a community for themselves.

Online (or virtual) spaces provide a place for them to connect with other disabled people that are Black. It gives them a place to voice their experiences that would otherwise be shot down and brushed off by the majority white disabled community overall. Online spaces also give Black disabled individuals the freedom to create their own narratives about what it means to be disabled through their own eyes, without input from those who don't understand the intersections of Blackness and disability. I suspect that there are even more intersections in this community, but to date, the ways in which Black disabled individuals construct meaning of disability, Blackness, and community have not been examined.

One hand, there is some research on Black community and culture in digital spaces, but they do not examine any other intersections such as disability, gender, and sexuality (Graham & Smith, 2016; Bonilla and Rosa, 2015; Brock J.R., 2020; Devlieger et. al, 2000; Yang 2016). On the other hand, there is also research that focuses on the experiences of individuals with disabilities at the intersection(s) of disability, gender, and sexuality however, they do not include black community or culture in their research (Sannon et. al, 2019; Kanter et. al, 2019; Samuels, 2003; Egner, 2019). However, in this thesis I will address this gap by looking at Black disabled community on Twitter. Specifically, using a Black Feminist approach that considers how the intersections of race, gender, sexuality, and disability are connected to one another (Haywood, 2022). Such an approach will allow me to be aware of these intersections while simultaneously allowing for the self-narratives of users from Twitter to speak for themselves without altering or erasing their experiences.

The goal of this project is to explore narrative productions and meanings of disability, Blackness, and community in online spaces designed for and by Black disabled people. In doing so, the research seeks to reaffirm Black disabled people as an important part of the disabled community. In this thesis, I use narrative analysis, inductive textual analysis, and observation of Twitter to explore the self-narratives of Black folks with invisible disabilities. In the next section of this thesis, I will briefly discuss self-narrative and self-stories. Then, I will give a brief overview of disability followed by Blackness and Black Twitter, intersectionality, and Black Disabled community. Next, I will discuss and introduce my research questions and theoretical approach. After, I will discuss my methods. Finally, I will discuss my findings and conclude.

## **Background**

Defining Disability

This research is centered around three key concepts, disability, Blackness, and community, which are important to define. Let us start with the term disabled. Who does it refer to and what does it mean to be disabled? What is a disability? According to Berger and Wilbers (2020) a disability is, "...an inability to perform a personal or socially necessary task because of that impairment or the societal reaction to it" (pg. 6). The term disabled refers to someone with a disability. Some people prefer the term 'person with a disability' instead of 'disabled person' because of the negative connotation that can sometimes come along with it. Others embrace the term and refer to themselves as a disabled person because they view it as reaffirming their identity and personal experiences. The term handicap is no longer used because it has a negative connotation when it is used to refer to a person with a disability (Berger and Wilbers, 2020).

For the sake of this paper, I will be using the terms disabled people and people/person with a disability interchangeably out of respect for people who prefer one term or the other. Person first language is preferred by many, but there are also people who prefer to use the disabled term first. I personally prefer the latter, but making people feel included in a way that they are comfortable in a safer space is more important to me than my opinion.

In this project, I use the term "disabled communities" to refer to safer spaces where disabled people gather (literally or figuratively). Some disabled communities are formed as a need for support based on the type of disability they have or, a specific condition. A few examples are communities for wheel-chair users, those who are mute, deaf and/or hearing impaired, have an intellectual and/or learning disability, or an entity such as the Muscular Dystrophy Association. Communities also refer to organizations, formal or informal, that are for

disabled people who are interested in disability activism and advocacy. An example of this is the National Black Disability Coalition or the American Association of People with Disabilities.

Communities such as these are often formed due to the exclusion of people with disabilities. This can be through physical barriers like areas being inaccessible to them or institutional ones that prevent them from being in the same spaces as everyone else.

### Disability Studies

Disability studies is a relatively new area of study in the social sciences (Gerschick, & Stevens, 2016; Egner, 2016; Green and Loseke, 2020). Even early in the creation of the American Sociological Society (ASA), disability was rarely discussed as an area to explore using social research. According to Gerschick and Stevens (2016), of the available articles from the yearly ASA meetings between 1907-1916, 64% of them did not mention disability at all. Of those that did, most referred negatively to disabled people. This included ableist language, some pitying, and language that labeled disability as a non-normative and "defective" state. This negative language was often the result of viewing a disability as a personal moral failing on the part of disabled people and/or their families. It wasn't until the 1970s and 80s that disability began to become a part of the larger conversation in academia and politics because of the Disability Rights Movement (Green and Barnartt, 2017). Much of the work that is being done in disability studies is still fairly new in comparison to the rest of the discipline. It is especially limited in areas that look at a number of different intersections at one time.

#### Disability Theory

The Disability Rights Movement directly affected the development of disability theories. These theories criticized dominant conceptualizations of disability within prominent literature from the medical sociology field. This field located the "problem of disability" in the minds and bodies of individuals rather than in negative societal reactions to bodies and minds that differ from the "norm" (Egner, 2016). Medical sociology also tended to focus on the experience of doctors and other medical professionals in relation to society at large and the social structures related to medicine rather than the experiences of people with disabilities themselves. (Egner, 2016; Hollingstead, 1974). Medicalization is described by Conrad (1992, pg. 209) as "a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illnesses or disorders (Egner, 2016). In relation to disability, the medical model viewed a disability as something that an individual needs to have treated, fixed, and/or cured (Berger, 2013). Critiques of the medical model theories would later become central to the formation and continued expansion of the sociology of disability (Egner, 2016).

The medicalization of human differences led to the development of other theories. The constructionist, social model, and feminist critiques came about as a result. Other theorists continued to build on these critiques which became the foundation which queer/crip theory were built upon. Social construction critiques of medical theory argued that the medical community has power over individuals because they have the "medical expertise" to determine which behaviors, activities, and experiences are medical problems that need to be cured (Egner 2016). Crip theory built upon this by arguing that the medical community defines some bodies and behaviors as deviant by normalizing rhetoric that describes some bodies as "normal" and others as abject. Crip theory also builds on ideas from the social model of disability such as being aware

that disability is reliant on social and historical contexts and not viewing disability as a personal failing (Egner, 2016). However, the social model focuses on disability in physical environments while crip theory focuses on discourse.

Although, they both agree that disability is not something that can be cured by doctors because it is a social issue, crip theorists conceptualize disability as an interaction between bodily experience and society rather than as a purely social phenomenon. They argue that it is important for disabled people to have agency over their own bodies, even if that means they wish to seek treatment or cure. Crip theorists also reject narratives of disability that equate a cure with progress and dehumanize disabled people in the process, such as the medical model. Crip theory argues that it is important not to oversimplify someone's personal identity and emphasizes the importance of equally considering disabled experiences of the body as well as physical and social environments (Egner, 2016). Crip theory also suggests that future research should look into the life experiences of people who have an intersectional queer/crip lived experience, something that is a major goal of this project (Egner, 2016).

In this section, I gave background on disability by defining disability, locating disability studies within the discipline, and gave an overview of disability theory. It is important to give this background for users who may have no context or previous experience with disability or sociology in general. In addition, being clear about what terms I will be using and why I am using them ensures that everyone who reads can fully understand what I mean when discussing the experiences of Black disabled people and their self-narratives. In the next section, I will discuss Blackness and Black Twitter, intersectionality, and Black disabled culture to give background on the experiences of Black folks in general and how it is related to disability.

#### **Blackness and Black Twitter**

The first important key term related to race that readers may not be familiar with is Blackness. For the purposes of this research, I define Blackness as, a word used to describe how a Black person feels about their personal identity in regard to their race. Mainly, it refers to one's feelings about what it means to be Black and how it shapes their life. It is a term generally used by Black Americans although it can be used by any person with African/Black ancestry.

Blackness is very similar to the concept of Black identity. The only difference is that Blackness is used as more of a descriptor of what it means to identify as a Black person. It is used to describe a state of being, a way of doing things, a way of looking at the world that is unique to only Black people (Gates, Jr., 1963; Brock Jr. 2020). It is difficult to define because it has a different meaning for different people. However overall, most view it as an important but separate part of Black identity that describes the action of expressing one's identity. Black identity is a broad term that describes identifying as a Black person (Greenwood, 2022).

