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POSITIONING DISABILITY IN WILDERNESS SPACE

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POSITIONING DISABILITY IN WILDERNESS SPACE

by

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BACHELOR OF SCIENCE, UNIVERSITY OF NEW MEXICO, 2021

THESIS

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DEDICATION

To my mom for showing me crip resilience.

To my sibling Alexis for exemplifying radical queer and crip solidarity.

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"We are the queer groups, the people that don't belong anywhere, not in the dominant world nor completely within our own respective cultures. Combined, we cover so many oppressions. But the overwhelming oppression is the collective fact that we do not fit, and because we do not fit, *we are a threat*."

Gloria Anzaldúa in *This Bridge Called My Back, Writings by Radical Women of Color*

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by

Rebecca Juliet Hobart

B.S., Environmental Science, University of New Mexico, 2021

M.S., Geography, University of New Mexico, 2024

ABSTRACT

This thesis examines the social construction of the disabled body in recreational wilderness space. A political ecology framework guides the research questions: What are the actual or perceived barriers to participation for differently abled hikers in wilderness recreational spaces, and how do these challenges manifest in long-distance hiking spaces? In situating Foucault’s theories of the body as shaped by power relations, this thesis asserts wilderness spaces to be privileged based on power conceptualized in normative notions of ability. 44 participants who self-identified as wilderness recreationalists with a disability and/or chronic health illness completed this study’s mixed-method questionnaire. Themes around practices, values, motivations, adaptations, and barriers to participation emerged. I used principles of eco corporeality to interrogate access to wilderness spaces as socially constructed fallacies which strategically exclude disabled and chronically ill recreationalists. This thesis finds that disabled hikers subvert the social construction of normative bodies in wilderness, and will challenge health, physical, cultural, and social barriers of participation to negotiate and secure greater access to self-determination and ecological fulfillment.

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Chapter 1

Introduction

This thesis interrogates the social construction of dis/ability within the context of American recreational wilderness spaces. It explores the social, physical, cultural, and health challenges related to accessibility of these outdoor recreational spaces. This research centers corporeal ecology and narrates lived experiences and embodied knowledge within the American wilderness to develop arguments around the cultural, sociopolitical construction of the disabled body in space. Disabled individuals and their experiences are shaped by and through the myriad influences of social and political wilderness spaces. By examining long-distance hiking experiences of disabled and chronically ill outdoor enthusiasts, this thesis centers the voices of disabled people to analyze issues of accessibility and barriers to participation. The guiding question of this research is: What are the actual or perceived barriers for differently abled hikers and backpackers in accessing wilderness spaces, and how do these differences manifest in long-distance hiking spaces?

Why it Matters.

This research project explores gaps in accessibility for hikers who identify as having a disability and/or chronic health illness. In the United States, six in ten adults have a chronic disease, a condition which lasts one year or more. The CDC defines these conditions as those needing ongoing medical attention and/or which limit daily living activities ("About" 2022). On the other hand, one in four adults have a disability, which is defined by the CDC to include impairment of the body of mind which limits activities and/or creates participation restrictions (“Disability” 2023). Disability and chronic health illness reflect a significant population of individuals which experience diverse challenges.

Drawing on political ecology and feminist geography frameworks, I interchangeably identify disabled individuals with the terms “disabled” and “crip” to interrogate disabled experiences as they relate to those of able-bodied individuals. The term “crip” is exercised to assert power in disability justice and disrupt social conceptions of disability in nature. This study also considers chronic illness and disease, drawing on discussion by Bernell (2016) to ascribe an empirical, ethical viewpoint in using the word “sick” to represent nuances of nonuniform terminology. Thus, I seek to understand the opportunities and practices of engaging wilderness space for crip and sick outdoor recreationalists. Through capturing dynamic experiences of the crip and sick individuals in outdoor environments, this study interrogates wilderness practices, barriers, and adaptation strategies for participation. Nature-based tourism and wilderness spaces are accessed by communities with dynamic abilities and experiences (Wall-Reinius et al. 2022, 336). Akin to Western cultural values of able-bodied individuals, disabled and chronically ill communities share experiences which shape wilderness values. However, not all persons with disabilities and chronic illnesses who desire wilderness experiences have the same access (Corazon et al. 2019; Gleeson 2006).

This thesis employs a theoretical analysis of wilderness space as a socially constructed recreational environment that hosts dynamic social communities and strategically decenters differently abled individuals from participation. In response to this decentering, this study explicitly holds space for the experiences of crip and sick recreationalists, asking about their barriers, possibilities, and strategies for fulfilling engagement with outdoor recreational spaces. Assertions of crip theory as a response to the “social construction of normalcy” moves to celebrate crip social and cultural differences and knowledge. Robert McRuer, in *Crip Theory: Cultural Signs of Queerness and Disability (2006)*, proposes crip theory to empower disability visibility and justice to challenge the social neoliberal capitalist systems which have upheld the able-bodied construct of disability. Crip theory and disability justice rises to the forefront as a reflexive praxis toward equity, while decentering the epistemological power of able-bodied experiences (Boda 2022). This thesis examines power structures in wilderness spaces to interrogate the strategic, sociopolitical exclusion of differently abled individuals from equitable access to participation.

This study positions crip and sick knowledge within wilderness and research spaces to disrupt conventional assessments of disability. The epistemology of embodiment drives critical disability studies in practice, reflecting on lived crip experiences and knowledge to interrogate meaning and materiality of the body (Flynn 2020, 635). Through a critical refocus of disabled participation in wilderness space, this thesis moves to situate power in disabled experiences and challenge the construction of able-bodied space. Environmental humanist Sarah Jaquette Ray asserts the disabled person as the "ecological other" to examine their exclusion in the environment relative to able-bodied persons. In conversation with Ray's work *The Ecological Other: Environmental Exclusion in American Culture* (2013), this thesis builds upon this concept of the "ecological other" and the inverse "ecological subject," situating Ray's theoretical language within arguments around dis/ability and participation.

In conversation with Foucault's ideas of the body as political, Ray examines the body within environmentalism, which "reinforces many hierarchies along the lines of race, class, and gender" (Ray 2013, 4). Ray's concepts of the "ecological other" and "ecological subject" are discussed to develop arguments around social and political hierarchies which exclude disabled bodies in wilderness space. “Wilderness is a resource, not only in the physical sense of the raw materials it contains, but also in the sense of a distinctive environment which may, if rightly used, yield certain social values” (Leopold 1925, 398). As Ray positions the “ecological other” as it experiences power structures within the environment, this thesis examines the experiences of the disabled body with the wilderness environment.

Historically, disability has been presented as an individual manifestation of pathological accounts rather than a cultural minority group subject to marginalization. This reality is reflected in the “stigmatization of the disabled body that often leads to socio-economic disparities and social exclusion” (Agmon 2016, 15). In positioning the crip and sick body in wilderness space, this thesis moves to reveal “ability hierarchies,” which stigmatize and subvert disabled individuals in hiking and backpacking environments. Assertions of feminist and crip theories challenge the paradigm in which the disabled body becomes subverted to the able-bodied in social, cultural, and geographical contexts. The work of Foucault in conversation with contemporary black and dis/ability scholars – including Carolyn Finney, Janae Davis, Sarah Jaquette Ray, Brendan Gleeson, Alison Kafer, and Robert McRuer, provides a study foundation for interrogating power in identity structures.

Positionality

I position myself as a disabled scholar and hiker, researching within the field of disability studies while negotiating insider/outsider researcher status (Mohler et al. 2022). As a disabled hiker and scholar, I use critical reflexivity to understand how my positionality is part of the production of knowledge. Insider knowledge of experiences in disabled communities shaped my perspective in developing this research study. In connection with this study’s participants, my intersectional queer and crip identity offered a social advantage in engaging crip spaces to negotiate research. Further, my own situated and embodied knowledge of disability shaped research questions and the interpretive framework (Watson 2021, 125). As an insider to this community of crip and sick hikers, I can access research spaces which may otherwise be less accessible. I experience insider/outsider status primarily through recruitment and writing practices. In interpretation of study findings, I move to center practices of reflexivity to produce knowledge which reflects the subjective construction of space, identities, and experiences.

In academic writing, my insider status, as well as the theoretical work of critical disability scholars, informs language used to represent participants. For this reason, I position the term "crip" to acknowledge the historical oppression of disabled persons. Crip used interchangeably with disabled further serves to challenge the social construction of dis/ability and compulsory able-bodiedness in wilderness environments. As a scholar informed by the theoretical conceptualization of queerness and disability, qualitative methods allows me to center lived experiences and embodied knowledge of crip communities. Thus, a qualitative questionnaire is mobilized to survey participants, with efforts to capture, amplify, and empower disabled voices. Qualitative analysis of questionnaire data supported the observations and vignettes of participants, allowing for the embodied narratives of crip bodies to guide research findings. Situating data as political and subjective shaped my inductive coding strategies of participant responses.

Background

Disability

The Center for Disease Control estimates via the Behavioral Risk Factor Surveillance System (BRFSS) that approximately one in four noninstitutionalized US adults have a disability (Disability 2023). This estimate adds value to the national conversation on dis/ability, accessibility, and visibility by highlighting the prevalence of disability for persons in the United States.

The medical model ascribes physical and mental differences as a reality of the body, which is then subject to medical intervention to normalize such differences for functionality. In contrast, the social model asserts dis/ability as a sociopolitical construct, where the individual's interactions with society inform the crip body's experiences (Haegele and Hodge 2016, 193). Disability scholar Alison Kafer rejects compulsory able-bodiedness and challenges the medical model's conceptions of the disabled body in *Feminist, Queer, Crip (2013).* Kafer centers "those who lack a 'proper' (read: medically acceptable, doctor-provided, and insurer-approved) diagnosis for their symptoms" to normalize crip identity and experiences (Kafer 2013, 12). Individual differences in ability are manifested as physical and mental limitations by way of the medical model, whereas the social model challenges disability as an identity which reflects power structures of its environmental and geographical contexts. In grounding Kafer's assertions around normalizing disability, this thesis displaces the medical model in favor of the social model to characterize chronically ill and disabled hiker's experiences.

Legal

This section gives background to the legal dynamics of wilderness environments; this background is helpful in contextualizing discussion of the Americans with Disabilities Act (ADA), Rehabilitation Act of 1973, Architectural Barriers Act of 1968 (ABA), and Wilderness Act of 1964 as discussed in the Results chapter (Page 41). The Wilderness Act of 1964 (16 U.S.C. 1131 et seq.), Rehabilitation Act of 1973 (29 U.S.C. § 794), Architectural Barriers Act of 1968 (42 U.S.C. 4151 et seq.) and Americans with Disabilities Act of 1990 (U.S.C. § 12101 et seq.) are discussed in conversation with one another.

The ADA concerns state and local government services, organizations open to the public, and public accommodations. The ABA, on the other hand, requires some federal and federally funded facilities to be designed and constructed to ensure accessibility standards are met. Separately, the Wilderness Act of 1964 authorizes Congress to designate and manage wilderness areas. The ADA is a federal civil rights law which prohibits discrimination against persons with disabilities in everyday activities. Title II, Subtitle A protects individuals with disabilities from discrimination "in services, programs, and activities, including employment, that are made available by public entities." This Title extends ADA protections, including reasonable accommodations to recreation services and activities, to state and local governments. Section 504 of the Rehabilitation Act of 1973 protects "camping, hiking, and other recreational activities." It states:

> "No otherwise qualified individual with a disability in the United States shall, solely by reason of disability, be excluded from the participation in, be denied the benefits of, or be subject to discrimination under any program or activity conducted by Federal Financial Assistance or by any Executive Agency" (Public Law 93-112).

While “program accessibility” is clarified as services being readily accessible, and “(not) every existing facility or part thereof has to be made accessible,” assignment of aids and alternation of existing facilities are highlighted in the Rehabilitation Act of 1973 (Public Law 93-112).

The Wilderness Act of 1964 established the National Wilderness Preservation System, a network of more than 800 federally designated wilderness areas. These areas are federally funded and managed spaces by way of the National Park Service (NPS), U.S Fish and Wildlife Service (FWS), United States Forest Service (USFS), and the Bureau of Land Management (BLM), as denoted by the 1964 Wilderness Act and National Trails Systems Act of 1968 (16 U.S.C. § 1241 et seq.). Title V, Section 508(c) clarifies federal wilderness areas as not required to “uncharacteristically develop or reconstruct such wilderness spaces to accommodate persons with disabilities.” However, agencies that receive federal funding, such as the United States Forest Service, are directed by the Rehabilitation Act of 1973, Section 504 (29 U.S.C. § 701 et seq.), to offer civil rights protections for individuals with disabilities from exclusion and unequal treatment in federally funded facilities.

Wilderness

In an analysis of hiker diversity in long-distance trail spaces, one academic exploration of minority representation (race and gender) in thru-hiking environments recognized a need for including disabled perspectives (Williams 2014, 243), while another amplifies Sarah Jaquette Ray’s theories of ecological otherness to argue the outdoors as a space offered to the privileged able-bodied (Cox 2019). While motivations for hiking in long-distance environments has been captured for able-bodied participants (Stefanek 2020; Lum 2020; Basil 2022; Berg 2015), and disability within nature has been captured by others (Zhang

2017; Stiggsdotter 2018; Nisbett 2005; Goodwin 2009), there is a gap in the literature connecting barriers for participation positioned within the social world of long-distance hiking and backpacking. This section examines the social construction of wilderness and disability as co-constituted variables in producing space.

As a space that moves adjacent to the social world of its participants, “wilderness is a relative condition” that exists in all degrees (Leopold 1925, 399). For some, wilderness could be for camping, fishing, or hiking. Its land-use is predicated on the practices of its participants. This study evaluates land-use of wilderness contextualized by hiking, in which day-hiking and long-distance hiking are examined through participant experiences. Day-hiking specifically represents shorter hikes completed inside of a day and do not necessitate a backpacking setup. On the other hand, long-distance hiking includes section- and thru-hiking, as longer-term hiking and backpacking adventures which occur over multiple days, weeks, or months. Section hiking is typically construed as one section of a long-distance, point-to-point and continuous thru-hike.

Within the physical construction of long-distance, thru-hiking trails exists a social world of its participants. For hikers, thru-hiking is a subculture that reflects the intensity of their hike through participation and ideology. Within this subculture of trail participants, there are subgroups of hikers, namely the *purist* and the *social hiker* (Lum 2015, 7). The purist hiker recognizes a right and wrong way to hike the trail and is motivated by conquering the trail itself, whereas the social hiker is motivated by social culture and community on the trail (Lum 2015, 10). Among *social* and *purist* hikers there is a shared commitment to hiking, though intergroup conflict exists around the ideologies and how trail spaces are to be used (Lum 2020). Hiking offers community and identity to its participants, a space which becomes exclusive based on motivations and subworlds, which include day-hiking, section-hiking, and thru-hiking. Values of how trails should be engaged are thereby materialized through and reflected in individual hiking practices. The social world of participants is shaped by the type of relationship they have with hiking trails. It is through this differentiation in types of hikers, hiking styles, culture, shared characteristics, knowledge and skills, frequency of participation, resources used, and commitment to the social world activity that the broad community of hikers becomes fragmented (Lum 2020).

