

“You Look Fine!”: Ableist Experiences by People With Invisible Disabilities

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Abstract

Much existing research on ableism focuses on individuals whose disabilities are more apparent to others. Using a phenomenological approach, this study interviewed 14 participants, exploring how people with “invisible” physical disabilities experience ableism. In addition to multiple examples of microaggressions, emergent themes included the policing of bodies, tension in roles, a desire for justice, and internalized ableism. Many of the participants recounted experiences of having bodies and actions policed by others, and several struggled with their role in educating others about policies, needs, and accommodations. The theme of desire for justice included frustration at having to educate others, the energy this education took, and the desire for overarching justice regarding ableism. The theme of internalized ableism reflected both explicit experiences of individuals sharing their self-judgment and ableist statements during interviews. These findings indicate the need for a more nuanced understanding by social workers of how ableism is experienced by those with invisible disabilities as well as additional research on how to support these members of the community.

Keywords

ableism, disability, invisible disabilities, microaggressions, phenomenological research, qualitative research

In the literature on diversity, a significant amount of work has been undertaken on issues of racism, sexism, and more recently, heterosexism, and their corresponding privileges. However, despite discussion on disability being more than decades old, with the mainstream disability rights movement gaining momentum in the 1960s and 1970s (Wolbring, 2012), and the Americans with Disabilities Act having been enacted in 1990 (United States Code, 2008), notably less academic literature has addressed ableism, particularly within the field of social work. Even disability policy as an area of focus in the literature is relatively new, given the large number of disabled individuals in the United States (Schriner, 1990). This study examines whether and how the experiences of

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ableism by people with invisible disabilities (someone who might not be assumed to be disabled at first meeting, such as individuals with chronic pain, traumatic brain injury, multiple sclerosis, HIV, etc.) are disparate from those whose disabilities may be more evident to others. Although members of this community use both identity-first (disabled people) and person-first (people with disabilities [PWD]) language (Dunn & Andrews, 2015), this article will focus primarily on identity-first language, as this language comes from a self-determination paradigm in line with both social work and feminist values (Ladau, 2014; National Association of Social Workers, 2017).

The United States Census Bureau (2012) reported that in the 2010 Census, 21.3% of those of age 15 years and older had a disability or impairment. From these statistics, it can be inferred that approximately one fifth of U.S. residents are currently living with a disability or impairment. Disability in and of itself is a community with blurred lines—people can acquire disabilities (both short term and long term) throughout their lives, making the concept of membership to the disabled community one that is frequently difficult for other marginalized groups to understand (Davis, 1999). Although individuals with “invisible” disabilities (those that are not always, or ever, apparent to others) may not receive as much overt or explicit social stigma as those with more apparent disabilities, they are still exposed to forms of rejection, ableism, and discrimination; in fact, they may even have more trouble accessing support services than their visibly disabled counterparts due to being expected to prove their disability (Davis, 2005). Disabled individuals with invisible disabilities may struggle with “passing” as nondisabled persons in many settings (Samuels, 2003). While passing may be seen as a privilege, it can also be a challenge for these individuals to find community and be validated by disabled people. The decision on whether to pass or not comes with not only personal implications of stigma and discrimination but also more societal and political implications of outing themselves as disabled (Brune & Wilson, 2013). They may also have issues in accessing the services, support structure, and even physical spaces that they need, given assumptions about what their bodies and minds are able to do, and whether those given the power to make the distinction decide whether they are “disabled enough” (Lightman, Vick, Herd, & Mitchell, 2009). Therefore, it is possible that members of this community experience ableism in different ways than those who have apparent disabilities.

Ableism is the overarching act of prejudice and/or discrimination against disabled people and the devaluation of disability (Hehir, 2002) and corresponds with able-bodied/neurotypical privilege, the set of unearned privileges held by nondisabled individuals. They are both interconnected systems that maintain stratification around disability. Ableism values physical, emotional, and mental capital, following socially constructed expectations of ability (Loja, Costa, Hughes, & Menezes, 2013). Queer/disability theorist McRuer (2006) posits that like the ideal of compulsory heterosexuality, ableism results in a compulsory able-bodiedness, demanding that disabled individuals do whatever it takes to enact a nondisabled identity however possible.

While sexism, racism, and other isms certainly are prevalent in all types of systems and interactions, Wolbring (2008) argues that ableism is one of the most accepted and widespread isms in society and works in conjunction with many other isms. Because of the lack of conversation around ableism and able-bodied/neurotypical privilege, prejudice against disabled people may at times be more prevalent and socially acceptable than many others types of prejudice (Ford, 2009). Although ableism is insidious and apparent in all aspects of society, little research has been conducted to understand the lived experiences of ableism by disabled individuals, nuanced disabled identities (such as those who have invisible/less obvious disabilities), and intersections of other marginalized identities with disability identities. Moreover, while there have been some publications in the field of social work around ableism, much of it focuses on policy (El-Lahib & Wehbi, 2012), sanism (discrimination around mental health) specifically (Poole et al., 2012), or the general need for better culture competency in social work practice and education regarding disabled populations (Carter, Hanes, & MacDonald, 2012; Dupré, 2012).

Disabled individuals also experience higher rates of poverty and chronic health issues than their nondisabled counterparts (Hehir, 2002; Roux et al., 2001; Storey, 2007), and there are few instances of social work around the experiences of disabled people of color, transgender disabled people, and the ways that other marginalized identities interplay with disability and ableism. Feminist disability scholars in particular have brought up the need for intersectional frameworks and connecting disability to conversations around diversity (Kafer, 2013; McRuer, 2002; Olkin, 2002). In *Feminist, Queer, Crip*, feminist disability studies, scholar Kafer (2013) explains that not only did feminist theory gave her the ability to critically examine notation of disability but also emphasizes the bridge between theory and practice, something incredibly relevant to the discussion of disability and ableism in social work.