In contrast, Blackness is all about feeling, existing, and expressing. Blackness can refer to the way that Black people wear their hair for example. Hair has always been an important part of our Black identity and a way to express our Blackness (Owusu, 2003; Tissa, 2021). To give another example, Blackness can also mean simply existing as a Black person. Everything that we do is scrutinized as a Black identifying person in America because we are not white. Blackness was assigned to us, Black people, to oppress us, to make clear that we are different from white people and that to be Black, is not good (Owusu, 2003; Gordon, 2022). To be Black is to be "other" and white is viewed as the default. That is whether it was by physically separating via segregation, the school to prison pipeline, or more subtle like the wealth gap between Black and white people (Winant, 2004). Therefore, to embrace and express and exist as ourselves in all of

our Blackness, in all of who we are, means to challenge systems of racism. It is central to the concept of Black identity.

Regarding social media, Black Twitter refers to the collective of Black identifying people on Twitter. More than that, it is a space where Black people have started powerful movements that have created real change online and offline. Black Twitter is an important place for Black people because it is a place where they can make their voices heard when it is drowned out and excluded in "mainstream" society.

Graham and Smith (2016), argue for Black Twitter as "having the form and function of a counter public" as described by Nancy Fraser in which "parallel discursive arenas where members of subordinated social groups invent and circulate counter discourses to formulate oppositional interpretations of their identities, interests, and needs". In other words, they argue that Black Twitter is a space that came about as a response to the oppression of other groups who exclude them and do not consider their identities, interests, and needs. Disabled communities can be viewed in the same way. Thus, Black disabled communities are those formed by Black disabled people who do not feel seen or heard in Black community or broader disabled community. Twitter is currently a popular medium for Black disabled community development.

In order to understand Blackness, disability, and community, we have to take a look at how these meanings are constructed by Black disabled people. This topic has not been explored and should be researched. It is important that we analyze a medium such as Twitter because the data comes directly from Black disabled people, who are often excluded in both the Black and disabled community.

## **Intersectionality As It Was Meant to Be (Actually Intersectional)**

Much of the work in the field of sociology claims to be intersectional, while simultaneously leaving out people of color, LGBTQ+ folks, and disabled people. This work is a critique of current uses of intersectionality and a step toward what intersectional research should look like. According to Egner (2019), "Crip theory offers a variety of tactics that can be useful to scholars interested in adding nuance to intersectionality. One tactic is to understand intersectional identities as fluid and complex". This is exactly the approach that I am aiming for with this project.

It was hard to find one solid definition of the term intersectionality, it seems to be constantly changing and evolving from how Crenshaw used it (Hill Collins, 2015). The concept originated from KW Crenshaw in an article from the Stanford Law Review. In it, she discussed intersectionality but was focused on the violence and oppression(s) faced specifically by women of color, community organizing, and identity politics. The term was later re-taken and popularized by Hill Collins. Since then, it has become an important topic inside and outside of academic circles. However, much of the work done that uses the word intersectionality in recent years, does not mention any of these topics, never even discussing women of color in most instances (Hill Collins, pg. 10, 2015).

For these reasons, it is important for me to understand and define intersectionality in the context that it was meant to so that I can apply it to my own work. According to Hill Collins (2015), "Despite its ubiquity, intersectionality as critical praxis remains underemphasized within intersectionality as a field of study and within scholarship that draws on intersectionality as an analytical strategy. This underemphasis may be due in part because these areas valorize studying and/or writing about intersectionality over practicing it. In addition, the underemphasis on

intersectionality as critical praxis within academia most likely reflects efforts to avoid the implicit political implications of intersectionality itself (pg.16). For this project, intersectionality is not about throwing multiple lenses on and writing about what can be seen. Instead, I'll be working and researching in a way that actively practices it. For the purposes of this thesis, I will use the term intersectionality as defined by Hill Collins. In the words of Hill Collins (2015), "Intersectionality references the critical insight that race, class, gender, sexuality, ethnicity, nation, ability, and age operate not as unitary, mutually exclusive entities, but as reciprocally constructing phenomena that in turn shape complex social inequalities" (pg. 2).

Although there is work out there at the intersections of disability, technology, and queerness (Kafer, 2013; Maloney 2011; Samuels 2003), it does not include much, if any, on race. Similarly, there is much work being done on race in sociology, but much of it does not include disability or look at multiple intersections at once. There is no specific methodology that makes a piece of work intersectional. Black women are often used as the 'default' group of people to study only because the concept of intersectionality was introduced by Black women. This doesn't mean that Black women shouldn't be understood, but, that the intersection between their blackness and woman-ness is the only one that is being focused on. It leads to the assumption that there aren't other areas, like class, gender, disability, among others, that can shape their life experiences (Naples, Mauldin, and Dillaway, 2018).

#### Black Disabled Community Matters: Taking Into Account Black Culture

The lack of literature and research interest on Black disabled people leaves a huge gap in the literature (Shifrer & Frederick, 2019). There are a couple of reasons for this, one major reason being that there are assumptions that there is no disabled culture or community in Black communities (Devlieger, Albrecht, & Hertz, 2007), (Devlieger & Albrecht, 2000). Work by Devlieger et. al (2000) investigates the experiences of low income Black disabled people in inner city Chicago neighborhoods. Their findings acknowledge that Black people understand disability differently through what the writers call a "culture of persecution" that is closely tied to their day-to-day experiences with racism, their disability, and the harsh realities of life in poor inner city communities. At the same time, they deny Black people a place in the disabled community because their understanding and "participation" did not fit into "disability culture" at large. This gap becomes much larger when you consider the already understudied group of disabilities that are/could be considered invisible disabilities.

My counter is this: Are their day-to-day experiences as Black disabled people not enough? Is living, surviving, and existing simply not enough? Who is to say that their culture and understandings do not make up a disabled community simply because it does not appear the same way? How can one know for sure that there is no Black disabled community if there is no one investigating outside of specific, limited instances? Should the experiences of a few Black men speak for the entire community? This leads to an important point, scholars don't know what to look for as Black communities have their own unique and specific culture. Considering that many of the scholars who are in positions to do this kind of research are white, many do not have any reference for, are aware of, or understand these differences. Therefore, they assume that there is no disabled culture or community because it does not show up in the same way as it

would in white "mainstream" disabled community. That is not to say that research on Black communities can't be done by white researchers, but, they have to, at the very least, understand Black culture and to do that, you have to know or get to know people within the culture.

In addition, it is important to consider how the history of slavery and oppression have influenced Black culture and disability. Revealing one's disability was (and still can be) dangerous for Black people, especially during enslavement. If a person could not accumulate capital in the manner that enslavers wanted them to, then they were deemed unvaluable and thrown away, literally and figuratively (Barclay, 2016). As a result, Black people had to minimize and hide their disabilities to survive. Even today, centuries later, the effects of this still affect the way that Black people communicate and disclose to one another. If they are sharing that they have arthritis, they may say something like "my arthritis is acting up" or "you know grandma got bad arthritis". Similarly, for diabetes people may say something like "Mm-hmm, they got sugar." or "Oh no, I can't eat that, it'll run my sugar up!"

Something else to consider is the impact that America's racist past (and present) has had on Black Americans regarding health and disability. Black people have had to be "twice as good" at everything to get by because of the ableist stereotypes and stigmas that assert Black men and women are naturally stronger than everyone else (Bailey and Mobley, 2018). Their bodies were, only viewed as a means of production. So, identifying as disabled was not an option for them, they had to do the opposite and be "hyper able" (Abdullahi and Oliver, 2020). For generations, we have had it instilled in us, often against our will, that we are only useful if we are productive (Washington, 2006). It leaves little to no room for Black people to identify as something that denies productivity any importance in our lives (Bailey and Mobley, 2018). That is not to say that Black people don't or cannot identify as disabled, many do but, it is stigmatized

in the Black community because of the history of health, eugenics, and disability in America. Miles (2020) elaborates on this in saying, "In the Black community, most are not conscious of the oppressive belief that disabled people are inferior members of the community and really should not be active, visible parts of it. If the old saying is that children are to be "seen and not heard," then disabled people are considered to be "unseen and unheard."

