

**WHO'S AT THE TABLE? THE HOMOGENIZATION OF CRIP QUEERS IN
DECISION-MAKING AND POLICY-MAKING PROCESSES**

by

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Abstract

The ways that disabled persons are represented in mainstream media, as well as political and social institutions, are shifting. A significant contributor has been the field of critical disability studies, in which disabled persons are viewed through intersectional lenses instead of hegemonic ones. It brings forth discussions that would otherwise remain silenced by dominant narratives – but the marginalization of disabled persons still prevails, particularly within the realms of sexuality.

There is an evident intersection between disability and sexuality, and while more scholars are taking it up, there remains a gap in literature that readily addresses it. Disabled persons are accordingly being portrayed as non-sexual. In instances where their sexuality is acknowledged, they are frequently deemed as heterosexual – which omits the realities of individuals who experience intersectional key dimensions of marginalization, such as disability and sexuality. Individuals self-identifying as crip queers experience further marginalization because they are readily excluded from decision-making and policymaking process. This is evident with the implementation of the Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol (OP).

Crip queers are readily attempting to disrupt the ways that they are constantly portrayed through the means of organizing collective and social movements, such as Sins Invalid – a performative project centering intersectional experiences of disabled persons as well as members of other equity-seeking groups. Specifically, these movements are using various art platforms to exemplify accurate encounters of crip queers within contemporary society. In doing so they amplify struggles and triumphs that they readily experience to dismantle ableist beliefs and misconceptions perpetuated upon them.

Keywords: Activism; Crip; Crip Theory; Critical Disability Theory; CRPD; Disability Justice; Queerness; Queer Theory.

For my father.

Il y a longtemps que je t'aime. J'aurais jamais je ne t'oublierai.

For Élodie.

Honored to be part of your journey.

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List of Abbreviations

CRPD	Convention on the Rights of Persons with Disabilities
LGBTQ2S+	Lesbian, Gay, Bisexual, Trans, Queer/Questioning, Two-Spirit, Intersex, Pansexual, Androgynous, Asexual
OP	Optional Protocol of the Convention on the Rights of Persons with Disabilities
UN	United Nations

Chapter 1

Introduction

The emergence of critical disability studies challenged dominant assumptions imposed upon disabled people and normative ways of thinking about disability communities, both in academia and throughout the greater society. Although critical disability studies has fostered important dialogue pertaining to disability, it represents a Eurocentric and homogenous narrative that does not accurately represent the lived experiences of disabled persons. Shaun Grech¹ and Helen Meekosha², amongst other disability scholars, identify these marginalizing narratives within the field of critical disability studies, but these gaps most often address the intersection between disability and poverty, as well as disability and race – not disability and queerness. Hence, disability frameworks reinforce the marginalization that is already perpetuated upon crip queers.

Together, Alison Kafer³, Robert McRuer⁴, and Leah Piepzna-Samarasinha⁵, have engaged with disability and sexuality simultaneously, rejecting normalization through affirmative crip and queer politics. Crip politics refers to a critical reaffirmation and reformulation of disability, which ultimately challenges ableism and understandings of

¹ Grech, “Recolonising Debates or Perpetuated Coloniality? Decentring the Spaces of Disability, Development and Community in the Global South”; Grech, “Comment from the Field: Disability and the Majority World: Challenging Dominant Epistemologies”; Grech, “Decolonising Eurocentric Disability Studies: Why Colonialism Matters in the Disability and Global South Debate.”

² Meekosha, “Decolonising Disability: Thinking and Acting Globally.”

³ Kafer, *Feminist, Queer, Crip*.

⁴ McRuer, “As Good as It Gets: Queer Theory and Critical Disability”; McRuer, *Crip Theory: Cultural Signs of Queerness and Disability*; McRuer, “Taking It to the Bank: Independence and Inclusion on the World Market”; McRuer, “Disabling Sex: Notes for a Crip Theory of Sexuality”; McRuer, “The Then and There of Crip Futurity”; McRuer, *Crip Times : Disability, Globalization, and Resistance*.

⁵ Piepzna-Samarasinha, *Care Work : Dreaming Disability Justice*.

disability as a bioeconomic loss. There remains, however, a gap of research depicting the lived experiences of crip queers. This is ultimately reflected in international disability policies, which ultimately impede the creation of meaningful opportunities for political and social participation for crip queers. For instance, important international disability development policies like the Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol (OP), do not accurately respond to multiple marginalizing experiences faced by crip queers. Hence, through this thesis, my goal will be to apply these same crip and queer politics to marginalizing policy frameworks in the CRPD and OP.

My research interest stems from my academic and personal lives. Some of my undergraduate work was interwoven between community engagement and the ways in which disabled persons were represented in international disability policies. I travelled to three different countries (in both the ‘Global North’ and the ‘Global South’) during my undergraduate studies and, through these experiences, I developed an interest in unpacking disability narratives and representations and analyzing how the CRPD, and its OP, was influenced by colonialism. After much deliberation, I decided to dedicate my master’s thesis to pursue both interests, and ultimately analyze how (mis)representation of disability communities are applied in the conceptualizations and enactment of international disability policies – particularly the CRPD and OP.

Chapter Three (“Disability: The Tale of Homogeneous Narratives”) has been constructed from my experiences as a student in the field of critical disability studies. Most texts presented to me in courses were placing disabled persons within a homogenous community, where intersecting lived experiences were not presented in the

scope of these disability research projects. This chapter analyzes critical disability studies literature, derived from both the ‘Global North’ and ‘Global South’, to demonstrate how disability is constantly being (mis)represented, to analyze how theoretical models of disability perpetuate this (mis)representation, and finally to unpack how disabled persons are being engaged through decision-making and policy-making processes.

The fourth chapter (“Does an International Sphere of Crip Queers Even Exist?”) stems exclusively from personal interest and is the one I enjoyed writing the most – but that of which I had the least background knowledge. Before this thesis, I had yet to engage with the intersecting history of disability and queerness, in both local and global contexts, and most particularly with its prominent scholarship. Chapter four looks to scholars such as Kafer⁶, McRuer⁷, and Piepzna-Samarasinha⁸, each of whom challenge the single-axis framework that has come to dominate white, homogenous, northern critical disability studies. This chapter is particularly interested in moving from a politics premised on architectural inclusion (like the social model of disability), to a politics of desire, analyze current disability and sexuality scholarship through a queer theory lens.

The fifth chapter (“*All For us Without us: Where is the Pride at (Homogenous) International Decision-Making Tables?*”) has two goals: firstly, to represents my interest in inclusive and meaningful policy engagement for disabled persons, which is ultimately where my desire to write this thesis first derived; and secondly, my urge to understand how the CRPD and its OP (mis)represent narratives and needs of crip queers. Here I look

⁶ Kafer, *Feminist, Queer, Crip*.

⁷ McRuer, “As Good as It Gets: Queer Theory and Critical Disability”; McRuer, *Crip Theory: Cultural Signs of Queerness and Disability*; McRuer, “Taking It to the Bank: Independence and Inclusion on the World Market”; McRuer, “Disabling Sex: Notes for a Crip Theory of Sexuality”; McRuer, “The Then and There of Crip Futurity”; McRuer, *Crip Times : Disability, Globalization, and Resistance*.

⁸ Piepzna-Samarasinha, *Care Work : Dreaming Disability Justice*.

to policy frameworks to substantiate my more theoretical work in an empirical case to implement the previous two chapters in practice. As such the fifth chapter explores the international policy landscape to make my overall case. I argue that anti-oppressive frameworks should be more intentionally be embedded in the CRPD and its OP so that these international policies recognize and address prevalent gaps in resources and services for multiply marginalized persons, specifically crip queers. I will specifically look to the following articles of the CRPD for my analysis: ‘Awareness-raising’ (Article eight), ‘Education’ (Article twenty-four), ‘Health’ (Article twenty-five), as well as ‘Participation in cultural life, recreation, leisure and sport’ (Article thirty).

Chapter 2

Literature Review

Disability Theoretical Frameworks

Katie Ellis, Rosemarie Garland-Thomson, Mike Kent, and Rachel Roberston's⁹ edited collection explores fundamental debates and tensions within the field of critical disability studies through interdisciplinary and intersectional lenses to ultimately deconstruct homogenous views of disability. Dan Goodley¹⁰ highlights how critical disability studies first emerged by applying different frameworks and theories to disabilities, frameworks that continue constitute the field's founding ideologies. These include the medical model, the social model, and so on, to be explored in further detail below. Similarly, Tobin Siebers¹¹ argues that key attributes of critical disability studies must be unpacked using intersectional frameworks, such as critical race theory and queer theory. Both Mia Mingus¹² and Liz Crow¹³, through ethnographical pieces, illustrate gaps that are readily apparent in disability theoretical frameworks. Here a quick statement on the models used throughout the thesis is in order.

Biopsychosocial Model

George L. Engel¹⁴ proposes the biopsychosocial model as an alternative way of researching and thinking about healthcare in order to include behavioral, psychological,

⁹ Ellis et al., *Interdisciplinary Approaches to Disability: Looking Towards the Future*.

¹⁰ Goodley, "Dis/Entangling Critical Disability Studies."

¹¹ Siebers, *Disability Theory*.

¹² Mingus, "Access Intimacy: The Missing Link"; Mingus, "Changing the Framework : Disability Justice How Our Communities Can Move beyond Access to Wholeness."

¹³ Crow, "Including All of Our Lives: Renewing the Social Model of Disability."

¹⁴ Engel, "The Clinical Application of the Biopsychosocial Model"; Engel, "The Need for a New Medical Model: A Challenge for Biomedicine."

and social dimensions in the discussion. The model suggests that an individual's disability is not only defined by the physical condition itself, but also by society's construction of and response towards disabled persons. Ultimately, the biopsychosocial model removes the onus from disabled persons themselves, as well as the healthcare system, and attributes it to other social institutions – such as decision-making and policymaking processes. A comparison is drawn between the biomedical and biopsychosocial models to explain existing flaws within the healthcare system, and ultimately how the biopsychosocial model can be applied to challenge normative ways of thinking. Derek Bolton and Grant Gillet's¹⁵ text offer a more contemporary overview of Engel's biopsychosocial model by locating it within humanities and pure sciences. Through their text, Bolton and Gillet argue that the biopsychosocial model is deeply flawed and thoroughly unpack its supposedly-critical sentiment.

Disability Justice Model

The disability justice model dismantles the preconception that disabled persons represent a homogenous community. It recognizes therefore that disabled persons are not only marginalized by disablement, but other key dimensions as well, such as geography and sexuality – some of which are not always examined within disability policies and service delivery practices. Patty Berne's¹⁶ founding text illustrates how the disability justice model, under the influence of scholars and international disability movements, was first conceived as a reputable framework. Berne also notes the reality that disability justice organizers and scholars are predominantly disabled persons with intersectional

¹⁵ Bolton and Gillett, *The Biopsychosocial Model of Health and Disease : New Philosophical and Scientific Developments*.

¹⁶ Berne, "Disability Justice - A Working Draft."

lived experiences. Sins Invalid¹⁷, in applying the disability justice framework in artistic and political practice, adds the fact that disability justice reinforces the relationship between ableism and other forms of oppression. Thus, multiple and multiply marginalized communities must work together in order to alleviate oppression and stigma. The disability justice model suggests that disability movements remain, at times, framed by colonialized beliefs pertaining to disability, and traditionally neither acknowledge nor represent the realities of multiply marginalized persons. Stefanie Snider's¹⁸ text analyzes the impacts of disability justice in queer activism. The scholar explores the intersecting lived experiences of disabled individuals, queer individuals, as well as crip queers.

Human Rights Model

The human rights model of disability fosters processes of inclusive decision- and policy-making, ensuring that disabled persons have access to the same rights as their non-disabled counterparts. This model was first created in tandem with the CRPD and its OP. Anna Lawson and Angharad E. Beckett¹⁹ argue that, while both disability theoretical models are distinct from one another, the human rights model and social model do not work against one another, but rather in tandem to generate international disability policies – such as the CRPD and its OP. They also challenge the comparison that is prominently drawn between both models by reinforcing how they complement each other in the realm

¹⁷ Sins Invalid, “What Is Disability Justice?”

¹⁸ Snider, “Moving toward Disability Justice: Introduction to ‘Lesbian Lives, Disabled Lives.’”

¹⁹ Lawson and Beckett, “The Social and Human Rights Models of Disability: Towards a Complementarity Thesis.”

of human rights. Contrastingly, Theresia Degener's²⁰ texts position the human rights model as an improvement of the social model and claim that it is a tool to shape and monitor the CRPD and its OP. The scholar notes, however, that most signatories do not yet comprehend the human rights model's framework and accordingly still view disability through a medical model lens.

The Medical Model

The medical model encapsulates the way in which disability is constructed within healthcare fields – as something that should be rehabilitated and changed to conform to social norms. Disability, through this model, is often regarded as a deficiency, and disabled persons are often victimized as a result. Critical disability studies attempts to dismantle this perception by removing the ownness of disability from disabled persons themselves and attributing it to policies and social institutions that ultimately reinforce the marginalization and stigmatization of disabled persons. Andrew J. Hogan²¹ identifies the origins of the medical model and highlights various proponents that shaped how the model is perceived in contemporary society. The scholar's thorough discussion engages with other disability theoretical models, such as the biopsychosocial and social models, which ultimately shapes critiques outlined throughout the piece. Yeng Wally²² provides a brief narrative that illustrates how the medical model can become detrimental to the lives of disabled persons, especially throughout the 'Global South' where healthcare is already scarce for marginalized persons.

²⁰ Degener, "A Human Rights Model of Disability"; Degener, "Inclusive Equality and the Human Rights Model of Disability – 10 Years Jurisprudence of the United Nations Committee on the Rights of Persons with Disabilities Introduction."

²¹ Hogan, "Social and Medical Models of Disability and Mental Health: Evolution and Renewal."

²² Wally, "Disability: Beyond the Medical Model."

Social Model

The social model highlights the differentiation between disability, a state that society inflicts upon individuals as a result of disablement, and individuals' diagnoses or medical conditions, which are referred to as 'impairment'. Similar to the human-rights model, the social model recognizes the barriers that are imposed upon disabled persons, which amplifies the marginalization and stigmatization faced by these individuals. Maria Berghs, Karl Atkin, Chris Hatton, and Carol Thomas²³ examine the origins and legacy of the social model, and claim that it continues to impede political and social engagement opportunities of disabled persons. They assert the need for an alternative model that would ultimately ensure complete and meaningful participation for all individuals within disability communities and the greater society.

In contrast to Berghs et al., Christopher A. Riddle²⁴ argues that the social model need not be replaced because it accurately represents the needs of disabled persons. Rather, Riddle argues this model should work in parallel with the disability justice model to implement disability policies in a more meaningful manner. Tom Shakespeare's²⁵ *Disability Rights and Wrongs* delves extensively into the conceptualization and application of the social model. The scholar warns about dangers of the social model in political actions and discusses the challenges inflicted upon both critical disability studies and the disability movement. Finally, Mike Oliver²⁶ reflects on how the social model has been shaped since writing the first introductory book thirty years ago. The scholar

²³ Berghs et al., "Do Disabled People Need a Stronger Social Model: A Social Model of Human Rights?"

²⁴ Riddle, "Why We Do Not Need a 'Stronger' Social Model of Disability."

²⁵ Shakespeare, *Disability Rights and Wrongs*.

²⁶ Oliver, "The Social Model of Disability: Thirty Years On."

discusses the model's potential for improving the daily lives of disabled persons while addressing some critiques that have emerged against the model.

Queer Theoretical Framework

Annamarie Jagose²⁷, as well as Chrysanthi Nigianni and Mel Storr²⁸, have written foundational texts in queer theory, central to my analysis below. They chart both the emergence of queer theory, and its influence within other scholarly fields, by engaging with scholars, such as Judith Butler. Robert McRuer's²⁹ texts, while also providing some groundwork, address the history of intersectionality between disability and queerness to then explore the presence (or lack thereof) of crip queers' narratives in contemporary international discussions and scholarship. Mark Sherry³⁰ draws similarities and differences between the fields of critical disability studies and queer theory, and specifically illustrate how they both use performativity as a fundamental concept.

Colonialism

Claire Barker and Stuart Murray³¹, bridging both critical disability studies and postcolonial studies, highlight the reality that disabled narratives are not represented adequately in postcolonial scholarship. Shaun Grech³² argues that colonialism, disability, as well as development practices are inevitably all intertwined, and that ultimately international disability debates cannot dismiss the impacts of colonialism upon the lived

²⁷ Jagose, *Queer Theory: An Introduction*.

²⁸ Nigianni and Storr, *Deleuze and Queer Theory*.

²⁹ McRuer, "As Good as It Gets: Queer Theory and Critical Disability"; McRuer, *Crip Theory: Cultural Signs of Queerness and Disability*.

³⁰ Sherry, "Overlaps and Contradictions between Queer Theory and Disability Studies."

³¹ Barker and Murray, "Disabling Postcolonialism: Global Disability Cultures and Democratic Criticism."

³² Grech, "Decolonising Eurocentric Disability Studies: Why Colonialism Matters in the Disability and Global South Debate."

experiences of disabled persons. Julian Go³³ explores the waves of postcolonial theory to analyze how universal social theories have been conceptualized through dominant narratives and offers alternative means of studying interactions between individuals with differing lived experiences.