Microaggressions: Death by a Thousand Papercuts

The concept of microaggressions is used to explain the phenomena of the implicit perpetuation of racism, sexism, heterocentrism, transphobia, anti-Semitism, and other forms of power and oppression in society (Sue, 2010). Microaggressions are everyday interactions that perpetuate inequalities and stereotypes against people who belong to marginalized communities (Solórzano, Ceja, & Yosso, 2000; Sue, 2010). They are perpetuated against many individuals holding many different identities, including race, gender, sexual orientation, religion, and disability (Solórzano et al., 2000; Sue, 2010). Frequent exposure to microaggressions, including ableist microaggressions, can result in higher incidence of negative mental health outcomes, feelings of being excluded, and lower positive outcomes including reduced academic performance (Khattari, 2017; Nadal, Griffin, Wong, Hamit, & Rasmus, 2014).

Microaggressions are a common means of perpetuating ableism. These may include telling someone that they speak very well for a deaf person, telling someone they are lucky to get to bring their dog everywhere with them, asking a group of people to all stand for an activity (making the assumption that everyone can stand), or making a joke about how fast someone can go in their wheelchair (Storey, 2007). Many of these microaggressions are a result of assumptions about disabled people. Storey (2007) found that perpetuation of these microaggressions and assumptions result in disabled people feeling excluded or unwelcome in educational settings and produce outcomes including anger, frustration, and other feelings that can be harmful to an individual's engagement with their community.

Invisible Disabilities

People with invisible disabilities or illness may be more likely to experience ableism indirectly, including through ableist microaggressions. For example, while someone might not use language like "lame" in front of someone they perceive to be mobility impaired, they may be less reticent to use such language in front of those they identify as nondisabled, whether or not those individuals actually are. Additionally, people with invisible disabilities may experience ableism when using adaptations for PWD, such as disability-designated parking spaces or elevators, when others view them as nondisabled individuals. It is possible that this is a result of unintentionally fulfilling the role of compulsory able-bodiedness suggested by McRuer (2006), simply by not having disabilities that might make themselves visibly distinct as disabled to outsiders.

Disabled bodies are frequently othered and feared by society at large (Hirschmann, 2013), but there is little knowledge on how this may be experienced by those with invisible physical disabilities. Mad studies, a subset of disabilities focusing on mental health and sanism, have noted similarities in the "coming out and facing stigma/not being out and facing different marginalization" decision as faced by other individuals with sometimes invisible identities (Pilling, 2012). Therefore,

research is needed to help understand how disabled individuals who may not be read as disabled experience ableism in their lives. Bridging the theoretical understanding of ableism into the lived experiences of this community is a crucial move forward in creating more disability inclusive social work practice. This study explores the experiences of ableism specifically for individuals with invisible disabilities because, given that this invisibility often prevents these individual from being viewed as disabled, it is likely that their experiences may differ from disabled individuals with more apparent disabilities.

Methodology

Conducted in 2014 in a metropolitan city in the Southwest, this study was approved by an institutional review board at a local, private, liberal arts university. A modified phenomenological approach (Padgett, 2012) was used to explore the lived experiences of people with invisible disabilities, explicitly examining their experiences with ableism, including ableist microaggressions. We conducted loosely structured in-person interviews, and our questions explored the participants' disabilities, definitions of ableism, their experiences of ableism and ableist microaggressions, and how they and others close to them reacted when these ableist microaggressions occurred.

Accessibility was of utmost concern to use throughout the process. We ensured that all interview spaces were physically accessible, a definition of microaggressions was provided, and participants were allowed as much time as they needed. Participants were given an attribute sheet to complete, with questions regarding their age, race, gender identity, sexual orientation, relationship status, educational status, employment status, the disability/disabilities that they have, and how long they have had that disability/those disabilities. These attributes were collected for two reasons: first, to ensure that accurate identities were included in writing up the findings; and second, to potentially track trends that may appear among or across certain identities. All of the interviews were recorded using a digital voice recorder, we then transcribed them before moving to analysis.

Analysis began with one of us using inductive coding and emotional coding by hand for three of the interviews, creating an initial code list. The next step was partnering with another of our group to do consensus coding via second cycle coding (Saldana, 2013) on an uncoded transcript and collaborating to clean and develop a refined code list. When we discovered discrepancies, we discussed why we had chosen a specific code, and we research consensus on all incongruities. The refined finalized code list was then used to code the remaining interviews. After we coded all of the interviews, we wrote final codes on index cards and used the tabletop method of individual theme development (Saldana, 2013) to create potential themes. Finally, we achieved consensus around the themes, and this resulted in the themes enumerated below.

Recruitment and Participants

The sampling method included posting a call for participants in a variety of disability-specific social media groups. This call for participants identified inclusion criteria as adults ages 18+ who self-identified as having a self-defined invisible physical disability(ies), who were open about their disability(ies), and who were living in the metro area. Of the 14 participants, 10 identified as women, 2 identified as men/masculine, 1 identified as a transgender man, and 1 identified as having a nonbinary gender. Thirteen participants identified as white, and 1 identified white/Cherokee. Sexual orientations and relationship statuses varied widely. Age ranged from 19 to 55, with a mean age of 36 and a median age of 35. All but two participants had a bachelor's degree or higher; one was currently enrolled in college, and the other had completed high school. Disabilities represented in the sample included rheumatoid arthritis, psoriatic arthritis, fibromyalgia, aortic valve insufficiency, chronic costochondritis, traumatic brain injury, chronic pain, limited mobility, deaf/hard of hearing,

cochlear implants, anxiety, depression, post-traumatic stress disorder, end stage liver disease with hepatic encephalopathy, residual neuropathy from compressed spinal cord, attention deficit hyperactivity disorder, multiple sclerosis, fibromyalgia syndrome, mixed connective tissue disorder, peripheral neuropathy, lower back fusion, torn labrum, chronic migraine, scoliosis, stroke survivor, artificial knees, bipolar disorder, Von Willebrands disease, subseptate uterus, hearing loss, mitochondrial disease, and HIV.

