Columbia University Graduate School of Arts & Sciences
Human Rights Studies Master of Arts Program

Fragility, Division And Exclusion: Identity and the Intersectional Limits of the Disability Rights Movement

Polly Maton

Thesis Advisor: Frank Guridy

Submitted in partial fulfilment of the requirements for the degree of Master of Arts

January 2025

Acknowledgements

A big thank you to my advisor Frank Guridy, for his invaluable insights throughout his class and personal supervision in guiding this thesis. Thank you also to my general academic advisor, Tim Wyman-McCarthy, for his immense help during my turbulent studies at Columbia.

For BarBar and Grumps, who were my biggest supporters throughout my academic journey.

An Authors Note

It seems fitting in a thesis on disability rights that a disclosure of my own disability should be front and central. I am Disabled. I do not have my right hand or forearm and I also have dyslexia. The interviewees were informed of my disability and this of course informs this research. I hold, as well, immense privileges: I am white, I am wealthy, and I am college-educated, to name but a few. In the context of an intersectional analysis, this is also implicitly important to acknowledge.

My dyslexia informs the ways I write. I lose control of grammar and sentence structure, and concepts are not always clearly established. I continually correct myself, as I have here. In the spirit of a crip-based approach, however, I ask you, as a reader, to be kind if my writing has not been sufficiently contained and try not to let it distract from the content of my ideas.

Word count: 12,999 (Max: 13,000)

CONTENTS

1 ABSTRACT

This thesis asserts that there are acute barriers facing the US pan-disability rights movement's progress towards embodying intersectional praxis: a necessary feature of any social movement furthering human rights. These obstacles largely revolve around the fragility of disability's collective sociopolitical identity. The porosity and heterogeneity, combined with persistent medicalised perceptions, which characterise the Disabled experience, undermine the manufactured common identity the movement hinges on. In so doing, not only do contentious impairment-based politics subsume activist theorisations of inclusion, but a lack of external validity stalls intersectional practices in its own right as well as inspiring a culture of marginalisation and victimhood, which motivates actors to double down on disability essentialism. The paper utilises oral history sources, survey data, eight expert interviewees and website content analysis in making its conclusions. The first section starts by establishing the current state of intersectional praxis in the US disability rights movement, which can be deduced to be failing those in the movement who are multiply marginalised. The development and nature of disability identity are then established before its impacts on the movement's intersectional praxis are substantiated. This thesis concludes with the suggestion that not only can DRM itself learn from understanding its own internal culture and mechanisms but other movements as well.

2 INTRODUCTION

The UN Convention on the Rights of Persons with Disabilities is clear in its concern for 'persons with disabilities who are subject to multiple or aggravated forms of discrimination'.[1] Ensuring rights are realised by everyone, particularly those at the margins, is imperative for human rights work and, concomitantly, the work of a human rights-based social movement. However, the US-based **disability rights movement (DRM)**, in alignment with other single identity-based forms of collective action, still has a long way to go before embodying intersectional praxis.[2] This is particularly poignant considering as early as 1999, Vernon's seminal piece established that the majority of the Disabled community hold multiple identities and are subject to simultaneous oppression.[3]

This thesis argues that the mainstream US- based DRM has acute barriers in acknowledging and implementing intersectional praxis specifically pertaining to the fragility of collective identity cultivation and politics. The sociopolitical identity the DRM hinges on is uniquely fragile, lacking homogeneity, a broader indigenous culture, and recognition from those with impairments or other identity movements, let alone broader society. The weak foundations on which this disability identity is based allow for all-consuming impairment-based fractious power politics within its own narrow umbrella, leaving conversations around further identity inclusion concerns at the wayside. Moreover, the persistence of the charity and medical

[1] Preface paragraph (p) - United Nations. "Convention on the Rights of Persons with Disabilities." https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities. (accessed 04/12/2024)
[2] Conejo, Mıriam Arenas, "At The Intersection Of Feminist And Disability Rights Movements. From Equality Indifference To Human Diversity Claims." In *Disability and Intersecting Statuses* edited by Sharon N Barnartt and Barabara Altman, (Bingley: Emerald Group Publishing Limited, 2013)., p.38.; Evans, Elizabeth. "Political intersectionality and disability activism: Approaching and understanding difference and unity", *The Sociological Review,* Vol. 70 No. 5 (2022), p.994.
[3] Vernon, Ayesha. "The Dialectics Of Multiple Identities And The Disabled People's Movement". *Disability & Society,* Vol. 14, No.3 (1999)

models of disability, undercutting the movement's own positive assertions of identity and validity, has hampered cross-movement ties and, as such, intersectional praxis in its own right. It is in this context, compounded by perceptions of marginalisation and victimhood, a predominantly norm-conforming core to the movement have fiercely defended a narrowly framed identity, threatened by the idea that others will subsume or challenge it. These mechanisms deriving from a fractious collective identity are critical in understanding the barriers behind the actualisation of intersectional disability rights in the US.

Due to constraints on length, the thesis is not centrally comparative; the focus is instead on providing an in-depth analysis of the specific mechanisms pertaining to the DRM. It is, however, asserted throughout that disability identity and the concomitant challenges the DRM faces in terms of intersectional praxis are unique and, in so doing, begets analogy. Identity-based social movements have gone through similar exclusionary and essentialist processes in their cultivation of collective unitary identities and, as such, share barriers to intersectional praxis. [4] Where other forms of collective action differ, however, is that all these movements have a stronger basis for their identity-based coalition building, which provides a sturdier foundation in which to develop intersectional praxis. Black civil rights activists of the 60s, for example, shared large aspects of history and culture, particularly emanating from the Church.[5] The LGBTQ+ community, as implied by interviewees and survey respondents, also has a more substantial- if divided- culture in comparison to that of disability activists, stretching

[4] Montoya, Celeste. "Intersectionality and social movements: Intersectional challenges and imperatives in the study of social movements." *Sociology Compass,* Vol. 1, No. 8 (2021)., p.3.; Davis, Lennard J. "Identity Politics, Disability, and Culture". In *Handbook of Disability Studies*, edited by Gary L. Albrecht, Katherine D. Seelman, and Michael Bury (Thousand Oaks, CA: Sage Publications, 2001), p.536, p.538.; Alcoff, Linda Martín, Michael Hames-García, Satya P. Mohanty, Paula M. L. Moya. *Identity Politics Reconsidered* (New York: Palgrave Macmillan, 2006)., pp.12-3. Gamson, Joshua. "Messages of exclusion: Gender, movements, and symbolic boundaries." *Gender & Society*, Vol. 11, (1997)., pp178-180.; Luna, Zakiya. 'Truly a women of color organization': Negotiating sameness and difference in pursuit of intersectionality." Gender & Society, Vol. 30 No. 5, (2016)., pp.769-771.

[5] Morris, Aldon. *The Origins of the Civil Rights Movement: Black Communities Organizing for Change* (New York, 1984), p.91. ; Lewis, John. *Walking with the wind*. (Boston: Mariner Books, 1999). p.381.

into the early 20th century as established by Stulberg (2018), amongst others.[6] The Disabled community's own cultural lineage pales in comparison,[7] and, as such, creates a unique set of parameters for the movement.

[6] Stulberg, Lisa M. *LGBTQ Social Movements*. (Cambridge, UK; Malden, MA: Polity Press, 2018.), p.13.
[7] Davis. "Identity Politics, Disability, and Culture". , p.536.

2.1 CURRENT LITERATURE AND THEORETICAL FRAMEWORK

Identity

Literature pertaining to identity and specifically identity politics constitutes, in large part, the theoretical foundations of the thesis. Identity as a philosophical concept of self has deep roots, but the academic discourse surrounding identity politics arose fairly recently- at least by Wendy Brown's (1995) estimation- by the 1970s, inspired by the emergence of a plethora of identity-based movements in the US during the 20th century .[8] Indeed, at its core, identity is both an academic and political term, both shaping the other simultaneously, as established by Brubaker's 2000 article 'Beyond "Identity"' which provides a particularly illuminatory starting point. [9] While not denying the reality of what the term has come to represent and its political utility, Brubaker makes a point to underline that the use of identity, particularly aligned with the notion of identity politics, 'is riddled with ambiguity, riven with contradictory meanings, and encumbered by reifying connotations'.[10] Through its nebulous definition, identity has come to represent 'a specifically collective phenomenon'; an 'interactive development of the […] solidarity or "groupness" that can make collective action possible'; a foundational selfhood as well as 'the evanescent product of multiple and competing discourses'.[11] Some of these terms are evidently mutually exclusive. There is simply not space here to do justice to a comprehensive analysis of identity in all its iterations. What can be broadly accepted in the context of social movement studies, while concomitantly

[8] Brown, Wendy. *States of Injury: Power and Freedom in Late Modernity*. (Princeton, NJ: Princeton University Press, 1995.), p.60.
[9] Brubaker, Rogers and , Frederick Cooper. '"Beyond" Identity". *Theory and Society*, Vol. 29 No.1, (Feb., 2000),. p.4.
[10] Brubaker and Cooper. '"Beyond" Identity"., p.34.

[11] Ibid., pp6-8.

acknowledging its nuance, is that identity symbolises 'a ground or basis of social or political action'.[12]

Much has been discussed on the nature of identity cultivated for political action in the context of 20th-century collective action. Scholarship is unified on the fact that all the mainstream identity movements- from women's activism to gay rights- have focused on unitary collective identity (e.g. 'Polletta & Jasper, 2001; Taylor & Whittier, 1999').[13] Within such movements, it has been noted that a singular group identity was perceived essential by organisers as it was assumed this would provide a point of unity across the activist space[14], and hence 'generate and sustain commitment and cohesion between actors over time'. [15] Collective identity has been seen as creative product, tying into but ultimately separate from individual identities, 'expressed in cultural materials' and 'carr[…ying] with it positive feelings for other members of the group.'[16]

The basis of single-dimension identity politics has been critiqued from its inception as creating fragmentary and essentialist groupings which fail to analyse macro-level drivers of inequality and injustice.[17] Look no further than Ruth Gilmore's influential theorisations in *Abolition Geography* of 'racial capitalism' or Wendy Brown's critique in *States of Injury.*[18]

[12] Brubaker and Cooper. '"Beyond" Identity"'., p.6.
[13] Montoya. "Intersectionality and social movements: Intersectional challenges and imperatives in the study of social movements"., p.3.; Brubaker and Cooper. '"Beyond" Identity"., p.2.
[14] Evans. "Political intersectionality and disability activism"., p.992.; Almeida, Paul, *Social Movements: The Structure of Collective Mobilisation*. 1st ed. (University of California Press, 2019). p.72.
[15] Fominaya, Cristina. "Collective Identity in Social Movements: Central Concepts and Debates". *Sociology Compass*. Vol. 4, No.6 (2010). p.393.
[16] Polletta, Francesca, and James M. Jasper. "Collective Identity and Social Movements." *Annual Review of Sociology.* Vol, 27 (2001). p.285.
[17] Hill Collins, Patricia and Sirma Bilge. *Intersectionality* (Cambridge: Polity Press, 2016). pp.127-8.
[18] Gilmore, Ruth. *Abolition Geography: Essays Toward Liberation*. (Brooklyn: Verso, 2022). p.472.; Brown, Wendy. *States of Injury: Power and Freedom in Late Modernity*., p.28.

Unitary identity cultivation innately necessitates exclusion and othering, as noted most prominently by Butler (1991, 1993); Connoley (2002)[19] and Gamson in his 1997 article "Messages of exclusion"*:* all social movements are 'in the business […] of exclusion'.[20] It is within this sentiment that intersectional criticism has been birthed, spearheaded formally by Kimblere Crenshaw.[21]

The uniqueness of disability identity has been discussed a fair amount in relevant literature and indeed has been used to highlight the wider limitations of single-identity based movements, most notably in Lennard Davis' 2001 piece.[22] Critical to understanding disability is the assertion, as Tobin Siebers underlines, that 'people with disabilities do not present immediately as either an identity or minority group'.[23] Due to multiple factors 'disability' has had historically weak foundations as a sociopolitical categorisation, lacking identification and recognition both internally by those with impairments as well as by wider society. The literature points to several reasons for this. Of most importance, the disabled population in the US is extremely heterogenous. Making up around 1/5 of the population , and dubbed the US' largest minority,[24] disability covers a broad range of families, circumstances and other identities. [25] For the vast majority of the community- 85%- impairment(s) is(are) something that is acquired later in life as opposed to a condition that one is born with.[26] The term, moreover, covers a plethora of health experiences from chronic illness to blindness. As such, the lines surrounding the group are nebulous and can, at any point, encompass anyone in

[19] Connolly, William E. *Identity/Difference: Democratic Negotiations of Political Paradox*. 1st ed. (Minneapolis: University of Minnesota Press, 2002.), p.64.

[20] Gamson, Joshua. "Messages of exclusion: Gender, movements, and symbolic boundaries.",. p.179.

[21] Evans. "Political intersectionality and disability activism"., p.992.
[22] Davis. "Identity Politics, Disability, and Culture".,p.543.
[23] Tobin Siebers in Alcoff, Hames-García, Mohanty, Moya. *Identity Politics Reconsidered*. p.10.
[24] Shapiro, Joseph. *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Times Books, 1993).p.7.

[25] Tobin Siebers in Alcoff, Hames-García, Mohanty, Moya. *Identity Politics Reconsidered*., p.11.
[26] Ibid., p.10.

society, while those who do fall inside the tentative partitions often reflect very little of other's experiences: '[d]isability is hardly a unitary label.'[27] This heterogeneity also interacts with the prevailing medical model of disability[28] and the centuries of ableist practices it has fuelled. Dominant attitudes towards the Disabled populations in the West saw disability as an individualised condition, at best pitiful and at worst shameful, which debilitates those in question and should be treated through medicalisation and, if unsuccessful, segregation through institutionalisation. [29] While the DRM has been based on the refutation of these assumptions[30] and the insistence that impairments were made disabling by society[31] - an alternative social model- attitudes have remained persistent. Watson's 2002 study on disability identity is illusory in this context; the vast majority of Disabled participants in the study rejected disability as part of their identity in an effort to be perceived as normal and evade the negative connotations. [32] Persistently ableism within the community itself leads to internal dissociation,[33] and this ableism is potent in society at large, with a failure to recognise disability as 'meaningful category and identity'.[34] The discussion on the existence of the identity at all is critical to understanding the circumstances in which the DRM functions.

Intersectionality

[27] Scotch, Richard. "Politics and Policy in the History of the Disability Rights Movement". *The Milbank Quarterly*. Vol. 67, No. 2 (1989),. p,385.
[28] Teti, David and Lorot, Salem. *Disability: Law and Rights.* (Nairobi: Sparrow Press Limited, 2017)., p.9. (**Medical model definition** : the belief that 'considers the restrictions and difficulties that people with impairments go through as personal tragedies that they need to deal with in order to compete with other members in the mainstream society')
[29] Fleischer, Doris Zames and Frieda Zames. *The Disability Rights Movement: From Charity to Confrontation* (Philadelphia: Temple University Press, 2001), p.525.
[30] Manuel Aramayo , Mark H. Burton , and Carolyn Kagan, 'Revising and Using the Social Model in the Global South: A Venezuelan Exploration'. In *Disability in the Global South: The Critical Handbook* edited by Grech, Shaun, and Soldatic, Karen, (Cham: Springer Publishing 2016), p.517.
[31] Tregaskis, Claire. "Social Model Theory: The story so far". *Disability & Society*. Vol. 17, No. 4 (2002). p.458.
[32] Watson, Nick. "Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person: Identity and disability". *Disability & Society*. Vol. 17, No. 5, (2002). p.514; p.522.; p525.
[33] Linton, Simi. *Claiming disability : knowledge and identity* (New York: New York University Press, 1998). p.5.
[34] Evans. "Political intersectionality and disability activism"., p.990.