Land-use values and practices are represented within the social world of recreationalists (*purists* and *social* hikers). Thus, well-established trail communities may move to exclude disabled participants based on lack of shared characteristics, knowledge, and resources used. Though many practices of disabled recreationalists may mirror those of able-bodied hikers (e.g. food, emergency contact beacons, hiking poles, development of planning networks), ability-normative hikers may exclude crip and sick individuals based on underlying value difference in what constitutes a long-distance hike. Whether hikers were ideologically aligned with purist or social values, tension within able bodied hiking communities exists. Lum (2020), in conversation with Fondren (2015), illustrates tensions between hikers on the grounds of: hiking approaches, point of entry, and the direction of their hike. In the contested conversation on how to “hike your own hike,” a catchphrase of long-distance hikers, unwritten social regulations on how to engage trails persist, and create social barriers for participants who can’t conform.

The social world of long-distance hiking recognizes hiking practices and ideologies that reflect in whose bodies are seen on the trail (Goldenberg et al. 2008, 4). Thru-hiking offers opportunities to engage with exclusive wilderness spaces, though increased usage of these trails lends itself to concerns of wilderness integrity and conservation. “Increased usage of the trail will likely bring various impacts, for better or worse, into bold relief. Although long distance hikers may be irritated by trail regulations, some may recognize the need to preserve the trail” (Lum 2020). The culture within wilderness recreation excludes differently abled participants through ability-hierarchies and upholding social, physical, and cultural expectations of thru-hiking spaces. However, crip and sick hikers actively contest and resist these ideas, and through their continued engagement with these spaces, by finding accommodations and generating access, they subvert ability-normative constructions of dis/ability and wilderness.

Positioning accessibility within an examination of hiking culture reveals tensions in utilizing accommodations or tools to complete a hike. In accessing nature-based tourism, disabled participants navigate “societal attitudes, including misconceptions about the ability levels of persons with disabilities, regularly creat[ing] barriers to travel and tourism for individuals (Darcy & Buhalis, 2011; McKercher & Darcy, 2018; Scheyvens & Biddulph, 2018; Yau et al., 2004)” (Wall-Reinius 2022, 336). For disabled hikers within the social world of long-distance hiking, they may have to grapple with outsider status, neither able to conform to purist or social hiking culture.

Fondren in *Walking the Wild Side: Long-Distance Hiking on the Appalachian Trail* (2015) examined this tension in the experiences of one (presumably able-bodied) hiker who “slackpacked” part of the Appalachian Trail, which occurs “when hikers want to make big miles without the weight of a heavy pack” (49). For this hiker who slackpacked part of the trail, Fondren identified differences in both how she viewed herself and how trail peers de-legitimized her thru hike. Values of tools and assistive devices on the trail, such as smartphones, are viewed as antithetical to what trail experiences should be (Lum 2020, & Dustin 2017). Strategies of achieving relief or accommodation during a long-distance hike, including taking time off, “slackpacking,” using apps to locate water sources, or skipping sections of the trail, create tension among hikers who have different ideologies about what it means to hike, especially in a long-distance hiking context.

In thru-hiking wilderness environments, participants subject their bodies to significant physical and physiological challenges (Berg 2015, 6). For disabled hikers, these trails create disproportionate figures of risk. In wilderness spaces, which are characterized by risk, participants are subjected to extreme weather conditions, mental exhaustion, physical duress, inaccurate trail information, negative social situations, and rough terrain (Berg 2015, 6). This recognizes the materiality of the body and how long-distance trails exacerbate the challenges of disabled hikers to participate safely.

For hikers with disabilities, accommodations and adaptation strategies may disenfranchise them from the social world of thru hikers. Accommodations for the ecologically-othered body, which is criticized for use of adaptation strategies, are political. Inversely, though, it is not uncommon for ability-normative hikers (social and purist) to utilize trekking poles or implement strategies for optimal participation (vis-à-vis gear, planning, and food). Though disabled and chronically ill hikers may more closely align with *social* hikers, relative to *purists*, tensions around characteristics, resources, and ideologies shape communities on the trail. Considering difference in characteristics and resources used, hikers with different adaptation strategies to participation are socially consolidated and excluded. This is explored by Wall-Reinius, who says:

> "It is common to lump all persons with disabilities into a single group, assuming they are all equally limited in what they can achieve while being outdoors in nature. This, in turn, leads to myopic approaches where dedicated facilities for persons with disabilities focus narrowly on safety, providing only a small taste of the overall experience of the natural setting (e.g. a wheelchair accessible path so that persons with disabilities can "sample" the destination)" (Wall-Reinius et al., 2022, p. 5).

Wall-Reinius captures two critical ideas which this study and its participants build upon. First, disability a group is diverse and dynamic in their abilities and needs; thus, this study includes chronic illness in examination of this community of hikers. Identification only of a wheelchair accessible path reflects accessibility being narrowly focused on one facet of disability (mobility). Secondly, Wall-Reinius' discussion of accessible wilderness as limited in space and scope is developed further in this thesis to argue the importance of full, inclusive, and equitable access to wilderness trails. This quote speaks to able-bodied "myopic" ideas of what an inclusive outdoors means and challenges it as insufficient. In conversation with Wall-Reinius, though, this thesis identifies a key difference between disabled accommodations and normative-hiker strategies to be a long-distance trail phantasm.

Minority Representation in the Outdoors

In conversation with a political ecology, a theoretical framework that recognizes power in the social production of nature and society, this thesis employs work of critical race scholar Carolyn Finney to interrogate marginalization in wilderness environments. In spaces characteristically developed for able-bodied, heteronormative, financially privileged white persons, black scholars like Finney have captured strategic inequity in access for non-white participants. Thus, the conversation of wilderness accessibility reaches beyond the dis/ability scope, frequently highlighted in academic discussion around blackness and exclusion in wilderness. In discussion with black scholars around diversifying racial and ethnic participants in wilderness space, disability scholars have begun to acknowledge parallels of wilderness exclusion for disabled individuals (Williams 2014, 99-100; Cox 2019, 99-100).

The marginalization and underrepresentation of African American people in the outdoors is addressed in Carolyn Finney's 2014 monograph *Black Faces, White Spaces*. Finney engaged readers to think about the voices that are centered in natural spaces in "effort to airbrush the definition of an American collective identity on the national landscape" (Finney 2014, 76). In challenging the idea that "skin color is the primary determinant in one's ability to act and engage all environmental issues" (Finney 2014, 109), Finney asserts the existence of power structures in identity and contests them.

The historical marginalization of African Americans in outdoor recreation and stifled access to benefits of participation inform theories of environmental racism, which black scholar Dorceta E. Taylor explores in *The Rise of the American Conservation Movement* (2016). Theoretical and political discussions have been brought to the forefront of conversations on supporting minority representation in outdoor environments, problematizing the lack of representation and inclusion of American wilderness spaces (Stanley 2019, 241; & Eck 2020). This study builds upon work that has been pushed forward by Janae Davis, who often shares Finney's sentiments. Davis' criticism of The Wilderness Act of 1964 lies in the systemic black erasure in wilderness spaces at the nexus of environmental practice, access, and power (Davis 2018, 89). Sami Schalk, author of *Black Disability Politics* (2022), examines ableism in conversation with racism to recognize the intersectional systems of oppression. In discussion of contemporary justice work, Schalk says:

> “Black disability politics are, after all, not limited to issues specific to Black disabled people alone. Moreover, if we take a Black feminist and disability justice perspective here, then we understand that a politics that centers those who are most marginalized and most impacted will benefit those less marginalized and less impacted as well” (Schalk 2022, 151).

Through significant contributions to political ecologies of wilderness spaces at the intersections of race and colonial legacies, Finney, Taylor, Schalk, and Davis have authored space to critique the problematic history of nature-based environments. In this thesis’ contemporary examination of ability and identity structures in wilderness, I continue to recognize the work of black scholars around marginalization in the outdoors as foundational. By virtue of relating the subjugation of minority groups through The Wilderness Act of 1964, this work serves to realize and radicalize the dynamic between the great outdoors and disabled humans who have been historically and systematically excluded. Neither Finney nor Davis specifically researched power and coloniality within long-distance hiking communities, though both identify experiences of power and representation in relation to environmental racism and The Wilderness Act of 1964. This thesis recognizes and builds upon the work of black scholars around wilderness space to construct similar arguments concerning disability.

The main objective of this research is to explore what barriers to participation in wilderness spaces exist for differently abled individuals, and strategies for adaptations they employ. This section positions disability within historical, legal, and wilderness background to examine marginalization in the outdoors. Black scholars have reconciled a socially constructed wilderness with the exclusion of marginalized communities, thus creating space to position disabled and chronically ill recreationists. Power structures which have decentered black recreationalists from equitable access to participation are thereby discursively expanded to invite disability to discussion around marginalization and ability-hierarchies. The main argument of this research is two-fold. First, wilderness spaces, specifically long-distance hiking trails and communities, are privileged based on normative notions of ability, which disenfranchises disabled individuals through social and physical barriers, from accessing their eco-corporeality and self-fulfillment of nature. Secondly, within this context, sick and crip individuals contest these barriers and subvert the social, ability-centric construction of wilderness spaces, finding accommodations and generating spaces of belonging in nature.

Chapter 2

Theory

Empowering Disabled Voices in Feminist Research

In *Situated Knowledges*, Donna Haraway positions physical, natural, social, political, and biological traits as relevant in characterizing the production of knowledge as subjective and active (Haraway 1988, 575). Haraway explores knowledge production as relevant to the broader social and cultural contexts of the body, whose "boundaries materialize in social interaction" (Haraway 1991, 201). Thus, situated knowledges are develop based on the individual's lived experiences and sociocultural environment. In positioning the researcher to the object and examining production of institutionalized knowledge, Haraway identifies epistemological privilege in political and partial perspectives, which do not consider the dynamic influences of the object's embodied knowledge (Haraway 1988). Thus, Haraway recognizes embodied knowledge as a feminist, subjective position which highlights lived experiences and 'materiality of knowledge' of its subjects.

Though this research is not explicitly feminist as an interrogation of gender in wilderness spaces, it is foundationally feminist in its assertions around visibility and social justice, which challenge social hierarchies of identities (Johnson and Madge 2021, 60). To ascribe power and human qualities to the disabled and chronically ill body in research space, this study shifts the authority of illustrating crip and sick narratives to participants (Lourens 2020: 849). Feminist geographies center crip theory and disability justice to interrogate ability-normative power structures. McRuer says crip theory interrogates "how bodies and disabilities have been conceived and materialized in multiple cultural locations, and how they might be understood and imagined as forms of resistance to cultural homogenization" (McRuer 2006, 33). Crip theories emerged from the work of feminist and queer theorists, as social movements have coalesced to consider a broader view of oppressed identities, creating space to examine the marginalization of disability in social and cultural structures.

To actively dismantle misconceptions about what disabled people look like and what their needs are, this thesis challenges ideologies about whose bodies desire those spaces. In *Crip Theory*: *Cultural Signs of Queerness and Disability*, McRuer explores dominant paradigms around the production of dis/ability in space to situate "geographies of uneven development" (McRuer 2006, 72). This section builds upon McRuer's ideas to introduce the socio-historical construct of dis/ability as an opportunity for space to be "torn down and replaced by inclusive social relations (Gleeson 1999, 31).

Conceptions of dis/ability as "conceived, materialized, spatialized, and populated" (McRuer 2006, 72) are positioned in wilderness space to challenge hegemonic ideologies that have historically excluded persons with disabilities. Crip theory moves to normalize representation, justice, and care for disabled bodies. There is justice in creating "non-oppressive and inclusive social spaces" (Gleeson 1999, 11). To further this argument, I highlight McRuer's vision for space, in which he says: "a disabled world is possible and desirable" (McRuer 2006, 71).

Hierarchies of Power

Haraway's feminist approach informs practices of empowering subjective knowledges and their materiality in discussion of this study's participants and their experiences. Discussion of the knowledge as materialized by and through the body's sociocultural influences are echoed in Foucault’s theories of the body. Foucault argues power relations as formative in conceptualizing power as “inherent in social relationships, embedded in a network of practices, institutions, and technologies- operating on all of the micro-levels of everyday life” (Pylypa 1998, 21). According to Foucault, the body acts as a medium for sculpting social relationships as the site which internalizes and reproduces cultural knowledge, power, and concepts of normality (Pylypa 1998, 22). In conversation with Haraway’s *Situated Knowledges* and Foucault’s theories of the body and social regulation, this study positions the body as the site of transformation.

In an investigation of dis/ability as a hierarchy which holds power, discourses around wilderness in America privileges some bodies over others. This privilege manifests to decide power and access to wilderness recreational spaces, which reinforces power differentials and amplifies objective knowledge over subjective experiences (embodied knowledge), which this thesis seeks to examine. The embodied nature of this research is political as it moves to empower and investigate dis/ability in practice socially and politically.

Docile bodies, as discussed by Foucault, are malleable and receptive to social and political institutions which discipline it (Foucault 1920, 135). Though Foucault does not explicitly mention disability, he discusses modality of “uninterrupted, constant coercion” for discipline, control, and subjugation of the body (Foucault 1920, 136). In time, space, and movement, Foucault argues the body as “subjected, used, transformed and improved,” which this thesis uses to examine the control of able-bodied modality to assert power and transform the differently abled body. Building off Foucault’s discussion of materiality in bodies, Rosemarie Garland-Thomson explores the cultural construction of bodies in *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (1997). Garland

Thomson reframes disability paralleled to race, gender, class, ethnicity, and sexuality to assert its identity as thoughtfully produced and constructed. Through empowering practices of this thesis, which centers disabled voices in research and space, normative institutions which marginalize the malleable, crip body are challenged.

In this section, I define wilderness space as a social artifact that promotes hierarchies of power. Leaning on Gleeson's discussion of social valorization, which strives to preserve social hierarchies, I position social valorization and the production of "higher" and "lower" bodies (Gleeson 1999, 42) within risk-intensive wilderness environments. Stigmatized by and through the social construction of wilderness, dis/ability status is utilized to assert hierarchical value in access to participation, problematizing the differently abled body for its "unfit" nature (Cox 2019, 99-100).

Production of Space

Brendan Gleeson in *Geographies of Disability* articulates Henri Lefebvre's theories of historical-geographical materialism, which asserts "it is through each society's unique social practices that materially-different spaces are produced" (Gleeson 1999, 45). In positioning this within wilderness space, I conceptualize the active and passive role of nature in shaping people as the environment is both "produced socially and socially producing" (Gleeson 1999, 43). Gleeson draws on Foucault, who argued the body as shaped by power structures, and Lefebvre, who argued the co-constitution of space adjacent to social relations, to situate social hierarchies within nature. In reference to Lefebvre, Gleeson says:

> "The unique character of each social space is informed by the manner in which each is productively occupied. This does not imply a narrow, economistic focus, but rather an inclusive consideration of the entirety of ways in which the

> production and reproduction of human needs is realized in a particular setting through local and endogenous material practices" (Gleeson 1999, 48).

I situate this quote by Gleeson in reference to Wall-Reinius on page 12, as both criticize the production of material practices which stifle disabled needs and exclude disabled individuals in wilderness space.