We offered all participants the option of having an American Sign Language (ASL) interpreter at each interview and gave each participant the choice between being interviewed at their residence or in a private campus room. Approximately, half of the participants chose to be interviewed on campus. None requested an interpreter. Interviews ranged from 25 to 70 min in duration, averaging 45 min.

Establishing Trustworthiness

As with any qualitative study, it is incredibly important to establish credibility and trustworthiness with the participants in the research in order to ensure the accuracy and quality of the data being collected (Morrow, 2005). In order to establish rapport and demonstrate insider status within the disability community, both of us doing the interviews chose to share during the study introduction to the participants that we have disabilities which would be considered invisible or nonapparent by others (Morrow, 2005). By doing so, we hoped that participants would avoid feeling as though they were being observed from an outsider or pathologizing/marginalizing perspective. Another of our objectives was to help the participants feel more connected to the research being done by building connection and collective affinity (Kafer, 2013). Finally, sharing can also allow the researcher to “own one’s perspective” (Elliott, Fischer, & Rennie, 1999), recognizing the potential for researcher bias and acknowledging the need to bracket oneself throughout the interview and analysis process (Fischer, 2009).

Results

After the coding and theming process, several themes emerged, including (a) *policing of bodies*, (b) *tension in roles*, (c) *desire for justice*, and, interestingly, (d) *internalized ableism*. Many participants recounted their experiences of having their bodies and actions policed by others, including other disabled people challenging their actions on a regular basis. Several of the participants grappled with their role as a disabled person and how they were expected to educate others about their specific disability/impairment/illness as well as about policies, needs, and accommodations. The theme of desire for justice speaks to the frustration participants expressed at having to educate others, how much energy it took to provide this education, and desire for societal education regarding ableism. The theme of internalized ableism reflects both explicit experiences of individuals sharing their self-judgment about disabilities as well as unintentional ableist statements made throughout the interviews. Each participant was assigned a pseudonym to maintain confidentiality when reporting the findings.

Theme 1: Policing of Bodies

This theme evolved from the various stories of participants having their bodies “policed” and commented on by others, both nondisabled individuals and other PWD. Many times, they were verbally called out for needing accommodations, the underlying assumption being that they were “lazy” or did not deserve or need to use chairs, elevators, disability parking, and other access and accommodation support systems that allowed them to function in the world. Public spaces seemed to

give strangers free reign to police disabled bodies. For Ash, a 41-year-old woman, public transportation was the site of being told what she could and could not do with her own body:

I rode public transportation all the time and I would need to sit. And sometimes I would sit in the disabled chairs if they were there because I would be in a lot of pain, especially when the train was crowded and people were jostling and stuff and that was really hard for me. And people would give me dirty looks or actually say something like, “What is wrong with you?” you know, “Get out of that chair.”

In some cases, more than just ability expectations were at play in the assumptions others made; Cal, a 27-year-old transgender man, works in a retail setting that often requires lifting heavy objects. Even after he shared information about his disability—a back impairment—people referred to his strength (or lack thereof) to lift things, instead of recognizing his disability.

... especially since I look and identify as male, people ask me to do things that I can't do. Especially at work, lifting heavy things specifically, or making assumptions that I don't have the strength for it after I've told them about it. I have the strength; it's just my back can't do it.

For Shay, a 27-year-old nonbinary identified individual, having family not understand the extent of Shay's disabilities felt as though they were policing Shay's body. Shay is on disability due to several medical issues, but their family continues to ask when Shay will get off of disability and get a job or go back to school, since “clearly it can't be all that bad.” With Shay's family policing them regarding not working or going school, there is an implicit judgment, as they are not “disabled enough” to have earned being on disability. Hayden, a 23-year-old woman with mitochondrial disease, also experienced policing of her body from her family:

They expect me to be able to walk up and down the stairs when we're going out somewhere or be able to walk from the car to the restaurant that we're going to or pick up my niece. And when I'm not doing those things they make rude comments about it, they think I'm not trying hard enough, and they don't realize that there's a real reason why I'm not doing those things.

Ainsley, a 35-year-old woman who identifies as Deaf¹ and uses cochlear implants, experiences a lot of policing when people find out she has the option of wearing cochlear implants in both ears, but often chooses not to. Because she is able to use this technology to make life “easier” for other people, they expect her to do so all of the time, often at the expense of her own body and energy levels.

I don't wear both my implants right now ... when I wear both, it's exhausting. My brain is not used to hearing sounds from all over, and so it's like when you cram for a test or something. You study, you get a headache, your eyes hurt, your neck hurts, your body tenses up. I just can't do it and people are always like, “Why don't you wear both?” Well, it's not like it just turns the sound on. My body has to do all this extra work for it.

