

Bridging the Gap Between Intentions and Impact: Understanding Disability Culture to Support Disability Justice



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Persistent ableism in higher education, counseling practice, and society necessitates disability justice advocacy. In this article, the author explores the historical context of disability and the importance of disability knowledge for counselors and counselor educators. In addition to discrimination and inaccessibility, able privilege and lack of representation present significant barriers to equity and empowerment of disabled people. Better awareness of disability culture and community-oriented frameworks for the collective liberation of disabled people, such as disability justice, can improve disability equity and allyship within counseling and counselor education.

Keywords: ableism, disability justice, advocacy, allyship, counseling

The disability rights motto, “Nothing about us without us,” highlights the importance of including disabled people in decisions that affect them. However, in a society dominated by able privilege, this motto has at times translated into “Nothing at all.” The absence of disabled representation and empowerment leads to a lack of understanding, empathy, and action toward improving the lived experiences of the disability community.

Over 60 million Americans live with a disability, making them the largest minority group in the United States (Centers for Disease Control and Prevention, 2023). The Americans with Disabilities Act (ADA) defines a person with a disability as “a person who has a physical or mental impairment that substantially limits one or more major life activity” (ADA National Network, 2024, para. 1). These activities include daily tasks like breathing, walking, talking, hearing, seeing, sleeping, taking care of oneself, doing manual tasks, and working. The year 2020 marked the 30th anniversary of the ADA, the major law granting protections to disabled individuals. Yet institutional ableism continues to persist in higher education, counseling practice, and public life. Disabled people face various obstacles, including unresolved barriers to physical access (including of health care and mental health services), social stigma, and insufficient funding for rehabilitation programs. Able privilege (also referred to as ability privilege or able-bodied privilege) is a viewpoint in which non-disabled bodies are considered normative (Lewis, 2022). Able privilege is pervasive in society and continues to contribute to societal stigmatization of and discrimination against disabled bodies, minds, and lives.

Positionality

The positionality of authors engaged in disability justice work is crucial for acknowledging biases and perspectives that influence the writing process. This practice also allows for transparency for readers to better understand the context this article is situated in. This is particularly important given the diversity of cultural norms within and between disability subcommunities and the differences of perception of ableism, access, and disability equity shaped by individuals’ unique experiences of disability.

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I identify as a White, queer, disabled academic who aligns with crip culture. The term “crip” is a reclamation of the derogatory slang “cripple,” much as “queer” has been reclaimed by the LGBTQ+ community. I integrate the principles of disability justice and bring lived experience into advocacy, clinical, and research work pertaining to the disability community. I have navigated ableism personally and professionally and am invested in critical examination of ableist systems and advancement of cross-disability liberation. I use an anti-ableist and identity-affirming ideological lens to approach disability advocacy. The use of identity-first language throughout this paper reflects this positionality and is an acknowledgement of many disability subcommunities’ preference for this language.

A Brief History of Disability in the United States

Attitudes and policies surrounding the disability experience in the United States have historically imposed harsh restrictions and exclusions grounded in ableism. In the late 19th and early 20th centuries, the eugenics movement promoted the view that disability was undesirable and needed to be purged from society (Rutherford, 2022). Many proponents of eugenics were scientists, doctors, and policymakers. This contributed to forced sterilization and institutionalization of disabled people, restrictive immigration policies, and segregation in education. These policies, along with social stigma, led to disabled people being socially and economically disadvantaged and pushed to the fringes of society (RespectAbility, 2021).

In the 1970s, The Independent Living Movement and Centers for Independent Living (CILs) emerged as a civil rights campaign spearheaded by and for the disability community (Hayman, 2019). This movement pushed back against the discriminatory environments and paternalistic professionals of the time and focused on providing peer support, dignity, civil rights, and autonomy through direct service and advocacy. At this same time, the 504 protests (referring to section 504 of the Rehabilitation Act) paved the way for the civil rights work that eventually culminated in the passage of the ADA in 1990, which finally extended similar federally protected rights to disability as those that cover race and gender (Cone, n.d.).