Scholarship around 'intersectionality' as a formalised concept is newer than 'identity', only coined by Kimberlee Crenshaw in 1989.[35] That, however, is not to denounce the rich history of intersectional thinking before the academic term. The notion of multiple levels of exclusion and oppression was developed in Black feminist spaces, emerging as a direct critique of singular-identity-based movements and thinking. Anna J Cooper's remarks in her 1892 *Voice from the South* and Sojourner Truth's 1851 polemic "Ain't I a woman?" are marked examples.[36] Building on centuries of critique, Crenshaw spoke initially to the Black female experience and described the experiences of those who fell between the gaps of the discrete categorisations of identity politics. In her own words, the concept of intersectionality establishes 'that many of the experiences Black women face are not subsumed within the traditional boundaries of race or gender discrimination as these boundaries are currently understood, and that the intersection of racism and sexism factors into Black women's lives in ways that cannot be captured wholly by looking at the race or gender dimensions of those experiences separately.'[37]

Understanding expands beyond the experience of Black women. Erevelles and Minear's (2010) article, for example, formatively brought disability into academic theorisation around intersectionality that had been previously forgotten.[38] Indeed, a growing literature has also been produced that deems ableism to be a manifestation of the same oppressive structural

[35] Crenshaw, Kimberle. "Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics." *University of Chicago Legal Forum*. Vol. 1, No.8 (1989). p.140.

[36] Cooper, Anna, *Voice from the South: By a Black Woman of the South* (1892), pp.139-140.; Strolovitch, Dara Z. *Affirmative Advocacy: Race, Class, and Gender in Interest Group Politics*. 1st ed. Chicago: University of Chicago Press, 2007., p.57.

[37] Crenshaw, Kimberle. "Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color". *Stanford Law Review*. Vol. 43, No. 6 (1991).p.1244. - **Moya Bailey went on to coin the term 'Misoynoir' in 2008 to explicitly represent this experience** (Bailey, Moya. *Misogynoir Transformed: Black Women's Digital Resistance*. (New York, USA: New York University Press, 2021.), p.1.)

[38] Erevelles, N and A. Minear. (2010). Unspeakable offenses: Untangling race and disability in discourses of intersectionality. *Journal of Literary & Cultural Disability Studies*, Vol. 4, No.2, (2010). p.127-146.

forces that marginalise groups that are also 'Othered'. Goodley (2014) notes 'crip theory' as 'catalysed' by [t]he work of Robert McRuer (2006)' to be an early connection of specifically queer and disability activism for this very reason[39] and associates ableism more broadly with a wider system of neoliberal capitalism.[40]

Intersectionality, as Gordon (2016) asserts, 'has come to signal both a new militancy and a challenge to single-issue, single-factor analyses' and movement constructions.[41] All have struggled to fulfil Townsend-Bell (2011)'s conceptualisation of intersectional praxis, needing both 'the recognition of interlocking oppression' (necessary but on its own leads to tokenistic intersectional activism) and 'the representation of those locating at the intersection of those oppressions'.[42] Movement fragmentation on the basis of strong sub-group affiliations, often grounded in those at intersectional boundaries, such as the place of trans-women within the women's movement, is regularly documented '(Adams 1989; Coles 1999; Echols 1989; Flesher Fominaya 2007b; Gamson 1995; Lichterman 1995; Snow 2001; Taylor and Whittier 1992)'.[43]

Sweeping intersectional analysis in regard to the mainstream DRM has been so far limited. Most examples from a disability studies angle are those starting to critique the movement from the specific perspective of Black exclusion. Erkulwater's 2018 article 'How the Nation's Largest Minority Became White' is particularly significant, as is Sami Schalk's

[39] Goodley, Dan,. *Dis/Abilty Studies: Theorising disablism and ableism* (Routledge: Oxon, 2014). p.38.
[40] Ibid. p.36.
[41] Gordon, Linda. "'Intersectionality', Socialist Feminism and Contemporary Activism: Musings by a Second-Wave Socialist Feminist". *Gender & History,* Vol. 28 No.2 (August 2016). p.340.
[42] Montoya. "Intersectionality and social movements: Intersectional challenges and imperatives in the study of social movements".p.7.
[43] Fominaya, Cristina. "Collective Identity in Social Movements". p.398.

2022 book *Black Disability Politics.* Indeed, disability studies as a practice have been challenged as a 'field of inquiry wherein individuals of color are treated as second-class citizens'[44] by Chris Bell (2006), and such criticism has given rise to the emergence of Disability Critical Race Theory.[45] This has no exclusive focus on the DRM but brings light to exclusionary practices that pervade the academic-activist divide. While in far smaller quantities, influential articles have been written on at the intersection and 'intersectional invisibility' of the LGBTQ+- Disabled experience[46] and feminist- disability theory dialogues are also present in the literature.[47]

Identity and Intersectionality in the DRM

Reference to disability in work explicitly regarding identity and intersectionality in social movements is also shockingly scant. Larger review articles such as Silke Rith's 2021 article 'Intersectionality and coalitions in social movement research—A survey and outlook' simply miss out discussions of the DRM altogether.[48] Almeida's *Social Movements,* a sweeping seminal work in the field, mentions 'disability' a total of four times in its 234 pages, in comparison to 'women' which is mentioned nearly 100. Unsurprisingly, analysis of the role

[44] Bell, Chris. "Introducing White Disability Studies: A Modest Proposal." In *The Disability Studies Reader*, edited by Lennard J. Davis, 2nd ed. New York: Routledge, 2006., p.281.
[45] Bank, Joy, Phillandra Smith, and D'Arcee Charington Neal. "Identity Politics: Exploring DisCrit's Potential to Empower Activism and Collective Resistance." In *DisCrit Expanded: Reverberations, Ruptures, and Inquiries*, edited by Subini A. Annamma, Beth A. Ferri, and David J. Connor, 202-218. New York: Teachers College Press, 2022.
[46] Egner, Justine E.(2021) "Being LGBTQ+ and Disabled, a Socially Contradicting Experience". In *The Oxford Handbook of the Sociology of Disability* edited by Robyn Lewis Brown (ed.), Michelle Maroto (ed.), David Pettinicchio (ed.) , pp.583.-608 (Oxford: Oxford University Press, 2021).

[47] Conejo. "At The Intersection Of Feminist And Disability Rights Movements."; Garland-Thomson, R. (2002). Integrating disability, transforming feminist theory. NWSA Journal, 14(3), 1 32.; Sheldon, Alison. (1999). Personal and perplexing: Feminist disability politics evaluated. Disability & Society, 14, 643–657.

[48] Roth, Silke. "Intersectionality and coalitions in social movement research—A survey and outlook". *Sociology Compass* (2021). https://doi.org/10.1111/soc4.12885 (accessed 15/04/2024). p.3.

identity plays in broad intersectional praxis of the mainstream US disability rights activism is hence wanting and where this thesis hopes to fill a gap.

The interaction between disability identity and intersectionality and the exclusionary nature regarding the former, however, does appear at several points in the existing literature, even if not the titular focus. Most notably, Elizabeth Evans' 2022 article, 'Political intersectionality and disability activism: Approaching and understanding difference and unity,' focusing on the UK movement, speaks at length on the issue. It is asserted within the wider remit of the paper that 'the emphasis […] on unity achieved through a disabled identity' in the movement and 'the desire to assert [… this] idea has meant those located at the interstices of disability, race, gender and class have often found themselves marginalised […]'.[49] Hiraide and Evans' (2023) article makes extremely similar conclusions.[50] This phenomenon of exclusionary practices premised on unified identity is indeed also discussed by Dan Goodley in his book *Dis/Abilty Studies: Theorising disablism and ableism* (2014). [51] Akemi Nishida, who studied how intersectionality impacted people with disabilities' political identity development, has equally described a hierarchical culture.[52] Conejo's chapter in *Disability and Intersecting Statuses* further deserves mention for its explicit discussion on how the DRM has 'emphasized unity rather than diversity, downplaying differences […] in order to generate a common front based on a single shared identity'. This was deemed to be 'crucial' for the disabled people's movement because '[i]n contrast with other oppressed groups, it comprises

[49] Evans. "Political intersectionality and disability activism". pp.990-1.

[50] Hiraide, Lydia Ayame and Elizabeth Evans. "Intersectionality and social movements: a comparison of environmentalist and disability rights movements". *Social Movement Studies*. (Jul 2023), p.8.
[51] Goodley. *Dis/Abilty Studies.* p.36.
[52] Nishida, Akemi. "Understanding political development through an intersectionality framework: Life stories of disability activists". *Disability Studies Quarterly.* Vol. 36, No.2 (2016).

a much dispersed identity'.[53] An older article, Ayesha Vernon's seminal article 'The Dialectics Of Multiple Identities And The Disabled People's Movement' also demonstrated an initial challenge to 'social model [… disability activists] for marginalising those experiencing simultaneous oppression, '[…driven by] an overwhelming desire to proclaim commonality in the experience of disablement'.[54] This thesis hopes to build on these theoretical foundations and forge new ground by focusing solely on the impact disability identity has on intersectional praxis in the mainstream US DRM.

2.2 BOUNDARY SETTING: SOME DEFINITIONS

With an awareness of the conceptual debates in the literature, this thesis takes the following positions on key terminology:

The thesis is centred on the 'mainstream' US-based **disability rights movement (DRM)** and established organisations affiliated with disability rights advocacy. Those within the DRM, - as set out by Scotch (1989) - are people or groups which have a 'rights issues orientation' and participate 'in in the identifiable disability rights movement network'[55] which grew out of the legislative-based action in the 1970s. The definition is intentionally broad and does not

[53] Barnartt, Sharon N and Altman, Barbara, Disability and Intersecting Statuses (Bingley: Emerald Group Publishing Limited, 2013), p.38.

[54] Vernon. "The Dialectics Of Multiple Identities And The Disabled People's Movement"., p.390.
[55] Scotch, Richard. "Politics and Policy in the History of the Disability Rights Movement". p.384.

mandate the need for a Disability Rights Group (**DRO)**[56] to be **DPO**.[57] Focus has not been placed on newer iterations of disability rights specifically disability justice groups such as Sins Invalid, that, as seen, have limited influence on the more traditional movement organisations.

Identity, and as such terms including but not limited to ‘disability’, ‘gender’, ‘religion’ and ‘race’ are understood in large part to be self-defined, informed at all times by current sociopolitical norms present in the United States. **Disability** is theorised through the guise of the social model (and the minority/ human rights model taken to be subsidiary to the social model)[58] and id defined as ‘a system in which people with impairments (whether physical, mental, cognitive, developmental or intellectual) experience discrimination and stigma’.[59] While there is not the capacity to debate the politics of identity-first language, the decision has been made to use Disabled with a capital ‘D’, in line with a variety of activists.[60]

The focus of the analysis is on movement and movement-organisational **intersectional praxis**. Taking into account numerous scholars' own definitions, intersectional praxis will here be defined to have two elements.[61]

[56] Disability Rights Group- any group involved with formalised and mainstream disability rights advocacy
[57] Disabled People’s Organisaton: a group where over 50% of the board, staff, and membership identify as Disabled (Enns, Henry. "The Role of Organizations of Disabled People: A DPI Discussion Paper." *Independent Living Institute.* https://www.independentliving.org/docs5/RoleofOrgDisPeople.html. (accessed 13/12/2024)
[58] Teti, David and Salem Lorot. *Disability: Law and Rights.* (Nairobi: Sparrow Press Limited, 2017). p.18.; Scotch, Richard and Kara Sutton. “The Disability Rights Movement”. In *The Oxford Handbook of the Sociology of Disability*, edited by Robyn Lewis Brown (ed.), Michelle Maroto (ed.), David Pettinicchio (ed.) pp.790-806. (Oxford: Oxford University Press, 2021)., p.793.

[59] Evans. “Political intersectionality and disability activism”.
[60] Brown, Lydia. “The Significance of Semantics: Person-First Language: Why It Matters”, *AUTISTIC HOYA* (Aug. 4, 2011), https://www.autistichoya.com/2011/08/significance-of-semantics-person-first.html (accessed 27/12/2024)
[61] Strolovitch, Dara Z. *Affirmative Advocacy.*, pp.27-8.; Montoya. “Intersectionality and social movements: Intersectional challenges and imperatives in the study of social movements”., p.7-8.; Cole, Elizabeth, ‘Beyond Identity: Intersectionality and Power’. In *The Palgrave Handbook of Power, Gender, and Psychology* edited by Eileen L. Zurbriggen and Rose

1. The first is descriptive, with a group acknowledging systemic and interrelated issues to oppression and having representation of historically multiply marginalised voices.
2. The second is action based, with a group embodying values and practices that take forward everyone within a movement, uplifting those with experiences of intersectional oppression. Identities are acknowledged as coalitions and active coalition building internally and externally is practiced.

In light of the second parameter, it is further attested here that intersectionality and identity-based social movements are not inherently adversarial when it can be acknowledged that collective identity, in the words of Hill Collins and Bilge (2016), is manufactured; 'strategically essentialist' and 'inherently coalitional'.[62] Identity-based movements have the potential, as asserted by Hobson (2016), to be 'continually remade' [63] as interior coalitions that encompass all potential movement actors.

2.3 METHODOLOGY

In investigating the relationship between the nature of identity cultivation and intersectional praxis in the US DRM, this thesis used a triangulation of data retrieval and a mixed-methods

Capdevila (Palgrave Macmillan Cham, 2023); Getova, Simona, and Christos Zografos. "Intersectional Praxis for Social-Ecological Transformations: Lessons from North Macedonia's Grassroots Green Deal." *Political Geography* 113 (2024).

[62] Hill Collins and Bilge. *Intersectionality*. pp.133-4.
[63] Hobson, Emily K. *Lavender and Red: Liberation and Solidarity in the Gay and Lesbian Left*. (Oakland: University of California Press, 2016)., p.199.

historical-sociological approach to analysis. In terms of data collection, eight semi-structured interviews with US movement activists, an online survey- with 65 participants- and oral history archives were used. Ten disability rights organisations' websites were also examined as supplementary information. The principles for 'good qualitative research' as set out by Rogers (2003), were adhered to throughout.[64]

Interviews

The eight interviewees were all disability rights activists, the vast majority leaders of organisations, based in and around New York. With the focus of the thesis largely being on established movement actors' perspectives on identity and intersectional praxis, interviewees were sought who had experience and formal association with DROs. Their geographical location largely derived from practical concerns, although New York has been a historic hub of the DRM ever since Judy Heumann established Disabled In Action in 1970. Interviewees were contacted through utilising my own network and then snowball sampling, and as such, there is undoubtedly a personal element to the research.[65] My personal identity as a white- otherwise privileged Disabled woman. not only informed my own biases but shaped who I contacted, who responded and how interviewees responded to my questions during interviews.[66] As a non-American, my views of identity and specifically disability identity are also inherently informed by slightly different parameters, most notably specific

[64] Rogers, Annie, G. "Qualitative Research In Psychology: Teaching An Interpretive Process". In *Up close and personal: The teaching and learning of narrative research,* edited by Ruthellen Josselson, Amia, Lieblich, and Dan P McAdams, pp.49-60. (Washington D.C.: American Psychological Association, 2003). pp.58-9.
[65] Ibid., p.55.
[66] Inckle, Kay., James Brighton, and Andrew Sparkes. "Who is "Us" in "Nothing About Us Without US"? Rethinking the Politics of Disability Research." *Disability Studies Quarterly*, Vol. *42*, No. 3-4. (2023).

understandings of the social and minority models of disability and that awareness was needed throughout.[67]

Interviews were semi-structured and have been kept confidential, following general methodological principles.[68]

Survey

The survey was aimed at anyone over the age of 18 living in the United States. The hope was to potentially gain further qualitative and quantitative insights from Disablerd and non-disabled participants who were (a) in the movement but not in positions of leadership; (b) adjacent to the movement and (c) true outsiders.

Due to capacity limitations on a scope as large as the US DRM, convenience sampling was utilised. Surveys were distributed using online social media platforms and posters with a QR code placed around Columbia campus. In so doing, respondents reflected people who inhabited my spaces online and physically: the self-attributed demographics of participants swayed heavily towards a younger college-educated crowd of women and these identities are pertinent when using the data as a collective.

[67] Scotch, and Sutton. "The Disability Rights Movement". pp.793.
[68] Bryman, Alan, "Interviewing in Qualitative Research". In *Social Research Methods*, 2nd ed. (Oxford: Oxford University Press, 2004). p.472.