Intersectionality

Crenshaw³⁴, the scholar who first coined the term ‘intersectionality’, writes an essay that identifies the various key dimensions experienced by black womxn and explores the limits imposed by this theory. Hill Collins and Bilge³⁵ further unpack the history of intersectionality and analyze its application in international key debates, such as identity and globalization. Intersectionality was initially conceived to address multiple forms of exclusion faced by individuals, and yet disability is still largely absent from these discussions. Recently, conversations about disability and poverty, as well as disability and race, have been more frequent. There remains, however, a gap in knowledge about disability and sexuality – particularly in decision-making and policy-making processes.

Globalization

Helen Meekosha³⁶ is critical of critical disability studies for omitting narratives of disabled persons living in the ‘Global South’, and therefore being only grounded in the northern perspective of disability. Similarly, Nirmala Erevelles³⁷ depicts the representation of disability that is continuously perpetuated by critical disability studies,

³³ Go, *Postcolonial Thought and Social Theory*.

³⁴ Crenshaw, “Normative Discrimination and the Motherhood Penalty.”

³⁵ Hill Collins and Bilge, *Intersectionality*.

³⁶ Meekosha, “Decolonising Disability: Thinking and Acting Globally.”

³⁷ Erevelles, *Disability and Difference in Global Contexts: Enabling a Transformative Body Politic*.

by exploring the lived experiences of disabled persons on an international scale. Helen Meekosha and Karen Soldatic³⁸ analyze how the CRPD and its OP are firmly rooted in knowledge and theories derived from the ‘Global North’ – that of which lived experiences of the ‘Global South’ differ immensely.

In sum, disability scholars have argued that there is no singular experience of disability – despite often being represented as such in research and international development processes. There exists a foundational framework in the realms of disability and sexuality, but it seldom extends beyond that. This generates spaces where the existence of crip queers is not encouraged, especially in spaces of decision-making and policymaking. In the next chapter, I will begin this argument by investigating the (mis)representation of disability in disability studies.

³⁸ Meekosha and Soldatic, “Human Rights and the Global South: The Case of Disability.”

Chapter 3

Disability: The Tale of Homogeneous Narratives

3.1 Introduction

In this chapter, I assert that marginalization experienced by disabled persons is related to the power exerted upon them by historical frameworks – most particularly colonialism and homogeneity. Societal perceptions of disability (in both the Global North and Global South) were, and remain, a direct result of colonialism. Eurocentric (mis)representations of disability impacts involvement opportunities for disabled persons in decision-making and policymaking processes. Conclusively, international perceptions of disability cannot be understood without acknowledging the impacts of narratives, policies, and scholarship that are continuously derived from the Global North, as well as analyzing the power dichotomy between various countries.

Firstly, I will explore how disability studies operates through a colonial structure. I will then demonstrate that Eurocentric knowledge impacts how disabled persons in both the ‘Global North’ and ‘Global South’ are engaged with in both decision-making and policy-making processes – and will specifically draw connections to crip queers. Finally, I will analyze how prominent theories of disability, such as the medical and social models, misrepresent the intersectional narratives of disabled persons on an international level

3.1.1 Debate / Problem

Critical disability studies, primarily shaped by ideologies of the Global North, has emerged as a homogenous field that readily ignores diversity within disability communities in not only Global South – but also throughout colonized countries. The

historical impact of disability, that remains prevalent on an international scale, has been largely constructed (and continue to be imposed) by colonialism and neocolonialism. Prominent theories produced by critical disability studies, such as the medical model and social model, homogenize how disability is constructed. Critical disability studies have made strides to include other forms of marginalization, but have yet to fully explore disability and queerness. Though theoretical work grounded in both queer theory and disability studies has emerged in the past few years, critical disability studies has yet to encourage the participation of crip queers since their intersecting identities are not acknowledged in dominant representation. As such, international disability discourses remain products of neocolonialism, the outcome of Eurocentric knowledge.

There is much debate within theories of disability and coloniality about the problem of representation. I use three texts to provide an overview of the debate of disability representation: Shaun Grech's *Recolonising Debates or Perpetuated Coloniality?*³⁹, Julian Go's *Postcolonial Thought and Social Theory*⁴⁰, and Robert McRuer's *Crip Theory*⁴¹.

Firstly, Grech engages with normative theoretical frameworks that are continuously applied within critical disability studies, such as neo-liberalism and post-colonialism, to demonstrate the ways in which conceptualizations of disability remain products of power. The author notes that northern ideologies pertaining to disability studies are transferred to the Global South, despite the fact that southern populations do

³⁹ Grech, "Recolonising Debates or Perpetuated Coloniality? Decentering the Spaces of Disability, Development and Community in the Global South."

⁴⁰ Go, *Postcolonial Thought and Social Theory*.

⁴¹ McRuer, *Crip Theory: Cultural Signs of Queerness and Disability*.

not have the same lived experiences with disability. Grech ultimately calls for a global critical disability studies that represent the diversity within disability communities.

Secondly, Go invites scholars from all fields to consider how the postcolonial theory has shaped research and contemporary ways of thinking. The author does not specifically address critical disability studies, however the arguments articulated in the text about postcolonial thought and social theory can be applied to this field – and ultimately this can help explain both the apparent gaps and discourses in disability studies.

Thirdly, McRuer uses Foucault's work to interrogate the ways in which both disability identity and queer identity are conceptualized in neoliberalism. The author critiques critical disability studies for the absence of scholarship pertaining to the connection amongst disability and queer theory. McRuer also argues that disability studies has yet to unpack sites of representation. Furthermore, the author explores disability and queer social movements as heterogeneous sites of both identity and exclusion.

3.2 Beginnings of Disability Studies

Historical Movements.

The field of disability studies was born out of movements in both the United Kingdom and the United States, starting in the 1950s (and continuing past the 1970s), as a response to social isolation and marginalization experienced by disabled persons. In 1972, for instance, Paul Hunt mobilized the Union of the Physically Impaired Against Segregation (UPIAS) – an organization whose *Fundamental Principles* were used for the

development of the social model.⁴² Movements in the United Kingdom and United States were spearheaded by disabled persons themselves and their allies. Activists and scholars sought to articulate the impacts of oppression and stigmatization upon the daily lives of disabled persons, and accordingly provide awareness to dismantle social injustices perpetuating ableist beliefs.

In 1975, the first Disability studies graduate program was offered by Antioch University West, in conjunction with the Center for Independent Living in Berkeley, California.⁴³ The student body was comprised almost exclusively of disabled persons and their professors were affiliated with disability communities – either by membership or allyship. Students were introduced to new concepts about advocacy, the disability rights movement⁴⁴, as well as theoretical knowledge, all the while participating in meaningful discussions with key disabled and non-disabled activists and scholars. It was one of the first instances where they actively engaged together to help reduce barriers inflicted upon disability communities. This program was a pillar for disability studies, and it has continuously helped shape subsequent programs on an international level. It is now interdisciplinary and seek to reduce gaps in disability representation within other scholarly fields. Disability studies convey ways of understanding disability that actively disrupts ableist and powerful political and social structures and has become a discipline

⁴² Marshall, Kendall, and Banks, *Disabilities: Insights from Accross Fields and Around the World*.

⁴³ The Disability Studies Master's program at Antioch University West was created by disability rights scholar, Hal Kirshbaum. (O'Toole, *Fading Scars: My Queer Disability History*.)

⁴⁴ Please refer to chapter four of this thesis, as it presents an overview of international and intersectional disability movements.

“that follows ideas and connections wherever they lead, instead of following them only as far as its border.”⁴⁵

Theoretical Models and their Complexities.

Two primary models form the essence of disability theory: the medical (or individual) model and the social model⁴⁶. These contrasting models were developed when Disability studies first emerged and have not truly evolved since then. They are thus still reflecting previous ways of thinking about disability, and the ways in which ableism and disablism affect disabled persons. Responses offered by both the medical and social models remain tailored to dominant representations of disability (the white heterosexual male), and thus exhibit hegemony.

The social model, as argued above, neglects to consider how individuals are impacted by their impairment, but rather puts the onus upon the barriers readily imposed by society.⁴⁷ Identities of disabled persons are thus reduced to exclusion, and disablement is the only factor deemed important in the equation. Consequently, when applying the social model to research, scholars are dismissing additional layers that exist within the overarching disability experience – including cultural and intersectional components.⁴⁸

While the medical model is typically perceived as a stark contrast to the social model, it adopts a similar way of thinking about disability. Its responses to disability are solely connected to the medical experiences of disabled persons, and thus Shakespeare

⁴⁵ Grech, “Comment from the Field: Disability and the Majority World: Challenging Dominant Epistemologies” 97-98.

⁴⁶ Oliver, “The Social Model of Disability: Thirty Years On”; Shakespeare, *Disability Rights and Wrongs Revisited*.

⁴⁷ Gill and Schlund-Vials, *Disabil. Hum. Rights Limits Humanit.* 122

⁴⁸ Artiles, “Untangling the Racialization of Disabilities: An Intersectionality Critique across Disability Models.” 331

notes that both the medical and social models’ “approaches are reactionary.”⁴⁹ The medical model is yet another perspective that does not acknowledge the complexities existing within the lives of disabled persons. As a result, these disability models are only relevant in specific circumstances of the past and “disabled persons now urgently need a new stronger tool for justice, rights and entitlements in society.”⁵⁰

Normative Disability Studies

Conventional academic forms in general are normalizing and reproduce systems of power and oppression. One’s positionality is not always addressed when participating in research and applying critical theory; ultimately, this perpetuates othering⁵¹ and reinforces existing social hierarchies within academy. Marginalization is further pronounced when members of equity-seeking groups are involved in the equation, and this can be illustrated by dissecting the core foundation of disability studies. Chris Bell⁵² accurately describes the field as “white disability studies”, but the othering and social hierarchies exhibited within disability studies extends beyond that of race and should be acknowledged as such.

While disability studies scholars often attempt to disrupt the power that is exhibited through normalcy, it views disability as a monolith experience – one that is rooted within colonialism, hegemony, and heterogeneity. Normalcy refers to the binary existing between disabled and non-disabled individuals, and structures that maintain it.

⁴⁹ Shakespeare, *Disability Rights and Wrongs Revisited*. 236

⁵⁰ Berghs et al., “Do Disabled People Need a Stronger Social Model: A Social Model of Human Rights?” 1037-1038

⁵¹ According to Huhana Hickey., “the process of 'othering' is applied to identities that fit outside the concept of what is perceived as natural, and leads to the negative fears around disability identity”. Hickey, “Marginalizing the Subaltern Within: How to Effectively Engage with and Monitor Diverse Cultural Identities with Disabilities When Individual Identity Dominates the Collective Identity Framework,” 230.

⁵² Bell, “Introducing White Disability Studies: A Modest Proposal.”

Those who embody normalcy through their behaviors and perceptions are identified as ‘normates’⁵³ since they can ultimately “step into a position of authority and wield the power it grants them.”⁵⁴ By applying such a homogenous lens to their scholarship, Disability studies subtly reinforces the value attributed to normalcy in representation, as well as decision-making and policymaking processes, instead of readily disrupting it. Normalcy perpetuates the belief that individuals who do not adhere to norms are in fact perceived as objects of divergence, and thus secluded from meaningful participation in society. Normalcy illustrates the binary that continuously exist between disabled and non-disabled persons and focuses on the oppression inflicted on the former as a result⁵⁵. Christopher Bell, Lennard J. Davis, and Nirmala Everelles, among other scholars, have asserted that normalcy is inexplicably intertwined in disability studies⁵⁶. Ultimately, the research derived from disability studies scholars often privileges a unified lived experience that does not exist and, by default, intentionally disregards any experience that differs from it.

Postcolonial Practices of Disability Studies.

Mark Sherry is one of the many disability studies scholars charting the impacts of postcolonialism upon disabled persons. He argues for the use of ‘postcolonialism’ instead of ‘colonialism’ because it unpacks “the relations of domination between and within nations, races, or cultures, recognizing the historical roots of such practices within

⁵³ The term ‘normate’ was coined by Rosemarie-Garland Thompson. Normalcy, for Jasbir Puar, privileges individuals who are “white, male, middle-class, [and] physically impaired” (Puar, *The Right to Maim: Debility, Capacity, Disability*, xix.).

⁵⁴ Dolmage, *Disability Rhetoric*, 22–23.

⁵⁵ McRuer and Mollow, *Sex Disabil.* 355-356

⁵⁶ Puar, *The Right to Maim: Debility, Capacity, Disability*, xx.

colonialism.”⁵⁷ Morris, however, believes the term postcolonialism “becomes a mere label in the representational politics of institutions”⁵⁸ that illustrates their incapability to completely engage in decolonization practices.⁵⁹ Taking inspiration from Indigenous critiques of reconciliation,⁶⁰ I recognize that disabled persons are often oppressed by postcolonial practices – as exhibited through this project. Postcolonial discourses, like disability studies, analyze the othering of communities that somehow differ from the ‘norm’.

Accordingly, Sherry notes that normative discourses enshrined within postcolonial practices often depict disabled persons as outside of meaningful political and social participation, and thus incapable of citizenship rights.⁶¹ It concentrates on “past legacies” instead of applying intersectional lenses that foster an understanding of diversity and relates to current lived experiences within equity-seeking communities which, in essence, is how some disability studies scholars still navigate their research⁶² After all, and as Helen Meekosha states, disability studies is “a form of scholarly colonialism.”⁶³

Where Does the Subaltern Enter?

Some disability scholars, such as Grech, analyze the impacts of postcolonialism theory upon disability studies – and this exists beyond ‘white disability studies’ Spivak’s

⁵⁷ Sherry, “(Post)Colonising Disability,” 11.

⁵⁸ Morris, in this context, refers to institutions in “academia and, more broadly, in the globalized space of nongovernmental and corporate elites” (Morris, *Can Subalt. Speak. Reflections Hist. an Idea*, 87.)

⁵⁹ Morris, *Can Subalt. Speak. Reflections Hist. an Idea*.

⁶⁰ Coulthard, *Red Skin White Masks: Rejecting the Colonial Politics of Recognition*.

⁶¹ Sherry, “(Post)Colonising Disability,” 10.

⁶² Barker and Murray, “Disabling Postcolonialism : Global Disability Cultures and Democratic Criticism,” 67.

⁶³ Meekosha, “Decolonising Disability: Thinking and Acting Globally,” 668.

essay ‘Can the Subaltern Speak?’ addresses of the ways in which voices of equity-seeking groups remain silenced by dominant discourses and narratives. Derived from Indian scholarship in the 1980s, the subaltern framework exhibits the dichotomy between institutions and members of equity-seeking groups in relation to top-down approaches.⁶⁴ By doing this, subaltern studies seek to deconstructs forms of othering and to advance the notion of individuality.

Rosalind C. Morris describes the term ‘subaltern’ as “the subordination of people in relation to caste, class, gender, language, culture and race.”⁶⁵ The work of Marcia Rioux, Paula C. Pinto, and Gillian Parekh discusses subaltern studies in relation to othering experienced by disabled persons – and this within an international sphere.⁶⁶ As noted by many scholars whose interests lay at the intersection of development and disability, such as Grech, McRuer, and Soldatic, institutions generate assumptions about the needs of disabled persons, as well as their representation, which (mis)guide their work. Rather than seeking out the opinions of those who are most impacted by decision-making and policymaking processes, they are readily diminishing their lived experiences and struggles. Individuals affiliated with these institutions are using their positionality to advance policies and projects that reflect dominant disability representations – ultimately dismissing needs of entire communities as a result.

Disability Studies in Development

⁶⁴ Morris, *Can Subalt. Speak. Reflections Hist. an Idea.*

⁶⁵ Morris, 52.

⁶⁶ Rioux, Pinto, and Parekh, *Disability, Rights Monitoring, and Social Change: Building Power out of Evidence.*

The integration of disability within development practices is not recent. It was throughout the 1970s that the United Nations first generated discussions pertaining to disability and hired a Special Rapporteur to investigate existing human rights of disabled persons, named Leandro Despouy. However, international decision-making and policymaking processes have yet to frame disability in a way that accurately represent the diverse intersectional lived experiences of disabled persons that exist throughout the Global North and Global South. This impacts how disability communities are being served by both academia and organizations (governmental and nongovernmental alike). Interestingly, Rebecca Yeo's work claims these "institutions have made widespread changes to their rhetoric."⁶⁷ but seems to be one of the few scholars holding such a perception. Representation of disability in development practices is most commonly hegemonic as institutions do not account for other key marginalizing dimensions in the lived experiences of disabled persons – for instance, class, gender, race, and sexuality. Accordingly, scholars such as Kaeřina Kolářová⁶⁸ believe development is conducive to reproducing dominant understandings of disability by establishing norms within the projects they generate.

Debates over misrepresentation of disability experiences and struggles in development have surfaced since the beginning. According to the World Report on Disability⁶⁹, 15% of the entire global population lives with some type of disability and

⁶⁷ Yeo, "Disability, Poverty and the 'New' Development Agenda: A Report to the KaR Programme," 7.

⁶⁸ Kolářová, "Performing the Pain: Opening the (Crip) Body for (Queer) Pleasures"; Kolářová, "Affective Politics of Disability Shame in the Times of Neoliberal Exceptionalism"; Kolářová, "What Kind of Development Are We Talking About? A Virtual Roundtable with Tsitsi Chataika, Nilika Mehrotra, Karen Soldatic and Kateřina Kolářová."