Drawing on Lefebvre, who says "it is by means of the body that space is perceived, lived, and produced" (Lefebvre 1991, 162), this study characterizes the co-construction wilderness space, society, and the body. The body recognizes and engages wilderness space as informed by its own spatial and social practices. The social construction of dis/ability and, separately, wilderness, reinforce one another to exclude the social, political, and cultural identity of dis/ability in the outdoors (Ray 2013, 35-41). In positioning Ray's argument within Lefebvre's theories: space is produced through hierarchies of ability, the body which is socialized within those hierarchies, and the society which enforces exclusion and barriers based on the perception of ability.

Wilderness space is both an objective reality and a site which produces social relations. These spaces are colonial social artifacts on account of whose bodies have historically been represented and cared for in the outdoors. This postulates geographies of disability as a theoretical framework to examine the disabled body's "social oppression and spatial marginalization" (Gleeson 1998, 2). In centering experiences and knowledge of differently abled individuals and their bodies relative to wilderness environments, a theoretical de-colonization of the space is set in motion. Disabled voices that have historically and socially been excluded are empowered through participation in both wilderness and research spaces.

Social Model of Disability

The social model of dis/ability is grounded in the idea that “disability is produced through the socialization of impairment” (Gleeson 2006, 31). In challenging the conventional, medical view of disability, attention is redirected toward the structures which have historically and socially oppressed disabled individuals. Gleeson says the “so-called ‘normal’ activities are structured by the general social and economic environment, which is constructed by and in the interests of non-impaired people” (Gleeson 2006, 19). Similarly, Sarah Jaquette Ray in *The Ecological Other: Environmental Exclusion in American Culture (2013)* says: “The outdoors are sentimentalized for the needs of the fit, able-bodied, oftentimes white, heteronormative “ecological subject”” (Ray 2013, 5-6). Contrasting the “ecological subject,” Ray’s “ecological other” identifies the crip body that experiences marginalization within wilderness space. Alison Kafer in *Feminist Queer Crip* (2013) then says: “people are disabled not by their bodies but by their inaccessible environments” (Kafer 2013, 129).

This “ecological other” is subject to marginalization and is displaced through the theoretical argument of wilderness integrity in conversation with accessibility. This argument of environmentalism in conversation with accessibility is a narrative that exonerates the marginalization of the disabled body “ecological other” (Ray 2013, 17). Throughout Ray’s text, she argues the ecological subject’s power in maintaining the exclusivity of the American wilderness. Ray and Kafer highlight normative-bodiedness in the environment through interrogating ableist assumptions about participation. In discussion with Ray and Kafer, this thesis moves to empower the participation of the “ecological other” in recreational wilderness spaces by resisting oppression and contesting privileges of the “ecological subject.”

Queering the Crip

Carrie Sandahl in *Queering the Crip* (2003) writes: “The term crip has expanded to include not only those with physical impairments but those with sensory or mental impairments as well. Though I have never heard a nondisabled person seriously claim to be crip (as heterosexuals have claimed to be queer), I would not be surprised by this practice. The fluidity of both terms makes it likely that their boundaries will dissolve” (Sandahl 2003, 27). By creating an epistemological space to challenge the physical and social construction of the American outdoors, this research amplifies the embodied knowledge and experiences of the crip to clarify accessibility arguments. In asserting the concept of the ecological subject at the core of wilderness construction, and the ecological other at the periphery, in between lies the bodies of senior citizens, children, families, and other nontraditional wilderness participants. This model also hosts relative purist and social hiker categories, which exist in conversation with the core-peripheral construction of wilderness. Through acknowledging the fluidity of crip (Sandahl 2003, 25), this thesis moves to assert the fluid identity of crip in discussion with Ray’s “ecological subject.”

Corporeality in the Environment

Examinations around the epistemology of embodiment refer to feminist corporeal theories, namely trans-corporeality, which recognize the body and its interconnectedness with the material world. Stacy Alaimo in *Bodily Natures: Science, Environment, and the Material Self* says “trans-corporeality, as a theoretical site, is where corporeal theories, environmental theories, and science studies meet and mingle in productive ways” (Alaimo 2020, 3). In conversation with Alaimo, this study positions theories of the disabled body in connection with the environment to emphasize eco-corporealities. Drawing on embodied knowledge which disabled bodies identify values and motivations around situating their bodies within the environment, a cross-examination of corporeality and critical disability studies takes place (Flynn 2020). Eco-corporeality relates human materiality to that of the non-human environment, highlighting the inherent bond and shared values between human and the environment (Alaimo 2010, 2). In discussing theories of eco-corporealities, I move to explicitly identify dis/abled bodies as having an undeniable connection to their environment. Parallels of values and motivations of dis/abled hikers are then contextualized within eco-corporeality as an informed epistemology of embodiment. For wilderness environments, eco-corporeality asserts the need for access to participation for self-determination and self-fulfillment.

Through crip and sick bodies engaging spaces characteristically developed against their best interests, hegemonic structures of normality are challenged, promoting greater equity and access to participation (Ray 2013, 35-82). In interrogation of power relations which create and uphold oppression of disabled individuals, feminist geographies move to deconstruct ability-normative recreational wilderness environments. Further, these recreational environments are grounded in hegemonic masculinity, as trail cultures exemplify white male dominance and physical challenges (Berg 2015, 4; Stanley 2020, 244). The excavation of historically marginalized experiences moves to queer knowledge and give power to crip voices. Robert McRuer in *Crip Theory: Cultural Signs of Queerness and Disability* (2006), speaks to this in saying: “Once we begin to realize that disability is in the environment then in order for us to have equal rights, we don’t have to change but the environment has to change” (McRuer 2006, 52).

Risk as a Privilege

Positioning this research within the discourse of risk, Ray (2013) argues that risk culture privileges the ecological subject by assigning the outdoors to those who are able to absorb the risks of participation. Wilderness culture is centered around risk and conquest(/dominance), a fundamental, ideological fallacy which excludes disability on account of dependence (Ray 2013, 47). Ray writes: “If the wilderness encounter is defined by the fact that it requires more extreme physical fitness than any other activity, then the disabled body literally has no place in the wilderness” (Ray 2013, 48). Adventure and risk culture shapes wilderness for individuals who can compete in risk-intensive environments (Ray 2013, 48). As Braun notes, “the freedom to take risks in nature is undoubtedly a white, middle-class privilege” (Braun 2003, 175).

Crip and sick individuals who engage in these wilderness spaces are participating in an environment that actively shifts the responsibility and assumed risk to its participants. However, as discussed by Ray (2013), able-bodied participants may be more physically and socially adept at absorbing these risks. Risk culture in wilderness environments upholds the able-bodied ecological subject in opposition to the identity of the crip body, an idea that builds upon disability language presented by McRuer (2006) and contextualized in wilderness space by Ray (2013). In positioning pastoral ideas of the Victorian era within the environment, Ray examines conceptions of space occupied by undesirable participants as “socially unhygienic” (Ray 2013, 41). The body that can participate in wilderness with minimal footprint on the natural environment, contributing to both conservation values and purity of the outdoors, is then rewarded by risk culture with access to participation.

Crip Participation is Radical

The participation of disabled individuals in outdoor recreation is not despite their body's challenges, but rather the radical choice of caring for their sick and crip bodies in spaces which strategically exclude them. In disrupting the antiquated ideologies set and enforced by ability hierarchies that bodies are forced into, crip individuals reflexively disrupt the social construction of the American wilderness. The radical choice to care for one's body in a space which was not created for their needs is the crip work of sick and disabled recreationalists.

To be a sick and/or crip hiker in a wilderness culture that centers bodily risk as a primary instruction for participating outdoors is to then assert that the body does not have to conform to the socially imposed requisite of risk to take up space in the outdoors. The body does not have to achieve a "personal record" for its time spent or space consumed for its participation to be valid. In response to the wilderness integrity cultural parameters enforced in outdoor recreation by normative hikers (social and purist), crip outdoor communities are holding power and space to accommodate their needs and care for their bodies.

The epistemological foundation of this thesis is in locating lived experiences and disabled narratives in an otherwise deafened conversation on barriers which privilege access to the highly valued, culturally significant American wilderness. Foucault and Haraway condition embodied and situated knowledges, Gleeson imagines space as a "social artifact" and landscape of identity politics, McRuer asserts the disabled body as the raw being in which space is created against, Ray positions the raw being in wilderness space, Kafer mediates disability on trails, and Sandahl positions the disabled body through fluid construction of space, research, and identity.

This section synthesizes these scholars to unsettle systems which oppress the queered, disabled body in long-distance hiking and backpacking spaces. Despite understood and even socially enforced differences that privilege able-bodied participants in a wilderness capacity, ableist attitudes prevail and challenge how crips are to navigate and adapt to a socially constructed wilderness. In investigating the exclusive nature of American wilderness, this study examines behaviors and values around long-distance hiking and backpacking as a risk-intensive, exclusive, wilderness phenomenon.

Chapter 3

Methods

Research Question

This section identifies how my research question took shape in developing a research study. To do this, I developed a methods section which revealed the “five W’s”: “who, what, when, where, and why” to help illustrate the decisions made throughout this study. The guiding question of this project is: What are the actual or perceived barriers for differently abled hikers and backpackers in accessing wilderness spaces, and how do these differences manifest in long-distance hiking spaces?

Questionnaire

This study uses a mixed-methods approach. The primary methods was a questionnaire with open and closed-ended questions designed to capture the motivations, values, and diverse experiences of disabled and chronically ill hikers (McGuirk and O’Neill 2021, 244). As a medium for gathering information through a mixed-method strategy, the questionnaire, deployed online to reach hikers with disabilities and chronic health illnesses, was resource-efficient and flexible for participants. Considering how to best capture the experiences of hikers and backpackers in long-distance hiking spaces, a characteristically transient environment, using a web-based questionnaire to study this population served as a flexible, practical, and powerful research method.

Following ethical standards and research practices developed by the University of New Mexico Institutional Review Board (IRB), this study was designed in accordance with IRB policies to protect participant confidentiality. As such, this questionnaire collected no personally identifiable information and participants were able to virtually complete the Informed Consent ‘Consent to Participate in Research’ process. This study encouraged honest responses to generate quality data about the characteristics of hikers and backpackers with disabilities and/or chronic health illnesses. This study aimed to provide information on the experiences of marginalized groups of hikers and backpackers to generate new knowledge about accessibility for people with disabilities and chronic health illnesses. Though there was no financial compensation for participation in this research, those who identify as disabled or living with a chronic health illness may benefit from future work informed by findings of this study.

The questionnaire was developed using Google Forms, an online survey platform, which allowed me to offer both closed and open questions to gather quantitative and qualitative data about the participants. Attribute questions offered an opportunity for participants to self-identify with easily coded characteristics, such as age, gender, race, chronic illness (Yes/No), and disability (Yes/No). Open-ended behavior and attitude questions served to capture embodied experiences and knowledge of respondents, supporting the “co-constitution of knowledge” between the researcher and research participant through an iterative coding process (McGuirk and O’Neill 2021, 244). Open questions offered an opportunity for participants to share how their personal disability and/or chronic health illness informs their experiences in wilderness spaces, capturing embodied knowledge. With both closed and open questions, this questionnaire is split into four sections: Participant Information (closed attribute questions), Participating in Wilderness Spaces (open and closed behavior and belief questions), Disability in Wilderness Spaces (open behavior and belief questions), and Disability Information (open and closed attribute questions).

Before distributing the questionnaire, I utilized Pre-testing to pilot the design of the questionnaire. I shared the question with two mentors of mine who identified as wilderness participants with a disability and/or chronic health illness. This practice allowed me to recognize and amend questions for clarity, making grammar and structure (order) changes to the questions. Further, getting feedback on this questionnaire helped me understand the time it took to complete the survey, which was helpful information to share with participants. Feedback on the overall performance of the study included easiness to understand, time to complete, and sensitivity to participant experiences. One helpful piece of feedback I received in this pre-testing phase was to order the questionnaire in which the Disability Information section would go at the end, instead of possibly discomforting questions going at the beginning and potentially discouraging participants from continuing.

Recruitment Strategy

To capture quality data to evaluate my research question, the recruitment strategy was focused on connecting with long distance hikers and backpackers with disabilities and chronic health illnesses. This study was not created to be geographically specific, but to reach as many participants as possible who would find this research a worthwhile expenditure of their time and to then feel compelled to participate. Knowing that I wanted participants to contribute thoughtful, reflective responses in engaging the questionnaire, I chose to strategically recruit participants. Because of my understanding of marginalized groups often having a special interest in supporting projects that recognize the dynamic realities of their lived experiences, I chose to recruit participants through online groups. In deciding on where and how to distribute the questionnaire, I prioritized distributing the questionnaire within self-organized groups of outdoor recreationalists with disabilities.

Briefly reflecting on my positionality in this section– my identity as a disabled hiker helped me gain access to organized Facebook pages and connect with study participants. One notable Facebook group is the Disabled Hikers Community Group, an organized, private discussion group which asserts virtual space for hikers with disabilities to ask questions, share experiences, facilitate community, and learn from others. As the Disabled Hikers Community Group acts as a private discussion page, I disclosed my researcher status upon joining. Even so, I was still wary of using this space to recruit potential participants as I didn't see any other posts about research studies. Upon being granted acceptance into this group, I had access to a wealth of knowledge and data about participants and a resource for connecting with self-identified disabled hikers. I was concerned about potentially overstepping my position in this group and losing access to these members and prospective participants, which informed my decision to recruit slowly.

In constructing this research, I strove for a minimum sample size of 20 respondents, 18+, of any gender identity, any racial/ethnic identity, who identified as having a disability and/or chronic condition. For disability, I considered mobility, sensorineural, neurodevelopmental motor disorders, and mental health conditions in my respondent pool. Within this demographic, my inclusion criteria were, primarily, long-distance hikers and backpackers. However, as I was interested in barriers to thru-hiking, I also accepted responses from backpackers who had not yet completed a long-distance hike but were open to discussing experiences with their disability on the trail.

Upon receiving approval from the Office of the Institutional Review Board in November 2023, I began recruitment and data collection, which continued until February 2024. In a three-prong approach, I first connected with nonprofit *Disabled Hikers* founder, Syren

Nagakyrie, to include my questionnaire in the *Disabled Hikers* December 2023 newsletter. *Disabled Hikers* boasts a substantial following online, with 6.2k Facebook followers '*Disabled Hikers*', 24.5k Instagram followers (@disabledhikers), and 1.7k[1] members their private community discussion board '*Disabled Hikers Community Group*'. Secondly, I directly messaged potential respondents from Facebook groups 'Disabled Hikers Community Group' and 'PCT Class of 2024 – The Yogi Group: Planning, Information, Zooms,' a community of prospective thru-hikers, with an introductory statement and a link to the Google Forms questionnaire. I utilized purposive sampling to invite group members to participate, with recruitment directed toward active participants of both organized Facebook groups. In the Disabled Hikers Community Group, I messaged active participants, which included new members and those who had recently posted, commented, or reacted to a post. In the 'PCT Class of 2024' group, I selectively searched for posts which mentioned "disability," "chronic pain," "chronic illness," and "wheelchair," and "accommodations" to strategically message from that space. This allowed me to independently recruit potential participants and assert my position as a fellow member of a shared, organized group. Thirdly, after I had exhausted the avenue of privately messaging group members, I created a general post to invite participation.