Considering all of this, it is especially important to me to understand the viewpoint of Black people with invisible disabilities specifically. They are at an important intersection where it is often not safe to disclose their disabilities publicly but also may not feel comfortable doing so around family either. Given the discussion on disability thus far, therefore intersectionality must be included in the work that is proposed in this project. To put it more plainly, disability is central to the social construction of race and directly influences culture because of that (Shifrer & Frederick, 2019). Disability is a social construction that is present at every other social construction such as race, class, gender, sexual orientation, and age. It intersects in many areas not only because people tend to have intersecting identities, but because of the way that such identities have been stratified (Shifrer & Frederick, 2019).

According to Shifrer & Frederick (2019), "Stratifying categories (e.g., class, race, and gender) are social constructs, legitimated through the social production of moral and biological attributions, separation, and dichotomization" (pg.2). That is to say, legitimization begins with moral and biological attributions which are then followed by separation, and dichotomization. Disability ideology came about as a direct result of capitalism when people moved from working in farms to factories during industrialization (pg. 5). Productivity became a way to legitimize the separation of disabled people from everyone else because they were "no longer useful" (pg. 5). Disability was later used to justify the stratification of race by deeming Black people as

"defective" to defend slavery (pg. 6). It was also used to justify the stratification of gender and gender discrimination in framing women as "being mentally, emotionally, and physically disabled" (pg. 6). Homosexuality was framed as a disability as well as being of an older aged person to legitimize discrimination against the two groups (pg. 6). Although many disabled people are older, it doesn't mean that all older people are disabled.

In this section, I defined and explained Blackness and why it matters relating to Twitter. Next, I discussed and defined intersectionality and its ever-changing nature. Lastly, I explained why it's important to consider and include Black culture in our analysis of disability. In doing so, it shows the importance and validity of considering these elements in my research. The next chapter will focus on discussing my research questions, narrative theoretical approach, and methods.

# CHAPTER TWO: RESEARCH QUESTIONS, THEORETICAL APPROACH, AND METHODS

#### **Research Questions:**

- 1. What meanings of disability are constructed in posts on Black Disabled Twitter?
- 2. What meanings of Blackness are constructed in posts on Black Disabled Twitter?
- 3. What meanings of community are constructed in posts on Black Disabled Twitter?

This is an important topic because the sociology of disability is a fairly new, and constantly growing field of research. Even within disabled community, a supposed safer and "wholesome" space, Black people and people of color are told that they don't fit into "disabled community" or have "disabled culture" (Devlieger & Albrecht, 2000). This research project is about helping to write the *whole* story, an opportunity that my Black ancestors did not have but still demand, for our generation and those who will come after us (Moore, 2020). To do this, I will use qualitative methods that are as intersectional as possible and narrative techniques to collect data that tell the story of Black disabled people in their own words and point of view. This project will be an investigation of Black disabled community and health culture in online spaces, specifically using Twitter hashtags as a starting point.

## **Theoretical Approach**

The Importance of Narratives in Meaning Making

Stories produce meanings that help us to understand and navigate the social world (Loseke, 2019), we call this process of producing meanings meaning making. These narrative meanings affect the way that we collectively come to an understanding of something as a society (Loseke, 2019, pg. 1). Meaning also affects the way that we make judgements, feel about something, and determine morality (Loseke, 2019, pg. 3). Our actions and interactions produce meaning at all levels of social life (Loseke, 2019, pg. 6). Even so, it does not mean that we all have the same shared understanding of stories or their meanings (pg. 16).

If you were to get on social media platforms, such as Twitter, Instagram, or Facebook, this immediately becomes obvious. Some of the most trending stories are those that have different meanings to different groups of people. Sometimes these narratives can be used to change the opinion of others and/or bring attention to important issues, something that was done on Twitter using the hashtag #BlackLivesMatter. According to Loseke, stories have power. "Cultural conventions embed storytelling within hierarchies reflecting and perpetuating power" (pg. 16), that is not to say that this hierarchy is fixed. This power also extends to who does or doesn't have the right to tell the story, entitlement, and who is deemed believable (Loseke, pg. 17, 2019). How narratives are presented also change depending on who is telling the story and where they are telling it (pg. 17).

An important form of narratives are "self-stories". Loseke (2019) describes it as "an important route to identity creation and maintenance" (pg.41). Self stories are narratives written "by the self and featuring the self as the main character and self-experiences as story events" (Loseke 2019, pg.41). This form of meaning making not only allows the individual to create their

own meaning and understanding from their own point of view, but also share it with others who are trying to make sense of their own experiences in a relatable way. However, self stories have some challenges of their own. Good self stories include personal experiences in the past and present as well as try to make predictions about the future (Loseke 2019, pg.41). This is difficult to do when the world is constantly changing and time keeps flowing forward. In addition, their stories must be deemed believable and practical by the social world, which leads to the exclusion and/or discrimination against the stories of marginalized groups (Loseke 2019, pg.17). This further leads to an oversaturation of one type of self story when people are looking for something new that looks similar to their own experiences. The self stories of Black disabled people are especially important considering this.

Inspired by Loseke's term self-story, I have come up with the term self-narrative. This idea is inspired by the work of Loseke (2019) on narrative productions of meaning and self-stories. According to Loseke (2019), self-stories are, "...a story authored by the self-featuring the self as the main character and self-experiences as story events. Rather than seeing a life as simply "one damned thing after another," self-stories allow the creation of coherence" (pg, 41). Self-narratives are different than self-stories because self-narratives detail the specific interpersonal experiences of a person or group of people. They focus on the current, present, experiences of the narrative maker, they aren't just the stories of some far away, unimaginable people. They are tangible, lived experiences, express their inner feelings, and identify with themselves and others. Self-narratives are powerful in the way that they allow marginalized groups to tell their own stories in their own way. It allows a person or group of people to tell their personal story in their own words, untouched and unchanged by outward sources that would otherwise ignore and/or change their stories.

#### **Narratives About Disability**

Neurodivergence, Chronic Illness, and Similar Harder To "See" Identities

Narratives are important because they help us to get better understandings of the life experiences of others, especially when the person's identities can be easily misunderstood. Work involving narrative is still fairly recent in the discipline; work did not begin in this area until the 1980s. Social scientists tended to focus on objective, measurable concepts instead of the subjective, emotional, moral, and complex meanings found in narratives. Loseke and Green (2020) argue that narratives are important in all aspects of social life because they are "a meaning-producing communication form and relatively shared meaning is necessary for individual well-being and social organization" (page 2). That is to say, narratives shape the way that we as individuals in a socially organized society come to shared meanings. Narratives about disability affect the way that we understand who can be disabled and what their disability "should" look like. Many of these narratives are often informed by ableism in relation to individuals with disabilities, especially those with invisible ones.

This becomes apparent in relation to disability in the following, "Although some disabilities are noticeable to onlookers because of the way a person looks or because they use an assistive device, many disabilities are not. Thus, disability studies have advanced the notion of invisible disabilities to refer to these types of conditions. Cognitive disabilities may be the most obvious kind of invisible disability, but physical disabilities can be invisible as well. This invisibility can lead to misunderstandings, false perceptions, and judgements from others" (Berger and Wilbers, pg.34, 2020). This goes against the often-preconceived narrative of what it means to be disabled, leaving people who are neurodivergent, chronically ill or disabled in other ways not immediately "visible" excluded in most cases.

Why Invisible Disabilities?

For my research interests, the term invisible disabilities is used to group disabled people who have similar experiences based on the invisible nature of their disability. This includes people who are neurodivergent, chronically ill, have a mental illness, or other disabled identity that is harder to "see". It is important to me to use this term because it is inclusive of many groups of people who are usually not considered "disabled enough" or told that they "look fine" (Kattari et. al, 2018). In addition, it includes the experiences of people with serious mental health conditions such as schizophrenia, bipolar disorder, dissociative identity disorder, etc., that aren't often classified as disabilities although these conditions are extremely disabling and directly impact the way that they live their everyday lives. Defining and grouping these conditions as disabilities will help people to understand what disability "looks like" and show that these groups of people should be included in government/public classifications of disability that would allow them to receive support resources.

The exclusion of persons with invisible disabilities from dominant considerations of disability leaves them to create their own spaces and narratives about what it means to be disabled, similar to the way that Black people create their own spaces on Black Twitter and disabled people create their own communities. Combining these and taking them all into consideration, invisible disabilities, Blackness, and disability, would make room for a new narrative to be seen and heard by others. This is why intersections are so important. Sexuality and gender identity are important narratives to consider as well because of this. Justine Egner does something similar with the term "neuroqueer".