⁶⁹ This report was the first one of its kind to be published by the WHO and World Bank in 2011 and contains information about disability that is secured in an accessible location. I recognize that analyzing its findings in this thesis is problematic, because they ultimately derive from a colonized lens. I also

80% of all disabled persons live in the Global South.⁷⁰ Yet most scholarly literature derives from the Global North, in particular the United Kingdom and the United States, and seldom accounts for the divergence of disability experiences found throughout the Global South. Issues prevalent for disabled persons in the North take precedence and ultimately deter attention from struggles only occurring in the South but that significantly impact these communities holistically. Mark Priestley accordingly notes that “the academic literature of disability studies consistently privileges minority world accounts.”⁷¹ Priestley’s use of ‘minority’ in this context is extremely powerful since it reinforces the fact that the current understanding of disability represents a fragment of the overall disability population – and this fragment is a hegemonic one. Some scholars, such as Anita Ghai, live in or have ties to the Global South, and actively work to dismantle dominant portrayals of southern disability communities. They should not be held accountable to shift this entire rhetoric on their own. Shaun Grech and Karen Soldatic are among Northern scholars who use their positionality and privilege to document the erasure of disability histories, as well as to amplify experiences of disabled persons that are readily disregarded by current literature. Yet the few scholars actively participating in Southern knowledge dissemination cannot reduce the imminent research discrepancies in disability studies.

acknowledge that these statistics may be flawed to represent the interest of privileged entities. Furthermore, it is noteworthy to mention that disabled activist and scholar, Tom Shakespeare, collaborated on this report while working at the WHO.

⁷⁰ The Global South includes all countries that are still impacted by colonist and development practices and tend to be some of the poorest countries in the world.

⁷¹ Priestley, *Disability and the Life Course: Global Perspectives*, 3.

3.3 Towards Critical Disability Studies

The Emergence of CDS.

Marian Hill Scott was a disability studies scholar monumental in establishing, throughout the past decade, a framework now known as critical disability studies (CDS). She drew on Judith Butler's writings to validate the need of critical analysis when exploring topics connected with disability.⁷² Hill Scott was also among theorists who included 'disability', 'impairment', along with 'normality', in relation to then-dominant disability discourse. CDS equally challenges colonialist and Marxist ideologies of disability. Hill Collins and Bilge define 'critical' as "criticizing, rejecting, and/or trying to fix social problems that emerge in situations of social injustice."⁷³ Critical theory accordingly disrupts normative representations of disability, for instance, that remain at the forefront of decision-making and policymaking processes so lived experiences are accurately portrayed and assumptions are disregarded. CDS contributes to knowledge creation and dissemination of ideas that are intersectional in nature, and therefore deconstruct assumptions that are readily imposed upon disabled persons – including within the field of disability studies.

CDS's frameworks are not only rooted in academic knowledge, but in activism as well. This ultimately fosters a collaboration between academia and community, which often exists in Indigenous studies and queer studies (for example). Projects executed by CDS scholars relate in some capacity to key dimensions that inevitably intersect with disability, such as (but not restrictive to): indigeneity, gender, race, and sexuality. My

⁷² Vehmas and Watson, "Moral Wrongs, Disadvantages, and Disability: A Critique of Critical Disability Studies", 639.

⁷³ Hill Collins and Bilge, *Intersectionality*, 70.

this project, at its core, pertains to disability and sexuality, but will nonetheless address other intersections as they all coincide together – in some form or another.

The Parallels of Critical Theory and Intersectionality.

Critical theory is not only located in academia but also in activism and various political engagements. Its values align with intersectional theory. Critical theory reinforces the importance of research demonstrating diverse lived experiences and accordingly challenges the presence of hegemony throughout the world – including the impacts of Northern scholarship on disability communities of the Global South. Critical theory and intersectionality both derive from spaces of social justice, where knowledge is recognized as “the knitting together of diverse understandings, norms, values, and personal histories.”⁷⁴ This ultimately creates spaces where activists and scholars collaborate amongst various equity-seeking groups and/or communities to challenge normative beliefs and behaviors. In some instances, however, an unequal power distribution may occur between activists and scholars since the latter group often has a more rounded understanding of theory – which ultimately increases the power differentiation in research engagements. Critical theory offers an alternative way of analyzing social issues that generates thorough understanding of equity-seeking groups’ identities. Yet, as with other critical discourses such as queer theory, negotiating the relationship between critical disability studies and intersectionality remains complex.

Why Intersectionality in Critical Disability Studies?

Disabled persons are readily impacted by key marginalizing dimensions, such as sexuality; but as demonstrated in previous sections, hegemonic frameworks were (and in

⁷⁴ Rioux, “Introduction: A North-South Dialogue on Participatory Monitoring,” 1.

some instances remain) embedded in disability scholarship. Scholars still do not recognize the prevalence of other factors that affect the experiences of disabled persons – in addition to ableism and disablement.⁷⁵ Since the emergence of critical disability studies, a movement of disability scholars have continuously shifted their praxis towards intersectional thinking to engage with complex topics in relation to disability. Hill Collins has not centred disability in the work on the intersectionality of Black women's experience. It was not until recently, however, that topics of disability were fully considered in intersectional dialogues.

To think through intersectionality, Hill Collins and Bilge propose that in a given society at a given time, power relations of race, class, and gender, for example, are not discrete and mutually exclusive entities, but rather build on each other and work together; and that, while often invisible, these intersecting power relations affect all aspects of the social world.⁷⁶

Intersectionality, as an analytical tool, aims therefore to center the lived experiences of disabled persons that remain disproportionately unrepresented within service delivery and dominant representations of disability – in both academia and decision-making/policymaking processes alike. By doing this, it demonstrates the power differentiation existing between equity-seeking communities and privileged communities. Intersectional framework is always evolving, and it takes on different meanings when applied to research projects. Ultimately, intersectionality brings together activists and scholars to collaboratively challenge and resist ableism, as well as other forms of oppression that affect the lives of disabled persons.

In the Literature: How Do Disability and Sexuality Intersect?

⁷⁵ 'Ableism' and 'disablism' will be further discussed in chapter 4.

⁷⁶ Hill Collins and Bilge, *Intersectionality*, 2.

Queer theory can be compared to critical disability studies in the sense that both adopt concepts and ideologies from feminism, as well as strive to disrupt political and social marginalization of equity-seeking groups. Queer theory also seeks to resist social hierarchies that are generated by heteronormative beliefs and practices. Both critical disability studies and queer theory help equity-seeking communities navigate systemic injustices, as well as “problematize the public and the private, the social and the biological, difference, stigma and deviance, and the construction of identities.”⁷⁷ Allison Kafer, specifically, perceives Queer Theory as a means of “forging a politics that does not marginalize, normalize, or criminalize queer bodies, practices, or desires.”⁷⁸ The distinct triumphs and struggles of disabled persons and Queer persons can be addressed and navigated through in similar ways, and thus their international movements are comparable in many aspects.

Despite these specific correlations between CDS and Queer Theory, topics pertaining to crip queers (as a two-axis identity) are not being recognized as potential and reputable research projects. The normative correlation between able-bodiedness/able-mindedness and heteronormativity⁷⁹ is more often exhibited than the one existing between crips and queers. They both act as key marginalizing factors in the lives of disabled persons. Diverse sexual identities are not usually considered when engaging with disability since disabled persons are frequently regarded as non-sexual. Robert McRuer and Anna Mollow accordingly note that dialogues relating to disability have

⁷⁷ Sherry, “Overlaps and Contradictions between Queer Theory and Disability Studies,” 169.

⁷⁸ Kafer, *Feminist, Queer, Crip*, 36.

⁷⁹ Pease defines heteronormativity as “the institutions, structures of understanding, and practical orientations that make heterosexuality seem not only coherent ... but also privileged.” (Pease, *Undoing Privilege: Unlearning Advantage in a Divided World*, 136.)

rarely been taken up by queer theory scholarship.⁸⁰ In fact, disability and sexuality were previously used against one another.⁸¹ Past scholarship pathologized disabled persons as “a threat to the gene pool or as sexual predator[s],”⁸² and such a perception remains prevalent in some (mis)representations of disability in mainstream policy and media.

Leng discusses how queer disability studies is drawing more attention to the problems of applying sexuality as a requirement of obtaining citizenship⁸³. It is also used to analyze and dissect that, in order to find sexual liberation, one must be ‘able-bodied’ and ‘able-minded’. Queer disability studies do not yet have a lot of traction as it still is not fully incorporated within either critical disability studies or queer theory. The concept of ‘queering disability studies’ is much more predominantly applied in critical disability studies. As for queer theory, many of its foundational texts do not discuss disability.

Research exhibiting the intersections between disability and sexuality has just recently fully emerged, and it is typically the same set of scholars that execute and publish it. Disability studies now have an impact on queer theory, albeit it remains quite small. In the field of critical disability studies, Robert McRuer has written a variety of texts discussing the intersecting dimensions of disability and sexuality and unpacks their correlations. His research identifies the ways in which they are similar and divergent from one another, as well as how they complement each other.⁸⁴ Other scholars, such as Eli Clare and Jasbir Puar, are also key players in the realms of disability and queerness –

⁸⁰ Shuttleworth, “Bridging Theory and Experience: A Critical-Interpretive Ethnography of Sexuality and Disability,” 58.

⁸¹ Dolmage, *Disability Rhetoric*, 71.

⁸² Markotić and McRuer, “Leading with Your Head: On the Borders of Disability, Sexuality, and the Nation,” 141.

⁸³ Leng, “Historicising ‘Compulsory Able-Bodiedness’: The History of Sexology Meets Queer Disability Studies.”

⁸⁴ Dolmage, *Disability Rhetoric*, 71.

and they both engage, in addition to McRuer, with their own intersectional lived experiences.

Acknowledging and Unlearning the Lived Experiences of Crip Queers in the Literature

Drucilla Cornell, in Morris's edited collection *Can the Subaltern Speak?*, reminds us that we need to recognize "systems of representation that go unacknowledged in positivist appeals to direct experience at the basis for political activism."⁸⁵ An example of this lies at the intersection of disability and sexuality. There remains an underlying assumption that disabled persons are asexual – or if they are granted sexuality, that they are heterosexual.⁸⁶ As a result, the privilege of heteronormativity in the daily lives of heterosexual disabled persons is often discounted within scholarship. A similar power dichotomy exists within queer communities in which their positionality is assumed as queer and non-disabled. Such an identity is deemed more privileged in comparison to crip queers since they do not have conflicting key marginalizing dimensions.

Reclaiming Identities in Academia: Crip Queer Unite!

'Crip' and 'queer': terms that were previously derogatory are now used by equity-seeking communities to reclaim their own identities. They exist to take up space in academia and to resist norms that are readily attributed to both crips and queers in critical disability studies and sexuality studies. According to Annamarie Jagose, there is no fixed way of defining the term 'queer' as it is continuously shifting to accommodate activism

⁸⁵ Cornell, "The Ethical Affirmation of Human Rights: Guyatri Spivak's Intervention," 102.

⁸⁶ Mohanty, "Under Western Eyes: Feminist Scholarship and Colonial Discourses."

practices.⁸⁷ When attributed to identities, however, queer is symbol of individual's resilience and success within society.

The term 'crip,' in particular, emerged throughout the twentieth century and was primarily used in the realm of activism. It was later further developed in disability studies, through its cultural model, but is now reappropriated to different models as well. Persons self-identified as crip are typically perceived as "non-normative" and "[non-represented]"⁸⁸ when compared to their counterparts who ascribe to the identity of 'disabled person'. The connotation of 'disabled persons', in many instances, can become very normalizing in the realms of disability and sexuality. Crip theory works against able-bodiedness and able-mindedness, both readily engaged in Robert McRuer's texts, to shift the representation of disability in such ways that deters society from contextualizing disability through norms.

The Margins of Research.

bell hooks and Gloria Anzaldúa state that research pertaining to equity-seeking communities are "sites of possibilities that are exciting and on the edge"⁸⁹. Other scholars agree, such as Stuart Hall, arguing that meaningful lives are those with intersectional key marginalizing dimensions. Research must aim to shift dominant narratives about crip queers that remain at the forefront of both critical disability studies and queer theory. Accordingly, intersectional research, particularly responding to the needs of crip queers is needed to dismantle normative thinking and shift scholarship towards a more inclusive and intersectional space – ultimately by applying a social justice framework. Spaces of

⁸⁷ Jagose, *Queer Theory: An Introduction*.

⁸⁸ McRuer, *Crip Times : Disability, Globalization, and Resistance*, 19.

⁸⁹ Tuhiwai Smith, *Decolonizing Methodologies: Research and Indigenous Peoples*, 95.

social justice recognize knowledge as “the knitting together of diverse understandings, norms, values, and personal histories”⁹⁰.

In *Decolonizing Methodologies*, Linda Tuhiwai Smith cautions that privileged researchers risk becoming marginalized because of their personal and engagements with individuals from equity-seeking communities, which can be attributed to a lack of awareness and support. Tuhiwai Smith, while specifically discussing supports for Indigenous studies, emphasizes the need for community-building capacity and for transparency in navigating power dichotomy between the researchers and communities being researched. It also takes years of studying distinct communities to accurately comprehend the extent of their triumphs and struggles and committing to these kinds of timeframes can become quite challenging – especially while working within equity-seeking communities⁹¹.

Ultimately, research that applies an intersectional social justice framework remains challenging to execute. Projects using such a lens are not supported in ways that encourage researchers of all types to seek out this kind of work. Researchers that engage in work within equity-seeking communities may already be connected to them on a personal level. As mentioned previously, however, it is more probable to derive from different (and more privileged) ones – obstructing the lenses they apply. Therefore, the absence of support impacts the ways in which research is being conducted. This is exemplified with the scarce research highlighting the intersection of disability and sexuality derived from both the Global North and the Global South. Discrepancies in

⁹⁰ Rioux, Pinto, and Parekh, *Disability, Rights Monitoring, and Social Change: Building Power out of Evidence*, 1.

⁹¹ Tuhiwai Smith

research impacts service delivery and ultimately the ways in which crip queers are (mis)represented in decision-making and policymaking processes – which, as will be discussed in the following chapter, can lead to depoliticization⁹²

3.4 Conclusion

Disability was once perceived as hegemonic within the academic disability studies context, and this was transferred in the overarching representation of disabled persons as unaffected by other forms of marginalization – including the realms of decision-making and policymaking. Disability studies is still embedded within colonial practices. The positionality of most disability scholars extends the power differentiation first produced by colonialism. It was not until the emergence of critical disability studies that scholars began to work through the problems amplified by disability scholarship. By using an intersectional framework as a means of analyzing and critically thinking through disability, critical disability studies aims to emphasize that disabled persons adopt intersectional identities formed by key dimensions of marginalization. Ultimately, this new stream of disability studies centers oppression experienced by disabled persons within interlocking factors of identity and power instead of simply ableism and disablism.

The following chapters will draw upon concepts and theories explored in the previous paragraphs to locate the correlations between academia and activism throughout crip queer movements. Sins Invalid, a prominent movement led by crip queers, draws connections between activism and scholarship. This will be highlighted at length in chapter 4.

⁹² Kafer, *Feminist, Queer, Crip*, 5.

Chapter 4

Does an International Sphere of Crip Queers Even Exist?

4.1 Introduction

Drawing on texts from disability scholars, such as Kafer⁹³ and McRuer⁹⁴, as well as from the disability justice movement⁹⁵, this chapter draws from disabled queer narratives to demonstrate that these individuals have yet to become subjects for community-based research and service delivery supports. Disability policies, in particular, are generated through homogenizing views of disability that do not account for diversity that prevails throughout disability communities. While crip queers are increasingly at the forefront of disability activism initiatives, the international disability agenda is not established in a way that encourages the participation of individuals with multiple-axes identities – especially within the realms of decision-making and policy-creating processes. Subtle omission of crip queers in international disability politics further exclude individuals who already experience double marginalization based on their intersectional identities.

Firstly, I will review materials highlighting the lived experiences of crip queers to evaluate the state of disability and queerness throughout the world – including activism initiatives spearheaded by crip queers. I will then illustrate how crip queers are (mis)represented in both the Global North and Global South. Lastly, I will demonstrate

⁹³ Kafer, *Feminist, Queer, Crip*.

⁹⁴ McRuer, *Crip Times : Disability, Globalization, and Resistance*; McRuer, “As Good as It Gets: Queer Theory and Critical Disability”; McRuer, *Crip Theory: Cultural Signs of Queerness and Disability*; McRuer, “Taking It to the Bank: Independence and Inclusion on the World Market”; McRuer, “Disabling Sex: Notes for a Crip Theory of Sexuality”; McRuer, “The Then and There of Crip Futurity.”

⁹⁵ Berne, “Disability Justice - A Working Draft”; Piepzna-Samarasinha, *Care Work : Dreaming Disability Justice*.

how they are further stigmatized, resulting in homogeneity in decision-making and policy-making processes.

Increasingly, the field of critical disability studies acknowledges some forms of intersectional lived experiences between disability and other marginalizing dimensions – but the intersection of disability and queerness often remain undiscussed within academia. Disabled persons are still primarily characterized as asexual beings, thereby ultimately prevents international recognition of crip queers. Despite crip queers spearheading grassroots initiatives throughout the world, such as disability justice movements discussed earlier, scholarly literature rarely articulates narratives derived by crip queers. Hence, critical disability studies seldom provides any premises to generate inclusive and meaningful engagement opportunities for crip queers, nor validate their triumphs and struggles in community organizing initiatives. Ultimately, crip queers, who are already multiply marginalized based on their double-axes identities, are further stigmatized because of the homogeneity deeply embedded within critical disability studies.

Some scholarship is actively engaging with the intersectionality between disability and queerness, but it is primarily within the realms of critical disability studies. McRuer's *Crip Times*⁹⁶, Kafer's *Feminist, Queer, Crip*⁹⁷, and Puar's *The Right to Maim*⁹⁸ are prominent texts that not only explore crip queer identities, but also highlight activist initiatives and movements spearheaded by them on an international level.

⁹⁶ McRuer, *Crip Times : Disability, Globalization, and Resistance*.