Coding and Analysis

This study produced data from 44 respondents, which I coded through a manual, inductive coding strategy. While this questionnaire included qualitative and quantitative data, coding qualitative data was complex and how participants responded to questions was reflective of their own cultural and social specifics. Dynamic participant realities were captured in how

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[1] Follower counts recorded in March 2024.

the questionnaire asks similar questions in different ways, recognizing the ways in which experiences are subjective, to capture nuances offered by respondents. Manually coding involved an iterative, inductive strategy which repeatedly familiarized me with the data set, question by question, theme by theme, and participant by participant. In coding 44 participants' and their data by hand, I became very invested in both what participants were sharing and how I was organizing and interpreting their experiences, investing in the co-constitution of knowledge.

Qualitative methods offered the opportunity for participants to reveal their experiences, and then for the researcher to interpret respondents' answers (McGuirk and O'Neill 2021, 244). Throughout this process I am mindful of critical reflexivity, considering how my positionality informs my interpretation and understanding of participant experiences. This ultimately led back to recognizing the co-constitution of knowledge, which ascribed value to both the participant's embodied knowledge and my own researcher knowledge in interpreting the data. In unpacking open questions, I utilized an iterative coding strategy to build and refine the data. I first formatted the responses from the questionnaire into a running document which organized data by participant. I then read through this document to identify quotes which especially stuck out to me; this also highlighted participants with contributions that I knew I wanted to build on further to construct arguments in the Results section.

In this process, I began to develop descriptive codes, recognizing themes which were presented throughout the data, and organized them into a concept map. This analytical strategy helped sort through empirical data to make sense of the findings. Insights into the data were then coded to identify key themes. As this research is grounded in empowering its participants, themes reflected the space for reflexivity as codes were developed in rounds.

Developing a coding structure of common themes informed the codebook for additional rounds of analysis. I distilled major concepts that represented individual threads or examples identified by participants, culminating responses into meta ideas for analysis and interpretation. From this process, the concept map yielded several key themes: tensions between conservation and accessibility, accommodations, pressures of existing as a disabled hiker, social networks and communities, and planning. For each of these themes, I identified words, quotes, and experiences of participants to interpret data and construct arguments. These larger themes then informed the structure of writing the Results sections.

Writing

In this process, writing was an opportunity to bring crip and sick experiences into focus on discussions of the theoretical wilderness. Building from Chapter 17 of Qualitative Research Methods in Human Geography, I wanted this section to be reflective of Foucault's discourses of power (Waitt 2021, 333). In Foucault's assertion of discourse as a dynamic between the "true" and "marginalized," I parallel this concept in structuring the results section as a conversation between the "ecological subject" and "ecological other." I do this through positioning the embodied knowledge in codes and quotes at the forefront of the results section, circulating knowledge as it empowers disabled and chronically ill voices. This practice speaks to the very idea of ability status being ascribed to bodies and then situating them within power hierarchies, an opportunity to challenge dominant sets of ideas about ability and value as they are constituted in space. Considering the "socially constituted qualities of all knowledge" (Waitt 2021, 340), this thesis produced arguments that recognize the embodied knowledge of lived, crip and sick experiences to represent the power held by participants.

This practice of centering disabled identities and experiences to construct arguments and producing geographic knowledge around dis/ability in space informed writing choices throughout. One decision was in deciding how to ascribe personhood to participants in the results section, rather than them only acting as data points. I made the choice to identify participants by the number assigned to them (which was based on the order in which they responded to the questionnaire), their gender, age, and disability status. Participants included as few as zero (declined to answer) and as many as ten responses when asked to identify their specific type of disability and/or chronic health illness. For length and clarity, I made the decision to include the first four conditions listed. This felt like an impossible choice to make because I would be reducing the full context of their identity. In working around this, I developed a Participant Index (Appendix A) and Glossary (Figure 1) for readers to fully reference the self-identified disability and illness status of participants. Appendix A and Figure 1 are included to help readers understand participants that were included in the results section without excessive in-text descriptive statistics.

Descriptive Statistics

This study had 44 participants, and this section moves to capture the diverse backgrounds of these disabled and chronically ill respondents. The average age of participants was 40 years old, with ages ranging from 21 to 79. In recording gender identity of participants, the data show 4.5% male (2), 22.7% nonbinary or agender (10), and 72.7% female (32). A potential limitation of this study is the lack of diverse gender perspectives captured; though, in Berg's discussion on gender, he says: "[thru-hikers] did not dwell on the particular social identities with which modern recreational practitioners or contemporary political struggles were often associated" (Berg 2015, 13).

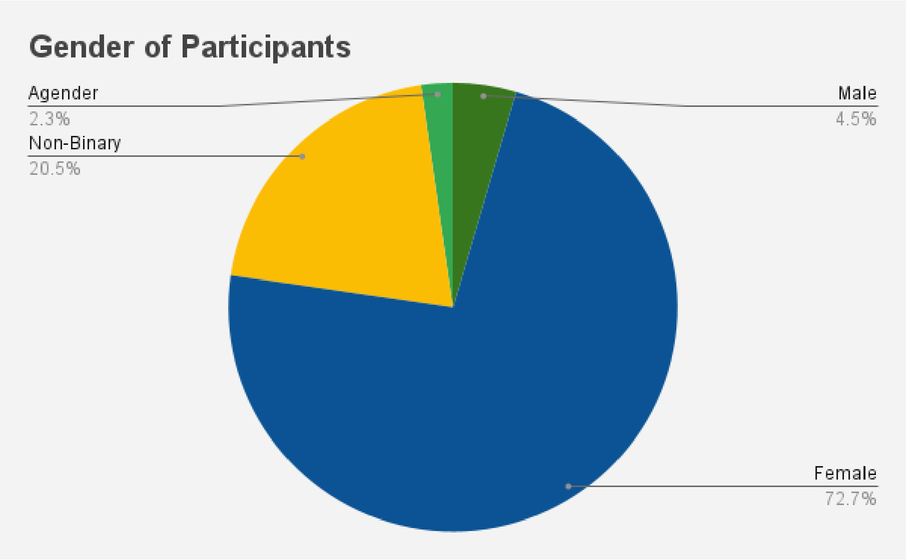

Figure II: Gender of Participants

The self-identified race/ethnicity makeup of this study was 81.8% White/Caucasian (36), 4.5% Hispanic (2), 2.27% Black (1), 2.27% "White and black" (1), 2.27% Asian (1), 2.27% "Adopted" (1), 2.27% "Mostly Irish" (1), and 2.27% declined to answer (1). In recognizing the lack of racial and ethnic diversity captured in this study, I move to contextualize these responses as a subset of the larger wilderness recreation demographic. One limitation of this study is that respondents are primarily white. However, this is not too far outside of expectations of the literature regarding participant demographics. Black scholar Janae Davis investigated this dynamic, with findings reflective of long-standing social discrimination in the outdoors. As wilderness spaces do not reflect the diversity of the American public (Davis, 2018), we do expect a greater representation of white participants in this data set.

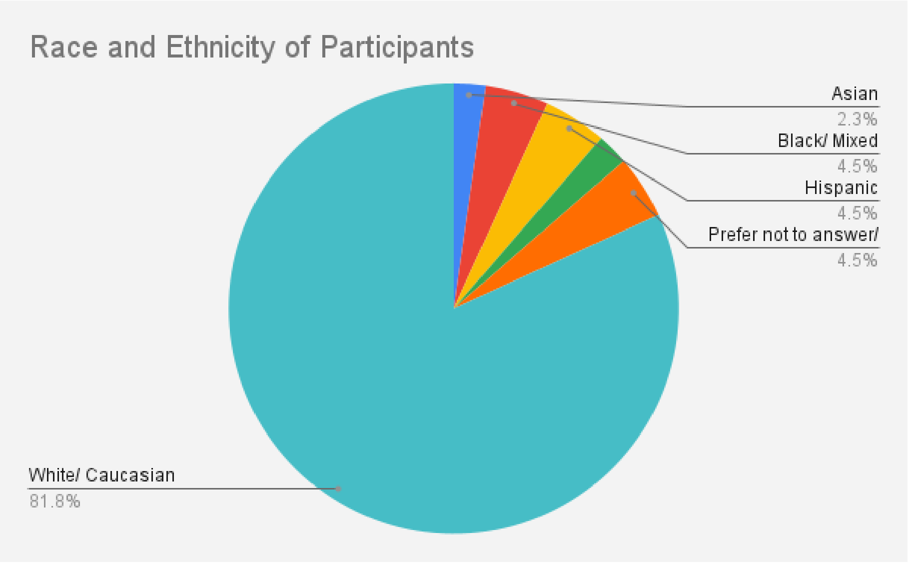

Figure III: Race and Ethnicity of Participants

Moving to capture participation in thru-hiking and long-distance wilderness treks, 25% of surveyed respondents said they had not participated (11), 25% responded “No, but I hope to someday” (11), and 50% responded that they had participated in thru-hiking and long-distance wilderness treks (22).

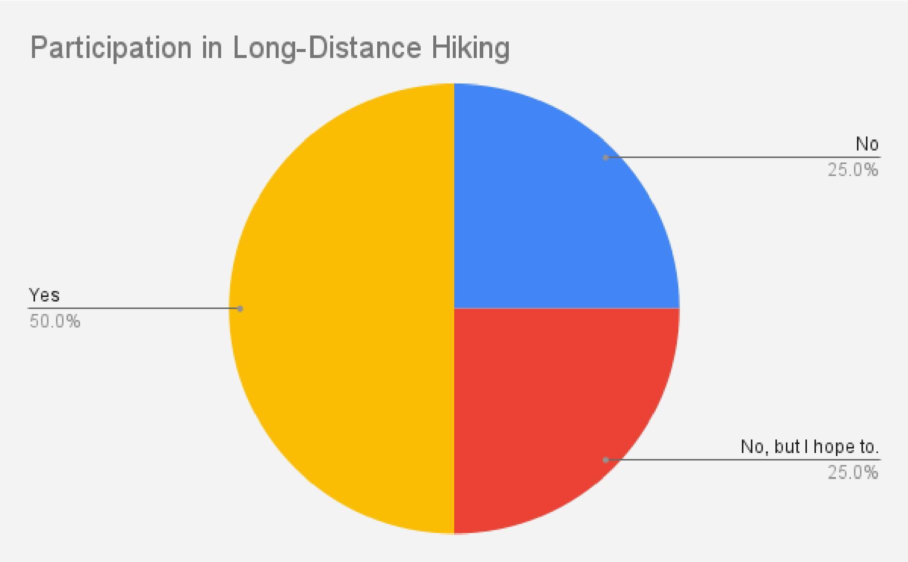

Figure IV: Participation in Long-Distance Hiking

Out of interest for capturing the types of hikes participants had engaged with and to select all that apply, participants were given a list which included: Day-Hike, Section-Hike, Thru-Hike, and Not Applicable as options. 54.5% selected "Day-Hike" (24); 18.2% selected "Section-Hike" (8); 6.8% selected "Thru-Hike" (3); and 36.4% selected "Not Applicable" (16).

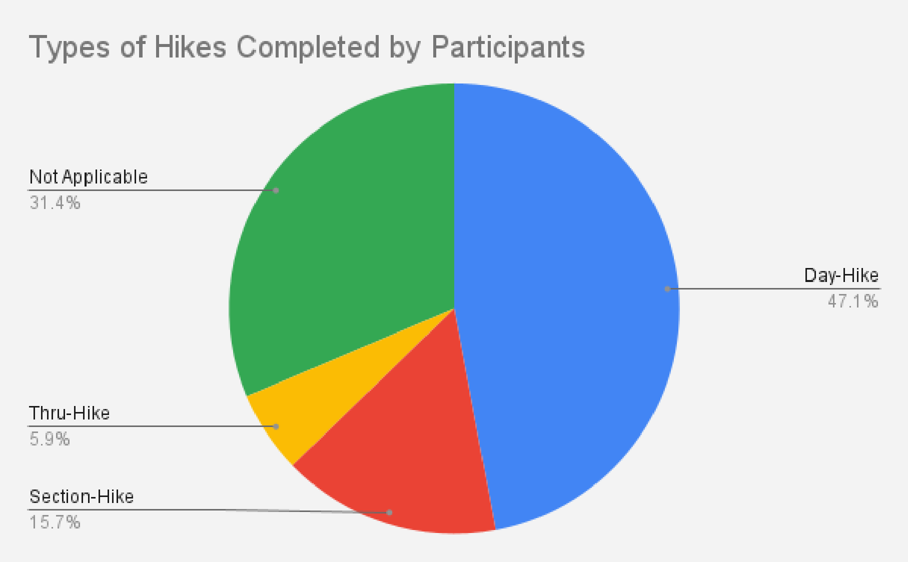

Figure V: Types of Hikes Completed by Participants

In an open-ended question of what assistive devices or adaptation strategies participations use while hiking, participants identified diverse themes around what helps them get outdoors and manage their needs in motion. 11 participants said gear (shoes, folding ramp, sunglasses, headphones, portable bathroom, folding chair), 10 said they use technology devices (Garmin, Apple Watch, Cell Service, Fitbit, Oura Ring), 21 identified mobility supports (wheelchairs, canes, trekking poles, powerchair, crutches, braces, off-roading walker), 9 said medication (NSAIDs, painkillers, dexcoms), 10 said planning (maps, parking, extra supplies), and 4 said they always bring a partner to hike with.

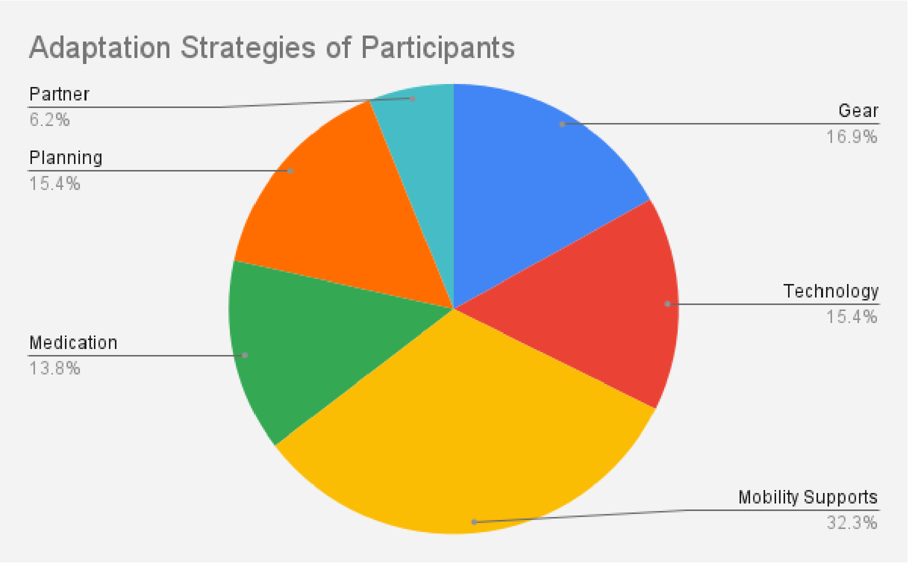

Figure VI: Adaptation Strategies of Participants

Chapter 4

Results

> I am connected to nature. Seeing the trees, birds, and wild things. I love the feel of the wind, and sun on my face. The smell of earth, pine, and other scents."
> – Participant 27

The chapter reports on the findings to develop the argument that hikers with disabilities and chronic illness want to exist on trails, and they will develop strategies to contest and overcome health, social, and physical barriers to achieve equitable wilderness participation. The fervent desire to enact shared values and motivations for wilderness participation is reconciled in diverse adaptation practices through which disabled hikers challenge the limitations of the outdoors to expand accessibility. With the directive of claiming power through highlighting crip and sick experiences in wilderness space, this section shares narrative excerpts from participants.