Theme 2: Tension in Role

Different participants had various thoughts on whether they should be responsible for educating others, particularly nondisabled individuals, on how to not be ableist. Some felt that people should figure it out on their own, while others were happy to take on the educator role. Most participants were torn between these two polarities; they discussed the tension they experienced between feeling the need provide information and education about disability and ableism, and how exhausting and vulnerable it made them feel when they were put in the position of being the disability educator.

Shay and Betty both struggled with the question of who should be responsible for educating the public about disability issues, specifically whether PWD or nondisabled individuals should be responsible for this education, but both agreed education needed to happen. For Deb, a 34-year-old woman, calling out microaggressions when other people perpetrate them usually ends in defensiveness and resistance, like people saying, “You know I didn’t mean it that way.” When participants encountered this type of pushback, they struggled with whether to continue to attempt to educate others or whether to back down in self-protection. However, sometimes there were opportunities to straddle that line, and these occurrences have the potential to create change. As Deb shared:

I think it’s really easy to be defensive and it’s hard to acknowledge how painful microaggressions can be. But there are a couple of people in my life, especially people that I work with or that are a part of a social justice community, that when . . . you really talk about it in a direct way . . . it’s private work that you’re making really public.

Some participants strongly believed in the need to educate others about disability, feeling that without disabled people educating those who are nondisabled, change would not happen. Bob, a 53-year-old man, felt very strongly that ableist language was not a huge problem and that his decision to educate others was based on whether he deemed their actions to be supportive of him and his disability:

If I call on them or if I am in having a bad day, are they going to help me? Are they going to have the patience to sit there and talk with me, even if I am taking five minutes to get a sentence out? Those people, I don’t care if they make a weird statement occasionally because Lord knows everybody has. Those people, they’ve proven to me by action that they are willing to work with me.

Ainsley elaborated on one of her challenges with experiencing microaggressions. She spoke to how people either tend to underestimate her because she is Deaf, assuming that she cannot do anything for herself, including enjoy concerts, parent, and work at a full-time job, or that because she does not “look” or “act” disabled, people “assume she is normal” and refuse to make accommodations or “make room for the disability.” Consequently, she feels challenged in how to push back against and educate others about ableism because

. . . with microaggressions, people they either, like I said they’re at opposite ends of the spectrum, they either overdo it or under do it. They either care too much or care too little. There’s no open-minded, “Oh so tell me how does it work” or “What would work best for you?” or—there’s no “How do you like it?”

As a student, Hayden ran into issues with some professors and her accommodations letter. When she experienced pushback, she had to decide whether to back down or to use this as a moment to educate her professor, both for her own advantage and for the sake of future disabled students;

I get accommodations to type my notes in class because it’s too tiring to hand write. And she [the professor] said that she doesn’t allow computers in class, and if she let me use my accommodations in class then everybody would know I have a disability. She highly encouraged me to not use my accommodations in class so that people didn’t know . . . I still did and was like, “it’s what you have to do, and maybe you can restructure your class so that it doesn’t out students with disabilities for instance.”

Theme 3: Desire for Justice

The theme of desiring justice brings together many of the sentiments the participants shared on educating the world at large, ideals of how they would be treated in a less ableist world, and feelings

of anger and/or resentment at the ableism they have experienced during their lives. For some, it was just expressing the desire to be themselves and meet their own needs without commentary or judgment from others. Whitney, a 35-year-old female, shared:

...justice would just look like I don't have to f*cking explain anything to you. I know what I need. I know I need a cane. I know I can't walk this far. I know I need a booth. I know if I have this I have to have my wheelchair... I don't have to explain it to you and you should just respect the fact that I know what I need, and I'm not trying to inconvenience you or hurt you or skip in front of you in line or otherwise put you out.

Betty, a 55-year-old woman, sometimes enjoys being in the role of educating others about disability, but only when it is her choice. She expressed frustration of being put in the role of having to educate others when she is in pain or exhausted. Particularly, she is annoyed when having to educate people in public and/or business settings, where "if they're accommodating for a wheelchair because someone has only one leg... they shouldn't have any other difficulty accommodating me that has arthritis and fibromyalgia or anything else." Her solution was to develop more guidelines for people regarding PWD, giving information on how to accommodate and engage them as customers.

Gabriel, a 28-year-old man, noted the importance of just having conversations about invisible disability in order to work toward change:

I think it's really significant that people start thinking about invisible disabilities and talking about them in the everyday because I think one of the problems with invisible disabilities... is that people don't believe they are real. And it's because you can't see or... you take for granted a body able to perform certain things that even when the manifestations of an invisible disability are apparent, because of the take for granted nature of ableism, they get glossed over.

Many of the participants spoke about this feeling, even outside of the recorded interview, from when they were setting up a time to meet, to when they were filling out the demographic form, or even after the interview was finished. Some spoke about their ongoing frustration with always straddling the line between being disabled (their real experience) and being seen as nondisabled by others. Several thanked us for "finally" creating a space to discuss their frustration and expressed their hopes that the results of this study, and ensuing conversation, would work toward making their community and world more validating and just.

Theme 4: Internalized Ableism

While ableism usually occurs based on the actions of others, many of the participants shared thoughts and beliefs that indicated their own internalizing of ableist beliefs and ideals. Some participants even named their experiences as such. Even though all of the participants self-selected into the study as individuals with invisible physical disabilities, some of them struggled with the term "disabled" and fitting in with the community. While some felt very comfortable with identifying as having a disability, others felt an internal conflict over not being able to do what they wanted to do. For Ash, having someone else point out her membership to the disability community led to an internal challenge:

... when my friend first pointed out to me that I was in a category of disabled... I had two reactions at the same time. One was sort of a relief that this thing existed for other people and that there were other people that I could talk to and there was a real validation in that, but the other reaction was really not to want that label. And to feel how the label disabled applied to me was really hard... part of my identity is physical strength and so—I mean even now I have both stories in my head at the same time. Like I am

unbelievably strong to do what I do, given the limitation and the pain that I experience, and I also have the story of I can't do all of that so I'm weak. So I do . . . I have major *internalized ableism*.