⁹⁷ Kafer, *Feminist, Queer, Crip*.

⁹⁸ Puar, *The Right to Maim: Debility, Capacity, Disability*.

Firstly, McRuer⁹⁹ unpacks the trajectory of international disabled queer activism that disrupt homogenous ways of thinking about disability, such as encountered often in critical disability studies. The book highlights various social movements and discusses how they seek to generate alternative means for development and neoliberalism practices. McRuer engages with the concept of ‘austerity’ to ultimately explore the representation of disability and queerness throughout the world.

Secondly, Kafer¹⁰⁰ investigates what is missing from disability theories through feminist and queer frameworks. The scholar interrogates the scholarship of critical disability studies, addressing contradictions that are often apparent in this field, such as those caused by the social model, and the problem of compulsory heterosexuality. Kafer emphasizes that disabled persons must be included in all spheres of political and literary engagement.

Lastly, Puar¹⁰¹ analyzes current constructions of disability through a biopolitical lense and explores how various intersectionalities are addressed in contemporary disability narratives. The author engages with theories, such as neoliberalism, to demonstrate how they are use to shape dominant understandings of disability. Puar unpacks the notions of ‘capacity’ and ‘debility’ throughout the text to illustrate the diverse struggles experienced by disabled persons on an international scale and highlight how disability is internationally perceived.

4.2 At the Intersection of Disability and Sexuality

A Brief Contextualization.

⁹⁹ McRuer, *Crip Times : Disability, Globalization, and Resistance*.

¹⁰⁰ Kafer, *Feminist, Queer, Crip*.

¹⁰¹ Puar, *The Right to Maim: Debility, Capacity, Disability*.

In *Disability Rights and Wrongs Revisited*, Shakespeare acknowledges that disabled persons have intimacy and sexual needs – just like their non-disabled counterparts¹⁰². The intersection between disability and sexuality (heterosexuality and queerness alike) has always been complex regardless. Disabled persons have been continuously portrayed as non-sexual beings¹⁰³ even though this is not the case. Alice Wong’s¹⁰⁴ collection of disabled persons’ narratives demonstrates how society currently interlocks disability and sexuality together – in ways that impede the sexual empowerment of disabled persons. Rather than being considered asexual, because some would argue that it is in itself a sexual identity, society often deems disabled persons as not having a sexuality at all.¹⁰⁵ Cubacub, within Wong’s anthology, asserts that “society says [disabled persons] are not beautiful and [they] are definitely not sexy.”¹⁰⁶ Such (mis)perceptions are reinforced by disability policies, and further articulated for crip queers. This is exhibited when matters relating exclusively to disability take precedence, despite the reality that both disability and sexuality intersect in the lived experiences of all disabled persons. Hence, according to Bob Pease, “sexual marginalization is deeply connected to political and social marginalization.”¹⁰⁷

Sexuality’s Multiple Facets of Oppression

Over a decade ago, disability activist Anne Finger asserted that “[sexuality] is often the source of [disabled persons’] deepest oppression”¹⁰⁸ and it currently remains as

¹⁰² Shakespeare, *Disability Rights and Wrongs Revisited*, 29:221–22.

¹⁰³ Watson and Vehmas, *Routledge Handb. Disabil. Stud.*, 439. Priestley 2001 chapter 3; 43

¹⁰⁴ Wong, *Disability Visibility: First-Person Stories from the Twenty-First Century*.

¹⁰⁵ Luczak, *A Queer Disability Anthology*, 3.

¹⁰⁶ Cubacub, “Radical Visibility: A Disabled Queer Clothing Reform Movement Manifesto,” 94.

¹⁰⁷ Pease, *Undoing Privilege: Unlearning Advantage in a Divided World*, 338.

¹⁰⁸ McRuer, “Disabling Sex: Notes for a Crip Theory of Sexuality,” 107.

such throughout the world. Interestingly, policies and practices generated as a response to oppression experienced by disabled persons typically do not acknowledge the impacts of sexual oppression – particularly in relation to the experiences of crip queers. Compulsory heterosexuality reinforces the misconception that wrongfully labels disabled persons as non-sexual. Stigma attached to both disability and queerness furthers the oppression and barriers inflicted upon them since they are multiply marginalized by societal norms of able-bodiedness/able-mindedness and heterosexuality. This is further established within service delivery, since it usually responds to one set of needs. Brown, for instance, illustrates this within the following narrative presented in Luczak’s anthology:

Queer sexuality and disability places me so far outside the realms of the everyday that it renders people silent. It is a display of queer, non-normative, crip lust that most people don’t want to think about.¹⁰⁹

Ultimately, as unpacked in an earlier paragraph, sexual needs of disabled persons are typically left at the margins. Crip queers repress their desire for belonging because they are not accurately represented in neither disability communities nor queer communities¹¹⁰.

Normate sex¹¹¹, for Wilkerson, represents the extent of oppression and its complexities experienced by disabled persons in relation to sexuality. The scholar reinforces the reality that sexual oppression is one of the most pervasive forms of oppression inflicted upon disabled persons by political and social institutions. Iris Marion

¹⁰⁹ Brown, “The Politics of Pashing,” 4.

¹¹⁰ Sherry, “Overlaps and Contradictions between Queer Theory and Disability Studies.”

¹¹¹ As explained by Wilkerson, normate sex “[integrates] insights from sex radicalism, disability studies, and what Judith Butler and others call the ‘new gender politics’ of transgender and intersex. Intersex and transgender medicalization illustrates how normate sex presumes both the sex/gender binary and conventional heterosexuality”. (Wilkerson, “Normate Sex and Its Discontents,” 186.)

Young's oppression framework helps understand how normative sex furthers the already existing oppression of disabled persons. This concept constructs expectations in the realms of sexuality and sets a sexuality hierarchy that is applied to all individuals without accounting for other key marginalizing dimensions. Normative sex therefore imposes divergent labels upon individuals who cannot conform to these set expectations and perceives them as sexually inept¹¹² – ultimately without any type of sexual identity.

Individuals experience social inequalities resulting from systems that are constructed to serve hegemonic communities. This remains prevalent in decision-making and policymaking processes that directly affect the lives of individuals who should feel supported – rather than further marginalized by them. Single-axis decision-making and policymaking processes impede meaningful political and social participation opportunities for most individuals in equity-seeking communities, but there is an additional marginal layer for those with conflicting identities.¹¹³ Such processes often do not think through intersectional identities: they consider the repercussions of one distinct identity and omit any other key marginalizing dimension that may also impact the same individual. In the realms of disability and sexuality, for instance, disability policies may address the needs of heterosexual disabled persons (albeit there remain gaps) – but not crip queers since these individuals are multiply marginalized. Heterosexual disabled persons are thus located higher on the social hierarchy when compared with crip queers.¹¹⁴

The Intersectional Margins of Sexuality.

¹¹² Wilkerson, 187.

¹¹³ McRuer, *Crip Theory: Cultural Signs of Queerness and Disability*.

¹¹⁴ Marion Young, *Justice and the Politics of Difference*, 42.

The term ‘sexuality’ has been conceptualized in an oppressive (ableist even) way that does not account for the complexities of intersectionality. Judith Heumann uses Trieschmann’s definition of sexuality to illustrate the prevalent absence of intersections with other key marginalizing dimensions. In 1988, Roberta Trieschmann believed sexuality to be:

the expression of a sex drive, through sex acts, within the context of the personal identity of the individual: the maleness and femaleness of the individual that is so heavily influenced by past cultural learning, one’s self-image, and the expectations that others have of the person.¹¹⁵

Trieschmann’s definition is still relevant, despite its age, because it indicates that only some individuals are deemed sexual – ultimately who are seen as sexual and who are not. Normalization, as discussed throughout the previous chapter, is generated from expectations that are inflicted upon equity-seeking communities by political and social institutions.¹¹⁶ Trieschmann’s definition thus reflects normalization through the means of hegemony and heteronormativity.

Heterosexual dominance refers to the process whereby individuals are, based on their sexual identities, characterized as either ‘normal’ or ‘deviant’. When included within the realms of decision-making and policymaking, it is rarely in correspondence with other key oppressions – especially ableism and disablism. As exhibited by Robert McRuer and Michael Bérubé, there is a connection between heterosexuality¹¹⁷ and able-bodiedness. Here we can add able-mindedness as well. All are sites of privilege that

¹¹⁵ Heumann and Joiner, *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist*, 437.

¹¹⁶ Butler, *Undoing Gender*.

¹¹⁷ Judith Butler believes that heterosexuality “offers normative sexual positions that are intrinsically impossible to embody” (Dolmage, *Disability Rhetoric*, 282.).

exert their dominance upon individuals who are perceived as inferior because of identities marginalized by society. The power attributed to able-bodiedness/able-mindedness and heterosexuality, however, cannot be sustained without the presence of disability and queerness; they co-exist even though the strength of the former deters the importance of the later. Despite multiple equity-seeking groups intersecting with queerness, this thesis will unpack the experiences of crip queers – and evidently those that belong to ‘crips’ and ‘queers’ exclusively as well.

How Do Crip Queers Obtain Sexual Citizenship?

Citizenship, in general, is difficult for disabled persons to express since they are not considered full participants in society. As explored by Michael J. Prince, these individuals are not included in political and social processes – when in fact they hold the same citizenship as their non-disabled counterparts.¹¹⁸

An added facet of citizenship is sexual citizenship (or ‘intimate citizenship¹¹⁹’) that identifies a remaining (mis)representation of disability on the front of sexuality, despite being one of the most marginalized equity-seeking groups today. Misguided beliefs portraying disabled persons without sexual identities further complicate access to sexual citizenship because mainstream representation does not begin to reflect their actual desires and needs. Jeffrey Weeks notes three dimensions in obtaining sexual citizenship: a demand of control, a demand for access, as well as a demand for choice.¹²⁰ The constant battle for sexual citizenship is significant because it misguides service

¹¹⁸ Prince, *Absent Citizens: Disability Politics and Policy in Canada*.

¹¹⁹ Kenneth Plummer defines intimate citizenship as “the control (or not) over one’s body, feelings, relationships: access (or not) to representations, relationships, public spaces, etc; and socially grounded choices (or not) about identities, gender experiences” (Mcruer & Mollow chap 1 p 38)

¹²⁰ Shakespeare, “Disabled Sexuality: Toward Rights and Recognition,” 165.

delivery and results in the creation of policies and practices that are not tailored to their diverse (albeit distinct) sexual needs – ultimately decreasing any opportunities for sexual empowerment and/or growth. Magrit Shildrick, however, states that society must move beyond the concept of sexual citizenship, as it does not highlight the reality that disabled persons are still readily silenced in decision-making and policymaking processes pertaining to sexuality.¹²¹

Furthermore, sexual citizenship, as presented by Weeks, does not account for the intersections that prevail in the sexual desires and needs of disabled persons. The sexual identity of crip queers, for instance, are stripped because there is double marginalization at play here. Their engagement in discussions pertaining to sexuality is non-existent because they do not conform to norms readily imposed by society – further reducing their sense of agency.¹²² Rather than primarily rely on the sexual citizenship of disabled persons, Abby Wilkerson is thus advocating for their sexual agency so that they can meaningfully participate in ways of that are most suited for them – even if their identities are marginalized by society. The scholar believes that “sexual agency is central to political agency and that sexual democracy should be recognized as a key political struggle.”¹²³

4.3 Towards the Mobilization of Crip Queers

Mobilization: The White Version.

¹²¹ Shakespeare and Richardson, “The Sexual Politics of Disability, Twenty Years On,” 213.

¹²² Linton, “Disability Studies/Not Disability Studies,” 526.

¹²³ Siebers, “A Sexual Culture for Disabled People,” 38.

It was in the 1990s that James I. Charlton¹²⁴ first wrote about the slogan ‘nothing about us without us’ in the realms of disability policy and research. Throughout the years it has been applied in international development work – notably within initiatives of Disabled Peoples International. Yet, ‘nothing about us without us’ can be quite marginalizing because the slogan derives from movements driven by disabled persons who are typically heterosexual white physically disabled men.¹²⁵ Crip queer activist Eli Clare states that “not many disabled and nondisabled progressive groups engage in multi-issue thinking”¹²⁶ and this is exhibited in the ways that disability movements are currently organized. Dominant disability movements led by such individuals still do not prioritize intersectional needs of disabled persons whose interlocking identities are readily ignored. This will be exemplified in chapter five through the application of the Convention on the Rights of Persons with Disabilities. As a result, some disabled persons collaborate and organize beyond disability movements to shift away from the perspectives of single-axis issues – ultimately generating spaces where multi-axis issues are at the forefront of all initiatives.

Claiming Identity Through Disability Politics

Too often, identities are fixed by colonialist and normative ideologies. In the realms of disability identities, their constructions are heavily influenced by thought processes the Global North; ultimately portraying Northern disability narratives, all the while omitting challenges and triumphs that specifically present lived experiences throughout the Global South. Despite identities being typically socially constructed to

¹²⁴ Charlton, *Nothing About Us Without Us: Disability Oppression and Empowerment*.

¹²⁵ O’Toole, *Fading Scars: My Queer Disability History*, 150.

¹²⁶ Clare, *Exile and Pride: Disability, Queerness, and Liberation*, xvii.

oppress communities differing from established norms, they can be used as a method of empowerment for members of equity-seeking groups.¹²⁷ Therefore, marginalized identities (double-axes identities as well) represent conflicting and interlocking power relations that still prevail – crip queers, for instance, who must navigate the gap of services that address both components of their intersectional identities (disability and queerness).

Disabled persons may struggle while finding a sense of belonging to disability identities because there is no single way of claiming identity – nor should there be. Developing a relationship with one’s disability is a challenging task and may shift to coincide with life’s occurrences. Individuals who adhere to the medical model of disability, as discussed in chapter 3, may find themselves less attached to a disability identity in comparison to those who value, for instance, disability justice. The complexities of finding and claiming disability identities are readily discussed in ethnographical work, such as *Becoming Heumann*¹²⁸, *Care Work*¹²⁹, as well as *Disability Visibility*¹³⁰, where disabled persons explore their own struggles and triumphs with disability identities. Alice Wong describes disability identity as “pain, struggle, brilliance, abundance, and joy [...] socio-political, cultural, and biological.”¹³¹

The social model of disability is still being used in academia and community-based initiatives and yet there remains debates on whether it is beneficial for the empowerment and growth of disabled persons in the realms of disability politics – or if it

¹²⁷ Siebers, *Disability Theory*, 32.

¹²⁸ Heumann and Joiner, *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist*.

¹²⁹ Piepza-Samarasinha, *Care Work : Dreaming Disability Justice*.

¹³⁰ Wong, *Disability Visibility: First-Person Stories from the Twenty-First Century*.

¹³¹ Wong, xxii.

is a problematic practice. Some scholars, such as Loree Erickson, argue that the social model is important for identity politics as it “provides for a stronger sense of identity.”¹³² The social model encourages disabled persons to think through barriers they experience as distinct from their own impairments, which will allow them to foster a positive relationship with their disabilities and improve their sense of self. In contrast, McRuer, amongst others, argues that the social model “neglects identity politics as a valuable component of disability policy.”¹³³ He claims that there are other disability models – the disability justice model, for instance – better suited for supporting the growth of identity politics within disability politics.

Disability activists and scholars use the term ‘disability identity’ when explaining disability as an “ethnic conception.”¹³⁴ Rather than having minority identities imposed upon them, activists are striving towards reclaiming marginalized identities by developing their own identities that affirm and express their cultures. Crip queers, for instance, are part of an encompassing culture that has “a common language, a shared historical lineage, cohesive social community, and political solidarity.”¹³⁵ By applying this lens, crip queers are therefore not perceived as lacking something that prevents them from adopting a certain identity; rather, they are reclaiming their positionality by adhering to an identity accurately representing their struggles and triumphs.

While Robert McRuer argues that disability identities “[themselves are] [...] neither necessarily nor automatically radical”¹³⁶, disability identities are part of an

¹³² Erickson, “Revealing Femmegimp: A Sex-Positive Reflection on Sites of Shame as Sites of Resistance for People with Disabilities,” 84.

¹³³ McRuer, “Disabling Sex: Notes for a Crip Theory of Sexuality,” 14.

¹³⁴ Shakespeare, *Disability Rights and Wrongs Revisited*, 29:94.

¹³⁵ McRuer, “Disabling Sex: Notes for a Crip Theory of Sexuality,” 14.

¹³⁶ McRuer, *Crip Times : Disability, Globalization, and Resistance*, 229.

encompassing disability culture, which has “a common language, a shared historical lineage, cohesive social community, and political solidarity.”¹³⁷ They do not only pertain to community and culture, but they also provide a framework that can be used when engaging with decision-makers and policymakers. This is also where the binary between disabled persons and non-disabled persons becomes further pronounced, because the discrepancies within disability politics are significantly more disproportionate when non-disabled persons are in leadership positions.

Crip Queer Movements

An alliance between disability communities and queer communities forged in the 1970s when disabled persons sought assistance from queers to build a new disability movement – and, despite not all having disabled identities, many queers aided. Interestingly, however, a few years later, disability movements failed to help queer communities when HIV/AIDS emerged.¹³⁸ Disability movements, then incredibly homogenous, did not create space for interlocking communities and instead focused on issues that predominantly impacted white heterosexually physically disabled men. The HIV/AIDS pandemic was evidently not one of them at that time.

Distinct international movements spearheaded by crips and queers emerged throughout the 1960s and 1970s as means to resist similar forms of oppression, such as ableism and heterosexism.¹³⁹ As unpacked in the previous chapter, historical disability movements were not concerned about the lack of organizing around disability and sexuality – coinciding with the absence of scholarly research in the same realm.