This study's guiding research question is: What are the actual or perceived barriers for differently abled hikers and backpackers in accessing wilderness spaces, and how do these differences manifest in long-distance hiking spaces? This Results chapter structures study results into six sections, including (I) values and motivations for hiking (II) tension between conservation and accessibility; (III) accommodations as a widespread opportunity for inclusivity; (IV) social dynamics of disabled hiking; (V) in-person and virtual disabled communities; and (VI) planning experiences while navigating health needs. The main argument of this research is that wilderness spaces, specifically long-distance hiking trails and communities, are privileged based on social constructions of ability, which disenfranchises disabled individuals through social and physical barriers, from accessing their eco-corporeality and self-fulfillment of nature.

Values and Motivations

> "(It's) Being in nature, seeing the gorgeous landscape, walking under tree branches, navigating mountain paths, breathing fresh air, listening to the birds and other animals." – Participant 26

44 surveyed participants answered the question: "What do you like about hiking and/or backpacking." Responses ranged from themes around peace and love of nature, physical challenge, the social aspect, solitude, simplicity of living minimally, beautiful scenery, senses (fresh air, the feel of wind and sun on your face), sense of accomplishment, hobbies (photography, birdwatching), and separation from their day-to-day work and stresses of "society."

A 27-year-old mobility impaired wheelchair hiker (Participant 41) identified values of wilderness access relative to an improved quality of life. For Participant 41, the outdoors provides an opportunity to move their body, calm their brain, and relieve chronic pain. Participant 41 references Spoon Theory, a contemporary term in the chronic illness community used to describe how much energy someone with a chronic health condition has (Pugle)[2]. They shared how they navigate "not enough spoons" and how their disability shapes access to trails close to home. When asked what their disability means for experiencing the outdoors, their response struck me:

> "My legs are slowly becoming paralyzed. As they have gotten worse, less of my favorite spots are accessible to me." – Participant 41

Participant 41 thoughtfully conceptualized their disability in motion while sharing how paralysis is shaping their access to spaces which have brought them joy. One 33-year-old

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[2] Spoon Theory is an analogy which represents the amount of energy, or proverbial spoons, a person has at the start of the day. This theory was developed in 2003 but has gained traction in contemporary discussion around understanding chronic illness and illustrating how health issues impact daily function. (Pugle, Michelle)

female respondent with Neural Tube Defects, Scoliosis nerve damage, and foot deformities (Participant 34) took an introspective approach in her response to the same question. Participant 34 encapsulated what it is to be a disabled hiker, as she shared both her wilderness values and the opportunity for orthopedic pain relief through participation. In highlighting her experiences, we get a full sense of how wilderness access is to her body and wellness.

> “Being outdoors just feels good. Most of the time I feel physically awful, but being in nature usually makes me feel better. While I can’t push myself as much as I used to, I still enjoy the sense of accomplishment when I am able to do something outdoors.” – Participant 34

Participant 28, a 46-year-old female hiker with Borderline Personality Disorder (BPD), Post-Traumatic Stress Disorder (PTSD), and Premenstrual Dysphoric Disorder (PMDD) navigates her self-identified mental health disabilities through participation in wilderness space. She said: “I feel better outside. Hiking (and) backpacking makes sense to my body and mind (...) It’s how I rejuvenate myself.” Participant 28’s responses contribute to poignant conversation in disability and non-disability specific literature on wilderness access about how outdoor access supports mental health.

While these are a few of the motivations of crip respondents in this study, I move to reference two studies which investigated motivations for “nature tourists.” Geiger’s (2023) study focused on general hiking experiences and Basil’s (2022) study centered on long-distance hikers. Both Geiger and Basil identified themes which paralleled this study’s participant motivations in investigating general hiker motivations for long-distance hiking. For the general population of hikers, love of nature, physical challenge, social contact, and health benefits were identified as motivations (Basil 2022, 282; Geiger et al. 2023, 315).

There are real, positive lived values and experiences situated in the wilderness by individuals who share reasons for participation akin to those of the ecological, able-bodied subject. This thesis moves to identify crip recreational values and what compels the "ecological other" to desire and participate in the outdoors. Disabled recreationalists share place-attachment practices and motivations in seeking wilderness recreation and outdoor experiences which are like those of able-bodied individuals.

Wilderness Integrity versus Accessibility

> "The nature of this activity [backpacking] isn't typically associated [with being] do-able for someone like me, but I do think nature trails could be made wheelchair accessible without necessarily paving them with asphalt." – Participant 17

While disabled hikers identify practices to participation similar to those of able-bodied trekkers, they also express conflict in values around accessibility needs and desire to protect the natural character of outdoor spaces. Participant 17 – a 27-year-old female hiker with Congenital Connective Tissue Disorder, Autonomic Dysfunction, Asthma and Vocal Cord Dysfunction[3] – carefully captures this stress between wilderness integrity and accessibility in the quote above. As Participant 17 speaks to concern around advancing one's own needs as they may impact the experiences of others, historical subversion of the crip body is enforced. Some hikers identify desires to experience equal participation in the outdoors, while they simultaneously refer back to the structural barriers of the able-bodied subject. This seems to

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[3] Participants identified as few as zero and as many as 10 disabilities and chronic health illnesses when asked to identify and describe their disability and/or chronic health illness. In effort to be concise, I listed up to the first four conditions listed. More information about each participant can be found in the Participant Index (Appendix A) and specific disorder/disease information can be found in the glossary (Figure I).

be indicative of the wilderness integrity versus accessibility debate in positioning tension of accommodations in characteristically able-bodied spaces.

Participant 31, a 64-year-old male with Rheumatoid Arthritis, hiked 110 miles of the Tour du Mont Blanc (TMB) in 2023 and plans to section hike the Pacific Crest Trail (PCT) this year, 2024. In his response on how accommodations support his wilderness participation, Participant 31 shared insight into his experiences:

> "I am excited and have been watching the popularity (of) the PCT and (Appalachian Trail). I chose to do the TMB first to see how its recreational areas are connected with the tourist/hiker and its surrounding communities. The PCT seems untamed to me with much relying on trail angels[4]. I would like to see more infrastructure for the trails of America without the loss of wildness/wilderness." – Participant 31

Participant 31's response captivated my attention as he described his interest in long-distance trails, including the Pacific Crest Trail and Appalachian Trail, as related to infrastructure. His comment about infrastructure development on trails while maintaining the character of wilderness spaces, which draws hikers of all backgrounds to participate, captured an important dynamic. It affirmed crip values in the wilderness integrity versus accessibility debate: disabled and chronically ill hikers aren't looking to distort the character of wilderness spaces, they just need accommodations to appreciate them, too.

> *"[There aren't] enough benches, though I understand not wanting to mess up the natural beauty. I need to rest very often. Other things (such as) soft or unstable ground (are difficult), but that's to be expected." – Participant 13*

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[4] Trail angels are volunteers who provide "trail magic" through their kindness and generous support to long-distance hikers.

Similarly, one 25-year-old female hiker with Postural Orthostatic Tachycardia Syndrome (POTS), hEDS[5], Generalized Anxiety Disorder, and Bipolar II Disorder (Participant 13), speaks on this dynamic of wilderness integrity from a conservation standpoint.

Accommodations

Respondents in this survey spoke of how accommodations could help them participate in outdoor spaces. When discussing barriers faced in the outdoors, Participant 32 synthesized the concerns of many in saying: “everything is made [for] ambulatory people with no disabilities.”

Participant 21, a 29-year-old, non-binary respondent with Lupus, Diabetes, Attention Deficit Hyperactivity Disorder (ADHD), and Post Traumatic Stress Disorder (PTSD), reflected on the barriers they’ve faced and accommodations they need. To navigate their disability and chronic health status, they identified accurate trail information and cell service as particularly helpful for their spinal issues, which manifests in their spine and joints. Participant 21 highlighted how disability isn’t one-size-fits-all and that access to reliable, accurate information about trail conditions is critical. However, they identified challenges of relying on this information in saying “(even) when accessibility information is available, it’s often not completely reliable as accessibility is often evaluated subjectively.”

Many participants identified the need for improvements to trail information, both online and through on-trail signage, to clearly convey critical information. Information resources are important for participants to set themselves up for success on the trail and manage their

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[5] hEDS is used interchangeably by participants alongside Ehlers-Danlos and Hypermobility.

condition while in motion. This concern is further amplified by most material not being specifically relevant to disability, as discussed by Participant 6. In similar questions, respondents also wrote about their experiences researching trails online to prepare. They shared that oftentimes information isn't accurate or reliable in practice. The inconsistency or unreliability contributes to worries around risk and safety for outdoor participants.

Respondents said they would spend more time outdoors if they had the necessary infrastructural support. Participant 18 – a 46-year-old non-binary with Fibromyalgia, Complex Post Traumatic Stress Disorder (C-PTSD), and Hypermobility – highlighted the critical importance of reliable access to trail information in their documented experiences. In response to the question "How do specific challenges related to your disability impact your participation in wilderness recreational spaces (..)?," Participant 18 shared that they suffer from anxiety in the outdoors and "inaccurate maps without accurate grades and difficulties (listed) add to that anxiety." Clearly marked online, paper, and on-trail signage alongside correctly defined and explained trail specifics are crucial for many hikers to successfully care for their bodies. Similarly, Participant 34's salient response shares how accessibility improvements would help her feel more confident in pain management and accessing wilderness space.

> *"I would be more confident in doing longer with more detailed information about the trails, wider trails would be safer for me, and pit toilets every 1-2 miles would be amazing although I know not always doable." – Participant 34*

Participant 32, a 40-year-old non-binary hiker who identifies as having AuDHD, Dyslexia, Fibromyalgia, Chronic Fatigue, and is a wheelchair user with plans to thru-hike coast-to-coast, spoke on the importance of accommodations. As a wheelchair user, Participant 32 identified wheelchair-friendly terrain, which includes bridges and space to turn around a wagon, as necessary accommodations participation. In discussing how their disability and chronic illness status has kept them from a section-hike or a long-distance trail in the past, they said:

> *"I cannot predict when my chronic fatigue will hit (and) finding trails to accommodate me has been rough; my dyslexia gets me lost all the time, which is terrifying to think about in a wilderness setting." – Participant 32*

Though she hasn't done a long-distance hike yet, Participant 22, a 51-year-old female hiker with Fibromyalgia, chronic nerve pain, and migraines, shared that she's training to hike the Camino de Santiago in Spain. When asked how campsites as an accommodation would relieve her chronic pain on the trail, she said it would allow her to not have to carry heavy camping gear. In discussion of how campsites would help foster safe participation, Participant 22 said:

> *"I can hike for long distances. As long as I keep moving I feel fine, but it can take up to 5 days to recover from a few hours of hiking. Once I've stopped, everything seizes up. (..) As such, long distance hiking is so daunting. Anyone I hike with will have to be prepared to stop for a day or more in the middle to allow my pain levels to decrease enough that I can move again. This is why I've avoided the long backpacking trails that required camping." – Participant 22*

The concern of inaccessibility also applies to bathrooms and rest. Many respondents identified bathrooms (Participant 2, 15, 17, 18, 20, 25, 34, 40) and rest (this language is more nuanced and difficult to quantify) as important accommodations for recreational spaces. Participant 25, a 54-year-old female hiker with chronic pain, fatigue, and digestive issues, shared: "As a chronically ill person I need restroom access & ability to get home quickly if needed." Throughout the questionnaire, participants identified concerns around the unpredictable nature of their health conditions (Participant 32, Participant 37) and of the trail terrain (Participant 17). Respondents shared how they navigate concerns about their needs on the trail and spoke to places of rest as an opportunity to assess risk and trail accessibility. Participant 4, a 53-year-old female with Hypoparathyroidism, Hypothyroidism, Asthma, and neck pain, shared challenges of wearing a backpack with cervical neck pain; this experience was reflected in her need for benches. Breaks from carrying heavy gear allows Participant 4's disabled body the space to hike and photograph scenery, safely accessing her wilderness values.

The opportunity to rest on the trail gives the crip hiker space to care for their bodies; that place may serve as a point to take medication, reprieve from heavy gear, an opportunity to pause and pace themselves before continuing, or the space to listen to their bodies and best support their needs. For Participant 11, a 29-year-old female hiker with Rheumatoid Arthritis (RA) and ADHD, access to rest helps structure hikes around arthritis needs, which she said has its own challenges due to her ADHD. In the absence of benches and shaded spots to rest, respondents noted that narrow trails are difficult to "let people pass while resting (Participant 37). Multiple hikers do carry a portable chair as a tool (Participant 15, Participant 18). For sick and crip hikers, rest becomes an opportunity to check-in and take care of their bodies – which becomes even more critical when absorbing disproportionate risk of participation.

> *"More places to sit and rest and water refill stations would allow me to feel more confident in my ability to keep myself safe." – Participant 13*

When asked "What assistive devices, technologies, or strategies do you use to help mitigate the challenges associated with your disability?," participants identified medication (glucose strips, painkillers, NSAIDS, allergy medication, supplements, oxygen, and omnipods and dexcoms), and technology support (cell service, smart watch with satellite, Garmin GPS) as useful to mitigate risk in the outdoors. Mobility aids including access for wheelchairs, canes, powerchairs, trekking poles, braces, forearm crutches, rollator/velopeds, hiking trailers, and electric bikes were identified as a critical accommodation for many respondents. Participant 21 said devices which can connect them to emergency services if needed helps them feel safer, and that some of their medical equipment requires periodic internet connectivity. Similarly, a 48-year-old female hiker with an Immunodeficiency disorder, PTSD, and POTS (Participant 35) said she preferred to stay "within reach of help" in the event of an anaphylactic reaction and uses a smartwatch to monitor symptoms. Participant 35 shared the utility of a smartwatch, such as an Apple Watch, Fitbit, and Oura Ring, to "inform whether I should keep going or if I should turn around, or if I need a rest day."

Mobility supports were identified as critical for many participants, though some said they have difficulty ensuring their effectiveness in the wilderness due to unpredictable terrain and insufficient trail maintenance efforts. Some trails are too narrow, an issue which impacts access rest and space for wheelchairs and other mobility aids. Participant 39 – a 42-year-old female with a spinal cord injury and hearing impairment – noted an issue with equipment from park rangers on trails in between workdays, impacting her abilities to safely get through the area. Some hikers commented on worn-out, ill-kept trails with abundant fallen trees and loose gravel, which contribute to risk and feelings of endangerment (Participant 30). Others noted switchbacks as preferred alternatives to steps, as they're easier to navigate with mobility aids through steep areas (Participant 23, Participant 26). Participant 7, a 79-year-old male with T12/L1 paraplegia, also discussed frustrations about limited accessibility on trails; he shared firm surfaces and limited cross slope as particularly useful for wheelchair users, like himself.