Gabriel also explicitly used the term *internalized ableism* in acknowledging some of his own use of language: "I think in terms of the mental health issues, I still sometimes catch myself using words like 'crazy' or 'hysteric,' and I am working on removing those from my everyday speech."

Because some people have had disabilities for years or their entire lives, a change in someone's pain level or how their disability impacts them can really challenge how they identify and seem themselves. Cal, who has had chronic pain and scoliosis for the last 16 years, has really struggled over the past few years as his pain levels have increased and changed his ability to do things in his day-to-day life. He questions himself around the change in his body and has concerns about what that means for his future: "I have thought of myself as able-bodied for so long while having this disability that I don't know if something went wrong. I don't [know] if it's just like how things like this go. How am I going to be when I'm 40 or 60?"

Another participant, Helen, a 45-year-old woman, was placed in the position of being a disability examiner for the state, interviewing individuals and deciding whether or not they qualified for disability. Once she herself was diagnosed with her multiple disabilities, she had more empathy for others who had invisible disabilities and were frequently told "you look fine." However, it also changed how she evaluated her cases, as she was the gatekeeper deciding if someone was *disabled enough*:

It made me better and harder. I felt like once I was convinced that you have some issues, you have some severe issues . . . Once I got there then I was very committed to trying to find a way to allow this person to be given a positive finding. And at the same time I was harder because if I didn't—honestly if you failed to convince me that you had a severe issue, then I was pretty much a hard ass about it.

Language came up frequently regarding participants' perpetuating ableist microaggressions, such as when Betty said, ". . . and people look at me and they don't see. I have all of my appendages, I am not obviously deformed or I don't have Down syndrome and have recognizable symptoms, and they just assume." Piper, a 19-year-old woman, also used other illnesses and disabilities to minimize her own experiences:

I don't have cancer, I'm not going to pretend that I know what it's like to go through having cancer . . . I don't have diabetes so I'm not going to pretend that I understand what it's like to have diabetes.

While the previous participants may not have recognized their use of ableist language, Susan, a 53-year-old woman, finds herself assimilating ableist language into conversation and doesn't take issue with it:

I use the same language. I've adopted you know "brain damage." "Oh that's too much brain damage, I'm not going to do that." I make fun of that. I use that and I perpetuate it because I mostly am ok with . . . It's interesting to me that more people say the word "crazy" all the time. I don't think much of it. I still am ashamed of that stigma somewhat but I say the words "crazy" and "brain damage."

Some participants shared stories of going years before being able to get a diagnosis for their disabilities or impairments and the ableism that occurred in various medical settings. However, Olivia, a 31-year-old woman, spoke to how she didn't feel her diagnosis was really an actual thing. On the form used to collect demographic information, she wrote "'fibromyalgia'—supposedly." When asked about this, she replied:

...there's always something that you can tell by test or like by actual science that there is definitely something going on with this person. Whereas with fibromyalgia, we can't do that with science yet, so I think that until we can... I don't really know what we can say about what fibromyalgia actually is.

However, she then also focused her skepticism of fibromyalgia on the beliefs of others, saying that "other people who don't have to go through anything physically kind of just don't believe in it and think that fibromyalgia is another way of saying that there is something, you know going that's not physical, that's more mental." She shared that she would only believe in a diagnosis that had tests that "proved" she had something and a way to treat it, subscribing to the medical model of disability, in that everything related to disability should be diagnosable in a clear manner and treated as to be "fixed." This skepticism about her own diagnosis is a form of internalized ableism, but one specifically tied to the ableism she experienced from others' attitudes, including both physical and behavioral health providers about her diagnosis.

Discussion

McRuer argues "that feminist and queer theories (and cultural theories generally) are not yet accustomed to figuring ability/disability into the equation, and thus this theory of compulsory able-bodiedness is offered as a preliminary contribution to that much-needed conversation" (2002, p. 89). It is this "compulsory able-bodiedness" or belief that nondisabled individuals are superior to disabled people, which contributes to ableism becoming an insidious part of culture. Research on disabled individuals and identities is growing; however, missing from much of this research are the experiences of those with invisible disabilities. In this study, the primary themes that arose demonstrate how these disabled participants who have invisible disabilities experience having their bodies being policed by others, feel torn between their roles, struggle with a deep-rooted desire for justice around their disabilities, and even experience internalized ableism. These are some of the results of experiencing ableism, including microaggressions, as disabled people with invisible disabilities.

Policing of bodies was an overarching theme that came up in almost every interview. Participants experienced being called out by strangers for using disability parking spaces, elevators, wheelchairs, laptops/technological devices, braces, canes, disability-designated desks, and more. They were also subject to others, including family members, coworkers, and friends, expressing disbelief and assuming they were lazy or overexaggerating their condition(s). The recollection of these ableist body policing experiences were fraught with shame, frustration, and the feeling of being stigmatized, solely for failing to adapt to a culture that is not designed to support disabled individuals. This policing of disabled bodies occurred in public spaces, in employment settings, and in educational venues, as well as in the privacy of the participants' own homes, leaving many of them to feel not only stigmatized but as though they were constantly under observation, being judged as to whether they were deemed "disabled enough" to be doing a given activity. Given the ubiquitous nature of this policing, several participants spoke to the utter exhaustion they felt from constantly having to experience these ableist microaggressions and particularly having others determine their "right" to identify as disabled and utilize disability-designated adaptations or accommodations.