¹³⁷ Shakespeare, *Disability Rights and Wrongs Revisited*, 29:94.

¹³⁸ O’Toole, *Fading Scars: My Queer Disability History*, 150.

¹³⁹ McRuer, *Crip Times : Disability, Globalization, and Resistance*, 78.

Shakespeare notes that sexuality activism and research must go beyond claiming that disabled persons are asexual to instead incorporate the reality that disabled persons are sexual beings into daily policies and practices¹⁴⁰ – not simply heterosexuality, but also queerness. Sexuality activism and research must further engage with diverse sexual identities to reduce the hegemony that still prevails in both the disability and sexuality realms.

Direct action as a means of resisting marginalization, validates the struggles experienced daily and provides “a symbolic challenge to an oppressive and exclusionary society.”¹⁴¹ Discovering disability identities can occur while participating in direct action and becoming more aware of disability politics in general – which can ultimately lead to growth as well as a larger sense of belonging and pride towards disability communities. Specifically, Shakespeare notes “the rise of disability politics has created a new [disability] category, a new [way] of affiliating and identifying, which did not exist before.”¹⁴²

Activism in the Margins: What it Sins Invalid?

Despite being key to instill much needed shifts within society, opportunities for crip queers to become involved in decision-making and policymaking processes remain scarce. These individuals are working to deconstruct dominant hegemonic representations of disability by sharing their intersectional lived narratives. Crip queers do so by engaging in activism initiatives, such as Sins Invalid¹⁴³: a performing art collective

¹⁴⁰ Shakespeare, *Disability Rights and Wrongs Revisited*, 29:220–22.

¹⁴¹ Shakespeare, 29:93.

¹⁴² Shakespeare, 29:94.

¹⁴³ Further information about Sins Invalid can be found at sinsinvalid.org

centering intersectional experiences of disabled persons¹⁴⁴ and members of other equity-seeking groups. Although Sins Invalid is based in the United States, the artists bring with them a breath of knowledge from all parts of the world. Intersectionality is a core component of Sins Invalid, and it is demonstrated through its artists and their various productions. The positionality of each artist is evident through within their performance.

Sins Invalid believes that disability movements “must work to understand [ableism], combat it, and create alternative practices rooted in justice.”¹⁴⁵ This collective thus uses disability culture to generate awareness and challenge (mis)representations of disabled persons in mainstream media and various political processes. Existing narratives that highlight intersections between disability and sexuality do not explore the interconnectedness with accounts of cultural, political, and social nature – which is essential to grasp disability and sexuality in a theoretical framework. Workshops are offered to both disabled and non-disabled communities to promote inclusive and leadership opportunities for individuals who are dismantling systems that render their social and political participation quite challenging (and at times even impossible).

Sins Invalid attempts to disrupt normative beliefs in relation to disability and sexuality, as well as other key marginalizing dimensions, by celebrating bodies who defy societal norms. Russell Shuttleworth notes that claiming to one’s body “has been foundational to disability scholarship and activism”¹⁴⁶, because it emphasizes sexuality as

¹⁴⁴ Disability here is contextualized within Sins Invalid’s definition: “We define disability broadly to include people with physical impairments, people who belong to a sensory minority, people with emotional disabilities, people with cognitive challenges, and those with chronic/severe illness.” (Sins Invalid, “Mission & Vision.”)

¹⁴⁵ Sins Invalid, “What Is Disability Justice?”

¹⁴⁶ Shuttleworth, “Bridging Theory and Experience: A Critical-Interpretive Ethnography of Sexuality and Disability,” 55.

a form of marginalization in political and social institutions. *Sins Invalid* is ultimately at the forefront of knowledge production and international disability movements in the realms of disability and its various intersectionality, and the work it produces is used in various academic fields – such as disability studies and critical disability studies. Conclusively, the impact of activism in disability scholarship can be witnessed through Jay Dolmage’s observation that “Disability studies as a political movement has been very much about claiming disability, owning disabled identity, and the right to define this lived experience.”¹⁴⁷

Disability Justice: Why Now?

The Disability Justice Collective was founded in 2005 by disability activists Patty Berne, Eli Clare, Sebastian Margaret, Mia Mingus, as well as Leroy Moore. Some of this collective’s aims include shifting beyond single-axes frameworks, dismantling existing hegemonic disability movements, and generating spaces where disabled persons with intersectional lived experiences could take on leadership roles. According to Berne, a member of *Sins Invalid*, “[disability] justice is a vision and practice of what is yet-to-be, a map that we create.”¹⁴⁸ It recognizes the ways in which ableism and disablism interlocks with other systems of oppression (colonialism, for instance) and shapes the realities of disabled persons accordingly. As such, movements that adopt an intersectional framework can diversify their activism practices to correspond to struggles experienced by multiple disability communities (not simply the hegemonic ones). Ultimately, Leah

¹⁴⁷ Dolmage, *Disability Rhetoric*, 95.

¹⁴⁸ Berne, “Disability Justice - A Working Draft.”

Piepzna-Samarasinha asserts that disability justice “centers everyone who is marginalized in mainstream disability organizing¹⁴⁹”.

It is ultimately challenging to recognize the prominence of ableism¹⁵⁰ in daily life because it has been rooted within societal beliefs and practices for a very long time – and perhaps even normalized. Ableism remains a system of oppression that is less discussed when compared with, for instance, racism. Disabled persons are often further marginalized by systems because ableism is deeply rooted within them and work is not being done to accurately dismantle these barriers inflicted upon diverse disability communities.

The understanding and implementation of intersectionality within the context of disability, however, has led to a shift in how ableism is defined, allowing for a more accurate representation in the interlocking of disability and other systems of oppression. Talila ‘TL’ Lewis developed the following working definition in community with disabled blacks and other racialized individuals. Ableism is:

A system that places value on people's bodies and minds based on societally constructed ideas of normality, intelligence, excellence, desirability, and productivity. These constructed ideas are deeply rooted in anti-Blackness, eugenics, misogyny, colonialism, imperialism and capitalism. This form of systemic oppression leads to people and society. determining who is valuable and worthy based on a person's language, appearance, religion and/or their ability to satisfactorily reproduce, excel and 'behave'. You do not have to be disabled to experience ableism.¹⁵¹

The Principles of Disability Justice

¹⁴⁹ Piepzna-Samarasinha, *Care Work : Dreaming Disability Justice*, 22.

¹⁵⁰ Disablism is “a set of assumptions ([conscious] and unconscious and practices that promote the differential or unequal treatment of people because of actual or presumed disabilities”. (Pease, *Undoing Privilege: Unlearning Advantage in a Divided World*, 155.)

¹⁵¹ Lewis, “January 2021 Working Definition of Ableism.”

Sins Invalid has created a framework – Ten Principles of Disability Justice – to ensure that components of disability justice are readily applied in social and political processes, as well as throughout movement building. Here I reproduce and annotate two of these.

1) Intersectionality

Although disabled persons are often portrayed as having single-axis identities, this is seldom the case. Key marginalizing dimensions readily impact their lived experiences, but decision-making and policy-making processes have yet to fully acknowledge this – specifically in discussions of disability and sexuality. This will be exemplified by engaging with the CRPD and its OP in the subsequent chapter.

2) Leadership of those most impacted

Actions and initiatives taken up by both crip and queer movements are often achieved through the form of direct action. This is an inclusive method to engage in various political processes as it validates the struggles experienced by members of equity-seeking groups – in this case, crips and queers specifically. Engaging in direct action can lead towards a greater understanding of crip and queer communities, including greater self-understanding, which ultimately can help strengthen one’s own identities. In relation to disability, Shakespeare states “the rise of disability politics has created a new [disability] category, a new of affiliating and identifying, which did not exist before.”¹⁵² While the scholar is only referring to disability in this instance, one could argue that all types of minority politics (including queerness) work in similar ways – and that

¹⁵² Shakespeare, *Disability Rights and Wrongs*, 94.

ultimately identities of crips and queers have been shaped by these politics, alongside social movements.

4.4 Conclusion

Disabled persons remain at the margins of society, and this is further amplified when they have intersectional identities. The lived experiences of disabled persons are still not readily addressed, and their political and social needs are too often disregarded – ultimately impacting how they perceive their own identities. Impacts of ableism/disablism that is being perpetuated upon disabled persons are not perceived in the same magnitude as other systems of oppression. Therefore, the reality that disabled persons are considered non-sexual beings is not readily addressed. As discussed in a previous section, for instance, they experience marginalization in the realms of sexual citizenship since they are perceived as non-sexual beings – which is translated in disability movements.

The predominance of normalizing disability research has also impacted the direction of disability movements. They were previously led by disabled and non-disabled persons who did not comprehend the extent of intersectionality that prevailed within the overarching disability community. Some disabled activists are working at the margins of disability movements to shift activist practices towards a framework that understand the complexities that currently exist throughout disability communities. *Sins Invalid*, for instance, aims to reduce systemic injustices and dismantle how disabled bodies are perceived through performances and educational offerings – which are methods not always applied within mainstream disability movements. Such initiatives are fostering engagement opportunities for crip queers, who otherwise are often barred from

decision-making and policymaking processes since systems are not yet in place to ensure their success. But this is simply the beginning.

Chapter 5

All For us Without us: Where is the Pride at (Homogenous) International Decision-Making Tables?

5.1 Introduction

This chapter demonstrates how decision-making processes and international disability policies are primarily conceived from (mis)representation of disability. Subtle exclusion of disabled persons from such processes are identified through an analysis of the Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol (OP). Consequently, this chapter will articulate the remaining gap between governing structures and disability communities, and ultimately the current dissemination of knowledge and lived experiences. While their primary goal is to disrupt homogeneity within the scope of disability policies, the CRPD and its OP may not accurately represent the lived realities of disabled persons and consider the diverse intersectional experiences that currently prevail within disability communities.

Firstly, I will provide an historical overview of the CRPD, and its OP, and analyze its impact within international disability communities. I will then emphasize that this policy has been implemented to represent homogenous needs of disabled persons, despite its prominence in disability communities, and explore the repercussions of such homogeneity in terms of community engagement and participatory opportunities. Lastly, I will critique international disability policies, particularly the CRPD and its OP, for not including crip queers within their frameworks. To demonstrate how these individuals are excluded from this treaty, I will dissect the following CRPD Articles: ‘Awareness-

raising’ (Article eight), ‘Education’ (Article twenty-four), ‘Health’ (Article twenty-five), as well as ‘Participation in cultural life, recreation, leisure and sport’ (Article thirty).

Critical disability studies, through its human-rights and social models, call for the creation of more inclusive and meaningful engagement opportunities so that disabled persons can voice their diverse needs – and ultimately participate in international decision-making and policy-making processes. Despite attempting to represent the needs of disabled persons, the field of critical disability studies fails to acknowledge lived experiences through an intersectional lens, thereby omitting the impacts of key marginalizing dimensions, such as queerness, and reproducing inequality within disabled communities. This is directly correlated with the ways in which discussion and policy processes are held – without recognizing the prominence of intersectionality within international disability policies. As such, the primary intent of international disability policies is to centre the perspectives of disabled persons who are classified within a homogenous group. Queer disabled persons, for instance, are denied participatory opportunities because policies and programming do not account for these types of realities, which were previously generated with the application of critical disability models.

Research is being conducted to exhibit the lack of inclusive participatory opportunities for disabled persons within international development processes. Magdolna Birtha’s *Nothing about CRPD Monitoring Without Us*¹⁵³, Jan Grue’s *Inclusive*

¹⁵³ Birtha, “‘Nothing about CRPD Monitoring Without Us’: A Case Study on the Involvement of the Disability Movement in Policy-Making in Zambia.”

*Marginalization*¹⁵⁴, and Ethan Levine’s *United Nations Policy and the Intersex Community*¹⁵⁵ are examples of such research.

Firstly, through discussing disability movements in Zambia, Birtha¹⁵⁶ explores key components of political and social engagement as well as effective decision-making and policy-making processes. The author analyzes how countries of the Global South participate in implementing and monitoring of the CRPD, and the financial toll to take part in such processes. Despite not addressing critical disability studies in this text, Birtha amplifies southern narratives and the impacts of policies upon disabled persons of the Global South – which can ultimately be silenced by mainstream disability studies.

Secondly, while Grue¹⁵⁷ draws upon critical disability studies to explore terminology applied within the CRPD, the author notes a lack of inclusivity in the articles. As such, Grue investigates the CRPD’s with normative perceptions of disability and how they generate more barriers for disabled persons instead of generating inclusive engagement opportunities.

Thirdly, Levine¹⁵⁸ provides a brief overview of the Intersex community and frames it within existing disability policies. The author notes that often such policies contradict efforts of policies empowering the Intersex community. Specifically, Levine expresses concerns about the CRPD not being inclusive for the Intersex community and provides textual examples to illustrate this gap. The author indicates that the field of

¹⁵⁴ Grue, “Inclusive Marginalisation? A Critical Analysis of the Concept of Disability, Its Framings and Their Implications in the United Nations Convention on the Rights of Persons with Disabilities.”

¹⁵⁵ Levine, “United Nations Policy and the Intersex Community.”

¹⁵⁶ Birtha, “‘Nothing about CRPD Monitoring Without Us’: A Case Study on the Involvement of the Disability Movement in Policy-Making in Zambia.”

¹⁵⁷ Grue, “Inclusive Marginalisation? A Critical Analysis of the Concept of Disability, Its Framings and Their Implications in the United Nations Convention on the Rights of Persons with Disabilities.”

¹⁵⁸ Levine, “United Nations Policy and the Intersex Community.”

critical disability studies does not readily address the binaries established in deploying its different models. We can extend this to the international policy sphere, below.

5.2 Understanding (Disabling) International Political Agendas

Unpacking the Hegemony in Decision-Making and Policymaking.

Political Philosopher Iris Marion Young's definition of politics

[...] includes all aspects of institutional organization, public action, social practices and habits, and cultural meanings insofar as they are potentially subject to collective evaluation and [decision-making].¹⁵⁹

The key term in this definition is 'collective' because it infers that decision-making and policymaking processes are conceived in such a way that facilitate the participation of members from all communities involved – including those from equity-seeking communities. Young calls this the 'recognition of group difference', which ultimately "entails establishing procedures for ensuring that each group's voice is heard in the public"¹⁶⁰. Young's vision of politics, in theory, is pertinent and applicable, as it strives to foster inclusive and meaningful opportunities for individuals to participate in the implementation and execution of such processes. Moreover, there is an underlying emphasis in Young's definition that members of equity-seeking groups must be at the forefront of processes that influence their daily life activities.

The actual practice of decision-making and policymaking does not reflect Young's definition. In fact, it remains quite the opposite, especially for crip queers. Decision-making and policymaking processes are still located within a hierarchical

¹⁵⁹ Marion Young, *Justice and the Politics of Difference*, 34.

¹⁶⁰ Marion Young, 11–12.

structure, and thus privilege individuals who adhere to norms that are heterogenous, as well as able-bodied/able-minded – dismissing all other lived experiences that may be constructed as divergent. Young therefore questions if societal and political institutions understand the necessity of centering members of equity-seeking communities in their processes instead of continuously excluding them, whether implicitly or overtly.

Most decision-makers and policymakers do not have the lived experience, nor the knowledge, required to generate policies and services that will accurately respond to the diverse needs of equity-seeking communities. There should be, at minimum, systems in place to support these individuals in generating decisions based on lived experiences of equity-seeking communities (such as crip queers) instead of drawing conclusions that are rather unfounded. Understanding complex debates about inclusion and intersectionality could ultimately shift how decision-making and policymaking are navigated and applied in daily life. As such, this chapter engages with Articles enshrined within the CRPD to demonstrate how crip queers are intentionally disregarded when in fact they could be become indispensable to the growth of international processes.

A Brief Encounter of Disability in the Political Agenda.

Disability, Rights Monitoring, and Social Change, edited by Marcia H. Rioux, Paula C. Pinto, and Gillian Parekh, provides a framework to understand and evaluate disability policies in the international sphere. Rioux argues that “the political agenda of disability rights is one of the most contested areas of social policy”¹⁶¹ since there are ample debates emerging from the Global North and Global South. The (mis)representation of disability discussed in previous chapters is extremely prevalent in

¹⁶¹ Rioux, “Introduction: A North-South Dialogue on Participatory Monitoring,” 7.

decision-making and policymaking processes. While more scholars are increasingly researching the discrepancy in international disability policies, such as Rebecca Yeo¹⁶², there is much more to be done.

Navigating processes to create and implement disability policies is challenging, as most often the individuals that readily engage in these processes are not the one impacted by them. As illustrated throughout the previous chapters, disabled persons are seldom offered opportunities to completely and meaningfully participate in these processes – especially in the international sphere. This signifies that policies are often enshrined within heterogeneity and able-bodiedness/able-mindedness.¹⁶³ Colonialism is prevalent as well since decision-makers and policymakers are frequently located in the Global North. Therefore, they only account for Northern realities when establishing policies and practices. Even in instances where disabled persons are consulted and included throughout decision-making and policymaking processes (in their entirety), there is an overrepresentation of white heterosexual physically disabled men.

The lives of crip queers are being disregarded by these homogenous processes – processes in which do not acknowledge prevailing diversity and intersectionality within disability communities.¹⁶⁴ Corresponding to the discrepancies in knowledge production within academia, decisions and policies are not parallel to the struggles experienced by most disabled persons, and this in an international sphere. To disrupt this cycle, disability activists and scholars must collectively decide on what consists of an inclusive society –

¹⁶² Yeo, “Disability, Poverty and the ‘New’ Development Agenda: A Report to the KaR Programme.”