According to Egner, "Neuroqueer is a collaboration of activists, academics, and bloggers engaging in online community building. Neuroqueer requires those who engage in it to

disidentify from both oppressive dominant and counterculture identities that perpetuate destructive medical model discourses of cure" (2019). A neuroqueer project not only questions typical conceptions of gender but also pivots away from normative gender categories altogether. Neuroqueer is a queer/crip response to normative discussions about gender, sexuality, and disability as pathology" (J. Egner, 2019). These definitions are closely related to neurodiversity. "The concept of neurodiversity, which first appeared in print in an article by Harvey Blume that was published in *The Atlantic* magazine in 1998, originated among self-aware members of autistic communities. Nowadays, neurodiversity is used to refer to a variety of atypical cognitive styles that are due to neurological differences, including autism, intellectual disabilities, learning disabilities, ADHD, epilepsy, posttraumatic stress disorder, bipolar disorder, Tourette's syndrome, and schizophrenia. But the impetus for neurodiversity as a social movement arguably comes from the community of relatively high functioning people on the autism spectrum. Within this community, people with conventional styles are referred to as "neurotypicals" or "normies", while people with atypical styles are viewed as part of the normal variation of human beings" (page 17, Berger and Wilbers).

## Narrative, Digital Ethnography, and Twitter

This brief literature review will focus on what we already know about meaning-making in online spaces from previous literature. It will consist of a brief review of empirical research on digital social movements in relation to hashtags on Twitter. The overview also includes platforms such as Tumblr where hashtags are used in relation to invisible disabilities and narrative. This is valuable for my work because it has examined the use of social media among Black and disabled individuals, separately, and helped to identify key concepts and methods that I will employ in my research.

Work by Bonilla & Rosa (2015) is an analysis of the digital social movement that occurred on Twitter under the hashtag #Ferguson after the murder of Michael Brown. Hashtags are words or phrases that are used on social media to keep track of a certain topic or discussion. The authors use hashtag ethnography to examine the way that hashtags were used on social media as a form of digital activism against police brutality and the racialization of Black bodies. Some of the most important concepts used in this article are digital anthropology, hashtag ethnography, digital activism, semiotics, Twitter, and Michael Brown. In discussing the use of hashtags, they found that hashtags were often used on Twitter as part of an indexing system that allows users to find a specific topic while simultaneously serving to quickly frame and assign meaning to their tweets. In doing so, they link together a wide range of tweets, even though they may not be used in the same way or have nothing to do with one another.

One important takeaway from this article is that Twitter allows for marginalized/ overly racialized groups to construct their own counternarratives using the digital platform. They serve as "entry points into a larger and more complex world". By taking a closer look into the experiences of individual users, it allows for tweets to be understood in the broader context of the movement or topic. The use of hashtags such as #HandsUpDontShoot, #IfTheyGunnedMeDown, and #NoAngel suggested that social media is an important place to emphasize the way that Black people are overpoliced, over-surveilled, stigmatized, and stereotyped.

Similar work done by Yang (2016) uses the case of #BlackLivesMatter to emphasize how important narrative agency is in hashtag activism. The concepts are agency, narrative, meaning making, hashtag activism, and #BlackLivesMatter. Yang applies Karlyn Cambell's theories on rhetorical agency to narrative in order to create his own concept combining the two.

Part of Yang's main argument is that narrative and narrative agency are central to hashtag activism. Hashtag activism occurs when there are large amounts of social media activity, such as likes, comments, and retweets, in response to a certain hashtag. A hashtag is an identifier that users on Twitter can add into their posts to link it to a specific event, person, place, and/or conversation. Narrative agency as defined by the author is "the capacity to create stories on social media by using hashtags in a way that is collective and recognized by the public". He argues that hashtag activism is narrative in form because the comments and retweets are made up of personal stories and are organized in the order that they were tweeted (from the time and date of the first instance to the last).

Using Karlyn Campbell's propositions of rhetorical agency, he justifies hashtag activism in the case of #BlackLivesMatter as communal, invented, skillful, and protean. It is communal because of the community engagement that occurs in an environment where people usually do not know one another beforehand. As a result of this, hashtags become used in combination with others that are about stories of racial in justice. He argues that #BlackLivesMatter is the result of a group of people who use skillful invention to start an influential social movement with a limit of 140 characters. In addition, this activism was not limited to words, but also evolved into photos, videos, songs, and other forms of narrative storytelling that has continued to grow into a massive worldwide movement. Lastly, #BlackLivesMatter is protean and promiscuous because there were racist and divisive discussions held under the hashtag, creating concrete evidence for the need for such a hashtag. The very last important point of the article is that the narrative forms of hashtag activism may change due to culture and society. This is because "agency responds to social conditions and articulates social issues".

To come to these conclusions, Yang used methods that treated the Tweets as one long narrative. They did this by inputting "#BlackLivesMatter" into the search feature on Twitter.

Then he saved 74 pages worth of Tweets and read them in reverse chronological order, as if they were reading a story.

There are also empirical studies that demonstrate the use of hashtags amongst people within the disabled community, including those with invisible chronic illnesses. One example is the article "We Love Each Other Into Meaning: Queer Disabled Tumblr Users Constructing Identity Narratives Through Love and Anger" by Justine E. Egner. It focuses on the use of Tumblr by disabled LGBTQ+ users, who were mostly people of color, to form their own narratives and meanings using the "Pride/Community and Self-Love" narrative and the "Our Lives Matter/Deserving of Life" narrative. Egner (2020) discusses identity and disability in writing, "the umbrella of disability identity is successful at uniting an extremely diverse group of people through the deployment of identity narratives that resist culturally salient stereotypical and negative depictions of disability" (pg. 263).

They used a mixture of virtual ethnography and analysis of Tumblr archives, specifically taking a look at the use of hashtags and reblogs. Egner identified Tumblr users and posts by searching using the keywords "LGBTQ and disability" as well as "queer and disability. In addition, the content had to be directly to disability *and* LGBTQ/Queer identities. Posts that included pictures, links, videos, or any other type of media were not included in the data set.

Although Tumblr is not easily visibly organized into communities like other social media platforms, they were able to use hashtags to understand meaning making and narrative construction. The hashtags themselves tended to be a form of narrative in itself, not created by

the researcher, but by the people within the communities themselves. The users decided for themselves what the hashtags meant and what narrative they should tell to others.

Similarly, Sannon et. al (2019) investigate how people with invisible chronic illnesses (ICIs), choose which platforms to use and how to use them based on their own preferences and needs. Sannon et. al (2019), define ICIs as "illnesses that cause chronic physical impairments that are not visibly apparent, such as Lyme disease, lupus, and fibromyalgia". Specifically, they are interested in the way that people with ICIs use social media to seek informational and emotional support, as well as disclose about their chronic illnesses.

The main findings show that people with ICIs choose and use social media platforms based on a number of different factors including where they are with their health, how they need to manage disclosure/identity, and negativity in ICI related communities. An important point is that these needs change over time as their health and personal journeys change. Those in early stages with their ICIs go to public spaces that aren't specifically for chronic illness, such as Twitter, to find more information on their conditions. Such platforms also allow them to do impression management. They do not want to separate themselves from their conditions or their previously healthy selves; rather, they are figuring out where the new parts of their identity as people with ICIs and the non-ICI components of their identities come together. As they gather more information and they have more needs related to their ICI and become more comfortable disclosing about their ICIs, they branch out to other social media sites such as Facebook.

The last main finding is that participants chose social media platforms based on how much mental and physical energy they have, avoided platforms that could be too toxic or overwhelming, and made use of anonymous accounts that allowed them freedom from the mental strain of disclosure.

Although these are significant findings that focus on the intersections of disability, chronic illness, gender, and sexual identity, they leave out race. My work will fill this gap by considering how racial identity, Blackness, can affect the way that people use social media, form their own narratives, and construct gender and sexuality. It will also investigate how meanings and narratives of disability are constructed on Twitter. By focusing on Twitter content and hashtags, I am able to fill a methodological gap. There have been others to focus on the use of hashtags relating to social justice such as #BlackLivesMatter, but disabled individuals have not been considered in many of these analysis to date. Or, the studies include disability, but do not consider race.