> *"We can't traverse mountains over rocks and thru rivers but we could traverse the mountains with a clear path and a wee bridge!" – Participant 32*

One 34-year-old respondent with post-traumatic arthritis, ankle instability, and chronic pain (Participant 24) shared that an icy hike resulted in a severe fall and consequent ankle fracture/dislocation. She shared that the outdoors offer space to "connect with nature, let (her) children play and explore, and look at all the beauty," but after the fall, she "can't walk well, even with short distances. The pain and swelling becomes too bad, especially chasing children. I also have PTSD related to ice and snow." Participant 24's story especially struck me because she became disabled at 33 and now uses forearm crutches, hiking poles, orthotics, and prescriptive NSAIDS to address pain and inflammation. I found it remarkable how she self-identified as 34, which speaks to how quickly she integrated adaptation strategies into her life to continue participating outdoors. In discussion of her chronic pain and ankle injuries, also shared insight into accommodations which would be helpful, saying: "Paved trails or well maintained, even trails are best. Spaces with restrooms at the trailhead because due to my limited ankle mobility I can no longer squat" (Participant 24).

> *I'd be out every single day if I had the accommodation and aids I need to navigate trails with the way my body functions now. We'd be like real people on the trail." – Participant 32*

The above quote by Participant 32 is echoed by Participant 23, who described her crip and sick experiences on the trail as informed by the larger ableist world. Participant 23, a 30-year-old female hiker with Spinal Muscular Atrophy Type III, uses a wheelchair to access nature. I was touched by her response when asked how improved wheelchair access would change her experiences outdoors, where she said:

> *"(My) wheelchair helps me navigate an ableist world not yet designed for me and others as a priority." – Participant 24*

She identified trail maintenance of fallen trees and loose rocks as important for easily using her wheelchair outdoors. In response to how her wheelchair makes a difference in wilderness spaces, Participant 23 talked about ableist attitudes in wilderness culture, which perpetuate inaccessibility in thinking that trail conditions are safe for different types of recreationalists. Participant 23's practice of enabling access for her body outdoors is two-fold: first is that trail conditions (rocks, steps) are not always conducive for her wheelchair but, secondly, using her wheelchair empowers her as a wilderness participant in "an ableist world."

Participant 3, a 66-year-old female hiker and wheelchair user with Multiple Sclerosis (MS), self-identified as an advisor to city, state, and federal planning agencies on backcountry trails for persons with disabilities and provided insight into her own disabled experiences in the backcountry. She points to specific trail structure and design as barriers, noting tread width hard obstructions on each edge as important for wheelchair access.

This thesis positions this respondent's embodied knowledge within the guidelines of ADA Section 508(c), which clarifies the 1964 Wilderness Act as not prohibiting wheelchair use in wilderness space. Though ADA Section 508(c) does explicitly state the legality of the use of assistive devices by a "mobility-impaired person" in spaces where "foot travel is allowed," ADA and ABA accessible features are not built into these trails to support persons with other medical needs. Participant 3's responses seem to speak to the limitations of the ADA and ABA in how they support differently abled individuals in their opportunity to safely participate and have needs met on the trail. She references the 1968 Architectural Barriers

Act (ABA) and 1990 Americans with Disabilities Act (ADA)[6] as a vessel for accommodation, saying:

> *"I use a powerchair to hike and need specific accommodations, such as: ADA restroom/campsite. ABA compliant water spigots, fire pits, etc. Otherwise, I (am) excluded from participating." – Participant 3*

Participant 3's message directly speaks to the message of the ADA and ABA and how their management of wilderness spaces limits equitable, safe participation on wilderness trails. She moves to interrogate the lack of nuance in wilderness spaces as environments are not constructed for diverse participants; she seems to express frustrations in the below quote.

> *"I won't travel long distances because of the disappointment of doing so and being faced with an insurmountable obstacle. Sometimes I need an accommodation, like an accessible yurt or campground surface and amenities." – Participant 3*

Participant 19, a 21-year-old nonbinary respondent, also shared that more allergy-friendly foods and access to spots on trail to safely rest and would help them navigate their Ehlers-Danlos syndrome, POTS, Myalgic Encephalomyelitis Chronic Fatigue Syndrome (ME/CFS), and allergies on the trail. When asked how these accommodations would help, they said that accommodations would positively impact their circumstances and they "would go out more and for longer. I would be in less pain." One 35-year-old female with bone spurs, C-PTSD, Depression, and Conversation Disorder (Participant 33), shared that her hiking partner and service dog help track and respond to psychogenic seizures on the trail. Concerns about support and hiking alone were also broadly shared by other participants (Participant 11, 19, 33, 34, and 36).

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[6] Reader's context for the Americans with Disabilities Act, Architectural Barriers Act, Wilderness Act, and Rehabilitation Act can be found in the Introduction chapter on page 6.

Accessibility improvements such as more reliable and accurate trail information, regular trail maintenance, benches, camp spots, or allergy-friendly foods would not solely benefit hikers with disabilities and chronic health illnesses, but rather a diverse array of trail users. Concerted attention toward accessibility actively challenges the able-bodied, normative wilderness environment to be more inclusive of diverse trail users. Extension of access to wilderness recreational spaces serves to benefit other groups between the ecological subject and the disabled periphery, including children, families, nontraditional hikers, and seniors. These improvements would help all individuals have an easier time accessing wilderness recreation.

Social Landscape of Disabled Hiking

Respondents identified experiences of social tension as differently abled participants, pointing to the lack of consideration from other trail users. One 41-year-old female hiker with Central Canal Stenosis, Arthritis, Fibromyalgia, and Depression (Participant 9) shared that "other hikers (ask) what's wrong with me before even acknowledging my presence and theirs with a hello." In highlighting discomfort experienced by behaviors and language of able-bodied peers, this quote captures tensions around sharing this space with different needs. Another 42-year-old nonbinary hiker located social bias "on and off the trail" toward disabled participants as a barrier in navigating wilderness spaces (Participant 6; declined to specify disability status).

Cultural attitudes toward disability extend into wilderness spaces and shape the experiences of disabled hikers on the trail. Even with the potential for successful health management strategies and integration of differently abled hikers in the outdoors, social concerns prevail and serve as a secondary barrier for participation. Many participants in this study reported reconciling how to support their needs and maintain connection to the outdoors after beginning to live with a disability and/or chronic health illness later in life. Participant 27, a 30-year-old non-binary hiker diagnosed with Autism, Myalgic Encephalomyelitis Chronic Fatigue Syndrome (ME/CFS), Long Covid, and Chronic Bronchitis, said:

> *"Since becoming chronically-ill, I don't have the energy to walk or hike like I used to. I wear oxygen so I am on a limited battery. I was accused of being too slow." – Participant 27*

Participant 27, who was diagnosed with their chronic illness at 23, shared tension faced around their needs being misunderstood by able-bodied hikers. In conversation with autonomy in caring for one's disabled body in an able-bodied space, other respondents reported receiving unwelcome medical advice. Participant 29, a 26-year-old female hiker with Type 1 Diabetes and Arthritis, discussed social pressures faced as a disabled hiker.

> *"Unfortunately, many people's response to being diabetic on a thru hike is to simply care for their diabetes poorly. There is a sentiment that you should just let your blood sugar run high because it's only for a few months. There are few resources for caring for it properly." – Participant 29*

These experiences shared by Participant 27 and Participant 29 highlight the social pressures of being a crip and sick hiker. Though Participant 29 didn't specify whether comments were from able-bodied trekkers or differently abled peers, I argue that the sentiment stands. In discussion of practices of care in wilderness spaces, a disregard for disabled, embodied knowledge persists and forges social tension in these environments.

Crip Communities: In-Person and Virtual

One space of social connection for many participants is that of disability and wilderness-centric virtual and in-person organized communities. Some respondents, such as Participant

30, a 40-year-old female hiker with cerebral palsy, identified the opportunity of “meeting like-minded people enjoying the same experiences” as a motivation for participation. Consistent themes around hiking as a social, community-centric space emerged. Respondents shared values of local community and professional organizations, Facebook groups, and hiking with others. Many respondents identified social connection through in-person and virtual outdoor spaces, which helped some disabled participants access those communities and opportunities.

Many respondents indicated participation in online community groups ahead as a positive space of discussion, information sharing, and access to social relationships with other disabled wilderness participants. In person and online community groups aim to foster disability justice and facilitate positive relationships for disabled hikers. In the absence of abundant representation of differently abled hikers within accessibility-insecure environments, virtual community discussion boards serve to connect disabled hikers.

For a geographically dispersed community, access to a combination of organized virtual and in-person resources helps disabled hikers develop meaningful social relationships. In this way, dynamic social opportunities for differently abled hikers become more accessible. The space to discuss pre-planning, accommodations, and adaptation strategies structures an environment which generates access to participant-identified values of social connection. In practice, access to organized, online disabled hiker spaces was how many respondents became familiar with and were recruited for this research. While this does speak to my recruitment strategy of strategically recruiting research participants through these spaces, it also illustrates their dynamic and interactive nature.

Planning

Respondents identified barriers around planning in two ways: the pre-planning work before a hike and managing health and accommodations on the trail. In the question "What, if any, barriers to hiking, backpacking, section-hiking, or thru-hiking have you faced in navigating these wilderness spaces?," themes around rest, relief, social dynamics, and accurate trail information emerged from the data. When asked to share how their disability or chronic illness shapes decisions around outdoor recreation, respondents shared how difficult it can be to find/access trails which meet their needs. Participant 21's response to this question especially struck me:

> *"My disabilities mean that I need the goldilocks trail. It has to be just perfect for me to be able to do it. And the few that meet that criteria are several hours by car away from where I live. So, if I want to actually go on those hikes, I have to make a several day trip out of it. With my medical needs (..), going out of town for several days on my own is logistically difficult." – Participant 21*

This participant captures the crossroads of pre-planning considerations and challenges which present even before starting a hike. Many participants shared how accurate trail information online also helps them make informed decisions around their health needs. Participant 12, a 33-year-old agender hiker with Myasthenia Gravis, said access to terrain information is crucial for pre-planning. Because of this, Participant 12 said they primarily hike in state and national parks, which publish more information online. Participant 34 shared planning concerns around managing her orthopedic challenges (nerve damage, scoliosis, foot deformities) on trail; she said:

> *"I have severe, chronic pain and need access to bathrooms. This poses challenges. I have orthopedic impairments and I really need an accurate idea of what a trail will be like to know if it is doable and safe. Often, the information I find is not always accurate to actual trail conditions or not specific enough for me to know if my walker will fit." – Participant 34*

For Participant 34, her primary accommodation is mobility support (walker). However, access to reliable, accurate information about trails ahead of participation is secondary accommodation. Without a complete picture of trail conditions and access for her walker, this secondary accommodation is then positioned as the barrier to participation. Several disabled hikers identified a combined need for assistive devices and trail information, otherwise a barrier to participation is upheld.

One 35-year-old female hiker with ADHD, Hemiplegic Migraines, Ischemic Colitis, and POTS (Participant 10) shared why pre-planning is the most important strategy in caring for her body on the trail. Her story was profound to me as she shared her plans for thru hiking the Appalachian Trail, starting in March 2024, with an emergency placement colostomy bag. In discussion of why accurate information around elevation and water is critical, she said:

> *"I have extreme sensitivity to heat and exertion that can lead to cardiac symptoms, such as tachycardia. (It) can also trigger migraines, so I must plan accordingly to be able to go slow. If it's hot, (I) wait out the hot parts of the day to make sure I have access to plenty of water." – Participant 10*

Strategies for participants reflect the diverse backgrounds, abilities, and health needs of respondents, like Participant 10. Even so, exercising care for one's body engages some critical challenges faced by crip and sick hikers in wilderness space. Participant 37, A 41-year-old female hiker with Ehlers-Danlos syndrome, POTS, Rheumatoid Arthritis, and Chronic Migraines shared her embodied insight into planning. In recognizing challenges of Participant 37's experiences, I first move to recenter spoon theory[7] (discussed by Participant 32, Participant 41). In Spoon Theory for chronically ill persons, planning can become a

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[7] Spoon Theory (first discussed on Page 36) speaks to how chronic pain, illness, and disability impact a person's capacity to perform everyday tasks (Pugle, Michelle)

challenge when bodies are unpredictable, and some days come with more proverbial spoons than others. Participant 37 characterized the pre-trail period as a hurdle in of itself, understanding that sometimes she doesn't "feel well enough to go" or might be "reluctant to plan a trip because of the unpredictable nature of (her) health conditions."

Sentiments about the ability to unwind and enjoy nature as remarked on by Participant 29 are echoed by others. Other respondents also shared their experiences of anxiety and stress on the trail as the result of inaccurate or unreliable trail information negatively impacting their ability to navigate their disability. For some, such as Participant 35, familiarizing oneself with trails ahead of time helps them plan for hiccups and successful mitigation of challenges. Concerns about flare-ups and the uncertain nature of many health issues and symptoms serves as a barrier for sick and crip individuals, one that able-bodied, fit hikers are less keen to experience. Participant 43, a 22-year-old female with hEDS, POTS, and chronic migraines shared how her health poses unpredictable challenges while hiking. She said:

> *"Due to vestibular migraine and concussions, hiking through forests makes me really dizzy, hEDS makes me more injury prone, those and POTS make me fatigue more quickly and I have to stop hiking due to symptoms." – Participant 43*

Pre-trail planning considerations can create tension for hikers because distance hiking spaces weren't designed to support diverse and disabled needs. Yet, accommodations may become even more necessary in isolated wilderness spaces. For many who can independently care for their health conditions in a traditional day-to-day environment, managing crip and sick bodies presents different and heightened challenges/stressors on the trail. Many participants identified tools to properly carry and store medication as a primary barrier (Participant 2, 5, 17, 22, 29, 31 and 37).

Participant 29 shared planning accommodations to be helpful, but that sometimes they "take away from the relax(ation) and ease of nature." For some respondents, pre-planning the hike is only part of the issue. Several participants highlighted experiences navigating dynamic, unpredictable health conditions on trail and that access points to ditch the trail and safely get to town would be helpful. Different challenges for many, including Participant 17, arise throughout a hike, making flexibility important. Participant 17 shared the potential for sudden and unaccountable changes with her health needs on the trail as a discomfort, saying:

> *"The other difficulty is theoretically being on a trail and not having a way to get back if I start feeling too sick, and the remoteness, not being near anyone who could potentially help me." – Participant 17*

For backpackers doing long-hikes or multi-day treks, backpacking planning involves food preparation, a basic need which is also challenged in accessibility for participants with restricted dietary options. Participant 40, a 31-year-old female hiker with Epilepsy, Chronic Pain, Irritable Bowel Syndrome, and migraines also identified food as a contributing factor to plan for to address chronic abdominal pain and struggles with low blood sugar. Facing similar food challenges to Participant 40, Participant 19 echoed her concerns, saying:

> *"I have to plan a lot more extensively and be a lot more flexible, if I want to go out for a weekend I have to dehydrate all the food myself/ make protein bars and snacks, I might have to cancel at the last minute more often." – Participant 19*

For so many participants, planning is how they care for their medical, dietary, social, and physical needs. However, the unpredictable nature of disability and chronic illness in motion can unexpectedly compound challenges. Though this strategy of planning routes out in advance is helpful in theory, many respondents struggle to utilize this tool on account of inaccurate, unreliable, or nonexistent information for many trails. The risk absorbed in wilderness participation is amplified by space and place for disabled hikers. In place, the trails aren’t always maintained or developed to support their needs, and in space, able-bodied hiking peers may not understand or adapt to them. Extra planning and care can make it possible for disabled hikers to get on the trail, but this extra planning can only go so far and can impact how fully participants are able to enjoy their wilderness experiences.