When examining the theme of tension in roles, the participants expressed intense discomfort felt when ableism occurred around them, particularly when they were forced to decide how to react in the moment. When discussing the microaggressions that had occurred around/to them, many of the participants expressed the awkwardness of having to make choices as to whether to educate or let something go. This moment of forcing individuals to choose whether or not to take on the responsibility of educating others in how to not be ableist unfairly places the onus of social change on the

very individuals negatively impacted by the ableism itself. Having to take time during a regular day to figure out how they want to address language and actions that others believe to be acceptable can become exhausting, especially when, as some participants pointed out, there seems to be no “right” way to address microaggressions without the other party reacting defensively. Conversely, not all participants felt as hopeless regarding this tension; one participant explained that he chose to educate about his disability to those who he felt supported him, opting to not give ableist language the same power given to it by others. These differing opinions demonstrate that not only does this tension exist within each individual but also within the community, showing that even within a nuanced identity such as adults with invisible physical disabilities, each individual has their own reaction to acts of ableism and their own way of dealing with this tension.

The theme of desiring justice was one that encompassed many feelings and emotions from various participants. Some simply expressed frustration at an unjust world that deems their disabilities, identities, and lived experiences as less than ideal, even unacceptable. Others expressed a need for human compassion and empathy regarding the physical struggles they face on a daily basis. Discussion of changing physical access to spaces, whether parking lots, public transit, supermarkets, or college campuses, arose in several interviews, while other participants more specifically wanted to see change in the beliefs, attitudes, and behaviors of individuals and groups in the world around them. Although no individual seemed to have a solid grasp of what would be needed to create all of these desired changes, almost all of the participants shared their resistance to the current ableist status quo, and a deep-seated desire to experience a reduction in ableism, not at some point in the future, but in real ways that directly impact them today.

A somewhat unique but not entirely surprising finding was that many of the participants shared how their journey to identify with their own disability(ies) sometimes resulted in internalized ableism. One participant is an elite athlete who spoke about microaggressions becoming so normalized that she barely noticed them anymore; she just wanted to be viewed as being like everyone else. Other participants used language like “crazy” or “nuts” to explain living with physical disabilities or used the word “lame” in general context. While some noted the stigmatization of those with mental disabilities caused by this use of language, others did not notice this language use at all. There were mentions for some of being “lucky” that their disability was not more severe, creating a hierarchy of disability types. The insidiousness of this is made evident by one woman, a former athlete, who named her struggle with herself as “internalized ableism,” recognizing how her self-policing and frustration with her abilities was a product of ability expectations by society. In contrast, most of the participants seemed not to recognize their own ableist language and other ableist microaggressions, further showcasing how ingrained ableism is in social interactions.

Implications

Based on the themes emerging from the data in this study, people with invisible disabilities experience ableism regularly and may potentially encounter ableism in different ways than individuals whose disabilities are more apparent to others. Because of these unique experiences of ableism, it is necessary that discussions of ableism, as well as interventions designed to reduce ableism, recognize these nuances and include examples of how ableism can directly impact not only those with visible disabilities but also those whose disabilities may not be apparent. Given the fact invisible disabilities are just that, it is incredibly important that conversations on reducing ableism and microaggressions be inclusive of all types of disabilities.

Ableism is very hard to change because it is so integrated in multiple facets of society. Ableism is ingrained in culture and society, in language, in the regulation of bodies, and even in judgments about whether someone is viewed “disabled enough” to be granted access to accommodations like disability parking spaces and elevators. Conversations around “healthy habits,” which may include

encouraging people to take the stairs or judging them for using the elevator, while usually well intentioned, can be ableist (in addition to sizeist). Jokes about accommodations, adaptations, and accessibility needs being a privilege, such as being lucky for getting a closer space or having an assistance animal at all times, are usually hurtful. Words like “lame” and “crazy” are commonly used to mean stupid and ridiculous/intense/frustrating but can further stigmatize individuals with a variety of disabilities.

However, these are all examples that are ripe for discussion and change. Social workers, educators, mental health professionals, health-care workers, and others have opportunities to change the way society engages with ableist behavior. Not only is social justice a core value for social workers (National Association of Social Workers, 2017), but the inclusion and support of disabled people is also noted explicitly by the Council on Social Work Education (CSWE, 2015) in their Educational Policy and Accreditation Standards. Social work instructors can consider how their classroom activities can be adapted, not only for when they have a participant with obvious limited mobility, hearing, or sight but also more universally in ways that give all students access options at all times. Social work textbooks, manuals, and presentations should include a variety of individuals with a wide range of disabilities. Offering more disability-inclusive training to social service and health professionals, including social workers, would allow their interactions with clients to be less ableist, which is more likely to lead to positive interactions and better outcomes. It should also be noted that there are social workers with invisible disabilities as well; it is crucial that the field ensure they are included in social work education, continuing educational trainings, and by the organizations who employ them. Connecting back to this value of social justice means practicing social work in the most accessible way possible and recognizing the need for awareness around disability and impairment in clients throughout all types of social work practice.

We would like to suggest a movement toward universal design (UD), which supports the natural diversity of human needs, and away from a focus on accommodations. UD is a proactive concept of creating spaces (physical, educational, etc.) that are inclusive in as many ways as possible (no stairs, different types of seating, addressing multiple learning styles, descriptions of images, captions on videos, scent free, etc.) to be able to support a variety of different individuals and their unique needs (Burgstahler, 2001; Story, Mueller, & Mace, 1998). This differs from the idea of asking for and being assessed for deservedness, either formally or by peers, for accommodations. As many of those with invisible disabilities shared, this process can be harmful and unjust, whereas UD would allow everyone to have the majority of their needs met without having to “out” themselves as disabled or request specific accommodations. UD has been used in many fields but is only recently being used in social work education and practice.