Since 2000, disability-related activism has been most prominent online. Within this environment, community-based efforts such as the #SayTheWord movement and disability-related hashtags began to trend on social media. Many within the disability community have embraced X, formerly known as Twitter, specifically because it is free, has accessibility features, and allows for global connection and unprecedented reach to businesses and public figures, as well as other individuals and organizations within the disability community (Wilson-Beattie, 2018). Facebook and other social media groups have been important gathering places for disabled individuals to connect, obtain information about their conditions and available treatments, and find others who can relate to their experiences.

Exclusion of Disability in Education and Practice

The Rehabilitation Act of 1973 and the ADA both extended disability protections into higher education settings. However, because of the lack of protections in these settings prior to these laws, colleges and universities were already built on inaccessible foundations both physically and socially (Dolmage, 2017). This has led to a continued lack of equity for disabled people within higher education.

The National Center for Education Statistics (2018) reported that 19.4% of the undergraduate student body report having a disability, but only 11.9% at the graduate level. The Center for College Students

with Disabilities reported that less than 4% of faculty members have disabilities (Grigely, 2017). This suggests barriers to recruitment and retention and/or biases that prevent disclosure of disability identity. Despite the requirements under the Rehabilitation Act and ADA to provide equitable access, providing disability-related supports is often in conflict with ableist systems within higher education. For example, very few universities and colleges embrace a holistic and affirming model to support disability inclusion on their campuses and instead use an accommodation-only-focused approach. Most colleges and universities do not have a disability cultural center or student organizations focused on disability, despite the benefits for students and the community that such a center can provide (Elmore et al., 2018).

Disability and Counselor Education

Unfortunately, there is very little research available on disability within counseling and counselor education. Disability is often absent from captured demographics in our research, including when studies focus on the experiences of diverse counselors, counselor educators, and students. There is no information currently available regarding disability representation among counselor educators or counseling leadership, and very little about the experiences of disabled individuals within the profession or even the experiences of disabled clients with professional counselors.

Counselor education programs, apart from rehabilitation-specific classes, seldom focus on disability topics. According to Feather and Carlson (2019), 36% of faculty surveyed believed their program was ineffective at addressing disability topics, while only 10.6% believed their program to be “very effective” in this content area. Faculty self-assessment of competence to teach disability-related content correlated significantly with previous work or personal experience with disability, underscoring the importance of exposure to and training about disability-related concepts being infused across core areas. Key elements related to disability competence such as accessibility, able privilege, disability culture, and disability justice are explored in the following sections.

Considering Accessibility

Accessibility is a word that is often co-opted in diversity, equity, and inclusion (DEI) spaces to mean attainability, affordability, inclusion, etc. However, *accessibility* is a concept that is legally related to the ability of disabled people to equitably interact with built environments and services. The Office for Civil Rights (OCR) defines accessibility as:

When a person with a disability is afforded the opportunity to acquire the same information, engage in the same interactions, and enjoy the same services as a person without a disability in an equally integrated and equally effective manner, with substantially equivalent ease of use. (U.S. Department of Education, 2013, p. 3)

Physical accessibility includes factors such as ample accessible parking, pathways without stairs, clear curb cuts, even paving, wide doors and pathways, clear signage, clear spaces for wheelchairs and mobility devices, and accessible bathrooms. Accessibility of websites and other digital services is also covered under the ADA. The accessibility of learning management systems, captioning and transcripts for videos, and accessible file types are all important factors in classroom accessibility. Despite the ADA requirements, many spaces fall short, emphasizing the need for continual self-evaluation and consultation (ADA National Network, 2016).