¹⁶³ Titchkosky and Aubrecht, “WHO’s MIND, Whose Future? Mental Health Projects as Colonial Logics.”

¹⁶⁴ Kafer, *Feminist, Queer, Crip*, 73.

one that is rooted in both inclusion and intersectionality.¹⁶⁵ This is heavily impacted by ‘who’ is participating in activism and ‘how’ movements are accordingly built. The disability justice framework is still absent from some disability movements – notably those exhibit hegemonic and heterosexual ideologies.

Existing Intersectional Decision-Making and Policymaking Processes

Intersectional frameworks are essential to evaluate how international decisions and policies are responding to key dimensions furthering the oppression and stigma experienced by members of equity-seeking communities.¹⁶⁶ They are also used to explore existing power dichotomies between individuals involved in decision-making and policymaking and those most impacted (in both positive and negative ways) by these processes.

In preparation for the 2001 UN World Conference Against Racism (WCAR), Kimberlé Crenshaw was tasked by the Genova Planning Committee to facilitate a workshop and present a paper – both pertaining to intersectionality.¹⁶⁷ Crenshaw’s involvement at the conference was crucial because it was the first instance where intersectionality was part of a conversation at the United Nations, and it marked the beginning of an ongoing discussion about intersectionality within the realms of decision-making and policymaking processes. This demonstrates that accounting for intersectional marginalization is possible in the sphere of international development, despite the reality that disability policy has not yet evolved to that level.

¹⁶⁵ Block et al., *Occupying Disabil. Crit. Approaches to Community, Justice, Decolonizing Disabil.*, 154–55.

¹⁶⁶ Crenshaw, “Normative Discrimination and the Motherhood Penalty.”

¹⁶⁷ Crenshaw, 104–5.

When Disability Becomes Part of the Intersection.

Yeo argues that disabled persons are marginalized in similar ways as their non-disabled counterparts¹⁶⁸, which may be correct to a certain extent. There remain, however, significant discrepancies in how decision-making and policymaking processes that acknowledge and readily address intersectionality. Consequently, processes may respond to one key marginalizing dimension and ignore any repercussions derived from others – this typically occurs when disability is part of one’s encompassing and intersecting identities. Some key marginalizing dimensions are deemed more prevalent, for instance race, and thus they may be more intentionally and meaningfully addressed. Specific processes may in fact be conflicting when located in parallel to others since they are essentially addressing needs that could potentially be divergent from one another. For instance, policies implemented to foster meaningful participatory opportunities for disabled persons may not include a component that pertains exclusively to their sexuality.

As noted by Lang et al., many disability policies are already adopting an intersectional framework. In this discussion they are mostly referring to policies pertaining to the realms of education, employment, social protection, as well as universal design.¹⁶⁹ Notably, Lang et al.’s text does not mention anything in relation to key dimensions of marginalization – except for gender and socio-economic status. Disabled persons are once again desexualized within the scholarship, and particularly throughout entire decision-making and policymaking processes as well.

¹⁶⁸ Yeo, “Disability, Poverty and the ‘New’ Development Agenda: A Report to the KaR Programme,” 44–45.

¹⁶⁹ Lang et al., “Implementing the United Nations Convention on the Rights of Persons with Disabilities: Principles, Implications, Practice and Limitations,” 213.

A Correlation Between Crip Queer Movements and Policy Implementation.

Prioritizing an intersectional framework in decision-making and policymaking processes pertaining to disabled persons is essential to address their diverse needs. Even in these instances, however, some key marginalizing dimensions are still not considered as part of disabled persons' encompassing identities. Lang et al. argue that disability movements have a fundamental role in ensuring that intersectional experiences are accurately depicted within all types of decision-making and policymaking processes – especially those that impact disabled persons the most.¹⁷⁰

While disability movements are increasingly portraying the intersectional experiences of crip queers, this reality is not being transferred, and ultimately represented, in decision-making and policymaking processes. Disability justice and other frameworks generated by *Sins Invalid*, for instance, may have forged the path for further inclusive and intersectional thinking within scholarship, but they have not been enshrined within decision-making and policymaking processes. The progress made by all disability communities, particularly crip queer activism, is not displayed at the international table because it remains predominantly occupied by white heterosexual physically disabled men. Specifically, Ahmed notes that “queer activism create a place at the table in hope that [it] will not keep its place.”¹⁷¹ This statement can very well be used in the context of disabled activists – or even more pertinently, to crip queers. Initiatives led by crip queer movements are not only beneficial to these individuals, but other communities as well (marginalized and privileged alike).

¹⁷⁰ Lang et al., 211.

¹⁷¹ Ahmed, *The Promise of Happiness*, 106.

A Note on DPOs

Disabled Persons' Organizations (DPOs)¹⁷² are primarily governed and led by disabled persons themselves. They are located throughout different countries – in both the Global North and the Global South. DPOs differ significantly from academic discourses in the way they approach knowledge production. Those based in the Global North are typically led by individuals who either live with, or have fostered meaningful relationships with, disabled persons throughout these specific locations. DPOs do not always adopt cross-disability lenses, and thus challenges sometimes occur when they compete against one another for their differing perspectives to be acknowledged by international key stakeholders. Intersectional identities are also at times disregarded by DPOs because their agendas are already overflowing with overarching disability advocacy without adding the complex layers of intersectionality.

Knowledge gathered by disability movements is often used to establish the goals of DPOs and define what type of initiatives they should take up. In fact, one of the first DPOs, the Disabled Peoples' International, was created as disability movements rose to prominence during the 1970s. Concerns and struggles experienced by disabled persons are validated throughout these organizations' initiatives and vision, because they are led by activists and stakeholders who have similar education and lived experiences. DPOs ultimately empower disabled persons to inflict much needed societal shifts and to generate awareness about topics pertaining to disability – including its intersection with sexuality. The growth of these organizations on an international level provides the outlet for disabled persons to further become involved in situating and executing (an

¹⁷² DPOs are also known as Organizations of Persons with Disabilities (OPDs).

homogenized version of) the disability agenda. DPOs also supplement the hierarchical knowledge production found in the academy. They should be thus viewed as indispensable in forging a working relationship between disabled persons and non-disabled stakeholders so that disability communities can readily govern their own lives.

The Disability Twist on Participatory Citizenship

A key component of inclusive and intersectional of decision-making and policymaking processes is participatory citizenship. Barker and Murray apply Edward Said's "participatory citizenship" in their work to explore how disability identities impact the ways in which disabled persons can fully and meaningfully participate in the realms of decision-making and policymaking. According to Said, participation refers to "the production of criticism and the possibility of democratic agency."¹⁷³ The scholar's understanding of participation considers a different notion of citizenship – one acknowledging the reality that citizenship cannot remain fixed since it must account for the diversity that prevails within society. Accordingly, the presence and insight of disabled persons in the implementation and execution of decisions and policies is essential to further inclusivity and intersectionality in the overarching international disability agenda.

5.3 Unpacking the CRPD

A Brief History of Disability at the UN

There is no singular way of experiencing or representing disability – especially within the international sphere. Disabled persons from the Global South have different

¹⁷³ Barker and Murray, "Disabling Postcolonialism : Global Disability Cultures and Democratic Criticism," 72.

encounters from those in the Global North. As in perceived in knowledge production within academia, stakeholders that are readily involved in influential processes pertaining to disability are typically rooted in perspectives of the Global North. Hegemonic and heterosexual depictions of disability, that only represent a fragment of the encompassing disability communities, take precedence in decision-making and policy-making – and this is evident in how the UN perceives disabled persons and how work in the disability realm is carried out.

Starting in the 1970s, disability rights achieved greater prominence in international decision-making and policymaking processes. The UN designated 1981 as the first International Year of Disabled Persons (IYDP) without much consultation amongst disability communities who predominantly believed that it would heighten the depiction of disabled persons as care and charity recipients.¹⁷⁴ Subsequently, in 1994, Leandro Despouy was appointed as Special Rapporteur to examine the relationship between disability and human rights and provide recommendations accordingly. This Special Rapporteur was influential in the advancement of disability discussions on an international sphere. Despouy, for instance, fostered discussions between activists, representatives from DPOs, as well as UN stakeholders. A recommendation was also made to establish either a Disability Ombudsman or a convention highlighting the rights of disabled persons¹⁷⁵ – and the CRPD was implemented more than a decade later.

The Moment that Changed Everything: Introducing the CRPD

¹⁷⁴ Lindqvist, “Background: Monitoring - A Key Element in Realizing Human Rights for All,” 14.

¹⁷⁵ Both recommendations are enshrined within Despouy’s final report, *Human Rights and Disabled Persons* (1993)

One of Despouy's recommendations took effect when the Mexican government proposed the elaboration of what is now called the Convention on the Rights of Persons with Disabilities (CRPD). The proposition was accepted at the UN's General Assembly in 2001. A drafting committee, comprised of state parties and DPOs representatives, presented a proposal for the CRPD in 2006 – and it was during the same year that the CRPD was officially adopted. The Optional Protocol of the CRPD (OP), a side-agreement, came into effect in 2008. DPOs and state parties have since then collaborated to ensure the CRPD becomes binding throughout countries.

The CRPD itself is comprised of 50 articles, and its OP presents another 18. It is noteworthy that countries who become signatories of the CRPD, or ratified, are not bounded to the OP – and vice versa. Although they are contained in the same treaty, the CRPD and its OP hold two separate entities. Articles enshrined within the CRPD include (but are not limited to): 'Awareness-raising' (Article eight), 'Education' (Article twenty-four), 'Health' (Article twenty-five), as well as 'Participation in cultural life, recreation, leisure and sport' (Article thirty). The OP's articles pertain to the ways in which State Parties are organized and managed. State Parties are required to submit regular reports informing how the CRPD is being implemented within their respective countries. A body of independent experts, known as the CRPD's Committee, will then make suggestions and recommendations after analyzing each report. It is important to note that 147 countries have become signatories of the CRPD, and another 97 have proceeded towards being ratified. Although these numbers may seem encouraging, they display a reason to be concerned: the ratified countries are not mandated by the CRPD to participate in implementation and monitoring initiatives because they have not signed, which defeats

the purpose of having a convention altogether. Ratification may deter countries from committing to generating inclusive spaces – especially if they do not have access to resources that could further support them in such significant undertakings.

Protocols and Perceptions

Disabled activists and scholars, such as Judith Heumann, argue that the CRPD has been instrumental in shifting societal perceptions of disabled communities¹⁷⁶ – in part because it is the first international human right treaty that exclusively pertains to disabled persons. Correspondingly, Harpur claims that the CRPD can draw more correlations between academia and activism because ‘the disability agenda’ acts as a commonality between them.¹⁷⁷ They, amongst others, believe the CRPD to be entrenched within the social model. Since it strives to dismantle environmental and societal barriers that impede the daily lives of disabled persons¹⁷⁸, as highlighted in the social model, the CRPD does not acknowledge the fact that experiences of ableism and disablement extend further than what is included in these types of barriers. Accordingly, for other disabled activists and scholars, such as Rioux, Pinto, and Parekh, the CRPD is a mere step into generating more inclusive spaces for all individuals because there it addresses only a fragment of the marginalization experienced by disabled persons.¹⁷⁹ Stakeholders have yet to completely acknowledge the other types of barriers that prevail for disability communities –

¹⁷⁶ Heumann and Joiner, *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist*, 191.

¹⁷⁷ Harpur, “Embracing the New Disability Rights Paradigm: The Importance of the Convention on the Rights of Persons with Disabilities,” 3–4.

¹⁷⁸ Mittler, “The UN Convention on the Rights of Persons with Disabilities: Implementing a Paradigm Shift,” 8–9.

¹⁷⁹ Boucher and Fiset, “Monitoring Individual Experiences: An Innovative Strategy to Initiate Social Change in the Exercise of Human Rights by Persons with Disabilities,” 126.

including attitudinal barriers and systemic barriers relating to other forms of identity and marginalization, such as gender, race, and sexuality.

The social model's impact can be found in the language used throughout the CRPD. 'Person-first language' (person with disabilities, for instance) is adopted throughout its entirety without any acknowledgment of other prevailing terminologies. Many disabled persons prefer using 'identity-first language' (disabled-person' because it demonstrates a sense of pride towards their disability and disrupts the medicalization of disability that remains prevalent in contemporary society.

Despite having a few articles mention 'culture' in subtle ways, the specifics of disability culture are not discussed within the CRPD (including its OP). This is rather interesting since culture holds a significant meaning in the lives of disabled persons – particularly those who adopt a 'disabled identity'. The absence of discussions pertaining to disability culture reinforces the fact that core principles of the Disability Justice framework were not applied upon adoption of the CRPD. Terms such as 'crip' and 'crip time', which are at the essence of disability identities and Disability Justice, are not even defined within the CRPD. This ultimately depicts disability as a single homogenous narrative, despite being an identity that may possibly coincide alongside other identities as well – such as the intersectional identity of crip queer.

5.4 Locating the Missing Crip Queers in the CRPD

Monitoring Rights and Measuring Hegemonic Participation.

One of the primary reasons for the CRPD was providing disabled persons with participatory opportunities so that they could be included in influential decision-making

and policymaking processes – and this in a way that was most beneficial to them.¹⁸⁰ Article 33, for instance, states that disabled person “shall be involved and participate fully in the monitoring process.”¹⁸¹ There is a lack of occasions, however, to guide countries in generating more inclusive participatory opportunities for disabled persons – particularly individuals who may be perceived as the ‘non-normative disabled person’ (such as crip queers). The lived experiences of crip queers, for instance, lie within the realms of two distinct communities and therefore the ways in which they navigate society may be different from an individual who adopt a perspective of disability that is more enshrined within the social model.

The participation of disabled persons in terms of the CRPD is more prevalent within the realms of monitoring rights. State Parties establish mechanisms to ensure the implementation of the convention’s articles within their own countries, and disabled persons have a role throughout the monitoring of impacts from the CRPD and its OP. To this extent, the UN writes that “[the] full participation of civil society, in particular [disabled persons] and their representative organizations is essential in the national monitoring and implementation process.”¹⁸²

Disabled persons who participate in monitoring initiatives have greater opportunities to dismantle preconceptions and advocate for resources and supports that coincide with their actual needs and are not derived from assumptions. Activists and scholars believe the CRPD has generated a new type of participation – one that becomes

¹⁸⁰ Samson, “Securing the Full Participation of Persons with Disabilities and Their Representative Organizations in Disability Rights Monitoring,” 237.

¹⁸¹ Samson, 238.

¹⁸² UN website monitoring

inclusive to a diversity of needs and where disabled persons are readily not excluded¹⁸³. Monitoring can be completed in different ways: discussion facilitating, institutional policy analyzing, as well as social media monitoring. Once again, however, monitoring frameworks are rooted within normative perceptions of disability that do not acknowledge diverse intersections prevailing throughout disability communities. The ways that monitoring is completed thus does not consider how disabled persons adopting intersecting identities are readily impacted by two distinct marginalizing dimension – disability and sexuality. Lang et al. recognize the complexity that prevail when an attempt is made to consider diverging lived experiences simultaneously, but state that removal of barriers is key to foster participatory opportunities in a way that is both inclusive and intersectional¹⁸⁴.

Understanding Prevailing Gaps of the CRPD.

Although the CRPD is the most inclusive and intersectional human rights treaty from the UN¹⁸⁵, many disability communities are not yet included within its purview because their needs were disregarded upon its implementation. Disabled persons, for instance, still experience marginalization in ratified or signatory countries of the Global South because the CRPD primarily represent northern ideologies – and ableism ultimately further perpetuates the colonialism and hegemony that already prevails within these communities. One subsection of the Preamble pertains to intersectionality:

(p) Concerned about the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms

¹⁸³ Kabue, “Disability Rights, Development, and the Roles of the Disability Movement from the International to the Grassroots,” 205.

¹⁸⁴ Lang et al., “Implementing the United Nations Convention on the Rights of Persons with Disabilities: Principles, Implications, Practice and Limitations,” 217.

¹⁸⁵ Lawson and Priestley, “Concurrent Multinational Monitoring of Disability Rights in the European,” 31.

of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status.¹⁸⁶

There are two articles, six and seven, that address the specific needs of intersecting identities: women with disabilities and children with disabilities, respectively. The CRPD recognizes that both groups “are subject to multiple discrimination”¹⁸⁷, and accordingly it impacts the ways in which they participate in society. These Articles (as well as Preamble) represent the extent to which intersectionality is discussed within the CRPD and its OP. A few themes enshrined within this treaty are subtly drawing a connection to intersectionality, however, and they are encouraging further awareness about such topics for both ratified and signatory countries. The fact remain that there is a lack of substance written in the CRPD and its OP to transfer what is noted within these Articles into tangible steps. For instance, should Articles eight, twelve, twenty-four, and twenty be further developed and concretized, they could not only be part of leading policies addressing the intersection between disability and sexuality.

‘Awareness-raising’ (Article eight), ‘Education’ (Article twenty-four), ‘Health’ (Article twenty-five), as well as ‘Participation in cultural life, recreation, leisure and sport’ (Article thirty) could all be reformulated to reflect the diversity existing within disability community. They would also have potential of forging much needed shifts, so that ultimately crip queers are viewed as essential participants within international decision-making and policymaking processes.

Article 8: Awareness-Raising.

¹⁸⁶ United Nations, Convention on the Rights of Persons with Disabilities and Optional Protocol.

¹⁸⁷ United Nations.