Chapter 5

Conclusion and Discussion

This thesis argues that wilderness spaces, specifically long-distance hiking trails and communities, are privileged based on the social construction of ability, which disenfranchises disabled individuals from equitably accessing their eco-corporeality and self-fulfillment of nature. In examination of the social construction of wilderness recreational spaces in conversation with disability and barriers to participation, I situate this research within a political ecology framework. The research question guiding this thesis was: What are the actual or perceived barriers to participation for differently abled hikers in wilderness recreational spaces, and how do these differences manifest in long-distance hiking spaces?

Discussion

In deconstructing wilderness recreational spaces, namely long-distance trails, into social and physical realities, this thesis positions disabled experiences within both. Exploring the physical and social construction of these spaces informed barriers and adaptation strategies for disabled participants. The main findings of this thesis, in conversation with the arguments of access to eco-corporeality and self-fulfillment of nature, are situated in the values and motivations of disabled participants and barriers faced.

In positioning disability within theories of eco-corporealities, which assert the innate material connection between human and the environment, this research interrogates participation values, motivations, and practices of disabled hikers parallel to those of able-bodied hikers. Examination of experiences within these spaces illustrated the social construction of long-distance hiking environments as they inform the production and maintenance of barriers to access. In amplifying shared wilderness practices and situating barriers in the crip body's barriers in accessing eco corporeality and self-fulfillment of nature, this thesis moves to empower disabled participation. This work built on narrative excerpts of participants, characterizing arguments through crip and sick voices and lived experiences. The results presented in chapter 4 illustrate why disabled bodies desire these spaces and what the limitations of wilderness environments are, illustrating concepts of ability hierarchies as privileging wilderness spaces. Power is situated in these disabled experiences to challenge existing structures around space.

Discussion of differences in trail experiences, values, and practices between ability-normative hikers and disabled hikers lends toward reconciling differences. There are several points where disabled and chronically-ill hikers employ strategies to participation which mirror those of able-bodied participants, including food, gear, and social networks. Ability-normative participants, similar to disabled participants, have extensive dialogue about generating success on the trail, with considerations toward ultra-light backpacking to save weight and move faster, efficient and strategic food choices, and engaging in online planning groups themselves. Strategies for participating as ability-normative hiker are seen as tools for them to conquer wilderness space, whereas the same practices as viewed as inclusion aids and contested by hiking communities. Shared practices of hikers of able-bodied and disabled backgrounds further highlights the social construction of ability hierarchies; adaptation strategies are more valid for ability-normative participants than crip and sick hikers.

Significance

Long-distance trails and backpacking should be accessible and safe for diverse groups of people, as understood through the Wilderness Act of 1964. Humans with disabilities have value-added relationships with the outdoors just the same as able-bodied individuals (Nisbett and Hinton 2005, 221; Goodwin, Peco, and Ginther 2009; Zhang et al. 2017, 703; Basil 2022, 282). However, in conversation with wilderness integrity and accessibility, Ray positions conservation adjacent to eugenics to “argue that contemporary environmental thought continues to treat the disabled body as a sign of our environmental crisis–it is ecologically other and out of place in nature” (Ray 2013, 32). Conversation is positioned to exonerate the exclusion of the disabled body in recreational space.

Wilderness spaces are socially and physically constructed primarily in conversation with the values of able-bodied, financially privileged, heteronormative, oftentimes male, white participants. Thus, these environments have historically excluded participation by marginalized groups, including non-white, queer, fat, crip, sick, poor, and femme individuals and communities. This thesis thoughtfully addresses the breadth of sociocultural barriers and compelling experiences of disabled and chronically ill recreationalists.

Work around amplifying representation and access of marginalized communities in the outdoors has been documented extensively by black scholars Carolyn Finney and Janae Davis, among others. This thesis builds on the black conversations on the exclusivity of American wilderness to develop arguments around these same spaces restricting safe, equitable, and just participation of disabled individuals. The significance of this work is that it moves to document and capture why and how disabled bodies desire and experience nature in long-distance trail environments. In doing this work, ability hierarchies are decentered and crip voices are empowered in sharing what access to wilderness means for them.

Embodied knowledge of crip and sick participants moves to challenge disability visibility in research and barriers in long-distance hiking trails. It was important for this thesis to position the embodied knowledge of its participants in wilderness to develop arguments around access, but it felt equally important for this research space to reflect the co-constitution of knowledge. This thesis is radical in its assertions and it moves to empower its participants; they are not victims, they are capable of hiking and backpacking, and this study captures how they address their challenges in motion and how they deserve equitable representation and accommodation in research and wilderness spaces.

Implications

Wilderness managers have an opportunity to make long-distance trail environments more inclusive to diverse participants. Potential for fostering greater accessibility on the trail include amendments to trail maintenance initiatives, managing and distributing information, places of relief, and developing inclusive gear. Practices of trail maintenance, including clearing fallen debris and equipment from trails, will eliminate some mobility barriers and help participants better maneuver compact trail spaces. Many respondents reported inaccessibility around inaccurate or unreliable trail information. I implore wilderness managers to update online resources with accurate, up-to-date information regarding trail conditions (e.g. trail width, debris status, lookout points, type of trail, length of trail, access to benches and restrooms, parking specifications). While this information can largely be conveyed through an online medium, further providing information via paper resources at the trailhead improves access and convenience. Reconstructing trails to support benches along the way for participants to rest, administer medication, and check in with their bodies is crucial. Including access to bathrooms, as simple as latrine toilets off the trail and as complex as a restroom facility at the trail head, will help participants navigate barriers to relief access. Inclusive gear includes concerted efforts around developing allergy-friendly foods for trails and creating disability-specific trail information to support diverse recreational space users.

Legal Discussion

The ADA is out of compliance with Title V, Section 508(c) as state and local outdoor services within national scenic trail environments are directly supported by federal funding. The 1964 Architectural Barriers Act, 1968 Wilderness Act, 1973 Rehabilitation Act, and 1990 Americans with Disabilities Act in conversation with one another highlights conflicting values and legal guidelines of accessibility and wilderness conservation in practice. This conflict between accessibility and conservation is manifested in tension between the two, a dynamic further explored in the chapter 4.

The accessibility loophole of ADA Title V, Section 508(c) is in the federal administration and management of national trails as outlined by the 1968 National Trails Systems Act. This loophole leverages federal funding to support maintenance and "the creation of trails at the state and local level to meet the outdoor recreation needs of the American people."[8] In effort to uphold standards for management and maintenance of federal, state, and local public wilderness spaces, persons with disabilities and their equitable access to wilderness space is left in the balance.

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[8] National Trails Systems, Before the House Resources Subcommittee on National Parks Concerning the National Trail Systems Act, 109th Congress, (2005)(Christopher K. Jarvi, Associate Director Partnerships, Interpretation, and Education, Volunteers, and Outdoor Recreation, National Park Service, Department of the Interior

Conclusion

Wilderness environments which have characteristically been idealized as spaces of grounding and refuge, an opportunity to escape the routine and anxiety of the day-to-day, crip and sick communities are marginalized in participation on account of production. It does not seem coincidental that bodies which effectively contribute to society and its capitalist model are rewarded with access to wilderness environments. These spaces are valued for their sparse occupation and opportunity to detach from everyday monotony of production, by definition, also detach the “ecological other” from participating.

In work to actively dismantle misconceptions about what crip and sick individuals look like and how their needs manifest on the trail, this thesis challenges the social construction of the wilderness space. In finding values and motivations for disabled recreationalists to be similar to those expressed by able-bodied individuals, this work subverts previously held conceptions about excluding the ecological other from equitable access to participation. The work of crip theory moves disabled voices and subjective experiences to the forefront of the conversation on disability justice, normalizing how crip and sick bodies are represented and cared for in American wilderness. In rebutting the dominant cultural and economic paradigms of the outdoors, which position the ecological subject as the medium of which wilderness development is informed by, crip theory asserts disabled voices and experiences to the equal of able-bodied individuals.

The ‘goldilocks trail,’ as discussed by Participant 21, refers to an ideal wilderness environment which is: in near proximity to one’s home; the trail must have accommodations built in, the social culture around participation must be flexible and welcoming, the disabled body must have structural support (medication and mobility supports); and there needs to be adequate information about the trail so disabled hikers can make educated decisions about their needs. It is difficult for disabled and chronically ill hikers to access wilderness spaces which are safe and conducive to their needs. This thesis finds that spaces are privileged based on ability differences, which disenfranchise disabled individuals through barriers to participation *and* disabled hikers will challenge health, physical, and social barriers to secure greater access to self-determination and ecological fulfillment.

In response to the social pressures which differently abled hikers experience in interfacing with an able-bodied wilderness, there's a poignant opportunity to reconstruct the outdoors to be more inclusive. An important outcome of this thesis is in working toward a non-oppressive, inclusive social space which embraces and empowers disabled experiences. With a fork in the road of wilderness construction, social and physical, an opportunity shines for western culture to pivot away from harmful, ableist attitudes. In doing so, there’s a chance to better support diverse groups of outdoor participants and to embrace nuance and diversity in these environments. This work is radical -- it is feminist in its assertions, it is crip in its stories, and it is human in its nature. In the words of disability scholar Alice Wong in *Disability Visibility*: Community is political. Community is Magic. Community is Power. Community is Resistance (Wong 2020, xviii).

Future Direction

This thesis was conceptualized within western cultural values of wilderness and participation. I am interested in positioning disability in the global south to evaluate differences in values and motivations to engage social and physical worlds of nature-based tourism.

Figure I Participant Glossary

This A-Z glossary was compiled to list and describe disorders, diseases, and conditions self-identified by participants for reader context. Definitions were publicly sourced from: Harvard Medical School, the American Academy of Allergy, Asthma, & Immunology, the Mayo Clinic, the National Institute of Health (National Library of Medicine), Stanford Medicine and the Cleveland Clinic.

Anxiety: People with anxiety disorders frequently have intense, excessive and persistent worry and fear about everyday situations. Often, anxiety disorders involve repeated episodes of sudden feelings of intense anxiety and fear or terror that reach a peak within minutes (panic attacks).

Arthritis: Arthritis means inflammation or swelling of one or more joints. It describes more than 100 conditions that affect the joints, tissues around the joint, and other connective tissues. Specific symptoms vary depending on the type of arthritis, but usually include joint pain and stiffness.

Asthma: A disease that inflames and narrows airways, causing wheezing, shortness of breath, coughing, and tightness in the chest.

Attention Deficit Hyperactivity Disorder (ADHD): People with ADHD may have trouble paying attention, controlling impulsive behaviors (may act without thinking about what the result will be), or be overly active. Although ADHD can’t be cured, it can be successfully managed and some symptoms may improve as the child ages.

AuDHD: An unofficial term merging Autism and Attention Deficit Hyperactivity Disorder. Participant 33 self-identified as AuDHD.

Autism Spectrum Disorder (ASD): Autism spectrum disorder (ASD) is a developmental disability caused by differences in the brain. People with ASD may behave, communicate, interact, and learn in ways that are different from most other people.

Autonomic Dysfunction (Also known as Dysautonomia): An autonomic dysfunction occurs when the autonomic nervous system, which controls functions responsible for well-being and maintaining balance, does not regulate properly.

Borderline Personality Disorder (BPD): Borderline personality disorder is a mental health condition that affects the way people feel about themselves and others, making it hard to function in everyday life. It includes a pattern of unstable, intense relationships, as well as impulsiveness and an unhealthy way of seeing themselves.

Bipolar II Disorder (BP): Bipolar disorder, formerly called manic depression, is a mental health condition that causes extreme mood swings that include emotional highs (mania or hypomania) and lows (depression).

Cerebral Palsy: Cerebral palsy is a group of conditions that affect movement and posture. It's caused by damage that occurs to the developing brain, most often before birth.

Chronic Bronchitis: Often developing from a cold or other respiratory infection, acute bronchitis is very common. Chronic bronchitis, a more serious condition, is a constant irritation or inflammation of the lining of the bronchial tubes, often due to smoking.

Chronic Pain: Pain that persists after an injury has healed or a disease is over.

Complex Post-Traumatic Stress Disorder (C-PTSD): Complex post-traumatic stress disorder (CPTSD) can result from experiencing chronic trauma, such as prolonged child abuse or domestic violence.

Conversion Disorder: Conversion disorder is a psychiatric disorder characterized by signs and symptoms affecting sensory or motor function inconsistent with patterns of known neurologic diseases or other medical conditions and significantly impacting the patient’s ability to function.

Diabetes: Diabetes mellitus (DM) is a disease of inadequate control of blood levels of glucose. It has many subclassifications, including type 1 and type 2.

Dissociative Identity Disorder (DID): Dissociative identity disorder (DID) is a rare psychiatric disorder diagnosed in about 1.5% of the global population. This disorder is often misdiagnosed and often requires multiple assessments for an accurate diagnosis. Patients often present with self-injurious behavior and suicide attempts.

Depression: Depression is a mood disorder that causes a persistent feeling of sadness and loss of interest. Also called major depressive disorder or clinical depression, it affects how you feel, think and behave and can lead to a variety of emotional and physical problems.

Dysautonomia (Also known as Autonomic Dysfunction): An autonomic dysfunction occurs when the autonomic nervous system, which controls functions responsible for well-being and maintaining balance, does not regulate properly.

Dyslexia: Dyslexia is a learning disorder that involves difficulty reading due to problems identifying speech sounds and learning how they relate to letters and words (decoding).

Endometriosis: Endometriosis is an often-painful condition in which tissue that is similar to the inner lining of the uterus grows outside the uterus.

Epilepsy: Epilepsy — also known as a seizure disorder — is a brain condition that causes recurring seizures.

Fibromyalgia: Fibromyalgia is a disorder characterized by widespread musculoskeletal pain accompanied by fatigue, sleep, memory and mood issues.

Ehlers Danlos (Also called hEDS and Hypermobility): Ehlers-Danlos syndrome is a group of inherited disorders that affect your connective tissues — primarily your skin, joints and blood vessel walls. People who have Ehlers-Danlos syndrome usually have overly flexible joints and stretchy, fragile skin.

Hearing Impairment: Hearing loss that comes on little by little as you age, also known as presbycusis, is common. More than half the people in the United States older than age 75 have some age-related hearing loss.

Hemochromatosis: Hemochromatosis causes your body to absorb too much iron from the food you eat. Excess iron is stored in your organs, especially your liver, heart and pancreas. Too much iron can lead to life-threatening conditions, such as liver disease, heart problems and diabetes.

Hemorrhagic strokes: This occurs when a blood vessel in the brain leaks or bursts and causes bleeding in the brain. The blood increases pressure on brain cells and damages them.