Accessibility is often viewed only as what must be done at a minimum legally, and sometimes it is unclear within a given structure who exactly is responsible for ensuring accessibility. This often results in a reactive approach that places the burden on disabled people to experience barriers and report them. Another common approach is an accommodation mindset, in which disability is seen as so unlikely within a setting that those who need disability supports are seen as burdensome and must request them in advance. This can be contrasted with a barrier reduction or universally designed approach, in which disability would be proactively considered and planned for within a system or space. The resistance to these more equitable approaches is largely the result of lack of awareness of disability prevalence and needs, rooted in ableism and able privilege (Dolmage, 2017).

Able Privilege

Able privilege (also referred to as ability privilege or able-bodied privilege) is a viewpoint in which non-disabled bodies are considered normative. This condition lends itself to the continuation of inaccessible environments and attitudes, which, in turn, further entrenches able privilege within society. To illustrate the implications of able privilege, one may consider the day-to-day experiences of non-disabled individuals and the stark contrast with the experiences of disabled people. The simple act of opening a door without strategizing your approach or having the liberty to choose any seat at a movie theater or concert are further indicators of able privilege. If you have always been able to access materials showcasing individuals of your ability as role models or had access to mentors who mirror your ability, you have experienced able privilege. The ability to move around with the assurance that housing options will generally be accessible to you is a distinct advantage, one that disabled people, particularly those who use mobility devices or who have physical limitations often cannot take for granted. The invisibility of these privileges to those who benefit from them is precisely what fuels the cycle of able privilege, leading to a lack of representation and empowerment for disabled individuals (Dolmage, 2017).

Able privilege is a major but often neglected aspect of social inequality, mostly because disabled individuals are systematically underrepresented. This exclusion is deeply ingrained in our society, impacting policies, cultural norms, and current structures, which further magnify able privilege. “Ugly laws,” a discriminatory legislation active in certain parts of the United States through the ‘70s and ‘80s, literally pushed disabled people out of public view, further contributing to their erasure (Schweik, 2011). The discomfort with the disabled body being seen and acknowledged in public continues, with organizations like the Ford Foundation finding a lack of disability representation in popular media (Heumann et al., 2019). Despite increasing emphasis on diversity, equity, inclusion, and accessibility (DEIA) in counseling, the reality is that the disability community often finds itself on the outskirts of these crucial conversations because of historical inequalities that are unchallenged or a continued lack of equitable access (Dolmage, 2017).

This cycle of exclusion parallels a common physical accessibility challenge: The lack of disabled people present in a space is often used to justify a lack of priority given to accessibility. However, the inaccessibility itself is the barrier preventing disabled people from entering and remaining in these spaces in the first place. Inaccessibility precludes disabled presence and advocacy, and barriers often then stand unchallenged.

Our educational systems and programs are no exception to the impacts of the exclusion of disabled bodies and minds. Ableist ideologies are often left unchallenged and unknowingly promoted, shaping the understanding of disability at crucial developmental stages. The exposure that most people have to disabilities is also skewed, leading to the formation of harmful stereotypes and stigmas discussed further below.

Disability Culture

Disability culture encompasses a group identity with shared experiences, a history of oppression, literature, art, language, and expression. This is highlighted through various forms of art and literature and through movements advocating for disability rights and inclusion (Brown, 2015). However, the disability community boasts a rich and diverse culture that's often absent from mainstream media and popular culture.

Representation

As with other minoritized and marginalized populations, the representation of disability in mainstream media, film, and literature can have significant impacts on the societal view of disability and bias and stigma experienced by disabled individuals. Because of the various challenges in access presented by society and the taboos regarding discussions of disability, media is a primary way many people may form opinions about disability and disabled people. Unfortunately, these depictions are few and often convey misinformation and harmful tropes. In a review of 100 top movies in 2016, fewer than 3% of characters had a disability (Smith et al., 2017). Heumann and colleagues (2019) found in their examination of disability in media that most disabled characters in film fell into four stereotypes: the *Super Crips* who triumph over disability and provide the message that disability is merely a negative thing to be overcome; *Villains* who are often portrayed with disfigurement of some kind and play on fear and discomfort of disability and difference; *Victims* who are defined only by their disability and often are shown as better off dead than disabled; or *Innocent Fools* who embody negative stereotypes of those with intellectual disabilities or neurological differences. These issues with one-dimensional and negative representation in the small number of examples of disability shown on the screen are compounded by a lack of input from disabled writers, actors, or directors. Most disabled characters are played by non-disabled actors, and disability is the most underrepresented minority in the Hollywood film industry (Woodburn & Kopic, 2016).