A crip-based approach[69] was at the heart of the survey and an alternative following Easy Read principles was provided.[70] The layout of the questions intentionally allowed for self-definition, rejecting box-ticking, and this enabled self-description of identities in the multiple, in line with the intersectional outlook of the paper and reflecting upon previous failings of quantitative data as noted by Settles and Buchanan.[71] A significant decision was made to use terms around representation and inclusion as opposed to intersectionality when reflecting on the DRM's current practises and beliefs. This was done to ensure accessibility and not isolate those who did understand the term. In so doing, accuracy was inevitably lost.

Oral History Archives

The oral history interviews used primarily came from the Disability Rights and Independent Living Movement oral history collection at the Bancroft Library and the 'Patient No More: People With Disabilities Securing Civil Rights exhibit created by Paul K Longmore Institute on Disability. Fred Pelka's book 'What Have We Done: An Oral History of the Disability Rights Movement' is also a useful addition, Pelka himself drawing on the latter two sources alongside his own interviews[72] although his own significant influence as the compiler and author of the book was noted and integrated into historical analysis.

[69] Jillian Pearsall-Jones, Caris Jalla and George Hayden. 'Human Doing vs Human Being'. In Looking towards the Future. Vol. 2 of Interdisciplinary Approaches to Disability Studies. Edited by Katie Ellis, Rosemarie Garland-Thomson, Mike Kent, and Rachel Robertson, 131–141. New York: Routledge, 2018., p.135.
[70] Australian Government. "Style Manual: Easy Read". Available at: Easy Read | Style Manual (accessed 17/04/2024)

[71] Settles, Isis and Nicole T. Buchanan. "Multiple Groups, Multiple Identities, and Intersectionality". In *The Oxford Handbook of Multicultural Identity* edited by Verónica Benet-Martínez and Ying-yi Hong (Oxford University Press, 2014). p.163.

[72] Pelka, Fred. *What Have We Done: An Oral History of the Disability Rights Movement* (University of Massachusetts Press, 2011). p.x.

Websites

The network of disability rights organisations throughout the US is vast, and as such, apart from a couple of key national NGOs including ADAPT, the National Council on Independent Living and the National Disability Rights Network, the groups were prominent disability advocacy organisations in the New York area.

There is an awareness that nascent grassroots organisations are unlikely to have the capacity for websites, and as such, the focus- as consistent with the research overall- veers towards established activism organisations.

Analysis

The vast majority of the data was analysed using a thematic qualitative approach, categorisation and coding was utilised for the interview transcripts and also in the case of the survey responses. *ATLAS.ti-*[73] was used to supplement personal analysis of the survey questions. In line with intersectional analysis, significance was not unduly placed on comments simply due to their quantity of occurrence.

Very basic quantitative techniques were used for the numerical answer questions to the survey. 65 respondees- in the context of the US population as a whole- was far too low to allow for a more complex analysis with the chance of establishing statistical significance. As

[73] An online qualitative analysis site

such, averages will be seen as part of contextualising qualitative data as opposed to standing on its own.

3 CHAPTER 1: THE STATE OF INTERSECTIONAL PRAXIS IN THE US DISABILITY RIGHTS MOVEMENT

The mainstream US DRM and pertaining organisations fall significantly short of embodying intersectional praxis. While efforts to increase diversity in membership and acknowledgement of intersectional principles demonstrate steps in the right direction, it is abundantly clear those with cross-cutting marginalised identities- and the issues they represent- have not been actively included or heard. This is evidenced in the interviews with activists, website analysis, and survey responses, further corroborated by wider scholarship.

3.1 THE DESIRE TO BE SEEN AS AN INTERSECTIONAL MOVEMENT

It is very clear that those internal to the movement have a desire for their activism to be at least externally perceived as diverse, inclusive and intersectional. Within the context of civil and human rights that have orientated such campaigns, this stance is entirely logical. The CRPD's establishment of intersectional principles made clear the international standard, even pertaining to the American movement, which was unaffected by its legislation.[74]

Awareness of intersectionality as a concept and the external pressure for its principles to be realised is the first step in praxis. To this end, every interviewee asked about intersectionality (7/8) and every person who claimed to be formally involved in the movement in the survey were (a) familiar with the term; and (b) largely aware of its importance. Interviewee 6 (I6)[75],

[74] Preface paragraph (p) - United Nations. "Convention on the Rights of Persons with Disabilities." Accessed December 4, 2024. https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities.
[75] I shall refer to Interviewees with a capital I and then their distinguishing number of 1-8 for clarity and conciseness

for example, a female Black Disabled activist, explained the logic behind the need for intersectional praxis:

> *"You know you can be disabled, Black, LGBTQIA and all of that. So we need to have a society that* […] *is aware of the various identities that we have and not exclude us because we are this or we are not that, and so on and so forth."*

Evans' 2022 paper points out those with multiply oppressed identities[76]- as with I6- are most likely to be aware of the need of intersectional praxis but I2, I3, I4 and I8 also held similar sentiments on intersectionality's weight. I4 further made the point that there was a growing trend "among advocates [… to] try[…] to be more aware of intersectionality". I8 even went on to underline that these principles were being actioned in her organisation:

> *" it's recognized and spoken about, because we want to make sure that we are representing the needs of everyone. […] we targeted, we kept statistics of the various groups that we serve"*

On organizational websites, the need to at least break down and analyse representation is prevalent: 7/10 gave some space to discuss participation shaped by differing identities in the movement either in statistical terms or through expressed aims.

[76] Evans. "Political intersectionality and disability activism"., p.994.

3.2 FROM DENIAL TO DENOUNCEMENT: INTERSECTIONAL PRAXIS LACKING

However, even within the assertions of interviewees – the vast majority holding positions in established disability advocacy organisations- their comments consistently revealed a clear trend towards a lack of true intersectional praxis.

Of perhaps most concern, I1 revealed a mixture of denial and apathy towards measures of inclusion. While asserting when pushed that the organisation she leads is inclusive, notably one of the forerunner groups in disability activism, and providing panicked assurances, her initial responses were revealing. Answering on potential tensions around gender and LGBTQ+ issues, she eluded to a culture of, at best, disinterest and, at worst, repression.

> *"it doesn't really come up like, you know, your love life. […] If people are upset about it. They don't say anything about it. […] and I, I really don't care. And I can't always, […] remember what everybody's preference is, […] it doesn't seem to matter, […] because we're talking about […] civil rights for people with disabilities, and we're talking about big issues and not little ones."*

It is evident in this statement that no active steps are made to make those activists who may be part of the LGBTQ+ community welcome or their issues heard- clearly falling short of any theorisations of intersectional praxis. Furthermore, these concerns of minority identities are demarcated as secondary or "little" issues in comparison to concerns exclusively surrounding disability. These sentiments are carried to more general comments around intersectional praxis:

> *"as far as intersectional [issues …] I don't remember anybody complaining about it or mentioning it […] in our organisation. I don't know if people are feeling that way […]"*

Less extreme than this evident desire to enshroud intersectional concerns, I8 demonstrated a lack of rigour in assessing intersectional praxis in his own organisation. Initially claiming intersectional principles had "become pretty normalised" within the movement, it transpired that his NGO had "no African Americans on [the] staff or on [… the] board". It was admitted this was "a real problem" and there had been a lack of effort to push for multiply marginalised voices: "we have not done as much as we should". This speaks to an established practice, paralleling findings made by Evans in a UK context, of NGOs paying 'lip service' to intersectional approaches without truly analysing or integrating said principles. [77]

The other interviewees did not present such overt dismissal of intersectional concerns. However, even when interviewees seemed aware of the issues, it was also made clear that the realisation of praxis was incomplete in their own organisations. Of the other six participants, four made explicit cases for the paucity of the diversity and inclusion of multiply marginalised people and their issues. I4 explicated that although "there's a growing shift in an effort to try and be more inclusive", "for too long, the movement leaders have been white and not intersectional". I5 detailed concerns around representation within the movement, asserting that the movement was not representative of the community at large, referencing

[77] Evans. "Political intersectionality and disability activism"., p.994.

that “last year was the first time I saw people that didn't identify as their sex” at the “grassroots organisation” she is a member of since she was 19.

These thoughts are consistent in the survey, particularly those who share multiply marginalised identities. One movement member who identified as being “disabled […] transgender, bisexual, and from a low income family” stated:

> *“Many Disability Rights Organizations […] tend to focus on cisgender white men and boys, disregarding transgender/gender non-conforming individuals, women, and BIPOC, especially those that are adults.”*

Similarly, another movement member- “a multiply disabled queer person” - established that:

> *“Disability rights organizations do a terrible job of protecting the rights of people with multiple disabilities and intersectional axes of oppression, for example Deafblind people or LGBT people of color.”*

Having those with intersectional minority identities speak out on Disabled activism and their lived experiences is particularly poignant, providing the most condemning conclusions for the movement’s norms.

Additionally, survey responses corroborate these determinations on the lack of intersectional praxis. When participants were asked about how inclusive they thought DROs and subsequent movement were, the mean averages across the board came out at 5.9 and 6.6 out

of 10 respectively (1 delineated “not at all” and 10 “completely”). Neither indicates a complete denunciation of the movement, but both equally do not demonstrate faith in inclusive practices. Importantly, this number was lower when specifically looking to Disabled participants with multiply marginalised identities.

The ten organisational websites further substantiate a picture of a movement with a long way to go. A synopsis indicates that intersectional praxis is not at the heart of the movement, even in its visual exterior: inevitably a cultivated reality aimed at aligning with aspirational standards. Only one of the ten websites , the NCIL,[78] makes an explicit pledge within their mission and values of acknowledging and counteracting intersectional oppression within the Disabled community.[79] This is indicated to be a sharp diversion from the group’s previous attitudes and actions.[80] Other references almost exclusively focus on representation or demographic breakdowns, without any suggestion these DROs embody active intersectional praxis. The CIDNY[81], mentions diversity almost as a laundry list exercise, stating that those in the group “speak 13 different languages” before continuing they “have various racial and ethnic identities, educational and work backgrounds, belong to different faith communities, and are LGBTQ inclusive.”[82] The only other example of productive measures made toward counteracting intersectional exclusion came from DRNY[83], who’s 2023 annual report discussed the establishment of a Committee on Advancing Racial Equity. Nothing is

[78] National Council of Independent Living
[79] National Council on Independent Living. "NCIL Guiding Principles." Accessed December 4, 2024. https://ncil.org/about/ncil-guiding-principles/.
[80] In the National Council on Independent Living. "2022-2023 Final Annual Report." Accessed December 4, 2024. - the ```new executive director stated that: “Acknowledging that past mistakes have been made, NCIL is actively committed to rectifying our history by ensuring that all voices from diverse groups and identities are both included and heard.”
[81] Center for Independence of the Disabled, New York
[82] Center for Independence of the Disabled, NY. "CIDNY 2022-23 Annual Report." https://www.cidny.org/wp-content/uploads/2024/03/CIDNY-2022-23-Annual-Report.pdf. (accessed 04/12/2024). p.4.
[83] Disability Rights New York

mentioned, however, on plans to uplift others who are multiply marginalised beyond race and disability (the focus on race is hypothesised to come from the direct external pressure of the 2020 BLM[84] protests).[85] The complete lack of acknowledgement from three organisations- prime movers in disability rights activism – is even more concerning. [86] Content analysis of these websites hence parallels what can be understood from the interviews and surveys. The DRM is largely aware of an issue with intersectional praxis and has taken initial steps, but is far from embodying practices that would make it truly intersectional.

The findings also accurately reflect what has been discussed in broader scholarship. Evans', 2022 and 2023 papers, align closely with the findings here, although perhaps the conclusions are more severe in terms of the lack of even intersectional discourse in the context of UK DROs.[87] Nishida's (2016) study, using expert testimonies from seven US-based disability rights activists, also noted an underlying culture of exclusion with a focus on single-axis disability issues.[88] Mulderink (2020)'s paper on the #DisabilityTooWhite has almost identical conclusions.[89]

[84] Black Lives Matter
[85] This was hypothesis by Evans (2022) in the context of the UK- Evans. "Political intersectionality and disability activism"., p.998.
[86] Disability Rights Advocates. "Advancing Equal Rights for People with All Types of Disabilities Nationwide." https://dralegal.org/ (accessed 04/12/2024) ; Center for Disability Rights. "Vision & Mission." https://cdrnys.org/about/vision-mission/.(accessed 04/12/2024) ; Disabled In Action of Metropolitan New York. "Nothing about us, without us!" Disabled In Action of Metropolitan New York. https://www.disabledinaction.org/. (accessed 06/01/2025)

[87] Hiraide and Evans. "Intersectionality and social movements". p.2.

[88] Nishida. "Understanding political development through an intersectionality framework".
[89] Mulderink, Carrie Elizabeth. "The Emergence, Importance of #DisabilityTooWhite Hashtag." *Disability Studies Quarterly*. Vol. 40 No. 2 (2020).

3.3 A DISCONNECT WITH DISABILITY JUSTICE

Disability Justice (DJ) – a splinter movement established in the Bay Area in 2005 [90]- is the most manifest evidence of the mainstream US DRM's intersectional failings. Sins Invalid, a leading DJ organisation, propounded in their 2016 mission statement that mainstream DROs are 'based in a single- issue identity, focusing exclusively on disability at the expense of other intersections […]'[91]

This research hypothesised that while mainstream activists have not truly integrated its teachings, discernible in the growing strength of DJ organisations and actors, the breakaway movement served at least as a point of accountability and introspection.[92] This paper however, found a complete lack of awareness of DJ's existence among its expert interviewees. Of the six activists asked, only one had heard of the term and subsequent critiques. The ignorance to the prevalent condemnation emanating from prevalent Disability Justice activists about their own groups[93] reveals a leadership further away from embracing intersectional praxis than expected with a clear lack of external engagement even within the disability community.

[90] Mattlin, Ben. *Disability Pride: Dispatches From A Post Ada World* (Boston: Beacon Press, 2023), p.74.

[91] Sins Invalid., *Skin, Tooth, and Bone: The Basis of Movement is Our People* (2nd ed.) (2019), p.13.

[92] Evans. "Political intersectionality and disability activism".,p.989.

[93] Piepzna-Samarasinha, Leah Lakshmi. *Care Work: Dreaming Disability Justice* (Arsenal Pulp Press, 2018). pp.209-210.

3.4 LEADERSHIP DEMOGRAPHICS: WHITE WOMEN IN WHEELCHAIRS

The demographics of the expert interviewees reveals the privilege inherent in the movement. Four of the eight did not identify as Disabled themselves, an insight into a larger problem of Disabled representation in the DRM.[94] All were university-educated; the majority identified as white; none affiliated with religion outside of Western Judeo-Christian norms; only one interviewee detailed identifying as part of the LGBTQ+ community. The notion that descriptive representation correlates with substantive representation has been rightly challenged,[95] but the severe lack of minority voices in established positions of power is a symptom of an endemic problem.

Where there is a clear disconnect regarding privilege is on the basis of gender. 7/8 interviewees identified as women. Over 90% of the survey respondents did not identify as men. The CIDNY 2023 annual report stated that 70% of their staff were female.[96] These do not represent random anomalies. As established by I2, "the global disability rights community, we've had amazingly strong women." This pattern is deep-rooted and referenced consistently throughout the oral history interviews. Judy Heumann,[97] pronounced during her series for the Longmore Institute that "[t]he disability movement has always been dominated

[94] Alexiou, Gus. "Are Disability Charities Excluding Disabled People From Leadership Roles?" *Forbes*. December 22, 2024. https://www.forbes.com/sites/gusalexiou/2024/12/22/are-disability-charities-excluding-disabled-people-from-leadership-roles/. (accessed 02/01/2025)

[95] Mansbridge, Jane. "Should Blacks Represent Blacks and Women Represent Women? A Contingent 'Yes'." *The Journal of Politics*, Vol. 61, no. 3 (August 1999)., p.630.

[96] Center for Independence of the Disabled, NY. "CIDNY 2022-23 Annual Report."