#### Methods

For this project, I conducted an inductive textual analysis, narrative analysis, and observation of Twitter (Yang, 2016; Egner, 2016; Sadler, 2018; Bates 2020). Twitter is a popular public social media platform that allows users to send, or "tweet", messages out to the world. Twitter was rebranded as "X" when Elon Musk acquired it in 2022. The app is still referred to as Twitter and now sometimes "X" (Mac & Hsu, 2023). Posts are also still called Tweets. These tweets are limited to 280 characters, an increase from the original 180 characters. However, users can create what is called a thread, in which they use multiple tweets linked together to start longer conversations or share information that will not fit into 280 characters. Pictures, videos, and links are also able to be shared in posts on Twitter.

They are intended to be a collection of short posts that will show up on the users' homepage called a feed. The Twitter feed is a page that shows posts other people have tweeted based on who you follow or topics that the application suggests for you to view based on your likes and follows. It is also referred to as a timeline because Tweets tend to be listed in

chronological order. Anyone can read tweets and search for hashtags, but you must sign up for an account to be able to make tweets of your own. To create an account, the user must be at least 13 years old. There are also options to restrict sensitive content on Twitter for those who are teens and/or do not want to see graphic content.

Users can view their own tweets, likes, and re-tweets on their profile page. It usually consists of profile picture, a small bio, and feed that consists of all the tweets created by that user. It also shows re-tweets, which is a function that allows one user to share a post written by another user onto their page. Users can follow accounts/users that make Tweets that they like, reply to and leave a "like" on posts written by others by pressing the heart icon. All of these interactions also appear on Twitter feed, specifically by those who you follow. There are also topics such as sports, news, gaming, etc., that you can follow and keep up with.

I analyzed tweets before the covid-19 outbreak began, during the quarantine period, and late stage between 2021-2022. These time periods are important for a couple of reasons. 2020 marks the beginning of the covid-19 virus which has been an important topic of discussion on and offline. The quarantine period is an important time because it is a time when many disabled people did not have access to at home care and/or other resources that they needed on an everyday basis. They had to find other ways to reach out to others and speak out about the treatment of disabled people during the pandemic. This is a continuing concern and topic of conversation as the pandemic has continued over the past 2 years, especially with those who are immunocompromised. Additionally, many people who have had covid in-between the start of the pandemic and now have become covid long haulers. These last two years have also been important as far as activism and the use of Twitter as a medium for making sense of important

events such as the murder of George Floyd. Both of these events have been significant in the lives of Black disabled people.

Hashtag Analysis

An important part of my methods was the use of hashtags to analyze tweets from within Black Twitter (Graham & Smith, 2016; Yang, 2016; Bonilla & Rosa, 2015). Using hashtags to narrow my search was the most sensible thing to do. According to Sadler (2018), "Rather than trying to interpret in the manner of a database, ever hungry for more data, the narrative mode provides a mechanism to cut through the noise on Twitter, disregarding vast amounts of information as irrelevant to the storied interpretation at hand. It provides a means for transforming ambient news into coherent mental narratives" (pg 7). That is to say, using hashtags is more sensible because it allows me to easily identify common, repeating themes and organize the vast amount of information that is on Twitter. It helped to narrow down the information during this wide range of time periods and to lessen the amount of data I had to sort through. I chose Tweets that are most relevant to my research question in no particular order. Once I chose a hashtag to analyze, I sorted them by "Top" Tweets, which is the default setting when clicking on a hashtag or using the search function. "Top" tweets refer to the most popular and/or posts that have the most engagement under a certain search criteria or hashtag. After that, I chose Tweets that contained words or topics that were mentioned by users repeatedly. My starting point was #BlackandDisabled, as use of this hashtag allows users to engage with Black Disabled people. To identify with invisible disabilities, I will search for Tweets with the hashtag #BlackandDisabled and at least one other tag used specifically by those with invisible disabilities. Some examples are #ActuallyAutistic, #AutisticWhileBlack, #BlackChronicPain and #Spoonie. After picking a few of these, I continued to examine and explore some of these hashtags in depth and pick those related specifically for invisible disabilities.

Deciding How to Analyze

I considered using a program like MAXQDA that would organize and export Tweets for me, but I decided against it for a couple of reasons (Sakar et. al, 2021). First, using MAXQDA would not allow me to be in the dataset, seeing the hashtags, people, and narratives as they appeared in the app for myself. This is important for taking an intersectional approach to this research because people's experiences are not just numbers and hashtags, but, important narratives that help us to understand what it's like to be at the specific intersection of Blackness, queerness, and disabled-ness/disability.

Something else important that influenced my choice to do all of the data collection by hand, is that I too exist at these intersections. I am Black, Queer, chronically ill, non-binary, asexual/demisexual, autistic, and pan-romantic. Being at this specific intersection means that I am able to see things that someone who does not have the same identities wouldn't be able to recognize. Since I am also somewhat familiar with some of the faces on Black Twitter, it means that I can trust myself in deciding what narratives to highlight and justify why they are important.

#### **Data Collection and Analysis**

Feeling is and was an important part of the research and writing process for me, I have to start by setting the mood. Traditionally, Black folks are strongly connected to feelings and vibes because of the way that African people and those descended from them understand and learn about the world. (DeGruy, 2017). According to DeGruy (2005), "They also learned much through subjective approaches, relying more on intuition and natural feeling. or example: a common way of describing an event might include statements like, "I was picking up something going on in the meeting," or, "There were some heavy vibes in the room," or, "I wasn't feeling her/him." These statements reflect a group tendency to place high value on internal barometers" (pg. 75).

To feel like I'm really connecting with the data and catching the vibe that I am receiving from the narratives set before me, I usually turn on music that reminds me of what blackness feels like, a mindset of Blackness. Sometimes I think of the group called Sounds of Blackness. So, I search for a random playlist on Spotify that has one of their songs, and let it play in the background as I begin the analysis with #BlackandDisabled.

Originally, I used the Snip App to screenshot the entire results of #BlackandDisabled that came up. Then, I would paste each piece of the feed into this word document. Lastly, I took each photo and put it into a free open source tool called gImageReader that can read photos and turn them into plain text. Those results were pasted into a different word document solely for the text so that I may read/search through it later during analysis. As I got deeper into my analysis, I realized that this process wouldn't be feasible for every hashtag as there were too many search results. So for the hashtags #DisabilityTooWhite, #BlackFatigue, and #AutisticWhileBlack, I used the same process, but only chose selected Tweets by trusting my intuition as an insider. By

the end of my data collection, I had six documents that contained plain text, photos, and screenshots of tweets (Bonilla & Rosa, 2015; Yang, 2016; Graham & Smith, 2016).

For my analysis of the data, I went back and looked through every document for each respective hashtag. When I found something that seemed relevant and important, I copied the tweet and/or photo and put into a new word document for analysis. I repeated this until I had enough data to create themes. I will describe the two major narrative themes below. "Stories about the Problem of being Black and Disabled: Violence, White Centering, and Black Fatigue" and "Stories about Community Building as Resistance and Response: Organizing, Boundary Maintenance, and Mutual Support" emerged as I read back through the data collected for the hashtags #blackanddisabled. The hashtag #blackanddisabled was used as a starting point from which to look for other hashtags and/or words that showed up repeatedly on the timeline. #blackfatigue, #BlackDisabledTalk, and #AutisticWhileBlack were all commonly tagged along with the starting point, #blackanddisabled. After taking note of these hashtags, I looked through each of them to understand how they were connected to blackness and disability. Once I established how they were connected to each other and why it mattered, I was able to group my themes. I organized the data under each theme so that each contained a few photos and quotes. Afterwards, I went back through the data again to find things that I may have missed before that fit into the theme. I also added relevant notes, descriptions, and references for each category to report later in my findings. I will describe the themes further in the section following ethical challenges.

#### Ethical Challenges

The major ethical issues that I encountered related to personal information shared by the people I'm observing or in the content I am analyzing. Considering that Twitter, especially specific corners of the internet like disabled twitter and/or Black Twitter, is a space where people can share more about themselves than they would in real life. Although Twitter is public, it could be seen as an invasion of privacy and extremely unethical to specifically name users because they never intended for certain groups (family, friends, co-workers, etc.) to learn/read this information about them. In fact, many users create multiple accounts solely for this reason, so that they could not be identified, separating their irl (in real life) life from their online life. Revealing personal information about their disability could greatly affect their job and relationships with others who do not know they are disabled. I took steps to protect posters' identities by removing personal identifying information when provided and creating pseudonyms for them when writing about them within the content analysis. The exception to this are disabled advocates who use Twitter for their advocacy. I also made sure the data was kept in a protected folder in a secure location.