Within the disability community, a starkly different narrative emerges, often directly hitting back at the misrepresentation and villainization of disability that is commonplace in mainstream media. For example, *Disfigured: On Fairy Tales, Disability, and Making Space* by Amanda Leduc (2020) critically analyzes the narratives ingrained in our culture around disability. Leduc particularly explores the impact of fairy tales and their modern retellings on identity development and belonging for disabled people, centering her own story and other disabled people's narratives. *Crip Camp*, a Netflix documentary, discusses the disability rights movement through the personal stories of advocates such as the late Judy Heumann (Hale & LeBrecht, 2020). Heumann's autobiography, *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist* (2020), is a powerful work in the disability space along with early commentaries on empowered language and identity choice such as Nancy Mairs's essay, *On Being a Cripple* (1986).

"Crip culture" is one notable aspect of disability culture. In the anthology *Criptiques*, compiled by Caitlin Wood (2014), *crip*, slang for *cripple*, is embraced as a powerful self-descriptor, representing audacity, noncompliance, and a direct challenge to disability being pushed into the shadows. It is an example of the arts and expression of "crip culture," which draws on shared experiences of ableism, creating a community that affirms and reflects its members' originality and beauty. *Criptiques* presents a diverse set of essays embodying this revolutionary spirit and fostering discussions about disability experiences (Wood, 2014).

Social media platforms, particularly X/Twitter, have catalyzed the formation of a global disability community. Hashtags like #DisabledandCute and #AbledsAreWeird have trended, fostering discussions and highlighting the shared experiences within the disability community. “The disability revolution will be tweeted” because of the critical role social media plays in fostering community in accessible formats (Wilson-Beattie, 2018).

Emerging trends in disability spaces include the #SayTheWord movement, which seeks to reclaim the term *disability* and challenges forced person-first, euphemistic language often pressed on the disability community by able-bodied individuals, discussed further below. *Spoonie* communities are also prevalent in chronic illness and even some mental health circles. These spaces use the spoon theory by Christine Miserandino (2003), which describes how there is a set amount of energy for daily tasks that can be lowered by disability-related factors such as pain or fatigue. Spoon theory seeks to help disabled people and those close to them understand the fluctuating nature of chronic illness and better communicate about it.

Language and Empowered Expression

It is essential to understand how to talk about disabilities and disabled people in an empowering and inclusive way. *Person-first language* (e.g., “person with a disability” and “person with [condition]”) emphasizes the person before the disability. While this language is used primarily in academic spaces and was mandatory until the seventh edition of the American Psychological Association style manual (APA; 2020), it is often criticized for being avoidant and contributing to perpetuating rather than confronting stigma (Collier, 2012).

Alternatively, *identity-first language* proposes that the identity of an individual should lead the conversation. This mode of language is used more commonly within disability spaces, such as “disabled individuals” or “autistic people.” Some subgroups, like the Deaf and autistic communities, strongly identify with their disability factors, promoting a sense of disability pride.

Disabling language, such as “handicapped,” “wheelchair-bound,” or “crippled,” are terms that are outdated, inaccurate, and offensive. These terms can be stigmatizing based on social and historical contexts, like referring to someone diagnosed with schizophrenia as “schizophrenic.” The exception to this is in usages such as those outlined above in which some subcommunities have reclaimed words like “crippled” or find them accurate and therefore identity affirming. This highlights a trend that language and slang within the disability community often focuses on relevant factors of assistive technology or the disabilities themselves (e.g., “wheelies” for wheelchair users, “spoonies” for those who endorse spoon theory, or “potsies” for those with postural orthostatic tachycardic syndrome [POTS]), whereas out-of-group language typically rejected by disabled people is often designed to avoid using the word disability (e.g., “differently abled,” “diverse-ability,” or “special needs”).