This article reinforces the necessity for State Parties to generate awareness, dismantle marginalizing experiences for disabled persons, and disrupt preconceptions that hinder the creation of inclusive participatory opportunities – which are all key in fostering a more inclusive society that recognize intersectional identities. However, it does not emphasize the gap about intersectionality that is still evident in awareness initiatives, educational institutions, and mainstream media. It also does not specify what types of rights are included in training sessions pertaining to the rights of disabled persons. This could become an outlet where information about their sexual rights were presented to both non-disabled and disabled persons. To this extent, crip queers must be consulted so that stakeholders understand the complexities that exist when creating systems as responses to key marginalizing dimensions.

Article 12: Equal Recognition before the Law.

Article twelve states that disabled persons must have the right to “enjoy legal capacity on an equal basis to others in all aspects of their lives.”¹⁸⁸ Sonali Shah notes that “all aspects” include those relating to the sexuality of disabled persons – despite them not being defined as such.¹⁸⁹ Even so, stakeholders do not usually tend to acknowledge sexuality as an important component of disabled persons’ encompassing identity. Therefore, it is key to implement systems that allow individuals to think through sexuality without it being overtly stated.

Article 24: Education.

¹⁸⁸ United Nations.

¹⁸⁹ Shah, “‘Disabled People Are Sexual Citizens Too’: Supporting Sexual Identity, Well-Being, and Safety for Disabled Young People,” 1–2.

Education, as applied within this Article, refers to the knowledge gained within an institutional institution – such as primary and secondary schools. Again, thinking through intersectionality, this article simply reinforces the hegemony that prevails within education systems. The intersectionality between disability and sexuality is mostly absent from curriculums, and yet the CRPD is not addressing this gap of knowledge within education. Disabled persons are often excluded from sexuality courses, and in instances where they are immersed in these learnings, their cultures and needs are not represented in the content they are learning. If, for some reason, discussions about disability and sexuality are held, they typically do not exhibit the prevalence of diverse sexual identities. There is thus a misrepresentation of crip queers that begins at a young age, which evidently is a contributing factor to the lack of inclusive and intersectional participatory opportunities.

Article 25: Health.

‘Health’ is the only Article that addresses the physical impacts of one’s disability. The following subsection is one of the only instances where the sexuality of disabled persons is acknowledged within the CRPD and its OP:

(a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.¹⁹⁰

While this statement is quite progressive, no tangible steps have been undertaken to accurately address imminent challenges relating to sexuality that are experienced by disabled persons. Instead, they are still required to advocate for their sexual needs and

¹⁹⁰ United Nations, Convention on the Rights of Persons with Disabilities and Optional Protocol.

wellness with healthcare professionals. The reality is that these individuals remain subject to extreme medicalization, and therefore they are perceived as not having a sexuality, which bars all opportunities of fostering discussions about sexuality between disabled persons and healthcare professionals. Another component enshrined within this Article is the research that guides healthcare practices. According to Harpur, the CRPD requires State Parties to facilitate research and, while this may be the case for some health topics, research surrounding disability and sexuality, in the realms of international development, is seldom conducted.¹⁹¹

5.5 Conclusion

Disability did not take priority on the international agenda until a few decades following the emergence of disability movements. It was not until the 1980 that the UN hired its first Special Rapporteur to provide recommendations in the realms of disability and human rights. Among them was the creation and implementation of the CRPD, which was adopted in 2008. Both disabled and non-disabled stakeholders participated in the CRPD writing process, and thus it should accurately represent the needs and lived experienced of disabled persons – all the while encompassing the diversity that exists among disability communities.

Although the CRPD is regarded as one of the most inclusive UN treaties, it remains incredibly homogenizing. It caters to a specific disability population – one that is prevalently comprised of white heterosexual physically disabled men. Most of the CRPD's articles do not acknowledge the various intersectional dimensions that prevail

¹⁹¹ Harpur, "Embracing the New Disability Rights Paradigm: The Importance of the Convention on the Rights of Persons with Disabilities," 2–3.

within disability communities or, if they do, are addressing them in very subtle ways. Intersectionality between disability and sexuality is overtly disregarded from most articles of the CRPD, even in instances where they correlate in obvious ways. The CRPD holds incredible power on the international sphere, and yet it is participating in the misrepresentation and stigmatization of disabled persons, particularly in the realms of their sexuality and sexual identities. Crip queers were not consulted during the CRPD's establishment, and this is evident in the ways they are (or rather, are not) engaged with during influential international processes – despite spearheading contemporary disability movements that are rooted within disability justice principles.

Chapter 6

Queer Crips Unite! A Few Concluding Thoughts

6.1 Affect in Disability Scholarship

Sara Ahmed notes that theory is often perceived as rather abstract and argues when “something is more theoretical the more abstract it is, the more it is abstracted from everyday life”¹⁹². The narratives of equity-seeking members must then be located at the centre of theoretical frameworks, so that they can further represent the actual struggles and triumphs experienced by these individuals – instead of becoming too abstract and ultimately diverging from them. Two distinct ways are being used by scholars to ensure that normative discourses are disrupted by the creative and political work of individuals who are otherwise oppressed and restricted by societal and political barriers.

Firstly, affect is an important factor in critical theory that engage with activism and scholarship simultaneously. Carolyn Pedwell and Anne Whitehead examine the relationship between affect studies and women’s studies. While using this intersection as a guiding framework, they draw two distinct conclusions: firstly, they note affect studies is “an interdisciplinary space with often contradictory and oppositional takes upon the subject matter”¹⁹³; and secondly, they claim that “there is a shared interest [amongst affect studies and women’s studies] in the way feeling is negotiated in the public sphere and experienced in the body”¹⁹⁴. Affect theory is also applied to processes of both knowledge production and power distribution – which could ultimately be used to

¹⁹² Fournier, *Autotheory as Feminist Practice in Art, Writing, and Criticism*, 1.

¹⁹³ Dolmage, *Disability Rhetoric*, 199.

¹⁹⁴ Dolmage, 199.

describe the influence of critical disability studies. It also engages with Indigenous studies, postcolonial studies, as well as queer studies.

Although Pedwell and Whitehead do not identify with disability scholarship in their conversation about affect theory, there is an argument to be made that a similar relationship could be forged with disability scholarship. After all, to borrow the words of Pedwell and Whitehead, some disability research, including the work of Jasbir Puar and McRuer (to name a few), does engage with the ways that “[feelings] are [negotiated] in the public sphere and experienced in the body”¹⁹⁵ – particularly in the realms of disability and queerness. In fact, Ahmed’s *The Promise of Happiness* discusses compulsory forms of heteronormativity, in conjunction with compulsory forms of phenomenological normativity¹⁹⁶. This is also a topic of discussion, in correlation with able-bodiedness/able-mindedness, throughout McRuer’s *Crip Times*.

Another way that non-normative narratives are taking more space in theoretical frameworks is through the means of autotheory. The term ‘autotheory’ emerged throughout the twentieth century as a means of incorporating autobiography with theory¹⁹⁷. It does so by highlighting experiences that are regarded as marginal. Specifically, autotheory aims to emphasize the importance of theoretical frameworks that are rooted in struggles experienced by members of equity-seeking communities – or as Lauren Fournier states: “theory that emerges from the self.”¹⁹⁸ It does so by dismantling

¹⁹⁵ Dolmage, 199.

¹⁹⁶ According to McRuer and Mollow, compulsory forms of phenomenological normativity “[orients] the body into predictable channels of communication that can be directed, shaped, and controlled”. (McRuer and Mollow, *Sex Disabil.*, 161.)

¹⁹⁷ Fournier, *Autotheory as Feminist Practice in Art, Writing, and Criticism*.

¹⁹⁸ Fournier, 35.

social hierarchies existing in academia and beyond to ultimately reduce the impact that privileged communities exert upon knowledge production and political processes.

Fournier applies autotheory as a research lens to amplify the voices of specific communities continuously silenced by dominant political and social institutions, and to think through to think through contemporary cultural, political, and social debates. Autotheory does not distinguish ‘art’ from ‘theory’, but rather fosters conversations between one another to further inclusive thinking. While it is most notably applied in the context of feminism, one can argue that autotheory can also be used to further accurate representations of crip queers in scholarship as well as decision-making and policymaking process. Researchers that produce knowledge with autotheory do so with the intent of responding to social issues and generating inclusive space. I would include sins invalid as a form of autotheory here.

Affect and autotheory, although contributing in very distinct way, are at the essence of generating inclusive spaces for crip queers in both academia and the greater society. They both represent the historical movements and the cultures of crip queers and acknowledge how marginalization and stigmatization impact their (mis)representation in contemporary society. The daily lives of crip queers are usually perpetuated by mainstream media, as well as political and social institutions, in ways that do not reflect these communities – but rather deem them as marginal. Affect theory and autotheory thus act as methods to provide the necessary resources for crip queers to share their encounters. These systems also ensure that intersectional and diverse narratives are being understood and accurately reflected in academia, as well as various other institutions.

6.2 Performativity to Challenge Ableism and Heterosexism

There is a need for more conversations highlighting the various dimensions of intersectionality that may exist within the experience of sexuality. The sexual identities of crip queers, for instance, are stripped because they do not conform to norms readily imposed by society – further reducing their sense of agency.¹⁹⁹ Abby Wilkerson is thus advocating for further attention to their sexual agency so that they can meaningfully participate in ways of that are most suited for them, even if their identities are marginalized by society. The scholar believes that “sexual agency is central to political agency and that sexual democracy should be recognized as a key political struggle²⁰⁰”.

A correlation can be articulated between Wilkerson’s take on sexual agency and feminism’s mantra ‘the personal is political’ – also adopted by autotheoretical frameworks. The (mis)representation in the sexual identities of crip queers is directly impacting how sexuality is perceived within knowledge production and service delivery. These individuals are therefore further sharing their lived experiences and learned knowledge to demystify dominant construction of sexuality so that they can contribute to diversifying how sexuality is portrayed on an international sphere.

Knowledge dissemination by crip queers themselves ensures that narratives are captured and represented in meaningful ways. They are thus attempting to effect change with how these narratives are being articulated to political and social institutions – a practice that is rooted in Judith Butler’s performativity theory. According to Judith Butler, performativity is perceived as “not a singular or deliberate ‘act’, but, rather, as the

¹⁹⁹ Linton, “Disability Studies/Not Disability Studies,” 526.

²⁰⁰ Siebers, “A Sexual Culture for Disabled People,” 38.

reiterative and citational practice by which discourse produces the effect that it names.”²⁰¹

Butler originally conceived this theory to explain the ways in which norms impacted gender and sexuality, but it can also engaged be discussed parallel to disability.

Performativity theory is, in some extent, however, already interwoven with disability scholarship. Petra Kuppers, for instance, when applying to a disability context, states that performativity “points to the embodied, living quality of knowledge, and its continued production of truth”²⁰². Furthermore, as Sherry notes, however, performativity consists of “rituals and social processes which help constitute an identity”²⁰³; thus, it is an essential component of identity politics. Ultimately, this signifies that performativity could cultivate a different kind of meaning within the daily lives of crip queers – one that is not solely defined by the marginalization and oppression inflicted upon them by political and social institutions.

6.3 Imagining the Futurity of Crip Queers

Muñoz thoroughly engages with the concept of ‘queer utopia’ in his text, *Cruising Utopia*. He defines utopia as “a desire for a thing, or a way, that is not here but nonetheless is desirable, something worth striving for”²⁰⁴. Utopian work presents an opening for a more inclusive beginning. It guides equity-seeking communities towards a future that is located beyond systemic oppression. Utopia seeks to dismantle all notions of hegemony and instead replace it with opportunities for inclusion and diversification – or as Muñoz states, “of what might be”²⁰⁵. Individuals must thus confront and dismantle

²⁰¹ Sherry, “Overlaps and Contradictions between Queer Theory and Disability Studies,” 780.

²⁰² Pease, *Undoing Privilege: Unlearning Advantage in a Divided World*, 250.

²⁰³ Sherry, “Overlaps and Contradictions between Queer Theory and Disability Studies,” 780.

²⁰⁴ Muñoz, *Cruising Utopia: The Then and There of Queer Futurity*, 121.

²⁰⁵ Muñoz, 38.

barriers that are impeding on opportunities to be perceived as meaningful participants within society.

While Muñoz is predominantly referring to queerness, his contextualization of utopia can be applied to the experiences of crip queers in particular. There are increasingly more possibilities for crip queers to share their narratives and disrupt (mis)representations pertaining to disability and sexuality, but they still experience marginalization and stigmatization because of their intersecting identities. In the context of disability and sexuality, utopianism lies at the extremities of able-bodiedness/able-mindedness and heteronormativity. Consequently, crip queer activists are organizing beyond political and social systems to share narratives that are still readily dismissed – notably through the means of arts and other cultural components. Crip space and crip time are embedded in disability culture and are increasingly guiding society in becoming more inclusive to diverse needs.

Crip time refers to a society in which disabled persons are not restricted by the organization of time imposed by normative beliefs. It provides individuals with the flexibility they require to meaningfully participate within society and thus attempts to eliminate any constraints related to systems of oppression. McRuer uses crip time “to imagine a disabled sociality that likewise has historically refused the very distinction between the social and bodies engaged in a range of intimate practices”²⁰⁶. Crip time can disrupt oppressive systems and contribute to the evolvement of society. It can be perceived as a means of performativity and a glimpse into a utopian world, where the

²⁰⁶ McRuer, *Crip Times : Disability, Globalization, and Resistance*, 93.

presence of crip queers is not defined, as well as marginalized, by able-bodiedness/able-mindedness and heteronormativity.

6.4 Conclusion

When theorizing the lived experience of disability, Devva Kasnitz notes that “[we] occupy time/space. We also occupy ourselves²⁰⁷”. There is an argument to be made that the scholar is referring to a utopian world, one in which the needs of disabled persons are located at the centre of all decision-making and policymaking processes. This world is not concurrent to their current experiences – especially when observing how crip queers must readily disrupt dominant narratives to disseminate accurate knowledge about their experiences and needs.

This thesis exhibited how crip queers are using activism and theory simultaneously to dismantle inaccurate conceptualizations of disability and sexuality so that instead reinforce their intersectional realities as crip queers. Some initiatives and movements, such as Sins Invalid, are striving to reduce the marginalization and stigmatization of crip queers and foster spaces for discussions pertaining to disability and queerness – however this is only the beginning. Sins Invalid is ultimately offering a glimpse into a utopian world where crip queers are considered essential participants of society and located at the forefront of decision-making and policymaking processes.

Nothing at the table without us.

²⁰⁷ Marcus, Kasnitz, and Block, “If Disability Is a Dance, Who Is the Choreographer? A Conversation About Life Occupations, Art, Movement,” 351.

Bibliography

- Ahmed, Sara. *The Promise of Happiness*. London: Duke University Press, 2010.
- Artiles, Alfredo J. "Untangling the Racialization of Disabilities: An Intersectionality Critique across Disability Models." *Du Bois Review* 10, no. 2 (2013): 329–47. <https://doi.org/10.1017/S1742058X13000271>.
- Barker, Clare, and Stuart Murray. "Disabling Postcolonialism : Global Disability Cultures and Democratic Criticism." In *The Disability Studies Reader*, edited by Lennard J. Davis, 61–73. Taylor & Francis Group, 2013.
- Bell, Chris. "Introducing White Disability Studies: A Modest Proposal." In *The Disability Studies Reader*, edited by Lennard J. Davis, Second., 275–83. Milton Park: Routledge, 2006.
- Berghs, Maria, Karl Atkin, Chris Hatton, and Carol Thomas. "Do Disabled People Need a Stronger Social Model: A Social Model of Human Rights?" *Disability and Society* 34, no. 7–8 (2019): 1034–39. <https://doi.org/10.1080/09687599.2019.1619239>.
- Berne, Patty. "Disability Justice - A Working Draft," 2015.
- Birtha, Magdolna. "'Nothing about CRPD Monitoring Without Us': A Case Study on the Involvement of the Disability Movement in Policy-Making in Zambia." *ADRY* 1 (2013): 115–38.
- Block, Pamela, Devva Kasnitz, Akemi Nishida, and Nick Pollard, eds. *Occupying Disability: Critical Approaches to Community, Justice, and Decolonizing Disability*. New York: Springer Dordrecht Heidelberg, 2015. https://doi.org/10.1007/978-94-017-9984-3_12.
- Bolton, Derek, and Grant Gillett. *The Biopsychosocial Model of Health and Disease : New Philosophical and Scientific Developments*. Cham: Springer Nature Switzerland, 2019.
- Boucher, Normand, and David Fiset. "Monitoring Individual Experiences: An Innovative Strategy to Initiate Social Change in the Exercise of Human Rights by Persons with Disabilities." In *Disability, Rights Monitoring, and Social Change*, edited by Marcia H. Rioux, Paula C. Pinto, and Gillian Parekh, 125–36. Toronto: Canadian Scholars' Press Inc., 2015.
- Brown, Jax Jacki. "The Politics of Pashing." In *QDA: A Queer Disability Anthropology*, edited by Raymond Luczak, 3–5. Minneapolis: Squares & Rebels, 2015.
- Butler, Judith. *Undoing Gender*. Abingdon: Routledge, 2004.
- Charlton, James I. *Nothing About Us Without Us: Disability Oppression and Empowerment*. First Edit. Oakland: University of California Press, 2000.
- Clare, Eli. *Exile and Pride: Disability, Queerness, and Liberation*. Durham: Duke University Press, 2015.
- Cornell, Drucilla. "The Ethical Affirmation of Human Rights: Guyatri Spivak's Intervention." In *Can the Subaltern Speak? Reflections on the History of an Idea*,

- edited by Rosalind C. Morris, 100–116. New York: Columbia University Press, 2010.
- Coulthard, Glen Sean. *Red Skin White Masks: Rejecting the Colonial Politics of Recognition*. Minnaeapolis: University of Minnesota Press, 2004.
- Crenshaw, Kimberlé. “Normative Discrimination and the Motherhood Penalty.” *Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics*, no. 1 (1989): 139–67. <https://doi.org/10.4324/9781315631011-38>.
- Crow, Liz. “Including All of Our Lives: Renewing the Social Model of Disability.” In *Encounters with Strangers: Feminism and Disability*, edited by Jenny Morris, 124–40. London: Women’s Press, 1996.
- Cubacub, Sky. “Radical Visibility: A Disabled Queer Clothing Reform Movement Manifesto.” In *Disability Visibility: First-Person Stories from the Twenty-First Century*, edited by Alice Wong, 90–101. New York: Vintage Books, a division of Penguin Random House LLC, 2020.
- Degener, Theresia. “A Human Rights Model of Disability,” 2014. <https://doi.org/10.4324/9781315612881>.
- . “Inclusive Equality and the Human Rights Model of Disability – 10 Years Jurisprudence of the United Nations Committee on the Rights of Persons with Disabilities Introduction.” In *Theo van Boven Lecture 3 December*, 2018.
- Dolmage, Jay Timothy. *Disability Rhetoric*. Syracuse: Syracuse University Press, 2014.
- Ellis, Katie, Rosemarie Garland-Thomson, Mike Kent, and Rachel Robertson, eds. *Interdisciplinary Approaches to Disability: Looking Towards the Future*. Vol. 2. Abingdon: Routledge, 2019. <https://doi.org/10.1017/s0252921100086395>.
- Engel, George L. “The Clinical Application of the Biopsychosocial Model.” *American Journal of Psychiatry* 137, no. 5 (1980): 535–44. <https://doi.org/10.1176/ajp.137.5.535>.
- . “The Need for a New Medical Model: A Challenge for Biomedicine.” *Journal of Interprofessional Care* 4, no. 1 (1989): 37–53. <https://doi.org/10.3109/13561828909043606>.
- Erevelles, Nirmala. *Disability and Difference in Global Contexts: Enabling a Transformative Body Politic*. New York: Palgrave Macmillan, 2011.
- Erickson, Loree. “Revealing Femmegimp: A Sex-Positive Reflection on Sites of Shame as Sites of Resistance for People with Disabilities.” *Atlantis* 31, no. 2 (2007): 42–52.
- Fournier, Lauren. *Autotheory as Feminist Practice in Art, Writing, and Criticism*. Cambridge: The MIT Press, UK, 2021.
- Gill, Michael, and Cathy J. Schlund-Vials, eds. *Disability, Human Rights and the Limits of Humanitarianism*. Surrey: Ashgate, 2014.
- Go, Julian. *Postcolonial Thought and Social Theory*. New York: Oxford University Press, 2016.