[97] Known as "the mother of the DRM"

by women".[98] This is substantiated by other accounts by activists.[99] Such female-dominated leadership continues to defy patterns in single-identity-based collective action where governance has derived almost exclusively from positions of traditional privilege aside from the identity in question.[100]

However, such findings must be contextualised by comprehensive intersectional analysis. In Mary Lou Breslin's words, the historical trend that seemingly survives is of "leadership [which] definitely was not diverse" but instead "white women in wheelchairs".[101] Women holding positions of power creates interesting nuance to movement identity and power dynamics but -importantly- should not be viewed as an indication of comprehensive or active intersectional praxis.

As such, the DRM, at times ignorant, at times in denial and at times making first initial steps, is far away from any goal of embodying intersectional praxis widely throughout its organisations, leadership, culture and actions.

---

[98] Heumann, Judy. "Disability Activist Judy Heumann on being one of the key leaders of the Section 504 Protest". Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: Disability Activist Judy Heumann on being one of the key leaders of the Section 504 Protest - Paul K. Longmore Institute on Disability Collection (sfsu.edu) (accessed on 09/12/2024)

[99] D'Lil, Hollynn. "Disability Rights activist HolLynn D'Lil on her experience as a 1977 Section 504 Occupation photographer and protestor". Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: Disability Rights activist HolLynn D'Lil on her experience as a 1977 Section 504 Occupation photographer and protestor - Paul K. Longmore Institute on Disability Collection (sfsu.edu) (accessed on 09/12/2024); Cone, Kitty. "Disability Rights activist Kitty Cone on the 1977 Section 504 Occupation". Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: Disability Rights activist Kitty Cone on the 1977 Section 504 Occupation - Paul K. Longmore Institute on Disability Collection (sfsu.edu) (accessed on 09/12/2024). pp.82-4.

[100] Bello, Barbara Giovanna. "Intersectional Perspectives on Social Movements." *Global Dialogue*, October 9, 2022. https://globaldialogue.isa-sociology.org/articles/intersectional-perspectives-on-social-movements. (accessed 02/01/2025)

[101] Breslin, Mary Lou. "Disability Rights activist Mary Lou Breslin on her participation in the Section 504 protests". Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: Disability Rights activist Mary Lou Breslin on her participation in the Section 504 protests - Paul K. Longmore Institute on Disability Collection (sfsu.edu) (accessed on 09/12/2024)

4 CHAPTER 2: THE WEAK FOUNDATIONS OF DISABILITY AS A COLLECTIVE SOCIOPOLITICAL IDENTITY

Establishing the current deficiency of intersectional praxis in the DRM is concerning, although neither surprising nor unique in comparison to similar human rights-based forms of collective action.[102] Of greater significance are the particular internal and external mechanisms which have barred intersectional praxis' realisation and action by disability rights activists. These emanate from the weak foundations of the sociopolitical identity that the movement has hinged off since its inception. Indeed, there are two fundamental and interrelated strands at the base of disability identity that continue to disrupt its fruition. The first relates to its heterogeneity. There is no other identity grouping with such porous walls and a system of entry and reentry for anyone in the population at large, confusing and undermining a singular disability identity. The second pertains to the persistence of the medical model of disability which individualises, isolates, infantilises and most importantly, depoliticises the oppression of the disabled community, standing as an antagonistic disrupter of movement and individual identity and validity.

4.1 THE GENESIS OF DISABILITY AS A SOCIOPOLITICAL IDENTITY

"This was an era of the liberation movements all over the world. […] The disabled were ripe for becoming a liberation type of movement"[103]

[102] Luna, Zakiya. 'Truly a women of color organization'"., p.770. ; Gordon, Linda. "'Intersectionality', Socialist Feminism and Contemporary Activism". pp. 341; Strickland, Christopher. "The Fight for Equality Continues." *Phylon* 59, no. 1 (Summer 2022). p.75.

[103] Michael Fuss in Pelka. *What Have We Done*. p.211.

As the last of the major identity-based social movements of its era, the cultivators of the DRM actively followed the pattern of their forebearers in the hope of similar legitimacy and success. The heart of this was perceived to revolve around establishing a collective and cohesive identity, which could be legislatively protected and ensured rights and freedoms.[104]

There is consistency among almost all the accounts of major disability rights proponents in being directly influenced by, if not involved with, activism in the 60s. Kitty Cone was a member of the NAACP at the University of Illinois[105], Judy Heumann was actively involved in student politics including action against Vietnam, and Ed 'Roberts watched and learned from the civil rights movement and the nascent women's movement' at Berkley.[106] These, without a doubt, directly inspired what disability rights activism became. HolLynn D'Lil, an activist in the '77 sit-ins, candidly reflected when interviewed that disability advocates "were the tail-end of many civil rights movements for minorities […] and […] they set the pattern for us"[107] Their use of mirroring other forms of civil rights based collective action for nascent movement legitimacy is manifest in the archives. Ed Roberts, by 1974, when heading CIL Berkley, had 'started talking explicitly of disability being a civil rights issue' akin to African American calls for justice and equality.[108] Kitty Cone highlighted during her discussion on

[104] Watson. "Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person".p.524-5.

[105] Interview with Kitty Cone, 'Political Organizer for Disability Rights, 1970s-1990s, and Strategist for Section 504 Demonstrations, 1977,' conducted by David Landes in 1996-1998, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, (2000).Available at: Political Organizer for Disability Rights, 1970s-1990s, and Strategist for Section 504 Demonstrations, 1977 (cdlib.org) (accessed 24/01/2022), pp.25-6.

[106] Shapiro. *No Pity,* p.47.

[107] Interview with Hollynn D'Lil, 'Disability Rights activist HolLynn D'Lil on her experience as a 1977 Section 504 Occupation photographer and protestor', Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: Disability Rights activist HolLynn D'Lil on her experience as a 1977 Section 504 Occupation photographer and protestor - Paul K. Longmore Institute on Disability Collection (sfsu.edu) (accessed on 04/12/2024)

[108] Shapiro. *No Pity* , p.54.

the section 504 sit-ins that this method of protest was used as "a way of drawing the parallels between this issue and the civil rights movement of the sixties".[109]

Within this template, as Peters (1996) underlines, the DRM and its activists 'demanded unity and strength, derived from collective identities and promoted in the common experiences of oppression'.[110] The landscape, however, for creating a collective political identity was treacherous. While the movement desired a group with a collective political consciousness, they represented an incredibly heterogeneous population with disparate ties. Disability encompassed a spectrum from war veterans returning from Vietnam to a child growing up with dwarfism. Impairments varied in severity and visibility, and each had very little connection with familial or community ties and yet affected some 20% of the population.[111] The vast majority of Americans also acquire their disability,[112] and a variety of conditions are fluctuating, making disability an "open minority".[113] As historian Joseph Shapiro has pronounced, '[t]he disability rights movement spanned a splintered universe'.[114] Specific impairment groupings also represented very distinctive forms of collective action that had been established well before the 1970s and did not associate with larger cross-disability action. This included Deaf and Blind collectives emanating from the 19th and early 20th centuries, veteran-based activism and causes surrounding those with psychological impairments.[115] Activists were keenly aware of these internal divides. For example, Lee

[109] Pelka. *What Have We Done.* p.267.
[110] Peters, Susan. "The Politics Of Disability Identity". In *Disability And Society: Emerging Issues And Insights* edited by Len Barton, (London: Routledge, 1996) . p.215.
[111] Wong, Alice. *Disability Visibility : First-Person Stories from the Twenty-First Century* (Vintage Publishing, 2020). p.212. (the statistic has not fluctuated much since the 1970s)

[112] Tobin Siebers in Alcoff, Hames-García, Mohanty, Moya. *Identity Politics Reconsidered*., p.11.
[113] Pelka. *What Have We Done*. p.444.
[114] Shapiro. *No Pity.* p.126.
[115] Pelka. *What Have We Done.* p.258.; 284.

Kitchens,[116] spoke of the difference in such distinctive groupings in comparison to the civil rights movement:

> *But the difference was that the various handicapped groups were each out doing their own thing[…] and […] different handicapped groups were prejudiced against other handicapped groups […]"*[117]

Unique to this identity also was its sole contextualisation within a medical or charitable framework, which individualised Disabled Americans by treatment or institutionalisation, inspiring a mixture of pity and shame for those unable to eradicate or sufficiently mask their impairments .[118] Johnnie Lacy, a Black disability activist, discussed the desire she and others had to identify as anything other than Disabled – in contrast notably from other identities- during the '50s and '60s:

> *"[…] there was no disability group at that time, and every other disabled person I had ever met was in the same situation— they were trying to identify with something ethnic or some other thing. […] There wasn't a lot of disabled pride in those days […]"* [119]

Similar accounts are littered throughout oral history interviews of activists.[120] These innately negative medicalised attitudes percolated into the beliefs and actions of other forms of

[116] Founder of the Texas Coalition of Citizens with Disabilities
[117] Pelka. *What Have We Done.* p.154.
[118] Scotch, and Sutton. "The Disability Rights Movement"., p.791. ; Scotch, Richard. "Politics and Policy in the History of the Disability Rights Movement". p.385.
[119] Pelka. *What Have We Done.* p.352.
[120] Diane Coleman, director for advocacy at the Centre for Independent Living in Rochester, for example, also recalls that she dissociated with being Disabled during her childhood in the '60s: "[d]isability was bad—that's how I was raised. That part of you was bad."- Dianne Coleman in Pelka. *What Have We Done.* p.42.

collective action- both separate impairment movements, particularly the Blind and Deaf, and broader civil rights movements from Black activism and gay liberation were pivoted on establishing their own identities in rejection of the pathologisation associated with the Disabled label.[121] Taken in conjunction with the heterogeneity of experiences, the American Disabled population in the 1970s hence did not have any sense of a broad culture, community or 'group consciuousness', let alone a viable sociopolitical identity, as Shapiro notes. [122] Disabled American author Leonard Kriegel musings in a 1969 essay, "Uncle Tom and Tiny Tim: Some Reflections on the Cripple as Negro" summarise astutely the position of disability as an identity in the mid-20th century:

> *"He* [the Disabled person] *does not even possess the sense of being actively hated or feared by society, for society is merely made somewhat uncomfortable by his presence. […]; "The cripple's struggle to call himself I, which is, I take what we mean by a struggle for identity, is always with him."*[123]

Kriegel ends his paper with the suggestion that "the task of the cripple is to re-create a self".[124] Indeed, the nascent cross-DRM's primary objective was not only to push for greater equality legislatively but to deconstruct perceptions of disability from an unfortunate act of nature to a united class of discriminated people denied political and, more broadly, human rights.[125] The attack on medical theorisations and establishment of the social model of disability, therefore, went hand in hand with the advent of the movement. Coined by British

[121] Pelka. *What Have We Done.* p.10.; Kim E Nielsen. *A Disability History of the United States.* (Boston: Beacon Press, 2012). p.xix.
[122] Shapiro. *No Pity,* p.11.
[123] Kriegel, Leonard. "Uncle Tom And Tiny Tim: Some Reflections On The Cripple As Negro." *The American Scholar*. United Chapters of Phi Beta Kappa, 1969. Available at: disability history museum--"Uncle Tom And Tiny Tim: Some Reflections On The Cripple As Negro" (accessed 15/12/2024) , p.1; p.8.
[l]bid., p.8.
[125] Scotch, and Sutton. "The Disability Rights Movement"., p.792. ; Linton, Simi. *Claiming disability.* p.7.

activists 'in the context of their struggle against segregation and exclusion'[126] before being translated across the Atlantic, it recontextualised disability not as a plethora of conditions to be treated but as a socially produced phenomenon. In shifting the focus to societal wrongs, it was 'an explicitly political orientation that problematised the oppression of disabled people'.[127] The social model mandated disability to stand as a new political class and rested on the ability to cultivate a discrete and cohesive identity for the disability community. Kitty Cone[128] consciously explicated:

> *"[p]eople all over the country were not thinking of people with disabilities as an oppressed minority or a group deserving of civil rights; they were thinking of people with disabilities as […] people who were objects of charity, objects of pity, probably a group of people who were very weak. It just was not part of the public consciousness."*[129]

This new identity, particularly notable in the context of intersectional praxis, was cultivated by and hence shaped in the image of the original leadership of the movement: "white women in wheelchairs".[130] With a desire to follow the legislative success and state recognition of other single-identity based movements, disability identity was narrowly defined. In the context of these essentialist parameters, the identity was built with a lack of consideration of multi-dimensional oppressive forces. As Erkulwater (2018) notes, 'activists could not […] figure out how to incorporate minority voices in an identity-based movement forged around

[126] Aramayo , Burton , and Kagan, 'Revising and Using the Social Model in the Global South: A Venezuelan Exploration'.p.517.
[127] Ibid., p.518.
[128] A key leader and organiser in the 504 sit-ins
[129] Pelka. *What Have We Done*. p.267.
[130] Breslin, Mary Lou. "Disability Rights activist Mary Lou Breslin on her participation in the Section 504 protests".

disability rather than color.'.[131] Disability activists seem to have been increasingly aware of this. Corbett O'Toole[132], for instance, when interviewed in 2000 talked about activists treating disability identity as a monolithic entity, abiding largely to Western norms:

> *"*[…] *the disability community as a whole does not think we have a gender, does not think anyone has a race, […] there's sort of an assumption that we're talking about one type of person with an exact disability category. And usually it's a man and usually it's white, and it's rare that there's any deviation from that norm or from that perceived norm."*[133]

The 1992 National Council on Disability correspondingly observed "*a movement of the White majority. "*[134]

With the passing of the ADA in 1990, itself lacking intersectional parameters,[135] the initial wave of DRM undoubtedly reached its basic legislative goals, formally creating disability as a discriminated class. In broader society and within the movement, however, the collective sociopolitical identity created by the disability rights establishment was still plagued by its weak foundations. As Longmore acknowledged in 1995, the movement had to enter its 'second phase': this needed to focus on the more elusive and ultimately incomplete mission

[131] Erkulwater Jennifer, L. "How the Nation's Largest Minority Became White: Race Politics and the Disability Rights Movement, 1970–1980." *Journal of Policy History*. Vol. 30, No.3, (2018). p.365.
[132] Cofounder of the Disabled Woman's Coalition
[133] O'Toole, Corbett. "Advocate for Disabled Women's Rights and Health Issues". Interview conducted by Denise Sherer Jacobson in 1998, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, (2000). Available at: Advocate for Disabled Women's Rights and Health Issues (cdlib.org) (accessed on 09/12/2024)
[134] Wright, Tennyson J. and Paul Leung, "Minorities with Disabilities: An Introduction," in *The Unique Needs of Minorities with Disabilities: Setting an Agenda for the Future, Conference Proceedings*, edited by Wright and Leung, The National Council on Disability and Jackson State University, cosponsors, May 6–7, 1992. .p.2
[135] Chin, Natalie M. "Centering Disability Justice." *Syracuse Law Review* 71, no. 683 (2021). p.691.

of ‘creat[ing] a disability culture’ and concomitantly collective disability identity. [136] Thirty years on, and disability identity as a sociopolitical force remains as precarious as ever.

4.2 UNSTABLE FOUNDATIONS PERSIST

The dynamics prevalent in the 1970s have not changed much in the last half a century: disability identity begot by the movement still rests on unsolidified ground due to the persistence of the medical model and the immense diversity within the disability label have ensured that disability identity remains an ‘unstable category’ (L.T Davis, 2013) into the present day.[137]

Heterogeneity

Innate diversity continues to be a core component driving the dynamics of disability as a collective sociopolitical identity. Writing in 2022, Tobin Siebers makes clear that academics still ‘express[…] hesitation about conceiving of people with disabilities as an identity or minority group’, particularly noting the wide variety of impairments that the group attempts to encompass.[138] As Siebers expresses, the diversity of impairments, experiences and attitudes of those who comprise ‘the largest minority population in the United States’,

[136] Longmore, Paul, K. “The Second Phase: From Disability Rights to Disability Culture”, *Independent Living Institute* (1995). Available at: The Second Phase: From Disability Rights to Disability Culture | Independent Living Institute (accessed 27/12/2024)

[137] Hiraide and Evans. “Intersectionality and social movements”. ,p.8.
[138] Tobin Siebers in Alcoff, Hames-García, Mohanty, Moya. *Identity Politics Reconsidered*., p.13.

combined with the porous and nebulous nature of its boundaries, ensure that '[d]isability […] provide[s] an example of the extreme instability of identity as a political category'.[139] This was evidenced throughout expert interviews. I5, for example, was asked whether there was any kind of unified disability identity: "for me it doesn't exist […] It might exist for someone else, […] , but I think […] I'm too brutally honest".