#### **CHAPTER 3: FINDINGS**

### **Chapter Introduction**

The following chapter consists of the major findings from the narrative analysis as well as a conclusion. The narrative themes found in the research will be broken down into two main sections, "Stories about the Problem of being Black and Disabled: Violence, White Centering, and Black Fatigue" and "Stories about Community Building as Resistance and Response: Organizing, Boundary Maintenance, and Mutual Support". Overall, my lived experience of Black Disabled Twitter had a general vibe, which I will share with you now as it may add clarity and additional insight to the themes that emerged from Black Disabled Twitter which I describe below.

Black Disabled Twitter feels like hanging with your favorite cousins at the cookout. It feels like gathering at church. It feels like the after-church meals cooked by aunties with aunties' arms and fills your soul. Black Twitter feels like strength, pride, and solidarity. Black Twitter feels powerful. It feels like pain, frustration, and. Black Disabled Twitter is resistance. It feels like a Sunday dinner conversation. Black Disabled Twitter feels like conversations at the barbershop. It feels like that one aunt and uncle who always argue with each other at the get together. It feels like finally being able to sit at the adult table and talk about grown folks business. It feels like sitting with your elders on the front porch.

## Stories About The Experience of Being Black and Disabled: Violence, White Centering, and Black Fatigue

Much of the experience of being black and disabled is informed and shaped by violence. Violence from institutions, violence from police, violence from other disabled people in the community. There is always someone who has something to say about the way that black disabled folks exist, taking up space for themselves in a place that is our safe space. It's absolutely exhausting (Winters, 2020).

Police Violence Against Black Disabled Folks: "Being Black and Disabled Is A Constant Struggle"

A strong theme that came up frequently is police violence against disabled people. There are so many stories of black disabled folks dying and/or dying at the hands of the police. These stories are a constant presence when you are scrolling down the timeline of #blackanddisabled, #autisticwhileblack, and/or #blackdisabledtalk. It was difficult to choose just a few stories, but I picked a few that felt the most important.

The first is about the work of Angel Love Miles, a black disabled social justice advocate and policy analyst. In an article by The Atlantic, Miles, Keith Jones, and other folks share their experiences as Black disabled people, including experiences of police brutality.

She says, "I became an advocate not because I wanted to but because I had to, to survive. I was not very outspoken at all. But if you're trying to get home and the bus keeps passing you up because you're in a wheelchair, you have to scream out"

Here, Miles is speaking to the experience of having to speak up for themselves out of necessity because disabled folks are often ignored. Adding in the extra layers of race and gender, it becomes even more difficult for her, having to speak over people who ignore her and/or don't offer help because of her race and her gender. Existing and surviving is perceived as a threat to

individuals and institutions because of the necessary work they *have* to do. Speaking up and standing their ground is seen as resistance when it is really just someone existing. This is especially evident in the treatment of Black disabled people by police officers.

There is the story of Andrea Hollingsworth, a Black Deaf woman, who was interrogated and assaulted by police officers because she was using sign language, and they could not understand it. She was pulled out of her car in front of her two children, who were forced to interpret for their mother. Hollinsworth stated in an article by the Atlantic Black Star, "If my kids weren't with me, then I would have died that day. My kids saved my life". The police never gave any real reason for pulling her over or arresting her. This situation is just one example of many others that illustrates how existing as a disabled Black person is perceived as a threat. It also shows the necessity of having to speak out, as Hollingsworth and her children did to survive.

White Self Centering and Lack of Representation in the Disability Movement: "A Racist In A Wheelchair Is Still A Racist"

Another recurring theme from the data is white self-centering. This is when white disabled folks take up space in black disabled conversations even when black disabled folks are already underrepresented and excluded from the disabled community at large. While white disabled folks are not denied entry to black disabled Twitter, it is not a space that should be centered on them. Unfortunately, it occurs frequently, even when explicitly explained by black disabled users why they should not do so. For example:

Openly Catfish Black & Disabled, Esq. @4WheelWorkOut – June 25<sup>th</sup>, 2021 Reminder: #DisabledBlackTalk is for BLACK disabled folks. If this is not your descriptor, this is not a conversation for you to be in. You are more than welcomed to follow along, listen, learn, and amplify. But plz, respect the space.

This tweet is a reminder for non-black disabled folks to respect the #DisabledBlackTalk hashtag as a space meant specifically for Black folks. They are saying that anyone can passively be in the space in a way that helps amplify the voices of Black disabled people and/or learn from the topics being discussed. The author emphasizes that this is a space created for and by disabled Black folks and it should be respected as such. That is because white disabled folks tend to come into the space and/or use the hashtag in a way that centers themselves and erases the self-narratives of Black folks. The tweet below is a good example of that.

Here is another example of the theme:

The Chronic Campaigner @chroniccampaign - Jul 15,2020

Next #Ableismandivie meeting Saturday 25/07/2020! Next meeting and first part of the campaign - Focus on #tblackanddisabled voices and #disabledpoc of #everydayableism - please DM me to get involved! Follow me on Insta: @the chroniccampaigner -more infor #DisabledPeopleForBlackLives

This Tweet brings up a couple of different important points. First, is the way that white disabled people use black movements and/or communities as a form of performance. The inclusion of black disabled people into the meeting discussed by @chroniccampaign feels very showy, ingenuine, and low effort. The vibe of the tweet gives off, "I've included a few black disabled people in my/our meeting so that's all we need to do, my job here is done". This is especially important to note as it was tweeted on July 15<sup>th</sup>, 2020, around the same time that #BlackLivesMatter became mainstream after the murder of George Floyd.

The second important point is that black people are considered separate from disabled people. They use the hashtags #DisabledPeopleforBlackLives, #disabledpoc, and #blackanddisabled, all of which seem exclusionary in the way that they are used together. The hashtags are thrown into conversations centered around white disabled people instead of using them in practice. Much similarly to the way that the term intersectionality has been re-up taken

by white folks and misused in the way that was originally intended. Many use the word but do not put it into practice.

This is expressed in the data by two black and disabled protestors.

A black wheelchair user holds a sign saying: "Disabled BIPOC demand action, not just words" while another holds a sign saying, "To all disability orgs! Disabled People of Color demand change, not words and diversity plans/statements" #intersectionality.

Why would black and disabled people not be included in regular, reoccurring conversations about ableism and discrimination? Blackness and disabled-ness intersect in so many ways yet, they are discussed as something separate from the community and conversation of disability at large. According to Gordon (2022), white people have a "white license" that they use to do what they please. This is different from white privilege because white license makes white folks feel intitled to do what they want, often using the word "freedom" and complaining about the "infringement" of their rights.

Gordon explains this further in stating, "The unaccountable, outrageous actions that are the hallmark of abusive whiteness should be characterized not as privilege but as forms of license. Defenders of license often bring up freedom and liberty as if they were synonymous. Liberty requires a lack of constraint. So-called free speech advocates tend to build their case against "political correctness" by confusing freedom of speech with licensed (limitless) speech. They ignore a basic caveat: free speech does not entail the right to be a schmuck". Connecting this to the topic at hand, white disabled and non-disabled people feel entitled to all spaces, regardless of whether they are wanted there because of their white license. It makes them feel like it should be okay to invade spaces, spaces which exist as a direct result of white supremacy and exclusion out of fear of Black consciousness.

Black consciousness makes white people and those in power feel threatened because having this consciousness means that they can recognize and fight oppression. So, spaces like Black Disabled Twitter are a threat to white supremacy because it produces a sense of shared consciousness through the self-narratives of the community. In response to this, Black people are excluded from "regular" Twitter in order to maintain and re-establish a hierarchy (Winant, 2004).

The White Man's Burden: "No, Please Help Me!"