While person-first language is valid and should be used when it is the preference of the individual with a disability, there are many compelling arguments for normalizing and empowering identity-based language. Person-first language can be incongruent with people’s self-concept and with their experience of the perception others have of them. Person-first language can perpetuate stigmatization of disability, leading to perceived hypocrisy (Collier, 2012). The language choices made by able-bodied allies often disregard the preferences of the disabled community, echoing a history of erasure and opposing the principle of “nothing about us without us.” This has sometimes extended to able-bodied academics imposing their preference for person-first language on disabled people through academic standards and publishing norms. It can be argued that these restrictions historically have inhibited self-identification,

language preference, and the ability to produce scholarship that accurately represents disabled people and community values. This impedes collaborative research with the disability community and reinforces a division and lack of understanding between the disability community and counselors or other medical and mental health providers.

Allyship and Disability Justice

Allyship is not an identity but a practice. Allies for the disability community must operate in solidarity with and advocate for the rights of those oppressed by systems in ways that do not reinforce the system's oppression (Brown, 2015). This involves actively listening, observing dynamics of power, focusing on impact rather than intent, leaning into discomfort, modeling inclusive language, and offering kind and constructive feedback. In this context, it's vital to understand ableism, defined as, "a system of assigning value to people's bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence, and fitness" (Lewis, 2022, para. 4). Ableism devalues and discriminates against disabled people and gives preference and normative status to able-bodied people.

The Disability Justice framework (Sins Invalid, 2015) offers a comprehensive and inclusive perspective on human bodies and experiences. The Disability Justice framework was originally developed by the activist Patty Berne, a co-founder of the organization Sins Invalid, to reflect the collaborative work occurring in community spaces. Sins Invalid is a performance project that deconstructs the dehumanizing practices disabled people face and centers intersectionality and diversity of identities.

The Disability Justice framework emphasizes that every body is unique, important, and powerful. This framework understands that people are shaped by complex intersections of factors like ability, race, gender, sexuality, social class, nationality, religion, and more. Instead of isolating these factors, it insists on viewing them collectively. This viewpoint stresses that our pursuit of a fair society is rooted in these intertwined identities and points out a critical observation: Our current global system is essentially "incompatible with life" (Berne, 2015, para. 13). Disability Justice principles include "leadership of the most impacted," "interdependence," "collective access," "cross-disability solidarity," and "collective liberation" and focus strongly on intersectionality and cross-movement organizing to ensure no one is left behind or excluded (Sins Invalid, 2015, p. 1).

Although there are voices advocating for disability rights, these are predominantly from within the disability community itself, a testament to the lack of understanding and allyship from broader society. Historically, those who could have been allies—abled caregivers, academics, medical professionals, and others—have often worked against the community, whether consciously or not (Dolmage, 2017). This can be combated first by ensuring access to spaces so that disabled voices are present. Then, allies can elevate these voices while implementing a framework like disability justice to ensure that those impacted are leading and that cross-disability approaches are being implemented around equity and liberation work, in line with community priorities.

Implications for the Counseling Profession

Counselor Education and Preparation

Instructors have a critical role in supporting disabled counselors-in-training. Not only is this support mandated by law, but it also increases visibility, representation, and lived experiences of disability in the profession, thereby improving services for clients. Implementing Universal Design for Learning (UDL) can minimize the need for accommodations and provide access, engagement,

and learning motivation to the widest possible audience of learners (CAST, 2018). UDL is grounded in Universal Design principles, which are architectural strategies to make physical spaces usable by the widest number of people possible. The UDL principles include strategies such as multiple means of representing information to capture various learning types and multiple means of expression to allow learners to demonstrate learning in various ways (CAST, 2018). Adopting these principles can significantly contribute to making materials and learning environments more accessible. Instructors should consider how they can better focus on curriculum, activities, and assessments that increase exposure of counseling students to disability as a common multicultural factor and client identity. In addition, it is highly advisable to approach accessibility proactively in assignments and course materials and to become comfortable with the process required to swiftly provide equitable accommodations for students when a request is made.