The survey responses were also extremely compelling. When asked out of 10 how alike (homogenous) Disabled people were in their life experiences and outlooks on life, 1 being not at all and 10 being completely, the mean average score was 2.9. When looking solely at those who identified as Disabled, the number dropped even lower. It is clear that both those internal and external to the disability identity would see it as representing a tremendously factious space. Those who identified as Disabled and non-disabled alike spoke consistently of heterogenous disability identity, even within similar classifications of impairments:

> *"As an autistic person with serious mental illness I consider my conditions disabling, but they are disabling in very different ways compared to chronic illness or other physical disabilities, and knowing just the diversity in that aspect I'm sure there's a lot of differences even in the category I kind of view lumped together as "physical disabilities"*
>
> *"Disabled people are as varied and complex as the population as a whole, or even more so!"*

[139] Ibid., pp.10-11.

Another common theme throughout responses was the discussion of the ramifications of a heterogenous and porous identity in the resulting lack of a positive identity or concomitant culture outside of tentative similarities regarding discrimination.[140] Aside from specific experiences such as camps or pageants, commonality was described almost exclusively within the remits of potentially similar experiences of discrimination, negative cohesion in its truest sense - as opposed to positive cultural products.

> *"I think a common factor among all disabled people would be not experiencing a world in which their needs are thought of equally in regards to non-disabled people."*

> *"Anyone can become disabled at any time, so disabled people can hold whatever beliefs, outlooks, and experiences their particular lives lend them to.* […] *there are often some common experiences of social exclusion and society not being set up for disability […], but that isn't the defining feature of who I or anyone else is."*

Williams-Finlay in his 2024 book 'Disability Praxis' takes a similar stand, conceptualising 'the denial of access to standard mainstream social activities' to be 'the bedrock of disability culture'.[141] Indeed, amidst substantial academic debate, there are those who have theorised there to be a lack of disability culture completely, from Lennard Davis to Lois Bragg's 1999 infamous keynote address for the Disability Studies Annual Community.[142]

Even the ties of discrimination are a tenuous connection as the visibility and physicality of impairment drastically shape experiences. As one expert interviewee discussed in reference to

[140] Watson. "Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person".p525.
[141] Williams- Findlay, Bob. *Disability Praxis* (Pluto Press, 2024). p.74.
[142] Tobin Siebers in Alcoff, Hames-García, Mohanty, Moya. *Identity Politics Reconsidered*. p.13.; Peters, Susan. "Is There A Disability Culture? A Syncretisation Of Three Possible World Views". *Disability & Society*, Vol. 15 No. 4, (July 2010). p.584.

myself, my own ability to "pass" as non-disabled meant my encounters with disability identity and, indeed, affiliation with the broader community were different from her own:

> *"I can't pass as normal because I'm sitting in a wheelchair. So it must have been harder for you, because you can pass as normal"*

The Medical Model

The dynamics around invisible and visible disabilities and where those who fall inconclusively between the barriers of the non-disabled and the disabled choose to define themselves taps into larger conservation around the persistence of the medical model of disability and its alienation and apoliticisation of disability identity.[143]

The expert interviewees spoke consistently of negative external perceptions still being informed by medicalised views of disability. I6 rebuked that "[…] people just see disability as charity in need of charity […]" as opposed to being viewed as a member of an oppressed minority group. Indeed, both I5 and I6 discuss continual examples even more extreme than apoliticisation: infantilisation. As the two describe themselves as visibly Disabled, they both recounted interactions where their disability has been associated with incapacity to be deemed adult, I5 in the context of a doctor's appointment and I6 when ordering food.

A thematic analysis of survey responses from non-disabled participants also revealed a clear trend of disability being viewed as a physical failing as opposed to being in part a product of

[143] Davis. "Identity Politics, Disability, and Culture"., p.536.

a discriminatory society. The external perceptions are incredibly powerful in their own right and also feed directly into the conceptualisations of Disabled people themselves.

In sentiments similar to those described by Watson in 2002, many within the Disabled community itself seemingly wish to reject disability and its negative associations of incapacity as it is 'contradictory to their own views of their self.'[144] I5 in particular talks of the continued frustrations activists have at Disabled people denying their own identity, particularly when people have acquired impairments later in life, of course representing the majority of the Disabled community:

> *"[…] the people that acquire their disability are more likely to say that they're not Disabled, they just became this way from an accident or whatever […]"*

Even when Disabled people are aware of the sociopolitical theorisation of disability as a minority group, its strength is still challenged by alternative understandings. A Disabled survey respondent, involved with a DRO, explicated that:

> *"It took me a long time to identify with the label 'disabled'. Honestly, I'm still adjusting to it, but I've learned to see it more as a descriptor than the mark of insufficiency that it is often used as."*

Moreover, and perhaps even more poignantly, multiple expert interviewees who identified as non-disabled went on to describe invisible health conditions that would undoubtedly fall

[144] Watson. "Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person".p.521.

within the label. I7, for example, spoke of refusing medication on the grounds of not wanting to be associated with the disability identity:

> *"because I thought taking medication means that you are that you have a disability, and, you know, I was like, I don't want to take this. I don't want to have a disability. So still a lot of stigma within me."*

If those within the movement still feel shame, the medical model's persistence in comparison to a social understanding of the identity is still incredibly pervasive. Indeed, as Nishida (2016) paper discusses, all the activists they interviewed expressed how those who found a political identity did so first through another form of identity politics and their critical frameworks. The medical model is so persistent that even those with desire to engage in disability politics did not innately connect with disability as a political category. [145]

Where there is not active shame, pride, is also lacking. The prevailing attitude of activists who did identify as Disabled saw it as a journey to acceptance as opposed to holding minority identity with esteem, mandated on the premise of having inescapable and visible physical impairments. Indeed, when Disabled survey respondents were asked about whether they were proud of their disability identity, less than a 1/5 were in active agreement. As I5 details:

> *"I was born with a disability. I'm fine with it." ; ""there is a Disability Pride Parade, and I hate the word pride in there, because for me, I didn't ask for my disability. […] I'm sorry I can't seem to be proud."*

[145] Nishida. "Understanding political development through an intersectionality framework".

This discussion is particularly stark because it stands in direct contrast to a tangible culture the likes of the women's, BLM or, perhaps most overtly, the LGBTQ+ movements have cultivated, and as such establishes disability identity's background as distinct in its nature. This lack of pride fuels a dearth of wider community; collective consciousness and affiliation with a sociopolitical identity.

Ultimately, these foundations of heterogeneity and medicalised perceptions leave the identity the DRM hinges on as weak, fractured and lacking internal and external political legitimacy. It is within this framework that conceptualisations of intersectional praxis fail to thrive.

5 THESIS CHAPTER 3: A SECOND LAYER TO DISABILITY INTERSECTIONALITY- THE ALL-ENCOMPASSING NATURE OF IMPAIRMENT POLITICS

"In fact, Americans with disabilities are divided from one another not only by race and gender and sexual orientation—as are Americans in general—but also by disability itself […]" Fred Pelka[146]

The fragility of the mainstream pan-disability movement's collective identity has inspired and enabled patterns of behaviour to flourish which hinder the movement's capacity and desire for comprehensive intersectional praxis. In the first instance, and related primarily to its fluidity and heterogeneity, is the fractious impairment politics which consumes activism. Within the category of disability belies a myriad of differing impairments, some- as established- with separate originating forms of collective action and concomitant cultures. The hierarchies which have developed pertaining to various impairment groups have, in large part, absorbed the movement, pulling all focus on matters of identity and inclusion. As such, it is postulated that movement activists have not had the capacity to look beyond impairment-based power politics to more wide-ranging issues of exclusion and marginalisation.

[146] Pelka. *What Have We Done*. p.25.

It is important to note that with all single-issue identity movements, unity interior to the identity groupings has wrongly been taken for granted. As asserted at the beginning of the paper, all single-issue identity movements are in fact coalitions.[147] Within all identity groups whether large, such as 'women', or smaller, such as 'Black women' or, indeed, even more specific, such as Black British women, there is no wholly innate sense of connection, identity or purpose.[148] Iris Marion Young's (1994) conceptualisation of those with similar material conditions to be part of a serial- e.g. all women belong to a serial- which in turn does not necessitate membership to a group and its collective identity is an effective way to theorise all forms of identity. Within this context, the DRM's associated identity represents less of a coalition and more of a vague truce, forged with complicated and hierarchical identity politics surrounding identity. Attempting to bring other aspects to this coalition is deemed, albeit wrongly, to impose another layer to an already strained and fractured movement.

5.1 A FRACTURED MOVEMENT BASED ON IMPAIRMENT IDENTITY

A consistent theme throughout interviews and survey responses was the acknowledgement of how much fractious internal identity politics plagued the broader DRM. This reflects much of what has been consistently noted in wider literature of a fragmented movement divided over impairment, as the Pelka quotation above delineates.[149] As I2 delineated:

> *"I think it is a totally fractured movement. It is not cohesive at all. And it might be on the surface at certain times when groups have to come together, like around the ADA.*

[147] Hill Collins and Bilge. *Intersectionality*. p. 133.
[148] Cole, Elizabeth. R. "Coalitions as a Model for Intersectionality: From Practice to Theory". *Sex Roles*, Vol. 59, (2008). p.446.; Luna, Zakiya. 'Truly a women of color organization'"., pp.774-5.
[149] Chin, Natalie M. "Centering Disability Justice." p.705. ; Linton, Simi. *Claiming disability*.p.7.; Shapiro. *No Pity.* p.126.

But if you talk, probably talk to American disability rights advocates, they would say, "Yeah, we came together around the ADA, but it was, like, really hard.""

The activist in question, a key player in the American movement from the early 2000s, articulates clearly the reality of a diverse and fragile identity that has, in turn, created a movement of many parts, barely able to come together even around its own civil rights bill. Historians Shapiro, Fleischer and Zames have indeed highlighted the complex dynamics of unifying impairment-based groups over the ADA.[150]

Other expert accounts were also consistent in discussing how disability activists diverged on the basis of impairment. I5, for example, admitted that:

"[…]we fight amongst ourselves […] the blind people stay to the blind, the deaf, state of the Deaf, the deaf, they say they're not disabled. It's a culture."

5.2 HIERARCHIES OF IMPAIRMENT

As referenced also in I5's quote, disability rights-based collective action is more than divided by impairment: impairment holds intrinsic power hierarchies. These power discrepancies are complex, but their undeniable presence is of most importance in the context of this paper.

[150] Fleischer and Zames. *The Disability Rights Movement*. pp.105-6. ; Shapiro. *No Pity*. p.126.; Pelka. *What Have We Done.*, p.343.

One realisation of hierarchy comes in positioning based on ableist and, ultimately, medical constructions. In particular, Deaf and Blind communities, when interacting at all with the mainstream movement, distinguish themselves- as noted- in their rejection of being Disabled.[151] Intrinsically, this is a comparative exercise, as the medical reality of disability is not abandoned in its entirely, just that the label does apply to those within their remits. Those who are deemed completely outside the norms of ableist society are also actively excluded. This is particularly true of those with psychosocial disabilities. I8, who's organisation represents those who have been institutionalised, spoke of this population "still [being] undervalued and underrepresented within the disability community itself". I1 even admitted that within her institution she believed it would be unsuitable for someone with a psychological disability to hold a leadership role, revealing overt exclusion premised on impairment identity:

> *"There are stratifications. […] when you have somebody with an overt mental illness or[…a] really severe case of autism, […] or schizophrenia, […] and some people are really disabled, […] when it's somebody like that […] they can't be president."*

And yet, hierarchies are more complicated than being simply informed by ableism. Impairment politics is also centred on the visibility and physicality of disability. As a Disabled survey respondee, who is involved with the movement, discussed:

[151] Lane, Harlan. "Construction of Deafness". In *The Disability Studies Reader*, edited by Lennard J. Davis, 2nd ed., pp.79-92. (New York: Routledge, 2006.); Aronson, Josh, director. *Sound and Fury*. New Films International, 2000.; Fleischer and Zames. *The Disability Rights Movement*. p.22.

> *"I struggle with the label of "disabled" because I'm not physically disabled, and I think the disability rights movement is very focused on physical disabilities, which isn't a bad thing I just feel like it doesn't entirely apply to me."*

Wheelchair users, in particular, continue to hold power, a pattern that has been maintained since the movement's inception. Movement activist Fred Pelka, for example, remarked on his experiences of working at Berkley CIL in the 1970s that "the people in wheelchairs, the people that were physically disabled, basically ran the joint."[152] In an insightful if unnerving revelation of occurrences behind closed doors today, I3 spoke of attending a meeting last year (2023) run by a leading national advocacy organisation where exclusionary politics based on a wheelchair-based hierarchy were unmistakable:

> *"and I stopped going because […] the […] supposed leader, who was in a wheelchair, […] she made a comment about people in wheelchairs, and that's who she's here to protect. […] You have to speak to all of us, not just one select group."*

The specific symbolism of wheelchair users being at the top of the hierarchical impairment pyramid within the movement - maintained since its inception- feeds into a wider picture where discernible disability is valued. This is indubitably linked to the nebulous and porous boundaries of disability identity in which wheelchairs are able to demarcate certainty, consistency and tangibility. The International Symbol of Access, adopted by the UN in 1974 and by the US movement from its infancy, wheelchairs symbolically disability identity compact and digestible.[153] It is within this paradigm that those who identify with singular

[152] Pelka. *What Have We Done.* p.220.
[153] Guffey, Elizabeth. *Designing Disability: Symbols, Space, and Society*. (London: Bloomsbury Academic, 2018.) pp.141-144.

physical impairments are privileged, uncomplicated by the ableist stigmas surrounding psychosocial disabilities and the confusing fluctuation of chronic illnesses. The logic of internal hierarchies is far from without inconsistencies, though. I3 highlighted the exclusion of those with dwarfism and albinism from disability rights activism globally, despite their statuses as physical and visible disabilities. What can be conclusively established is that impairment-based power politics is a major element of movement dynamics.

5.3 What Inclusion Means to Disability Rights Movement

Impairment hierarchies undoubtedly add another layer to the dynamics of intersectional empowerment within the DRM. What can be observed, however, is that instead of holding the two layers of internal identity politics concordantly, impairment dynamics completely dominate activist discussions pertaining to inclusion.

When asked about inclusion and diversity, the focus of the vast majority of survey participants centred largely on disability-focused impairment dynamics of exclusion and power. This follows a pattern noted by Evans (2023) in the UK movement.[154] Survey answers mainly revolved around invisible disabilities and chronic illnesses being unrepresented at a movement level. While the dynamics of racism or lack of LGBTQ+ activism was also noted, it stood in a small proportion of the comments. A similar pattern was observed with expert interviewees. I1, when asked about coalition building, spoke of groups working with chronic illnesses (American Cancer Society and the MS Society) as opposed to differing identity

[154] Hiraide and Evans. “Intersectionality and social movements”. p.10

groups. I2 also understood coalition building solely within the context of the "hierarchy within the disability community". I8, when asked to affirm inclusive measures within the DRM, likewise focused solely on the potential exclusion of Deaf people.

It should be highlighted that 85% of survey respondents identified as White, and the interviewees followed the broader trend of movement leaders who, aside from disability, generally hold privileged identities in the context of American society. As such, impairment politics, as opposed to broader intersectional concerns, had personal ramifications which would naturally pull focus. This, however, does not fully explain the preoccupation with impairment inclusion. For one, around two-thirds of the survey participants identified as part of the LGBTQ+ community and yet this was not highlighted nearly as intensely, despite external commentary of exclusion.[155] I8 also identified as Black and this identity was not brought to the fore.

With the evidence here, inclusion conversations by disability activists would seem to be dominated by impairment politics due to its all-encompassing nature within the politics of disability identity. Heterogeneity and hierarchy within the disability label have enabled activists to take an insular look at intra-movement inclusion.