Given how tightly many of these participants tied the invisibility of their disabilities to their experiences of ableism as a whole, and to ableist microaggressions, it is clear that different types of disabilities may lead to individuals experiencing ableism in different ways. This indicates that future social work research needs to not only examine ableism and the experiences of disabled people overall, but should dig deeper, exploring different types of disabilities, and how these differences may impact people’s experiences of ableism. Additionally, intellectual and/or developmental disabilities are often left out of research regarding ableism, but it is crucial to include this population and learn more about how these individuals experience ableism and ableist microaggressions. Intersections of identities may also change how ableism is perpetuated, in which case ensuring that disabled people of color; low-income disabled individuals; lesbian, gay, bisexual, transgender, and queer disabled individuals; and non-U.S. citizens, indigenous people, and other disabled individuals who hold multiple identities that are socially marginalized are included in research is crucial to a deeper understanding of the multiple forms of oppression they may face in conjunction with ableism.

Limitations

As with most qualitative research, this study specifically looked at the experiences of the participants who were interviewed as part of this particular project. While these experiences may lead to a better understanding of the lived experiences of ableism and ableist microaggressions by people with invisible physical disabilities, the findings from this small sample size are not generalizable to a larger group of individuals or to a population of disabled people as a whole. While generalizability is not the purpose of modified phenomenological research, it is possible that the findings of these experiences are transferable to those with similar identities.

The sampling method of using the Internet to recruit participants also presents a limitation, as the voices of those who do not use or have access to the Internet, as well as those who may not participate in online communities, are not included in this study. Including these populations, as well as broadening the sample to include those who live in rural or suburban communities, may strengthen future research on this topic. Furthermore, while some of the participants had hearing-related disabilities, none required an ASL interpreter, all participants could speak out loud, and all participants spoke English fluently. There might have been different themes established by participants who were nonverbal, spoke through an ASL interpreter, or used an English language translator, as their experiences of ableism might have including issues surrounding communication, interpretation, and/or translation.

Lastly, it is important to take into account the demographics of the participants of this study. The majority of those who responded identified as white, and there were only a few participants who identified as male, masculine, and/or transgender/nonbinary. Individuals of different gender identities, racial identities, and ethnic identities may have dramatically different experiences than the participants in this study, and further research regarding invisible disabilities should certainly strive to include individuals with these identities in their sample. Additionally, socioeconomic status was not collected and might have also showcased differences across social class. However, all except for one of the participants had completed at least some college, and many had master's level or higher degrees. Given that many disabled people experience ableism in educational settings, resulting in disproportionately low rates of education in disability communities, this sample is not very representative of PWD typical educational status. Further research should aim to ensure that people with invisible disabilities and less education are included.

Conclusion

Based on the experiences of those interviewed in this exploratory study, it is important for social workers, educators, medical professionals, and others to better understand the experiences of disabled PWD that are invisible to others. Disabled individuals with invisible disabilities experience ableism and ableist microaggressions in unique ways, including frequently having their bodies policed by those around them, struggling with when to engage in dialogue about ableism, desiring change to create a more just society for disabled people, and even internalizing ableism in a multitude of ways. Not only does society need to be more inclusive of disabled people and work to reduce the perpetuation of ableism, but it should be recognized that many people have disabilities that are not apparent to others. There is a need for social workers to take a note from feminist theory, connect theory to practice, and engaging in understanding the experiences of their disabled clients and communities. By developing a more nuanced understanding of how ableism occurs and how it harms those with invisible disabilities, social workers and other human service professionals can work to reduce ableism and ableist microaggressions, and how these experiences effect all disabled individuals, rather than those whose disabilities may be more apparent.

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Miranda Olzman is now a PhD student at the University of Denver Department of Communication Studies.


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Note

1. When referring to Deaf culture or identity (as compared to the impairment of being deaf), the D is capitalized (Ladd, 2003) and Ainsley asked for it to be capitalized in her case.

References

- Burgstahler, S. (2001). *Universal design of instruction*. Seattle, WA: DO-IT.
- Brune, J. A., & Wilson, D. J. (2013). *Introduction. Disability and passing: Blurring the lines of identity*. Philadelphia, PA: Temple University Press.
- Carter, I., Hanes, R., & MacDonald, J. E. (2012). The inaccessible road not taken: The trials, tribulations and successes of disability inclusion within social work post-secondary education. *Canadian Journal of Disability Studies*, 1, 109–142. doi:10.15353/cjds.v1i1.23
- Council on Social Work Education. (2015). Educational policy and accreditation standards. Retrieved from https://www.cswe.org/getattachment/...EPAS/2015EPAS_Web_FINAL.pdf.aspx
- Davis, L. J. (1999). Crips strike back: The rise of disability studies. *American Literary History*, 11, 500–512.
- Davis, N. A. (2005). Invisible disability. *Ethics*, 116, 153–213. doi:10.1086/453151
- Dunn, D. S., & Andrews, E. E. (2015). Person-first and identity-first language: Developing psychologists' cultural competence using disability language. *American Psychologist*, 70, 255.
- Dupré, M. (2012). Disability culture and cultural competency in social work. *Social Work Education*, 31, 168–183. doi:10.1080/02615479.2012.644945
- El-Lahib, Y., & Wehbi, S. (2012). Immigration and disability: Ableism in the policies of the Canadian state. *International Social Work*, 55, 95–108. doi:10.1177/0020872811407941
- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215–229. doi:10.1348/014466599162782
- Fischer, C. T. (2009). Bracketing in qualitative research: Conceptual and practical matters. *Psychotherapy Research*, 19, 583–590. doi:10.1080/10503300902798375
- Ford, A. (2009). It's not just about racism, but ableism. *Diversity in Higher Education*, 26, 16. doi:10.1177/0959353596061009
- Hehir, T. (2002). Eliminating ableism in education. *Harvard Educational Review*, 72, 1–33.
- Hirschmann, N. J. (2013). Queer/fear: Disability, sexuality, and the other. *Journal of Medical Humanities*, 34, 139–147. doi:10.1007/s10912-013-9208-x
- Kafer, A. (2013). *Feminist, queer, crip*. Bloomington, IN: Indiana University Press.