Where a need for access or accommodations is established for a student, an opportunity also exists to proactively advocate for and support students in ensuring accessibility and equity in their practicum and internship placements, graduate assistantships, and other duties required for or connected to their program of study. Sometimes a student's disability and related accommodation needs are new. Even for those who have established what they need to succeed in a classroom, counseling programs with their clinical requirements are a new setting and students may not always know what they need in advance. It is therefore the responsibility of counselor educators to take a barrier reduction approach, take on the labor of researching the accessibility of approved sites and processes of accommodations specific to graduate students within their universities, and work collaboratively with the student at all stages of a program.

Counseling Practice

It is an ethical mandate that counselors become competent in working with disabled clients as addressed in the *ACA Code of Ethics* pertaining to nondiscrimination and multicultural issues (American Counseling Association, 2014). It is also important for counselors to work in ways that are respectful and promote client autonomy. This can begin with ensuring that proper etiquette is understood. Examples include speaking directly to a person, not their interpreter or attendant; not drawing attention to, commenting on, or interfering with assistive technology (including service animals); and asking questions rather than making assumptions. Working from a disability-affirming perspective is important, as well as being engaged in self-reflective work around disability bias and seeking appropriate supervision. Supervision might be with a peer to check for bias and process reactions to disability topics, or with someone with disability identity or rehabilitation training to consult on best practices around accessibility and disability-affirming approaches.

The physical counseling environment needs to be accessible according to ADA guidelines, and this should be determined based on the checklist for existing facilities and/or a professional consultant (ADA National Network, 2016). Continuing to offer telehealth as an option while still ensuring spaces are accessible helps to meet a long-standing need expressed by disabled people in ensuring access to mental health care. Websites need to meet web accessibility guidelines, and it is advisable to ensure accessible formats are available for documentation (e.g., large font and digital options). Within spaces, common triggers for various conditions should be considered. For example, fluorescent lights may trigger migraines or neurological conditions, while chemical sensitivities could be triggered by anything from bleach and other cleaning supplies to perfume, room fresheners, or lavender and other essential oils.

In working with clients, it should not be assumed a client is not disabled merely because they are not visibly disabled or have not disclosed a disability. If a client is visibly disabled or has disclosed

but not elaborated, signaling openness to further discussion while respecting boundaries and client priorities is warranted. Intrusive questioning is never appropriate, and client autonomy and treatment goals should always be respected. In my own work, I think of this similarly to when I may diffuse a question regarding trauma on an intake by acknowledging the client may not yet trust me; we can come back to discuss it further at any time in our work together, and I invite them to share to their level of comfort. An example of broaching a visible or previously disclosed disability might be simply asking if there is anything that can be done to increase accessibility or comfort in the space. Another approach might be to reflect the client's own language to describe the disability, chronic illness, assistive technology, etc. and to simply ask if there is anything specific that the client would like for you to know up front that would support your work together, or whether they would like to address things as they come up.

Conclusion

Disability culture is rich and complex, asserting its place in sharp contrast to mainstream narratives with defiance. It is a culture that celebrates wholeness and intersectionality and challenges ableist norms without apology for occupying space.

By understanding how ableism in counseling and counselor education fits into the broader history of disability oppression and increasing awareness of disability culture and disability justice, the counseling profession can better serve the disability community. Normalizing conversation about disability allows us to prepare ourselves, our students, and our supervisees to work with this large and diverse population. When we act intentionally to proactively make spaces accessible, we are providing disabled people with the same rights we provide to other clients. This allows them to share their stories gradually and comfortably, without having to disclose too early or fight for their basic rights.

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