[155] Egner. "Being LGBTQ+ and Disabled, a Socially Contradicting Experience". p.584.; Hiraide and Evans. "Intersectionality and social movements"., p.9.; Vernon. "The Dialectics Of Multiple Identities And The Disabled People's Movement"., p.395.

6 THESIS CHAPTER 4: THE VICIOUS CYCLE OF MARGINALISATION, VICTIMHOOD AND DISABILITY ESSENTIALISM

As established , the notion of disability essentialism, defending disability identity as a monolith crystallised in the image of an otherwise privileged leadership, is endemic within identity politics and by no means exclusive to the DRM.[156] Disability activists, however, have been trapped in a uniquely vicious cycle of marginalisation and victimhood, which has, in turn, cemented a culture of conceptualising disability issues as a unitary phenomenon to be privileged over all else. This cycle is fed ultimately by disability's fractured collective identity which has been consistently medicalised and thus apoliticised. In particular, the lack of external validity of disability as a political category by potential allies in other movement actors as well as funders, academics and state actors, has ensured a lack of coalition-building and accountability needed to forward intersectional praxis in its own right. [157] Concomitantly, internal actors, fuelled by the consciousness of the fragility of disability identity as well as this marginalisation experienced, have created a culture of particular victimhood and survival driving a double-down of a unitary identity. Evans, in her 2022 and 2023 articles, notes these movement dynamics in relation to the UK, stating explicitly that 'the desire to assert the idea of a disability identity has meant those located at the interstices of disability, race, gender and class have often found themselves marginalised'.[158] This "same-difference" strategy,

[156] Cole. "Coalitions as a Model for Intersectionality". p.444.; Hill Collins and Bilge. *Intersectionality*. p.125.
[157] Montoya. "Intersectionality and social movements: Intersectional challenges and imperatives in the study of social movements", p.7.
[158] Evans. "Political intersectionality and disability activism"., p.990.

focusing on sameness and stifling what would perceived to be dissident voices, as coined by Luna (2016) is clearly at play within the US movement currently. [159]

6.1 MARGINALISATION

Lack of External Validity as a Political Category: Perceptions of Disability Identity and the Movement

As established, a medical model, individualising disability and tethering ableism to a reasonable physical reality as opposed to ubiquitous sociopolitical forces, continues to depoliticise the collective identity and subsequent movement. Tobin Siebers, writing in the last couple of years, talks of disability still 'not […] having the advantage of a political interpretation' in comparison to notions of '"Blackness" and "femaleness"' and, as such, having issues ignored. [160] In so doing, disability activism has not been treated with equal reverence as its older siblings, in the words of Lennard Davis, 'seen generally as having a less legitimate minority status than other more high-profile identities'.[161]

Movement actors are keenly aware of these patterns. I8 spoke explicitly of disability rights being seen as "less political and less threatening" and the potential implications of this. Some are potentially advantageous. I7 talks of the leniency activists like herself are given by the government officials because of the perceived depoliticised and hence unthreatening nature of their campaigns. The ramifications of pervading perceptions of disability as a medical condition as opposed to legitimate political identity, needless to say though, heavily weigh in the negative. I5, for example, details the lack of support for disability pride celebrations in

[159] Luna, Zakiya. 'Truly a women of color organization'",. p.769.

[160] Tobin Siebers in Alcoff, Hames-García, Mohanty, Moya. *Identity Politics Reconsidered*., , p.17.
[161] Davis. "Identity Politics, Disability, and Culture". , 537.

direct comparison to the backing garnered by other minority identity groups by the population at large:

> "*and it's been going on for a few years [- the New York City Disability Pride event-] but there's nobody on the sidelines […]I mentioned it to a friend of mine[…] and […] she thought it was a gay pride parade for people with disabilities. […]"It is almost always empty. There's no media, there's nothing. […] As soon as there's a parade, somebody says it's always on the news or the radio – not ours."*

The stark differences in support can be blamed on a lack of organisational forethought or effective interactions with the media. Nevertheless, it would seem clear that the inability to cultivate interest, despite utilising a parallel format to other movements which have been indisputably successful [162] signifies a comprehensive lack of acceptance of the disability right's cause, inherently tied to its deficient collective identity and concomitant culture.

These evident external reservations pervade circles close to the movement itself. I3, for example, spoke in the context of funding about how disability persists in a forgotten minority group, this exclusion driven mainly by "fear" of the medicalised connotations of impairment.

> *"organizations of people with disabilities have fewer resources than even women […] Or, you know, LGBTQ even. […] there is this kind of hierarchy of funder favorites […] there's a lot of fear around disability. You know, people are afraid and perhaps aware that they, too can become part of the part of the disabled, but don't want to recognize that."*

[162] 2 million spectators came to New York's 2024 Pride Parade- Fadulu, Lola, and Gaya Gupta. "A Wave of Pride Lights Up New York City." The New York Times, June 30, 2024. https://www.nytimes.com/2024/06/30/nyregion/nyc-pride-parade.html. (accessed 04/01/2024)

Lack of Coalition Building

Most pertinent to intersectional praxis in its own right, the medical model of disability has been absorbed by other identity-based forms of collective action. This, as detailed in Chapter 2, has substantial historical context, with the rejection of medicalisation a core component of minority identity-based collective action within the US. [163] A variety of academic accounts analyse the women's movement work in divorcing themselves from being defined by their bodies and their associated traits of being 'needy, dependent and passive', closely associated, of course, with the medical model of disability.[164] Similarly, Egner (2011) discusses the intersectional invisibility that has occurred for Disabled people who are part of LGBTQ+ communities where the 'Born This Way narrative [… represented] a successful pushback to the historical pathologization of queer positionalities as mental illness.'[165]

One can by no means deny other more general factors that have driven a lack of enthusiasm from other movements to coalition build consistently with disability rights activists- whether based on the exclusionary and often competitive nature of identity politics as noted by historical disability activist Pat Wright-[166][167] - or matters of prejudice. Nevertheless, the inability of similar movements to acknowledge disability as an equally legitimate persecuted sociopolitical minority has undoubtedly created divides between themselves and disability activism. This experience is consistent throughout historical and contemporary accounts by movement actors.

Judy Heumann, for example, spoke of her difficulty in attempting to work with Black groups wishing to separate their identity from disability

[163] Pelka. *What Have We Done.* p.10.
[164] Sheldon, p,650.
[165] Egner. "Being LGBTQ+ and Disabled, a Socially Contradicting Experience". p.587.
[166] Pelka. *What Have We Done.* p.463.
[167] Davis. "Identity Politics, Disability, and Culture"., p543

> *I've really wanted to try to achieve in this job is to try to work more effectively with the race groups, because they don't accept disability. They see disability as a weakness, as a vulnerability."*[168]

Heumann's collective dismal undoubtedly reveals her own prejudices, although this does not cancel out the rejection felt by the DRM representative. Johnnie Lacy, a Black disability advocate active from the late 1970s, further discussed her own personal experience of identity erasure she experienced from the decision of Black communities to reject disability and all it represented:

> *I believe that African Americans see [people with] disabilities in the same way that everybody else sees us—worthless, mindless—without realizing that this is the same attitude held by others toward African Americans. This belief in effect cancels out the black identity they share with a disabled black person […]* [169]

Exclusionary practices by other minority identities were further formally noted by the 1992 National Council on Disability. [170]

These attitudes still prevail. Schalk provides important examples of disability being presently left out of mainstream Black narratives, most notably its omission in BLM's 2016 'A Vision for Black Lives' statement. [171] Indeed, two of the expert interviewees spoke on the lack of desire from BLM groups to include those with disabilities, driven by their own perceptions of disability identity.

---

[168] Heumann, Judith. "Pioneering Disability Rights Advocate and Leader in Disabled in Action". Interview conducted by Susan Brown, David Landes, Jonathan Young in 1998-2001, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, (2004). Available at:Pioneering Disability Rights Advocate and Leader in Disabled in Action, New York; Center for Independent Living, Berkeley; World Institute on Disability; and the US Department of Education, 1960s-2000 (cdlib.org) (accessed 09/12/2024). p.78.
[169] Pelka. *What Have We Done.* p.352.
[170] Wright and Leung, "Minorities with Disabilities: An Introduction,". The National Council on Disability and Jackson State University, cosponsors. p.2
[171] Schalk, Sami. *Black Disability Politics*. (Durham: Duke University Press, 2022.). p,.140.

> ***"****I have friends who are disabled, […] who are black, who didn't necessarily feel embraced in their personal lives by Black Lives Matter."* (I4)

> *"[…] with Black Lives Matter, if we are not there to speak up for ourselves, you know, they will just tend to forget us too. […] to be honest with you, disability is kind of a forgotten part of our society, because […] they tend to see people with disabilities as institutionalized."* (I6)

I6's quote is particularly pertinent, highlighting the persistence of the medicalised view of disability in institutionalisation- connoting incapability and pity- and its direct role in the disability identity not being taken seriously. This pattern is by no means exclusive to BLM. One of the most consistent trends from expert interviewees was being left behind by other civil and human rights movements due to disability not being discerned to belong within their remits. I8, for example, detailed consistent rejection on the basis of perceptions of collective disability identity:

> *[…] it [disability] was essentially invisible in the human rights community* […] *I can't tell you how many times I would approach a human rights organization to tell them about the issues we and they said, "Oh, no, we do human rights, not disability rights." […] I still consider disability undervalued, underrepresented […]"]*

I2 further speaks on women's organisations:

> *"there's power dynamics between the disability movement and other movements, which I've seen, you know, so, so women's groups kind of treating disability orgs like* […] *they don't know anything, like they don't have capacity to do advocacy."*

Again, the notion of incapacity, directly linked to the medical as opposed to the social model of disability, is explicitly underscored as the explanatory factor in movement marginalisation. In these failed interactions, an environment for intersectional coalition-building is continually broken down. In its place, disability essentialist beliefs and practices are further embedded by movement actors.

6.2 THE DOUBLE DOWN OF DISABILITY ESSENTIALISM

Defensive Rhetorics and the Paradigm of Victimhood

Within the context of a failure to successfully establish disability as a widely recognised cohesive sociopolitical identity, the DRM has, in large part, been left behind. As delineated, disability rights advocates have been ignored within a human and civil rights-based framework, driven by its failure to be deemed an minority identity. Only look to the signing of the ADA or internationally, that of the CRPD, both revealing the movement to at least chronologically sidelined. This is plain to see even for those not connected to disability activism. As a non-disabled survey respondee who is not part of the movement observed:

> *"Disability is supposed to be part of DEI initiatives and is often overlooked. I work at a large public university and i see this all the time. Basic digital accessibility is an*

afterthought at best, and whenever I try to run a short training on it, faculty never attend."

Of great importance, disability activists are not only aware of the marginalisation but have actively internalised the notion of being forgotten even within the context of minority identities, with begrudging comparison and, indeed, animosity being felt widely. Interviewees evaluated the stark differences in support and funding for the women's or LGBTQ+ movements in contrast to their own. I2, for example, discussed with resentment the marginalisation that occurred with "an organization like Amnesty International [where it was] was very supportive of Black Lives Matter movement, but less supportive of disability rights".

It was I5's take on the Black Lives Matter movement which clearly established animosity in response to feeling the disability agenda had been left out of BLM's discussions:

This is going to sound really bad. Every life matters. Yes, I'm not Black, but I feel like I've been discriminated since birth. […] yes, they have a lot of people discriminating against, but they're not the only class of people that get discriminated against. […] look around to people. There's discrimination in all groups, not just Blacks. And I'm not going to cry for you now, because nobody cried for me. So next."

In this statement, the dynamics at play within the larger movement are made clear, if not quite as extreme or blunt. Through disability activists' continued failed attempts to establish a cohesive collective identity, a victimised and defensive mentality comes to the fore, playing

into broader prejudices, in this case, anti-black rhetoric. As I4 notes,"I think that among white disabled people, particularly, there can sometimes be that defensiveness." Well, I understand prejudice too." Disability is clearly seen as an undervalued identity of greater importance than ethnicity and race. This is not a new mentality. An oral history interview with Elaine Brown, once leader of the Black Panthers reveals during the early days of the movement posters were bused during protests that claimed "at least Rosa Parks could get on the bus".[172]

Persisting Disability Essentialism and Exceptionalism at the Cost of Intersectionality

It is within this context of fear and victimhood that the core of the DRM has doubled down on disability essentialism based on an identity created by a privileged set of actors.[173] This has, by and large, not changed since its inception. Corbett O'Toole divulged retrospectively that due to the "all white, but very heterogeneous" community attempting to hold together a collective identity and movement, "we just kind of pull the blanket over our heads and just say, "We're all the same," and we're not."[174] Most poignantly, Donald Galloway, a Black Disabled activist at CIL during the 1970s, also explicated rejection of a proposed Black caucus in the need to maintain a cohesive and unified disability identity:

> *"I went to the board of directors and said, "We're going to start a black caucus to make sure we get our voice heard." That went over like a lead balloon, because the*

[172] Brown, Elaine. "Leader of the Black Panther Party Elaine Brown talks about the Party's involvement and support of the 1977 Section 504 Occupation". Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: Leader of the Black Panther Party Elaine Brown talks about the Party's involvement and support of the 1977 Section 504 Occupation - Paul K. Longmore Institute on Disability Collection (sfsu.edu) (accessed on 09/12/2024).
[173] In the words of Chin (2021), The "neutral" ground in which this essentialism is based 'presumes a white, heteronormative racial identity'. – Chin, Natalie M. "Centering Disability Justice."., p.709.
[174] O'Toole, Corbett. "Advocate for Disabled Women's Rights and Health Issues"., p,105; p.107.

> *attitude was, "We're all one, and there's no need for it. That would be like a blind group trying to say that we wanted the blind to be paid attention to more." It was part of the whole attitude that no special group should be dominant. Although the people in wheelchairs, the people that were physically disabled, basically ran the joint.[…],"* [175]

This quote really crystallises all aspects of movement dynamics, with traditional intersectionality being seen as a threat to cohesion in the same light as impairment politics.

Interviews Judy Heumann, that demonstrate how core these beliefs and practises of disability essentialism and exceptionalism were. When asked if gender was a bigger issue than disability she snorted. At the end of the discussion she concluded her own deconstruction of this idea with the following remark :

> *Ask her the following question: A women's shelter that denies a disabled woman entrance and services is denying it to her because she's a woman or because she's disabled? There is only one answer. It ain't because she's a woman, because everybody in there is a woman.* [176]

This sentiment has not left the DRM. I1's quote referenced earlier reveals the same thought process: "big issues" of disability rights cannot be undermined by "little ones"- those of marginalised concerns. As I1 went on to say: "I think disability is the worst of all the categories you could be in […] for being discriminated against." In a similar vein, I6, when

[175] Pelka. *What Have We Done*. p.220.
[176] Heumann, Judith. "Pioneering Disability Rights Advocate and Leader in Disabled in Action". pp.75-7.

asked about racial divides, countered that "disability exclusion affects all of us in pretty much the same way". Nishida's 2016 study is not only pertinent in corroborating the attitudes with the DRM where '*interrelated social issues (e.g., racism, xenophobia, and heterosexism) were often overshadowed by its exclusive focus on ableist issues'*- but in noting this disability essentialism in turn drives those with intersectional identities away from a movement they don't feel seen, further perpetuating an isolationist and exclusionary culture.[177] At the altar of cultivating a one-dimensional disability identity, the DRM has failed to serve the majority of the Disabled community.

[177] Nishida. "Understanding political development through an intersectionality framework".

7 CONCLUSION

The deficiency of intersectional praxis in the DRM is a major obstacle in the comprehensive realisation of disability rights in the US. Even though disability activists demonstrate a growing level of awareness of intersectional issues, the movement is not taking active steps to empower marginalised identities. Indeed, the need for intersectional discourses has not even been universally acknowledged. The DRM is not alone; other identity-based forms of collective action have also struggled to diverge from the exclusionary essentialism that has emanated from attempting to manufacture coalitions around cohesive collective identities. What, however, has been purported to be unique to the DRM is its especially weak foundations for a unitary sociopolitical identity. The heterogeneity and porosity of the Disabled experience, alongside persistent medicalised views, have served as powerful disrupters. The impairment power politics birthed from the movement's vast diversity- creating a second layer to intersectional theorisation- has preoccupied activist debates on inclusion. Moreover, a lack of external validity driven by disability identity's fragility has hampered cross-movement coalitions– impeding intersectionality in its own right- as well as creating a wider culture of marginalisation and victimhood which has inspired activists to double down on narrow essentialism. The framework of disability identity has thus created an acutely challenging environment for intersectional praxis to flourish.