- Kattari, S. K. (2017). Development of the Ableist Microaggression Scale and Assessing the Relationship Between Ableist Microaggressions and the Mental Health of Disabled Adults (Doctoral dissertation), University of Denver.
- Ladau, E. (2014). *What should you call me? I get to decide: Why I'll never identify with person-first language*. I: Caitlin Wood (red.) *Criptiques*. San Bernardino, CA: May Day.
- Ladd, P. (2003). *Understanding deaf culture: In search of deafhood*. Bristol, England: Multilingual Matters.
- Lightman, E., Vick, A., Herd, D., & Mitchell, A. (2009). 'Not disabled enough': Episodic disabilities and the Ontario disability support program. *Disability Studies Quarterly*, 29. doi:10.18061/dsq.v29i3.932
- Loja, E., Costa, M. E., Hughes, B., & Menezes, I. (2013). Disability, embodiment and ableism: Stories of resistance. *Disability & Society*, 28, : 190–203. doi:10.1080/09687599.2012.705057
- McRuer, R. (2002). Compulsory able-bodiedness and queer/disabled existence. In R. Garland-Thomson, B. J. Brueggemann, & S. L. Snyder (Eds.), *Disability studies: Enabling the humanities*. New York, NY: MLA.
- McRuer, R. (2006). *Crip theory: Cultural signs of queerness and disability*. New York, NY: NYU Press.
- Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology*, 52, 250.
- Nadal, K. L., Griffin, K. E., Wong, Y., Hamit, S., & Rasmus, M. (2014). The impact of racial microaggressions on mental health: Counseling implications for clients of color. *Journal of Counseling & Development*, 92, 57–66.
- National Association of Social Workers. (2017). Code of Ethics. Retrieved from <https://www.socialworkers.org/About/Ethics/Code-of-Ethics/Code-of-Ethics-English>
- Olkin, R. (2002). Could you hold the door for me? Including disability in diversity. *Cultural Diversity & Ethnic Minority Psychology*, 8, 130–137.
- Padgett, D. K. (2012). *Qualitative and mixed methods in public health*. Thousand Oaks, CA: Sage.
- Pilling, M. D. (2012). Invisible identity in the workplace: Intersectional madness and processes of disclosure at work. *Disability Studies Quarterly*, 33. doi:10.18061/dsq.v33i1.3424
- Poole, J., Jivraj, T., Arslanian, A., Bellows, K., Chiasson, S., Hakimy, H., . . . Reid, J. (2012). Sanism, 'mental health', and social work/education: A review and call to action. *Intersectionalities: A Global Journal of Social Work Analysis, Research, Polity, and Practice*, 1, 20–36.
- Roux, A., Merkin, S., Arnett, D., Chambliss, L., Massing, M., Nieto, J., . . . Watson, R. L. (2001). Neighborhood of residence and incidence of coronary heart disease. *New England Journal of Medicine*, 345, 99–106. doi:10.1056/NEJM200107123450205
- Saldana, J. (2013). *The coding manual for qualitative researchers* (2nd ed.). Thousand Oaks, CA: Sage.
- Samuels, E. J. (2003). My body, my closet: Invisible disability and the limits of coming-out discourse. *GLQ: A Journal of Lesbian and Gay Studies*, 9, 233–255.
- Schriner, K. F. (1990). Why study disability policy? *Journal of Disability Policy Studies*, 1, 1–7. doi:10.1177/104420739000100101
- Solórzano, D., Ceja, M., & Yosso, T. (2000). Critical race theory, racial microaggressions, and campus racial climate: The experiences of African American college students. *Journal of Negro Education*, 69, 60–73.
- Storey, K. (2007). Combating ableism in schools. *Preventing School Failure: Alternative Education for Children and Youth*, 52, 56–58.
- Story, M. F., Mueller, J. L., & Mace, R. L. (1998). *The universal design file: Designing for people of all ages and abilities*. Raleigh, NC: Center for Universal Design.
- Sue, D. W. (2010). *Microaggressions in everyday life: Race, gender, and sexual orientation*. Hoboken, NJ: Wiley.
- United States Code. (2008). *Americans with Disabilities Act of 1990, as amended*. Retrieved from <http://www.ada.gov/pubs/adastatute08.htm>
- United States Census Bureau. (2012). *Americans with disabilities: 2010*. Retrieved from <http://www.census.gov/prod/2012pubs/p70-131.pdf>
- Wolbring, G. (2008). The politics of ableism. *Development*, 51, 252–258. doi:10.1057/dev.2008.17
- Wolbring, G. (2012). Ethical theories and discourse through an ability expectations and ableism lens: The case of enhancement and global regulation. *Asian Bioethics Review*, 4, 393–309. doi:10.153/asb/2012/0033

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