In the data for #BlackAndDisabled, many people expressed confusion at the complaints of white disabled people who are annoyed when people try to help them. White disabled people say, "don't help me" while black disabled people are saying "please help me!". While white disabled people are helped without issue, black people with disabilities often can't get the help that they need, even when they ask for it. This is expressed by @singsongraptor and @powernotpity:

Deityosaurus (ze/zer/zers, xie/xyr/xem) @SingsongRaptor "I've been wondering about this for a minute, but do #BlackAndDisabled folks get "helped" without permission/against our will? It's a huge issue in the disability community but I can't help but notice it's mostly white folks who seem to discuss it & it's not something I deal with."

POWER NOT PITY @powernoipity
Sometimes black people just have pain that they have to deal with.
#HowToPissOffDisabledPeople #BlackAndDisabled #powemotpity

What we can take from this, is that black people are left to deal with issues on their own, especially pain. They are not readily offered help from others in the same way that white disabled folks are. Considering this, it is frustrating for black people with disabilities when the disability community at large complains about being helped and dismisses the experience of black people who need help. Especially, if they are doing it in spaces specifically for black folks

with disabilities. It all leads to exhaustion, existing as a black person with a disability is exhausting.

## Black Fatigue

Black fatigue is a term introduced by Mary Francis Winters in their book called, *Black Fatigue: How Racism Erodes the Mind, Body, and Spirit.* I stumbled across this idea as I was analyzing the data from #blackdisabledtalk and #blackanddisabled. The term black fatigue was often used with both hashtags and sometimes used by itself as a hashtag called #blackfatigue. It is used to describe the experience of the fatigue that comes with dealing with racism as a Black person (Francis Winter, 2018). It also is used to describe the exhaustion that comes with being a black person dealing with chronic pain or other invisible disabilities.

One infographic describes black fatigue as: The fatigue that comes from the pain and anguish of living with racism every single day of your life, the constant fatigue of not knowing whether you or a loved one will come home alive, being fatigued by those who are surprised and express outrage [with no action] that such inequities still exist, and the fear, frustration, anger, and rage that is part of many black people's daily lives (Francis Winters, 2018).

One example included in the data, is a photo of a Black woman posing at the red carpet, seemingly for an awards show or premiere. The photo is a screenshot of an article from People Magazine in which they incorrectly name her as Marsai Martin. The two women do not look at all the same and are different ages. This happens frequently, where very popular magazines do not take the time to properly label the picture, do the research when they aren't sure, or even double check because "we all look close enough anyways". They post it on the internet and black folks are the ones who have to correct them. I think this is a good summation of what it is like to

experience Black fatigue. Unfortunately, there are often negative counters against the Black fatigue that black people speak out about.

Kangz @NtR\_Odin - Mar 6 2023

The "fatigue" comes from sharing a country with blacks, actually. Everyone has black fatigue now. The ingratitude, the entitlement, the violence while being the most coddled and pampered people in the history of planet Earth. You need us, we don't need you."

Said in response to this article: "Where's Our Black Bereavement Leave?"-Professor Argues for Paid Time Off Leave for Black Staff to Deal with 'Fatigue' and 'Trauma' from Systemic Racism

(I know, I know, in 2023 ya'll. That's what I'm saying!)

This Tweet, as terrible as it is, is important to take note of. I hesitated to include this in the data because of how negative and offensive it is. However, it is important to remember that even the data that we do not like or does not immediately seem to support the work, is important to include. What stuck out to me about this tweet is that they chose to respond to black fatigue with skepticism and outright racism.

I think that this is very reflective of how many people think about Black people, especially those who have conditions like chronic pain and/or chronic fatigue who are called "lazy" because of their disabilities (Bayliss et. al, 2014). These people are in healthcare, policing, and government. You can see why black folks experienced so much fatigue, there are many who do not want to help (Stuart, 1992). Black disabled folks don't have the privilege of feeling annoyed by getting help because they are always fatigued (from racism, ableism, along with the other isms) and often in pain. This is discussed in Tinu's #DisabledBlackTalk sessions on Twitter. #DisabledBlackTalk is a event in which Tinu starts a conversation specifically for black disabled folks to discuss their experiences. It is led by Tinu in a call and answer fashion. Tinu starts by asking a question and users can quote the tweet with their own response to continue the

conversation. In the example below, Tinu starts by asking a question about pain and fatigue, Q5. The user responds to the question using A5.

Tinu – Empress of Twerk, Thirst of My Line @Tinu – Sept 23, 2021 Q5. How [does having] pain and/or fatigue interfere with being treated at the ER or by a doctor, especially as a Black person? #BlackFatigue #DisabledBlackTalk

Pain Hurts @Melandated Samus – Sept. 23 2021 A5. Being too exhausted to advocate for myself.

Today they put [me] on an IV drip with Toradol and reglan that I know from ER experience don't do a darn thing for my headaches but I just let them do it anyway. This is day 13 straight of pain. #BlackFatigue #DisabledBlackTalk

As a result, the black disabled community does their own advocacy, organizing, and mutual aid.

# Stories About Community Building As Resistance and Response: Organizing, Boundary Maintenance, and Mutual Support

A common theme that showed up in all of the hashtags that I analyzed is disabled black folks asking for help using crowdfunding and mutual aid. It is common for people to make infographics explaining what kind of help they need and where to send/donate money. For example:

Hello! My name is Ashely (They/She). I'm an autistic spoonie with a social work degree. I'm actively looking for a job with the help of a vocational specialist, but still need help financially. Funds will be used for: Monthly bills, personal care products, groceries & meals, and emergency expenses. Pay Links: Cashapp or PayPal

Some people, like Ashley, used it to help pay for bills, groceries, emergency expenses, and other necessities. Others use it to raise money for things that increase accessibility like support dogs and/or mobility aids.

Organizing: Advocacy, Awareness, and Support

Organizations created by black and disabled are important because disabled organizations created by non-profits or other entities are often harmful to and/or do not properly/accurately represent disabled folks.

Autism speaks and the story of Morenike Giwa Oniaiwu PhD who was gaslit and accused of attacking an organization for calling them out for not properly representing black autistic people in research leadership (research they were awarded 250,000 dollars to carry out btw). They also were not paying them an appropriate amount for their involvement in the proposal. A few quotes to support/give examples of representation that has come as a counter to these entities.

Disabled in Higher Ed - #DisinHigherEd @DisInHigherEd - Dec 3.2020 Yes! We look forward to working alongside @BlackinNeuro and other #BlackinX movements to ensure that #81ackAndDisabled people are represented, included, & uplifted in everything they want to do. #DisinHigherEd #DisabledinNeuro #BlackinNeuro #DisabledinSTEM

An infographic for Black Disabled Futures Month. A Black disabled wheelchair user is photographed wearing a shirt that says "Blacknificent". She/they look away from the camera as if thinking about something.

There is text next them that says,

Black Disabled Futures Month. Disability history is also Black history and there's Black disabled history happening right now. We'll be highlighting a different Black disabled entrepreneur every Friday in February. The infographic comes from @lavantconsulting.

The following is from a Tweet by Jen White-Johnson highlighting Black Disabled History. It includes a photo of disability activist Anta Cameron. A drawn/painted portrait of her is surrounded by flowers. She is a Black Autistic lesbian writer and activist that has been organizing and creating social change for 42 years:

Jen White-Johnson @jtknoxroxs – Feb 3

It's so important to honor black and disabled change makers that have paved the way for us! Give them their flowers while they are still here! There is no #BlackHistoryMonth without Black Disabled History and the present. Honoring @adaptanitaAnita Cameron today and always.

Invasion of Space and Boundary Maintenance: "Why Are You Here? You Literally Have
The Entire Internet"

It is important to remember that this is not a white space, centered around white folks. White folks are allowed and welcomed here, but sometimes they do things they shouldn't and need to be reminded that allyship is not about self-centering. People often use the community within #blackanddisabled to center themselves and promote their own campaign. Examples like this are the reason that #blackanddisabled was created in the first place. Yet, white disabled people still come into the community and make everything about themselves, in the space that black disabled people created because they were tired of being excluded. It should not be lost on us that they have the entire internet, yet still choose to invade this one specific space. Black disabled don't have access to all of the same spaces that white disabled folks do. Much of this is because of discrimination, exclusion, and outright racism that comes from within the disabled community. As stated by The Tripple Cripples:

The Triple Cripples @TripleCripples - Jun 1, 2020 "A racist in a wheelchair is still a racist"

Like our good sis @VilissaThompson told you with the creation of the hashtag #DisabilityToowhite, the disability community has a huge race problem. HUGE.