One could be forgiven for presuming that the abstractions from this thesis are aimed at dismantling the DRM. Instead, it is asserted that an awareness of the internal mechanisms halting intersectionality can provide the framework for progress. The DRM, in its failure to fit the singular identity model of the 20th century, may be more equipped to embrace a new wave of transversal movements in the 21st. It's vast heterogeneity and individualising

medicalisation have given activists requisite experience in forging alternative ties beyond one-dimensional sociopolitical identity: they simply must expand past their focus on impairment-based divisions. In so doing, the DRM must deconstruct its underlying adherence to racial capitalism, as other movements must deconstruct their implicit ableism-Disability Justice has shown the way. Further research on intersectionality within the DRM is thus imperative for its potential implications in theorising intersectional praxis broadly, but also, perhaps most importantly, so that all Disabled Americans can be brought forth of the rising tide of disability rights.

8 THESIS BIBLIOGRAPHY

Adams, Rachel, Benjamin Reiss, and David Serlin. *Keywords for Disability Studies*. (New York: New York University Press, 2015)

Adley, Mark, Hayley Alderson, Katherine Jackson, William McGovern, Liam Spencer, Michelle Addison, and Amy O'Donnell. "Ethical and Practical Considerations for Including Marginalised Groups in Quantitative Survey Research." *International Journal of Social Research Methodology*, (July 2023).*Ethical and practical considerations for including marginalised groups in quantitative survey research.pdf (accessed 17/04/2024)

Albrecht, G, Seelman, K, and Bury, M, *Handbook of Disability Studies* (Thousand Oaks, CA: Sage Publications, 2001)

Alcoff, Linda Martín, Michael Hames-García, Satya P. Mohanty, Paula M. L. Moya. *Identity Politics Reconsidered* (New York: Palgrave Macmillan, 2006)

Alexiou, Gus. "Are Disability Charities Excluding Disabled People From Leadership Roles?" *Forbes*. December 22, 2024. https://www.forbes.com/sites/gusalexiou/2024/12/22/are-disability-charities-excluding-disabled-people-from-leadership-roles/. (accessed 02/01/2025)

Almeida, Paul, *Social Movements: The Structure of Collective Mobilisation*. 1st ed. (University of California Press, 2019)

Anderson, Kathryn and Jack, Dana C. “Learning to listen: Interview techniques and analyses”. In *The Oral History Reader*, edited by Robert Perks, Alistair Thomson (London: Routledge, 1997).

Australian Government. “Style Manual: Easy Read”. Available at: Easy Read | Style Manual (accessed 17/04/2024)

Bailey, Moya. *Misogynoir Transformed: Black Women’s Digital Resistance*. (New York, USA: New York University Press, 2021.)

Bank, Joy, Phillandra Smith, and D'Arcee Charington Neal. "Identity Politics: Exploring DisCrit's Potential to Empower Activism and Collective Resistance." In *DisCrit Expanded: Reverberations, Ruptures, and Inquiries*, edited by Subini A. Annamma, Beth A. Ferri, and David J. Connor, pp.202-218. (New York: Teachers College Press, 2022.)

Banks, Lena Morgon , Arne H. Eide, Xanthe Hunt, Ola Abu Alghaib and Tom Shakespeare (2024) “How representative are organisations of persons with disabilities? Data from nine population-based surveys in low- and middle-income countries”. *Disability & Society*, Vol. 39 No.10, (2024): pp.2511-2527. (accessed 14/10/2024)

Bell, Chris. "Introducing White Disability Studies: A Modest Proposal." In *The Disability Studies Reader*, edited by Lennard J. Davis, 2nd ed., pp.275-287. (New York: Routledge, 2006.)

Bello, Barbara Giovanna. "Intersectional Perspectives on Social Movements." *Global Dialogue*, October 9, 2022. https://globaldialogue.isa-sociology.org/articles/intersectional-perspectives-on-social-movements. (accessed 02/01/2025)

Blee, Kathryn, and Verta Taylor. "Semi-structured interviewing in social movement research." In *Methods of social movement research*, edited by B Klandermans & S. Staggenborg, pp. 92–117. (University of Minnesota Press, 2002)

Brown, Lydia. "The Significance of Semantics: Person-First Language: Why It Matters", *AUTISTIC HOYA* (Aug. 4, 2011), https://www.autistichoya.com/2011/08/significance-of-semantics-person-first.html (accessed 27/12/2024)

Brown, Wendy. *States of Injury: Power and Freedom in Late Modernity*. (Princeton, NJ: Princeton University Press, 1995.)

Brubaker, Rogers and , Frederick Cooper. '"Beyond" Identity". *Theory and Society*, Vol. 29 No.1, (Feb., 2000): pp. 1-47.

Bryman, Alan, "Interviewing in Qualitative Research". In *Social Research Methods*, 2nd ed. (Oxford: Oxford University Press, 2004): 468-499.

Chin, Natalie M. "Centering Disability Justice." *Syracuse Law Review* 71, no. 683 (2021).

Coffelt, Tina. (2017). "Confidentiality and anonymity of participants." *The SAGE Encyclopedia of Communication Research Methods*, Vol.4 (2017): pp. 228-230. https://doi.org/10.4135/9781483381411 (accessed 1/11/2024)

Cole, Elizabeth, "Beyond Identity: Intersectionality and Power". In *The Palgrave Handbook of Power, Gender, and Psychology* edited by Eileen L. Zurbriggen and Rose Capdevila, pp.29-42. (Palgrave Macmillan Cham, 2023)

Cole, Elizabeth. R. "Coalitions as a Model for Intersectionality: From Practice to Theory". *Sex Roles*, Vol. 59, (2008): pp. 443-453.

Conejo, Mıriam Arenas, "At The Intersection Of Feminist And Disability Rights Movements. From Equality Indifference To Human Diversity Claims." In *Disability and Intersecting Statuses* edited by Sharon N Barnartt and Barabara Altman, (Bingley: Emerald Group Publishing Limited, 2013)

Connolly, William E. *Identity/Difference: Democratic Negotiations of Political Paradox*. 1st ed. (Minneapolis: University of Minnesota Press, 2002.)

Cooper, Anna J. *A Voice from the South*. (1892). Produced by Richard Tonsing, Mary Glenn Krause and the Online Distributed Proofreading Team. Project Gutenberg eBook #61741. April 2, 2020. Most recently updated October 17, 2024. https://www.gutenberg.org/cache/epub/61741/pg61741-images.html.

Crenshaw, Kimberle. "Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics." *University of Chicago Legal Forum*. Vol. 1 No.8 (1989)

Crenshaw, Kimberle. "Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color". *Stanford Law Review*. Vol. 43, No. 6 (1991)

Davidson, Michael. “Cripping Consensus: Disability Studies at the Intersection.” *American Literary History* Vol. 28, No. 2 (2016): pp.433–453.

Davis, Lennard J. “Identity Politics, Disability, and Culture”. In *Handbook of Disability Studies*, edited by Gary L. Albrecht, Katherine D. Seelman, and Michael Bury (Thousand Oaks, CA: Sage Publications, 2001)

Egner, Justine E.(2021) “Being LGBTQ+ and Disabled, a Socially Contradicting Experience”. In *The Oxford Handbook of the Sociology of Disability* edited by Robyn Lewis Brown (ed.), Michelle Maroto (ed.), David Pettinicchio (ed.) , pp.583.-608 (Oxford: Oxford University Press, 2021).

‘Equality Act 2010’, *UK Public General Acts* (2010). Available at: Equality Act 2010 (legislation.gov.uk) (accessed 09/05/2024)

Erevelles, N and A. Minear. (2010). Unspeakable offenses: Untangling race and disability in discourses of intersectionality. *Journal of Literary & Cultural Disability Studies*, Vol. 4, No.2, (2010): p.127-146.

Erkulwater Jennifer, L. “How the Nation’s Largest Minority Became White: Race Politics and the Disability Rights Movement, 1970–1980.” *Journal of Policy History*. Vol. 30, No.3, (2018) :367-399.

Evans, Elizabeth. “Political intersectionality and disability activism: Approaching and understanding difference and unity”, *The Sociological Review,* Vol. 70 No. 5 (2022)

Fadulu, Lola, and Gaya Gupta. "A Wave of Pride Lights Up New York City." The New York Times, June 30, 2024. https://www.nytimes.com/2024/06/30/nyregion/nyc-pride-parade.html. (accessed 04/01/2024)

Fleischer, Doris Zames and Frieda Zames. *The Disability Rights Movement: From Charity to Confrontation* (Philadelphia: Temple University Press, 2001)

Fominaya, Cristina. “Collective Identity in Social Movements: Central Concepts and Debates”. *Sociology Compass*. Vol. 4, No.6 (2010): pp. 393-404

Gamson, Joshua. “Messages of exclusion: Gender, movements, and symbolic boundaries.” *Gender & Society*, Vol. 11, (1997): pp.178-99.

Garland-Thomson, Rosemarie. “Integrating disability, transforming feminist theory.” *NWSA Journal*, Vol. 14, No. 3, Vol. 1, No.32. (2002).

Getova, Simona, and Christos Zografos. “Intersectional Praxis for Social-Ecological Transformations: Lessons from North Macedonia’s Grassroots Green Deal.” *Political Geography*, Vol. 113 (2024).

Gill, Carol. “Divided Understandings: The Social Experience of Disability,”. In *Handbook of Disability Studies*, edited by Gary L. Albrecht, Katherine D. Seelman, and Michael Bury, p.365–66.(Thousand Oaks, CA: Sage Publications, 2001)

Gilmore, Ruth. *Abolition Geography: Essays Toward Liberation*. (Brooklyn: Verso, 2022).

Goodley, Dan,. *Dis/Abilty Studies: Theorising disablism and ableism* (Routledge: Oxon, 2014)

Gordon, Linda. "'Intersectionality', Socialist Feminism and Contemporary Activism: Musings by a Second-Wave Socialist Feminist". *Gender & History*, Vol. 28 No.2 (August 2016): pp. 340–357.

Guffey, Elizabeth. *Designing Disability: Symbols, Space, and Society*. (London: Bloomsbury Academic, 2018.)

Hill Collins, Patricia and Sirma Bilge. *Intersectionality* (Cambridge: Polity Press, 2016)

Hiraide, Lydia Ayame and Elizabeth Evans. "Intersectionality and social movements: a comparison of environmentalist and disability rights movements". *Social Movement Studies*. (Jul 2023).

Hobson, Emily K. *Lavender and Red: Liberation and Solidarity in the Gay and Lesbian Left*. (Oakland: University of California Press, 2016.)

Hughes, Jennifer L., Abigail A. Camden, Tenzin Yangchen, Gabrielle P. A. Smith, Melanie M. Domenech Rodríguez, Steven V. Rouse, C. Peeper McDonald, and Stella Lopez. "Guidance for Researchers When Using Inclusive Demographic Questions for Surveys: Improved and Updated Questions." *Psi Chi Journal of Psychological Research* Vol. 27, no. 1 (Winter 2022): pp.1-13. https://research.usu.edu/irb/files/inclusivedemographics.pdf (accessed on 1/11/2024)

Inckle, Kay., James Brighton, and Andrew Sparkes. "Who is "Us" in "Nothing About Us Without US"? Rethinking the Politics of Disability Research." *Disability Studies Quarterly*, Vol. *42*, No. 3-4. (2023).

Lane, Harlan. "Construction of Deafness". In *The Disability Studies Reader*, edited by Lennard J. Davis, 2nd ed., pp.79-92. (New York: Routledge, 2006.)

Laub, Dori, *Testimony: Bearing Witness or the Vicissitudes of Listening*. (New York: Routledge, 1992).

Leavy, Patricia, ed. *The Oxford Handbook of Qualitative Research*. 2nd ed. (New York: Oxford University Press, 2020).

Lewis, John. *Walking with the wind*. (Boston: Mariner Books, 1999).

Linton, Simi. *Claiming disability : knowledge and identity* (New York: New York University Press, 1998)

Longmore, Paul, K. "The Second Phase: From Disability Rights to Disability Culture", *Independent Living Institute* (1995). Available at: The Second Phase: From Disability Rights to Disability Culture | Independent Living Institute (accessed 27/12/2024)

Lord, Janet E. "Mirror, Mirror on the Wall: Voice Accountability and NGOs in Human Rights Standard Setting." 5 Seton Hall Journal of Diplomacy and International Relations 93 (2004).

Luna, Zakiya. ‘Truly a women of color organization’: Negotiating sameness and difference in pursuit of intersectionality.” Gender & Society, Vol. 30 No. 5, (2016): pp.769–790.

Mansbridge, Jane. "Should Blacks Represent Blacks and Women Represent Women? A Contingent 'Yes'." *The Journal of Politics,* Vol. 61, no. 3 (August 1999): pp. 628-657.

Manuel Aramayo , Mark H. Burton , and Carolyn Kagan, “Revising and Using the Social Model in the Global South: A Venezuelan Exploration”. In *Disability in the Global South: The Critical Handbook* edited by Shaun Grech, and Karen Soldatic, pp. 517-530. (Cham: Springer Publishing, 2016)

Mattlin, Ben. *Disability Pride: Dispatches From A Post Ada World* (Boston: Beacon Press, 2023)

McCall, Leslie. ‘The Complexity of Intersectionality”. *Signs,* Vol. 30, (2005): pp. 1771–1800.

Meekosha, Helen and Andrew Jakubowicz. “Disability, Political Activism, and Identity Making: A Critical Feminist Perspective on the Rise of Disability Movements in Australia, the USA, and the UK”. *Society for Disability Studies* (2000)

Montessori, Nicolina Montesano. “Critical Policy Discourse Analysis”. In *The Routledge Handbook of Discourse Analysis,* edited by Michael Handford and James Paul Gee2nd ed. (London: Routledge, 2023): 610-624.

Montoya, Celeste. “Intersectionality and social movements: Intersectional challenges and imperatives in the study of social movements.” *Sociology Compass,* Vol. 1, No. 8 (2021)

Morris, Aldon. *The Origins of the Civil Rights Movement: Black Communities Organizing for Change* (New York, 1984).

Mulderink, Carrie Elizabeth. “The Emergence, Importance of #DisabilityTooWhite Hashtag.” *Disability Studies Quarterly*. Vol. 40 No. 2 (2020)

Nash, Kate, “Is It Social Movements that Construct Human Rights?” in Donatella della Porta and Mario Diani, eds., *The Oxford Handbook of Social Movements* (New York: Oxford University Press, 2017): 743-752.

Nielsen, Kim E. *A Disability History of the United States*. (Boston: Beacon Press, 2012)

Nishida, Akemi. “Understanding political development through an intersectionality framework: Life stories of disability activists”. *Disability Studies Quarterly.* Vol. 36, No.2 (2016)

Noy, Chaim. (2008). “Sampling knowledge the hermeneutics of snowball sampling in qualitative research.”. *International Journal of Social Research Methodology,* Vol. 11, (2008): pp. 327–344.

Oliver, Mike. “Identity and Difference by Kathryn Woodward Book Review”. *Disability & Society*. Vol. 14, No. 6 (Nov 1999): 875.

Oliver, Mike. *Capitalism Disability and Ideology: A Materialist Critique of the Normalization* (Leeds: University of Leeds, 1994)

Pearsall-Jones, Jillian , Caris Jalla and George Hayden. “Human Doing vs Human Being”. In *Looking towards the Future. Vol. 2 of Interdisciplinary Approaches to Disability Studies* edited by Katie Ellis, Rosemarie Garland-Thomson, Mike Kent, and Rachel Robertson, pp.131–141. (New York: Routledge, 2018.)