Hypoparathyroidism: A disease in which the parathyroid gland does not make enough parathyroid hormone.

Hypothyroidism: A disease in which the thyroid gland does not make enough thyroid hormone.

Immunodeficiency: Primary immunodeficiency disorders — also called primary immune disorders or primary immunodeficiency — weaken the immune system, allowing infections and other health problems to occur more easily.

Ischemic Colitis: Ischemic colitis occurs when blood flow to part of the large intestine is temporarily reduced. Any part of the colon can be affected, but ischemic colitis most commonly causes pain on the left side of the belly area.

Irritable Bowel Syndrome (IBS): IBS is a common disorder that affects the stomach and intestines, also called the gastrointestinal tract. Symptoms include cramping, abdominal pain, bloating, gas, and diarrhea or constipation, or both.

Juvenile Degenerative disc disease: Degenerative disk disease is when your spinal disks wear down. Spinal disks are rubbery cushions between your vertebrae (bones in your spinal column). They act as shock absorbers and help you move, bend and twist comfortably. Everyone's spinal disks degenerate over time and is a normal part of aging.

Long Covid: Post-COVID-19 syndrome involves a variety of new, returning or ongoing symptoms that people experience more than four weeks after getting COVID-19. In some people, post-COVID-19syndrome lasts months or years or causes disability. The most reported symptoms include: fatigue, respiratory symptoms, and fever.

Lupus: Lupus is a disease that occurs when your body's immune system attacks your own tissues and organs (autoimmune disease).

Mast Cell Activation Syndrome (MCAS): MCAS is a condition in which the patient experiences repeated episodes of the symptoms of anaphylaxis – allergic symptoms such as hives, swelling, low blood pressure, difficulty breathing and severe diarrhea. High levels of mast cell mediators are released during those episodes.

Migraine: A migraine is a headache that can cause severe throbbing pain or a pulsing sensation, usually on one side of the head. It's often accompanied by nausea, vomiting, and extreme sensitivity to light and sound. Migraine attacks can last for hours to days, and the pain can be so bad that it interferes with your daily activities.

Mixed connective tissue disease (MCTD): This is referenced as progressive congenital connective tissue disorder by Participant 18. MCTD has signs and symptoms of a combination of disorders — primarily lupus, scleroderma, and polymyositis.

Multiple Sclerosis (MS): An autoimmune disease in which the body's immune system mistakenly attacks myelin, the substance that covers nerve fibers.

Myalgic Encephalomyelitis Chronic Fatigue Syndrome (ME/CFS): Chronic fatigue syndrome (CFS) is a serious, long-term illness that affects many body systems. Another name for it is myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). CFS can often make you unable to do your usual activities. Sometimes you may not even be able to get out of bed.

Myasthenia Gravis: Myasthenia gravis, sometimes called MG, is a chronic (long-lasting) disease that causes weakness in your voluntary muscles.

Myositis: Myositis means inflammation of the muscles that you use to move your body. An injury, infection, or autoimmune disease can cause it. Two specific kinds are polymyositis and dermatomyositis.

Nerve pain (neuralgia): Neuralgia is a sharp, shocking pain that follows the path of a nerve and is due to irritation or damage to the nerve.

Neural tube defect: Neural tube defects are birth defects of the brain, spine, or spinal cord. The two most common neural tube defects are spina bifida and anencephaly.

Obsessive-compulsive disorder (OCD): Obsessive-compulsive disorder (OCD) is a mental disorder in which you have thoughts (obsessions) and rituals (compulsions) over and over. They interfere with your life, but you cannot control or stop them.

Osteoarthritis: Osteoarthritis, sometimes called OA, is a type of arthritis that only affects the joints, usually in the hands, knees, hips, neck, and lower back. It's the most common type of arthritis.

Paraplegia: Paralysis of the legs and lower part of the body.

Foot drop: Foot drop, sometimes called drop foot, is a general term for difficulty lifting the front part of the foot. If you have a foot drop, the front of your foot might drag on the ground when you walk.

Premenstrual Dysphoric Disorder (PMDD): Premenstrual dysphoric disorder (PMDD) is a condition in which a woman has severe depression symptoms, irritability, and tension before menstruation.

Postherpetic neuralgia: Called Post shingles neuralgia by Participant 10, postherpetic neuralgia is the most common complication of shingles. It causes a burning pain in nerves and skin. The pain lasts long after the rash and blisters of shingles go away.

Post-Traumatic Stress Disorder (PTSD): Post-traumatic stress disorder (PTSD) is a mental health condition that's triggered by a terrifying event — either experiencing it or witnessing it. Symptoms may include flashbacks, nightmares and severe anxiety, as well as uncontrollable thoughts about the event.

Postural Tachycardia Syndrome (POTs): POTS is a group of disorders that have orthostatic intolerance (OI) as their primary symptom. OI is a condition in which an excessively reduced volume of blood returns to the heart after an individual stands up from a lying down position. The primary symptom of OI is lightheadedness or fainting.

Rheumatoid Arthritis: an autoimmune and inflammatory disease, which means that your immune system attacks healthy cells in your body by mistake, causing inflammation (painful swelling) in the affected parts of the body.

Scoliosis: Scoliosis causes a sideways curve of your backbone, or spine.

Small fiber neuropathy: Small fiber neuropathy is a condition characterized by severe pain attacks that typically begin in the feet or hands. As a person ages, the pain attacks can affect other regions. Some people initially experience a more generalized, whole-body pain. The attacks usually consist of pain described as stabbing or burning, or abnormal skin sensations such as tingling or itchiness.

Spinal cord injury: Your spinal cord is a bundle of nerves that runs down the middle of your back. It carries signals back and forth between your body and your brain. A spinal cord injury disrupts the signals.

Spinal Muscular Atrophy (Type 3): Spinal muscular atrophy (SMA) is an inherited disease that affects nerves and muscles, causing muscles to become increasingly weak. Type 3 symptoms include mild muscle weakness, difficulty walking and frequent respiratory infections.

Spinal Stenosis: Called Central Canal Stenosis by Participant 10, spinal stenosis happens when the space inside the backbone is too small. This can put pressure on the spinal cord and nerves that travel through the spine. Spinal stenosis occurs most often in the lower back and the neck.

Vocal Cord Dysfunction: If you have vocal cord dysfunction (VCD), your vocal cords don’t open all the way when you breathe in. This blocks your airways, and you may struggle to breathe. VCD is often misdiagnosed as asthma, which has similar symptoms.

Appendix A: Participant Index

	Age	Gender	Race	Long-Distance Trails	Chronic Health (Y/N)	Disability (Y/N)	Opportunity to Self-Identify Disability Status
1	52	Female	White/ Caucasian	None	Yes	Yes	Surgical hypoparathyroidism
2	51	Female	White/ Caucasian	Appalachian Trail	Yes	No	no
3	66	Female	White/ Caucasian	Oregon Coast Trail, John Muir Trail	No	Yes	MS - primary progressive since 1998
4	53	Female	White/ Caucasian	Sinks trail Lander, Wyoming, Hidden Valley Riverton, Wyoming. Grand Teton National Park (9-mile trail to lake)	Yes	Yes	Hypoparathyroidism, Hypothyroidism, severe Asthma, severe neck pain, lumbar pain.
5	52	Female	White/ Caucasian	Appalachian Trail	Yes	Yes	Hearing impaired with a calcium disorder with chronic pain
6	42	Non-Binary	White/ Caucasian	Pacific Crest Trail, Appalachian Trail, Oregon Coast Trail	Yes	Yes	no
7	79	Male	White/ Caucasian	None	No	Yes	T12/L1 paraplegia - crushed spine from 35-foot fall
8	21	Non-Binary	White/ Caucasian	None	Yes	Yes	ME/CFS, Fibromyalgia, neurodiversity, etc.
9	41	Female	Black or African American	Local parks in the state of Georgia	Yes	Yes	Central canal stenosis, arthritis, fibromyalgia, depression, anxiety, post-traumatic stress disorder, post shingles neuralgia, asthma
10	35	Female	White/ Caucasian	Laurel Highlands Hiking Trail	Yes	Yes	ADHD, hemiplegic migraines, ischemic colitis, dysautonomia/POTs, anxiety, depression, PTSD, hemochromatosis
11	29	Female	White/ Caucasian	Pacific Crest Trail, Appalachian Trail, Continental Divide Trail,	Yes	Yes	Rheumatoid Arthritis. I also have ADHD, which makes keeping up self-care more challenging

				John Muir Trail, Tahoe Rim Trail			and compounds my physical issues.
12	33	Agender	White/ Caucasian	None	Yes	Yes	Myasthenia Gravis, which is a rare autoimmune neuromuscular disease. It causes severe weakness of any voluntary muscle (including the diaphragm) with use.
13	25	Female	White/ Caucasian	Day Hikes on local trails in Alabama	Yes	Yes	POTS and hEDS (along with Generalized Anxiety and Bipolar 2)
14	71	Female	White/ Caucasian	None	No	Yes	Partially dropped foot
15	53	Female	White/ Caucasian	Pacific Crest Trail	Yes	Yes	Muscle pain and weakness throughout body. Migraines. Lightheadedness from dysautonomia
16	32	Female	White and Black	None	Yes	Yes	I have arthritis and PTSD
17	27	Female	White/ Caucasian	Parker River Wildlife Refuge Hellcat Trail in MA, it is wheelchair accessible. Or Marginal Way in Ogunquit, Maine.	Yes	Yes	Multiple; progressive congenital connective tissue disorder, autonomic dysfunction, physical disability and mobility impairment, asthma, vocal cord dysfunction, MCAS, GI issues, small fiber neuropathy, various spine issues, arthritic changes in back, to name some. Autism, PTSD.
18	46	Non-Binary	White/ Caucasian	None	Yes	Yes	Fibromyalgia, C-PTSD, hypermobility
19	21	Non-Binary	Hispanic	Appalachian Trail, Pisgah National Forest, Congaree National Park, Smoky Mountains National Park, Blue Ridge Mountains	Yes	Yes	Ehlers-Danlos syndrome, pots, ME/CFS, Allergies, autism, DID, MCAS,
20	34	Female	White/ Caucasian	Appalachian Trail	Yes	Yes	I have several chronic health conditions, including long covid

							which is the most disabling
21	29	Non-Binary	White/ Caucasian	None	Yes	Yes	Lupus, Diabetes, ADHD, PTSD, Spinal Injury. And my spinal injury was from a car crash about five years ago. It’s not as bad as it could be, but it makes standing and walking difficult. I have other conditions/diagnoses, but these seem to be the main ones I would consider to be the most disabling.
22	51	Female	White/ Caucasian	None	Yes	Yes	Fibromyalgia, Chronic Nerve pain, migraine. Also: shoulder, foot, & ankle injuries which affect what gear I can use.
23	30	Woman	Adopted person/ unknown	None	Yes	Yes	SMA 3, muscle weakness
24	34	Female	Hispanic	Continental Divide Trail	No	Yes	Ankle instability, chronic pain, and post traumatic arthritis. I had an open ankle fracture/dislocation which resulted in emergency surgery. This was due to slipping on ice while hiking
25	54	Female	White/ Caucasian	Appalachian Trail, Oregon Coast Trail, John Muir Trail	Yes	Yes	Chronic pain, fatigue & digestive issues — all autoimmune
26	29	Non-Binary	White/ Caucasian	Pacific Crest Trail, Trails in Denali National Park	Yes	Yes	ADHD, Long Covid, Hypermobility, PTSD, an autoimmune disease that doctors haven't narrowed down what it is.
27	30	Non-Binary	White/ Caucasian	Bonneville Shoreline Trail.	Yes	Yes	Autism, ME/CF/long covid, chronic bronchitis, fibromyalgia, 'Ehlers Danlos/ Hypermobility"

28	46	Female	White/ Caucasian	Pacific Crest Trail, Continental Divide Trail	Yes	Yes	B.P.D. P.T.S.D. P.M.D.D
29	26	Female	White/ Caucasian	mostly shorter local trails	Yes	Yes	type one diabetes and arthritis
30	40	Female	Prefer not to answer.	Pacific Crest Trail	No	Yes	Cerebral Palsy
31	64	Male	White/ Caucasian	Tour du Mont Blanc 2023 110 miles, this year 2024 goal Pacific Crest Trail Section A-F	Yes	No	Rheumatoid Arthritis
32	40	Non-Binary	Mostly Irish	I don't know the names of any trails I've been on. I just went into the woods and followed the directions from others or went on adventures	Yes	Yes	I'm AuADHD, I have both types of dyslexia, I have fibromyalgia and chronic fatigue, and severe anxiety. So basically, I'm extremely anxious I get lost all the time and sometimes my body just doesn't work the way I need it to.
33	35	Female	White/ Caucasian	None	Yes	Yes	Spinal degeneration in the form of bone spurs, complex post-traumatic stress disorder, variable depression states, conversion disorder (psychogenic non epileptic seizures), unknown causes of chronic pain beyond the spinal spurs, unspecified dissociation disorder
34	33	Female	White/ Caucasian	None	Yes	Yes	Neural tube defect, nerve damage, scoliosis, foot deformities, OCD, anxiety, autistic (I do not find this to be disabling for myself personally, but I do approach situations differently because of it).
35	48	Female	White/ Caucasian	Appalachian Trail, Florida Trail, I have been to over 150 Florida State Parks and regularly hike on the Ocean to Lake Trail (maintained by the Florida Trail Association)	Yes	Yes	Immune Deficiency, PTSD, other health issues (undiagnosed POTS, etc.)

36	35	Female	White/ Caucasian	Pacific Crest Trail, John Muir Trail	Yes	Yes	Primarily fibromyalgia
37	40	Female	White/ Caucasian	Pacific Crest Trail, Appalachian Trail, Arizona Trail	Yes	Yes	Ehlers-Danlos syndrome, postural orthostatic tachycardia syndrome, rheumatoid arthritis, chronic migraine, asthma, primary immunodeficiency, ADHD, autistic
38	42	Female	Asian	Canberra Centenary trail, Tidbinbilla	Yes	Yes	PTDS, MDD, ADHD, autism, fibromyalgia, autoimmune, chronic pain, osteoarthritis
39	42	Female	White/ Caucasian	The Pennines, Wales Coast Path, Offa's Dyke Path	No	Yes	Spinal cord injury, hearing impaired
40	31	Female	White/ Caucasian	None	Yes	Yes	I had two hemorrhagic strokes at age 23, and brain surgery after the second stroke. I am now epileptic as well, due to the strokes and brain surgery. I have also dealt with irritable bowel syndrome in recent years, causing abdominal pain and digestive distress. I also deal with headaches and migraines.
41	27	Non-Binary	White/ Caucasian	None	Yes	Yes	[LEFT EMPTY]
42	60	Female	White/ Caucasian	None	Yes	Yes	Myositis, so weak muscles that weaken further at altitude. I get excessively sore and tired.
43	22	Female	White/ Caucasian	None	Yes	Yes	hEDS, POTS, chronic migraine
44	24	Female	White/ Caucasian	None	Yes	Yes	Many, primary ones include lumbar juvenile degenerative disc disease, scoliosis, dysautonomia, pots, endometriosis, post-covid, and others.

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