It is important, as shown by this user, to note that the disability community has a race problem. Not only do they invade spaces that aren't theirs, but they also talk over and dismiss the experiences of the black disabled community and consider the white disabled experience as the only one.

## Crowd Funding and Mutual Aid

A great example of crowdfunding and mutual aid is #ForTinu, a hashtag dedicated to help crowdfund for Tinu, who is a major advocate for Black disabled women. Tinu is well known for her work coordinating events and creating spaces for Black disabled folks to establish their own self-narratives, such as #BlackDisabledTalk, #TinuSpeaks, and others. These focus most specifically on those with invisible disabilities like Tinu has. The hashtag #ForTinu came about when Tinu openly expressed the need for help paying for her living expenses and healthcare. She started a Go-Fund Me and tweeted it out for people to send her help if they chose to do so. As a result of the role she plays in the community, people came together and helped to advocate and crowdfund for her under #ForTinu. It was really successful and broke into other spaces on Twitter outside of Black Disabled Twitter, which is a big accomplishment given how separated communities on Twitter are/can be, especially due to discrimination and whitewashing.

This example is really important because it is directly related to black fatigue. She does so much but doesn't/didn't have the money to pay for her own expenses. The amount of work she puts in doesn't match her living situation/money she makes for it. This is the case for so many Black disabled folks on Twitter, as fliers and links for donations were common to see inbetween every few number of tweets or so. Mutual aid is really common within the community and encouraged as a result of the circumstances that many Black disabled people have to deal with in their lives.

Identity: This Is What #BlackandDisabled Looks Like

#BlackandDisabled feels like a place to let people know what being Black and Disabled looks and feels like an open space for both allies and disabled folks. It shows the intersections that Black and Disabled people live at, not only considering race and disability, but also gender identity, neurodivergence, and sexuality. Users express this in many ways including using specific pronouns, using photos of themselves to show what it means to them to be confident, Black and disabled, and empower others. Here is the first example:

The first is a post by DeShanna (she/they) (@Trinsmamabear) in which they say: "Thanks to my friend for helping me show the world that being Black and Disabled doesn't make me any less beautiful." #disabled #disabledpeoplearesexy #blackanddisabled.

They also include a photo of themselves sitting in a rollator, posed with her hand resting under her chin as she smiles at the camera brightly.

In a similar example from the data, Black Creative Healing @BlackCreativeHG tweeted the following:

Who just bought THEMme-selves their first pair of compression gloves, remixed a few lipstick colors & updated the pronouns in her bio? C'est moi #BlackAndDisabled #DisabledAndBlack #BlackSpoonie #BlackCreativeHealing

In similar fashion to DeShanna, they include a picture of themselves looking and feeling confident. They pose with compression gloves in a selfie that shows off their red lipstick and confident smile.

In both of these examples, a common theme is identity and empowerment. Pronouns and gender identity came up over and over again within these themes and seem important to identity for Black disabled folks. Black Disabled Twitter is a women led space made up of Black women, trans, and non-gender conforming folks. Many identify using she/they, xei/xem, ze/zer, she/her, they/them, he/him, he/they, or any pronouns. It is a very queer space. Many make known their identities as trans, non-binary, queer, asexual, demi-sexual, pansexual, among others. They also

are largely neurodivergent (autism, adhd, audDHD, depression, anxiety) often including their self-diagnosed or "medically" diagnosed condition in their bios.

It seems like many black people with disabilities reject rigid construction of gender. Especially those that are oppressive to Black bodies, pushing away from heteronormative ideas of gender and embracing terms that are more flexible and comfortable like she/they or they/them. The construction of he/him and she/her are heavily connected to colonialism and enslavement, which were extremely harmful to the black body, especially for disabled folks. Future research should investigate, she/they, and black womanness as well as the proliferation of various pronoun usages. Recurring themes of pain, empowerment, and identity should also be explored.

## **CHAPTER 4: DISCUSSION AND CONCLUSION**

It is very evident from the themes found in the analysis above that self-narratives are important and powerful. To be more specific, the self-narratives of Black people with disabilities on Black Twitter are reflective of their life experiences and personal struggles. These self-narratives are not specific to just one or two people on Twitter, but a large community of people who share common experiences. Spaces like #BlackandDisabled and #ActuallyAutistic have allowed Black disabled people to empower themselves and others. It also gives them space to speak up about racism and exclusion within the disabled community at large and reframe their identity as Black and disabled people who belong, and always have belonged, within the disabled community.

I started this project with these three research questions:

- 1. What meanings of disability are constructed in posts on Black Disabled Twitter?
- 2. What meanings of Blackness are constructed in posts on Black Disabled Twitter?
- 3. What meanings of community are constructed in posts on Black Disabled Twitter?

# Blackness, Disability, Empowerment, and Meaning Making

I should start by saying that, based on the research I have done, meanings of Blackness and disability are bound together on Black Disabled Twitter. How could I analyze meaning making related to the experiences of black people with disabilities without examining both at the same time? How could I take an intersectional approach by separating the two? Defining what it means to be *black* and disabled is inextricably connected to defining what it means to be *disabled* 

and black (Banks, 2018). So, instead of thinking about the construction of these two meanings separately as I originally started to, I will be looking at them together.

One way that people with disabilities have constructed their self-narratives about blackness for themselves is through their usernames. People use identifiers such as @melanatedsamus, @4wheelworkout (not ANOTHER Black, disabled woman lawyer), @blackcreativehg (Black creative healing), Tinu (Empress of Twerk) and @powernotpity (a little bit of Skee). These usernames and titles all refer to some aspect of the person's blackness and/or disability. Power Not Pity, for example, is a podcast "for and about disabled people of color" that dismantles ableism and empower others by helping people to share their stories and listen to the stories of others.

In comparison to previous research, my findings confirm the exclusion of Black disabled people and need for disabled individuals to create self-narratives of their own. Banks (2018), examines the experiences of Black men with cerebral palsy in urban areas. They found that people immediately labeled them as gang members and assumed they were disabled as a result of gang violence. A participant, Corey, shared his experiences and described it as, "... worst is convincing my peers that I did not suffer a gunshot wound and I have been this way all my life. They can't believe that my body is disabled but my mind is not" (Banks, 2018). As he created his own self-narrative to counter the narrative placed upon him, he was able to empower himself and form his own sense of identity separate from what others thought he should be.

Empowerment is an important theme that came up constantly. One thing that is common in the black community at large is for us to find ways to empower and encourage one another, big or small. That may be lending someone else a couple of dollars to get something to eat, or giving words of encouragement to someone who seems to need them, whether we know them

personally or not. I didn't notice it at first because I am so used to it, it is just something that you do. Like nodding to another black person when you pass by them in the grocery store or walking down the street. Or, waving at other black folks as you walk into a room or drive through a neighborhood. These practices are present in black disabled community through the practice of crowd funding or the establishment of podcasts, organizations, and/or online events like #BlackDisabledTalk. Empowerment also showed up as a way of speaking up and speaking out for themselves and/or others.

## **Crowd Funding and Community**

Crowd funding is an integral and essential part of black disabled community. People within the community can reach out to one another on Twitter to support one another. This seems to be an important part of community building, especially for those who are advocates like Tinu. Advocates are strong pillars of the community who offer resources to other folks within the community while simultaneously relying heavily on the support of community members themselves. There is a shared give and take relationship that people are encouraged to participate but not forced to. Crowdfunding is viewed as a normal and necessary part of community culture.

### **Future Research**

There are still so many questions I have. How do these themes present themselves outside of online spaces? Why is this space women led? What is the life experience of Queer/non-binary black disabled people on and off of Twitter? Both within and outside of the disabled community? Why are so many people, especially black people who are disabled/neurodivergent, starting to use she/they pronouns? We also need more research on Blackness and what it means to be Black. This project barely scratched the surface of understands all aspects of blackness. Particularly because many of the disabled individuals in this project did not always specifically use the word

blackness. It would be a good project to continue to explore Black Queer Disabled identity online, maybe on another platform, along with in-depth qualitative interviews with users that discuss the use of pronouns and how it is related to disability, blackness, and queer identity. Specifically, I am really interested in the use of she/they pronouns, how and why black women in particular feel connected to it.

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