Peters, Susan. “Is There A Disability Culture? A Syncretisation Of Three Possible World Views”. *Disability & Society*, Vol. 15 No. 4, (July 2010): pp.583-601.

Peters, Susan. “The Politics Of Disability Identity”. In *Disability And Society: Emerging Issues And Insights* edited by Len Barton, (London: Routledge, 1996)

Piepzna-Samarasinha, Leah Lakshmi. *Care Work: Dreaming Disability Justice* (Arsenal Pulp Press, 2018)

Polletta, Francesca, and James M. Jasper. "Collective Identity and Social Movements." *Annual Review of Sociology.* Vol, 27 (2001): pp.283-305.

Portelli, Alessandro. “What makes oral history different?” In *The Death of Luigi Trastulli and Other Stories: Form and Meaning in Oral History* (Albany: State of New York Press, 2001)

Pruitt, Linda. “The Achievement (K)Not: Schools on the Couch”. In *Off White: Readings in Power, Privilege and Resistance,* edited by Michelle Fine, Lois Weis, Linda Powell Pruitt and April Burns, pp.235-245. (New York, NY: Routledge, 2004).

Reisigl, Martin and Ruth Wodak. “The Discourse-Historical Approach (DHA)”. In *Methods of Critical Discourse Studies*, edited by Ruth Wodak and Michael Meyer 3rd ed. 23-61. (Thousand Oaks: SAGE Publications, 2016)

Rogers, Annie, G. “Qualitative Research In Psychology: Teaching An Interpretive Process”. In *Up close and personal: The teaching and learning of narrative research*, edited by Ruthellen Josselson, Amia, Lieblich, and Dan P McAdams, pp.49-60. (Washington D.C.: American Psychological Association, 2003).

Roth, Silke. “Intersectionality and coalitions in social movement research—A survey and outlook”. *Sociology Compass* (2021). https://doi.org/10.1111/soc4.12885 (accessed 15/04/2024)

Schalk, Sami. *Black Disability Politics*. (Durham: Duke University Press, 2022.)

Scotch, Richard. “Politics and Policy in the History of the Disability Rights Movement”. *The Milbank Quarterly*. Vol. 67, No. 2 (1989): pp. 380-400.

Scotch, Richard and Kara Sutton. “The Disability Rights Movement”. In *The Oxford Handbook of the Sociology of Disability*, edited by Robyn Lewis Brown (ed.), Michelle Maroto (ed.), David Pettinicchio (ed.) pp.790-806. (Oxford: Oxford University Press, 2021)

Settles, Isis and Nicole T. Buchanan. “Multiple Groups, Multiple Identities, and Intersectionality”. In *The Oxford Handbook of Multicultural Identity* edited by Verónica Benet-Martínez and Ying-yi Hong (Oxford University Press, 2014)

Shapiro, Joseph. *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Times Books, 1993).

Shaw, Barrett. *Ragged Edge: The Disability Experience from the Pages of the First Fifteen Years of The Disability Rag*. (Louisville, KY: Advocado Press, 1994).

Sheldon, Alison. "Personal and perplexing: Feminist disability politics evaluated*." Disability & Society*. Vol. 14, (1999): pp.643–657.

Strickland, Christopher. "The Fight for Equality Continues." *Phylon* 59, no. 1 (Summer 2022): 71-90.

Strolovitch, Dara Z. *Affirmative Advocacy: Race, Class, and Gender in Interest Group Politics*. 1st ed. (Chicago: University of Chicago Press, 2007.)

Stulberg, Lisa M. *LGBTQ Social Movements*. (Cambridge, UK; Malden, MA: Polity Press, 2018.)

Teti, David and Salem Lorot. *Disability: Law and Rights.* (Nairobi: Sparrow Press Limited 2017)

Tregaskis, Claire. "Social Model Theory: The story so far". *Disability & Society*. Vol. 17, No. 4 (2002)

UN. "Convention on the Rights of Persons with Disabilities". UN Human Rights Office of the High Commissioner (2006). Convention on the Rights of Persons with Disabilities | OHCHR (accessed 08/05/2024)

United Nations. "Convention on the Rights of Persons with Disabilities." https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities. (accessed 04/12/2024)

US Rep. Ayanna Pressley & Rebecca Cokley. "There Is No Justice That Neglects Disability". *Standford Social Innovation Review* (2022). Center Disability Justice in Diversity, Equity, and Inclusion Efforts (ssir.org) (accessed on 23/04/2024)

Vernon, Ayesha. 'The Dialectics Of Multiple Identities And The Disabled People's Movement". *Disability & Society*, Vol. 14, No.3 (1999)

Watson, Nick. "Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person: Identity and disability". *Disability & Society*. Vol. 17, No. 5, (2002): pp.509–527.

Williams- Findlay, Bob. *Disability Praxis* (Pluto Press, 2024)

Wong, Alice. *Disability Visibility : First-Person Stories from the Twenty-First Century* (Vintage Publishing, 2020)

Ying, Robert. "When Intersectionality Hurts Effective Activism". *Aeturnalus*, (11 December 2015), http://aeturnalus.com/school/when-intersectionality-hurts-effective-activism/.=

Oral History Interviews

Bertaina, Beverly. “Disability Rights activist Beverly Bertaina on the 1977 Section 504 Occupation and being the mother of a disabled child”. Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: Disability Rights activist Beverly Bertaina on the 1977 Section 504 Occupation and being the mother of a disabled child - Paul K. Longmore Institute on Disability Collection (sfsu.edu) (accessed on 09/12/2024)

Billups, Dennis. “Disability rights activist Dennis Billups on the 1977 Section 504 Occupation”. Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: Disability rights activist Dennis Billups on the 1977 Section 504 Occupation - Paul K. Longmore Institute on Disability Collection (sfsu.edu) (accessed on 09/12/2024)

Brady, Judy. “Disability Activist Judy Brady on picketing at the 504 protests”. Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: Disability Activist Judy Brady on picketing at the 504 protests - Paul K. Longmore Institute on Disability Collection (sfsu.edu) (accessed on 09/12/2024)

Breslin, Mary Lou. “Disability Rights activist Mary Lou Breslin on her participation in the Section 504 protests”. Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: Disability Rights activist Mary Lou Breslin on her participation in the Section 504 protests - Paul K. Longmore Institute on Disability Collection (sfsu.edu) (accessed on 09/12/2024)

Brown, Elaine. “Leader of the Black Panther Party Elaine Brown talks about the Party's involvement and support of the 1977 Section 504 Occupation”. Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: Leader of the Black Panther Party Elaine Brown talks about the Party's involvement and support of the 1977 Section 504 Occupation - Paul K. Longmore Institute on Disability Collection (sfsu.edu) (accessed on 09/12/2024)

Cone, Kitty. “Disability Rights activist Kitty Cone on the 1977 Section 504 Occupation”. Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: Disability Rights activist Kitty Cone on the 1977 Section 504 Occupation - Paul K. Longmore Institute on Disability Collection (sfsu.edu) (accessed on 09/12/2024)

Cone, Kitty. “Political Organizer for Disability Rights, 1970s-1990s, and Strategist for Section 504 Demonstrations, 1977”. Interview conducted by David Landes in 1996-1998, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, (2000).Available at: Political Organizer for Disability Rights, 1970s-1990s, and Strategist for Section 504 Demonstrations, 1977 (cdlib.org) (accessed 09/12/2024)

Cranmer, Kathy. “Kathy Cranmer (Swami Suddhananda) on the experience of being a 504 protester”. Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: Kathy Cranmer (Swami Suddhananda) on the experience of being a 504 protester - Paul K. Longmore Institute on Disability Collection (sfsu.edu) (accessed on 09/12/2024)

D’Lil, Hollynn. “Disability Rights activist HolLynn D'Lil on her experience as a 1977 Section 504 Occupation photographer and protestor”. Paul K. Longmore Institute on

Disability, San Francisco State University, (2014). Available at: Disability Rights activist HolLynn D'Lil on her experience as a 1977 Section 504 Occupation photographer and protestor - Paul K. Longmore Institute on Disability Collection (sfsu.edu) (accessed on 09/12/2024)

Galloway, Donald. "The Independent Living Movement in Berkeley and Colorado: Blind Advocacy and Minority Inclusion'. Interview conducted by Fred Pelka in 2001, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, (2004). Available at: Blind Services and Advocacy and the Independent Living Movement in Berkeley (cdlib.org) (accessed 09/12/2024)

Grey, Gary. "Activist Gary Gray describes following coverage of the Section 504 protests remotely and the impact of the movement on disabled people of color". Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: Activist Gary Gray describes following coverage of the Section 504 protests remotely and the impact of the movement on disabled people of color - Paul K. Longmore Institute on Disability Collection (sfsu.edu) (accessed on 09/12/2024)

Heumann, Judith. "Pioneering Disability Rights Advocate and Leader in Disabled in Action". Interview conducted by Susan Brown, David Landes, Jonathan Young in 1998-2001, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, (2004). Available at:Pioneering Disability Rights Advocate and Leader in Disabled in Action, New York; Center for Independent Living, Berkeley; World Institute on Disability; and the US Department of Education, 1960s-2000 (cdlib.org) (accessed 09/12/2024)

Heumann, Judy. "Disability Activist Judy Heumann on being one of the key leaders of the Section 504 Protest". Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: Disability Activist Judy Heumann on being one of the key leaders of the Section 504 Protest - Paul K. Longmore Institute on Disability Collection (sfsu.edu) (accessed on 09/12/2024)

Jauregui, Joanne. "Deaf Disability Rights activist Joanne Jauregui on the 504 protests and the unique implications on the deaf community". Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: Deaf Disability Rights activist Joanne Jauregui on the 504 protests and the unique implications on the deaf community - Paul K. Longmore Institute on Disability Collection (sfsu.edu) (accessed on 09/12/2024)

Johnson, Bill. "Disability Rights activist Bill Johnson on the 1977 Section 504 Occupation". Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: Disability Rights activist Bill Johnson on the 1977 Section 504 Occupation - Paul K. Longmore Institute on Disability Collection (sfsu.edu) (accessed on 09/12/2024)

Magnan, Margaret Kocher. "Cofounder of the Boston Self Help Center and Massachusetts Coalition of Citizens with Disabilities; Director of the Project in Self Advocacy". Interview conducted by Fred Pelka in 2003, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, (2004).Available at: Massachusetts Activists and Leaders in the Disability Rights and Independent Living Movement, Volume III (cdlib.org) (accessed on 09/12/2024)

O'Toole, Corbett. “Advocate for Disabled Women's Rights and Health Issues”. Interview conducted by Denise Sherer Jacobson in 1998, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, (2000). Available at: Advocate for Disabled Women's Rights and Health Issues (cdlib.org) (accessed on 09/12/2024)

Parker, Ally Karen. “Ally Karen Parker on the 1977 Section 504 Occupation”. Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: https://diva.sfsu.edu/collections/longmoreinstitute/bundles/231040 (accessed on 09/12/2024)

Pelka, Fred. *What Have We Done: An Oral History of the Disability Rights Movement* (University of Massachusetts Press, 2011)

Rose, Karen. “Protester Karen Rose on the 1977 Section 504 Occupation of the Federal Building”. Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: https://diva.sfsu.edu/collections/longmoreinstitute/bundles/231040 (accessed on 09/12/2024

Ryan, Barry. “Disability Rights activist Barry Ryan on the 1977 Section 504 Occupation”. Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: Disability Rights activist Barry Ryan on the 1977 Section 504 Occupation - Paul K. Longmore Institute on Disability Collection (sfsu.edu) (accessed on 09/12/2024)

Sygall, Susan. “Cofounder and Director of Berkeley Outreach Recreation Program and Mobility International USA, Advocate for Women's Issues.” Interview conducted in 1998 by Kathryn Cowan, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, (2000). Available at: Cofounder and Director of Berkeley Outreach Recreation Program and Mobility International USA, Advocate for Women's Issues (cdlib.org) (accessed 09/12/2024)

Washington, Ron. “Activist Ron Washington on the Section 504 protests and Civil Rights”. Paul K. Longmore Institute on Disability, San Francisco State University, (2014). Available at: Activist Ron Washington on the Section 504 protests and Civil Rights - Paul K. Longmore Institute on Disability Collection (sfsu.edu) (accessed on 09/12/2024)

Other Historical Sources

Iman, Asata, producer. "We Shall Not be Moved: The 504 Sit-In for Disability Civil Rights." Audio documentary. Disability Rights Education & Defense Fund. (June 1, 1997.) https://dredf.org/.

Kriegel, Leonard. "Uncle Tom And Tiny Tim: Some Reflections On The Cripple As Negro." *The American Scholar*. United Chapters of Phi Beta Kappa, 1969. Available at: disability history museum--"Uncle Tom And Tiny Tim: Some Reflections On The Cripple As Negro" (accessed 15/12/2024)

Wright, Tennyson J. and Paul Leung, “Minorities with Disabilities: An Introduction,” in *The Unique Needs of Minorities with Disabilities: Setting an Agenda for the Future, Conference Proceedings*, edited by Wright and Leung, The National Council on Disability and Jackson State University, cosponsors, May 6–7, 1992.

Films/ Documentaries

Aronson, Josh, director. *Sound and Fury*. (New Films International, 2000.)

Newnham, Nicole and James LeBrecht, directrors. *Crip Camp: A Disability Revolution*. (2020).

Disability Rights Group Websites

ADAPT. "ADAPT Handbook." 2017. https://adapt.org/wp-content/uploads/2017/05/ADAPT-handbook-2017.pdf. (accessed 04/12/2024)

Center for Disability Rights. "Vision & Mission." https://cdrnys.org/about/vision-mission/.(accessed 04/12/2024)

Center for Independence of the Disabled, NY. "CIDNY 2022-23 Annual Report." https://www.cidny.org/wp-content/uploads/2024/03/CIDNY-2022-23-Annual-Report.pdf. (accessed 04/12/2024)

Disabled In Action of Metropolitan New York. "Nothing about us, without us!" Disabled In Action of Metropolitan New York. https://www.disabledinaction.org/. (accessed 06/01/2025)

Disability Rights Advocates. "Advancing Equal Rights for People with All Types of Disabilities Nationwide." https://dralegal.org/. (accessed 04/12/2024)

Disability Rights New York. “2023 Annual Report”. https://www.drny.org/page/annual-reports-58.html. (accessed 04/12/2024)

Enns, Henry. "The Role of Organizations of Disabled People: A DPI Discussion Paper." *Independent Living Institute.* https://www.independentliving.org/docs5/RoleofOrgDisPeople.html. (accessed 13/12/2024)

National Council on Independent Living. "2022-2023 Final Annual Report." https://ncil.org/wp-content/uploads/2024/11/2022-2023-Final-Annual-Report.pdf. (accessed 04/12/2024)

National Council on Independent Living. "NCIL Guiding Principles." . https://ncil.org/about/ncil-guiding-principles/. (accessed 04/12/2024)

National Disability Rights Network. "Staff & Leadership." https://www.ndrn.org/about/staff-leadership/. (accessed 04/12/2024)

New York City Mayor's Office for People with Disabilities. "About." https://www.nyc.gov/site/mopd/about/about.pa (accessed 04/12/2024)

New York City Mayor's Office for People with Disabilities. "DCP Population with a Disability 2021 ACS 5-Year Estimates." https://view.officeapps.live.com/op/view.aspx?src=https%3A%2F%2Fwww.nyc.gov%2Fassets%2Fmopd%2Fdownloads%2Fexcel%2Fdcp-pop-with-a-disability-2021ACS5yr.xlsx&wdOrigin=BROWSELINK. (accessed 04/12/2024)

New York State Independent Living Council. "Summative Review of 2022 SPIL Criteria." https://view.officeapps.live.com/op/view.aspx?src=https%3A%2F%2Fnysilc.org%2Fresources%2Fkey-documents%2F410-summative-review-of-2022-spil-criteria%2Ffile&wdOrigin=BROWSELINK. (accessed 04/12/2024)

Olmstead Rights. "New York Disability Resources and Advocacy Organizations." https://www.olmsteadrights.org/self-helptools/advocacy-resources/item.6474-New_York_Disability_Resources_and_Advocacy_Organizations. (accessed 12/12/2024)