- Goodley, Dan. "Dis/Entangling Critical Disability Studies." In *Culture - Theory - Disability: Encounters Between Disability Studies and Cultural Studies*, edited by Anne Waldschmidt, Hanjo Berressem, and Moritz Ingwersen, 81–97. Transcript Verlag, 2017.
- Grech, Shaun. "Comment from the Field: Disability and the Majority World: Challenging Dominant Epistemologies." *Journal of Literary & Cultural Disability Studies* 5, no. 2 (2011): 217–19. <https://doi.org/10.3828/jlcds.2011.17>.
- . "Decolonising Eurocentric Disability Studies: Why Colonialism Matters in the Disability and Global South Debate." *Social Identities* 21, no. 1 (2015): 6–21. <https://doi.org/10.1080/13504630.2014.995347>.
- . "Recolonising Debates or Perpetuated Coloniality? Decentering the Spaces of Disability, Development and Community in the Global South." *International Journal of Inclusive Education* 15, no. 1 (2011): 87–100. <https://doi.org/10.1080/13603116.2010.496198>.
- Grue, Jan. "Inclusive Marginalisation? A Critical Analysis of the Concept of Disability, Its Framings and Their Implications in the United Nations Convention on the Rights of Persons with Disabilities." *Nordic Journal of Human Rights* 37, no. 1 (2019): 3–17. <https://doi.org/10.1080/18918131.2019.1589165>.
- Harpur, Paul. "Embracing the New Disability Rights Paradigm: The Importance of the Convention on the Rights of Persons with Disabilities." *Disability and Society* 27, no. 1 (2012): 1–14. <https://doi.org/10.1080/09687599.2012.631794>.
- Heumann, Judith, and Kristen Joiner. *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist*. Boston: Beacon Press, 2020.
- Hickey, Huhana. "Marginalizing the Subaltern Within: How to Effectively Engage with and Monitor Diverse Cultural Identities with Disabilities When Individuak Identity Dominates the Collective Identity Framework." In *Disability, Rights Monitoring, and Social Change*, edited by Marcia H. Rioux, Paula C. Pinto, and Gillian Parekh, 221–36. Toronto: Canadian Scholars' Press Inc., 2015.
- Hill Collins, Patricia, and Sirma Bilge. *Intersectionality*. Cambridge, UK: Polity Press, 2016. <https://doi.org/10.1353/ces.2017.0006>.
- Hogan, Andrew J. "Social and Medical Models of Disability and Mental Health: Evolution and Renewal." *CAJ* 191, no. 1 (2019): E16–18. <https://doi.org/10.1503/cmaj.181008>.
- Jagose, Annamarie. *Queer Theory: An Introduction*. New York: New York University Press, 1996. <https://doi.org/10.2307/3618815>.
- Kabue, Samuel. "Disability Rights, Development, and the Roles of the Disability Movement from the International to the Grassroots." In *Disability, Rights Monitoring, and Social Change*, edited by Marcia H. Rioux, Paula C. Pinto, and Gillian Parekh, 201–5. Toronto: Canadian Scholars' Press Inc., 2015.
- Kafer, Alison. *Feminist, Queer, Crip*. Bloomington: Indiana University Press, 2013.
- Kolářová, Kateřina. "Affective Politics of Disability Shame in the Times of Neoliberal

- Exceptionalism,” n.d.
- . “Performing the Pain: Opening the (Crip) Body for (Queer) Pleasures.” *Review of Disability Studies* 3, no. 44–52 (2010).
- . “‘What Kind of Development Are We Talking About?’ A Virtual Roundtable with Tsitsi Chataika, Nilika Mehrotra, Karen Soldatic and Kateřina Kolářová.” *Somatechnics* 6, no. 2 (2016): 142–58. <https://doi.org/10.3366/soma.2016.0188>.
- Lang, Raymond, Maria Kett, Nora Groce, and Jean-Francois Trani. “Implementing the United Nations Convention on the Rights of Persons with Disabilities: Principles, Implications, Practice and Limitations.” *Alter, European Journal of Disability Research* 5 (2011): 206–20. <https://doi.org/10.1016/j.alter.2011.02.004>.
- Lawson, Anna, and Angharad E. Beckett. “The Social and Human Rights Models of Disability: Towards a Complementarity Thesis.” *The International Journal of Human Rights*, 2020. <https://doi.org/10.1080/13642987.2020.1783533>.
- Lawson, Anna, and Mark Priestley. “Concurrent Multinational Monitoring of Disability Rights in the European.” In *Disability, Rights Monitoring, and Social Change*, edited by Marcia H. Rioux, Paula C. Pinto, and Gillian Parekh, 27–44. Toronto: Canadian Scholars’ Press Inc., 2015.
- Leng, Kirsten. “Historicising ‘Compulsory Able-Bodiedness’: The History of Sexology Meets Queer Disability Studies.” *Gender and History* 31, no. 2 (2019): 319–33. <https://doi.org/10.1111/1468-0424.12428>.
- Levine, Ethan. “United Nations Policy and the Intersex Community.” In *Disability, Human Rights and the Limits of Humanitarianism*, 179–94, 2014. <https://doi.org/10.4324/9781315577401-11>.
- Lewis, Talila “TL.” “January 2021 Working Definition of Ableism,” 2021. <https://www.talilalewis.com/blog/january-2021-working-definition-of-ableism>.
- Lindqvist, Bengt. “Background: Monitoring - A Key Element in Realizing Human Rights for All.” In *Disability, Rights Monitoring, and Social Change*, edited by Marcia H. Rioux, Paula C. Pinto, and Gillian Parekh, 13–24. Toronto: Canadian Scholars’ Press Inc., 2015.
- Linton, Simi. “Disability Studies/Not Disability Studies.” *Disability and Society* 13, no. 4 (1998): 525–39. <https://doi.org/10.1080/09687599826588>.
- Luczak, Raymond, ed. *A Queer Disability Anthology*. Minnaepolis: Squares & Rebels, 2015.
- Marcus, Neil, Devva Kasnitz, and Pamela Block. “If Disability Is a Dance, Who Is the Choreographer? A Conversation About Life Occupations, Art, Movement.” In *Occupying Disability: Critical Approaches to Community, Justice, and Decolonizing Disability*, edited by Pamela Block, Devva Kasnitz, Akemix Nishida, and Nicholas Pollard, 347–58. New York: Springer, 2016.
- Marion Young, Iris. *Justice and the Politics of Difference*. Princeton: Princeton University Press, 2012.
- Markotić, Nicole, and Robert McRuer. “Leading with Your Head: On the Borders of

- Disability, Sexuality, and the Nation.” In *Disability and Sexuality*, edited by Robert McRuer and Anna Mollow, 165–82. Durham: Duke University Press, 2012.
- Marshall, Catherine A., Elizabeth Kendall, and Martha E. Banks, eds. *Disabilities: Insights from Accross Fields and Around the World*. Westport: Greenwood Publishing Group, 2009.
- McRuer, Robert. “As Good as It Gets: Queer Theory and Critical Disability.” *GLQ: A Journal of Lesbian and Gay Studies* 9, no. 1–2 (2003): 79–105.
- . *Crip Theory: Cultural Signs of Queerness and Disability*. New York: New York University Press, 2006.
- . *Crip Times : Disability, Globalization, and Resistance*. New York University Press, 2018.
- . “Disabling Sex: Notes for a Crip Theory of Sexuality.” *GLQ: A Journal of Lesbian and Gay Studies* 17, no. 1 (2011): 107–17. <https://doi.org/10.1215/10642684-2010-021>.
- . “Taking It to the Bank: Independence and Inclusion on the World Market.” *Journal of Literary Disability* 1, no. 2 (2007).
- . “The Then and There of Crip Futurity.” *GLQ: A Journal of Lesbian and Gay Studies* 20, no. 4 (2014): 532–34. <https://doi.org/10.1215/10642684-2721402>.
- McRuer, Robert, and Anna Mollow, eds. *Sex and Disability*. Duke University Press, 2012.
- Meekosha, Helen. “Decolonising Disability: Thinking and Acting Globally.” *Disability & Society* 26, no. 6 (2011): 667–82. <https://doi.org/10.1080/09687599.2011.602860>.
- Meekosha, Helen, and Karen Soldatic. “Human Rights and the Global South: The Case of Disability.” *Third World Quarterly* 32, no. 8 (2011): 1383–97. <https://doi.org/10.1080/01436597.2011.614800>.
- Mingus, Mia. “Access Intimacy: The Missing Link.” *Leaving Evidence*, 2011. <https://leavingevidence.wordpress.com/2011/02/12/changing-the-framework-disability-justice/>.
- . “Changing the Framework : Disability Justice How Our Communities Can Move beyond Access to Wholeness.” *Leaving Evidence*, 2011. <https://leavingevidence.wordpress.com/2011/02/12/changing-the-framework-disability-justice/>.
- Mittler, Peter. “The UN Convention on the Rights of Persons with Disabilities: Implementing a Paradigm Shift.” *Journal of Policy and Practice in Intellectual Disabilities* 12, no. 2 (2015): 79–89. <https://doi.org/10.1111/jppi.12118>.
- Mohanty, Chandra. “Under Western Eyes: Feminist Scholarship and Colonial Discourses.” *Feminist Review* 30, no. 1 (1988): 61–68. <https://doi.org/10.1057/fr.1988.42>.
- Morris, Rosalind C., ed. *Can the Subaltern Speak? Reflections on the History of an Idea*. New York: Columbia University Press, 2010.

- Muñoz, José Esteban. *Cruising Utopia: The Then and There of Queer Futurity*. New York: New York University Press, 2009.
- Nations, United. Convention on the Rights of Persons with Disabilities and Optional Protocol (2006). <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>.
- Nigianni, Chrysanthi, and Merl Storr, eds. *Deleuze and Queer Theory*. Edinburgh: Edinburgh University Press, 2009. <https://doi.org/10.5860/choice.47-0652>.
- O'Toole, Joan Corbett. *Fading Scars: My Queer Disability History*. Berkeley: Reclamation Press, 2019.
- Oliver, Mike. "The Social Model of Disability: Thirty Years On." *Disability and Society* 28, no. 7 (2013): 1024–26. <https://doi.org/10.1080/09687599.2013.818773>.
- Pease, Bob. *Undoing Privilege: Unlearning Advantage in a Divided World*. London, UK: Bloomsbury Publishing, 2010.
- Piepzna-Samarasinha, Leah Lakshmi. *Care Work : Dreaming Disability Justice*. Arsenal Pulp Press, 2018.
- Priestley, Mark, ed. *Disability and the Life Course: Global Perspectives*. New York: Cambridge University Press, 2001.
- Prince, Michael J. *Absent Citizens: Disability Politics and Policy in Canada*. Toronto: University of Toronto Press, 2009.
- Puar, Jasbir K. *The Right to Maim: Debility, Capacity, Disability*. Durham: Duke University Press, 2017.
- Riddle, Christopher A. "Why We Do Not Need a 'Stronger' Social Model of Disability." *Disability and Society* 35, no. 9 (2020): 1509–13. <https://doi.org/10.1080/09687599.2020.1809349>.
- Rioux, Marcia H. "Introduction: A North-South Dialogue on Participatory Monitoring." In *Disability, Rights Monitoring, and Social Change*, edited by M. H. Rioux, Paula C. Pinto, and Gillian Parekh, 1–12. Toronto: Canadian Scholars' Press Inc., 2015.
- Rioux, Marcia H., Paula C. Pinto, and Gillian Parekh, eds. *Disability, Rights Monitoring, and Social Change: Building Power out of Evidence*. Toronto: Canadian Scholars' Press, Inc., 2015.
- Samson, Rita M. "Securing the Full Participation of Persons with Disabilities and Their Representative Organizations in Disability Rights Monitoring." In *Disability, Rights Monitoring, and Social Change*, edited by Marcia H. Rioux, Paula C. Pinto, and Gillian Parekh, 237–48. Toronto, 2015.
- Shah, Sonali. "'Disabled People Are Sexual Citizens Too': Supporting Sexual Identity, Well-Being, and Safety for Disabled Young People." *Frontiers in Education* 2, no. September (2017): 1–5. <https://doi.org/10.3389/educ.2017.00046>.
- Shakespeare, Tom. *Disability Rights and Wrongs*, 2006. <https://doi.org/10.4324/9780203640098>.
- . *Disability Rights and Wrongs Revisited*. *Disability & Society*. Vol. 29, 2014.

- <https://doi.org/10.1080/09687599.2013.864874>.
- . “Disabled Sexuality: Toward Rights and Recognition.” *Sexuality and Disability* 18, no. 3 (2000): 159–66. <https://doi.org/0146-1044/00/0900-0159>.
- Shakespeare, Tom, and Sarah Richardson. “The Sexual Politics of Disability, Twenty Years On.” *Scandinavian Journal of Disability Research* 20, no. 1 (2018): 82–91. <https://doi.org/10.16993/sjdr.25>.
- Sherry, Mark. “(Post)Colonising Disability.” *Wagadu* 4 (2007): 10–22.
- . “Overlaps and Contradictions between Queer Theory and Disability Studies.” *Disability and Society* 19, no. 7 (2004): 769–83. <https://doi.org/10.1080/0968759042000284231>.
- Shuttleworth, Russell. “Bridging Theory and Experience: A Critical-Interpretive Ethography of Sexuality and Disability.” In *Sex and Disability*, edited by Robert McRuer and Anna Mollow, 54–68. Durham: Duke University Press, 2012.
- Siebers, Tobin. “A Sexual Culture for Disabled People.” In *Sex and Disability*, edited by Robert McRuer and Anna Mollow, 37–53. Durham: Duke University Press, 2012.
- . *Disability Theory*. Ann Arbor: The University of Michigan Press, 2008.
- Sins Invalid. “Mission & Vision,” n.d.
- . “What Is Disability Justice?,” 2020.
- Snider, Stefanie. “Moving toward Disability Justice: Introduction to ‘Lesbian Lives, Disabled Lives.’” *Journal of Lesbian Studies*, 2020. <https://doi.org/10.1080/10894160.2020.1778853>.
- Titchkosky, Tanya, and Katie Aubrecht. “WHO’s MIND, Whose Future? Mental Health Projects as Colonial Logics.” *Social Identities* 21, no. 1 (2015): 69–84. <https://doi.org/10.1080/13504630.2014.996994>.
- Tuhiwai Smith, Linda. *Decolonizing Methodologies: Research and Indigenous Peoples*. Second Edi. Dunedin: Otago University Press, 2012.
- Vehmas, Simo, and Nick Watson. “Moral Wrongs, Disadvantages, and Disability: A Critique of Critical Disability Studies.” *Disability and Society* 29, no. 4 (2014): 638–50. <https://doi.org/10.1080/09687599.2013.831751>.
- Wally, Yeng. “Disability: Beyond the Medical Model.” *The Lancet* 374, no. 9704 (2009): 1793. [https://doi.org/10.1016/S0140-6736\(09\)62043-2](https://doi.org/10.1016/S0140-6736(09)62043-2).
- Watson, Nick, and Simo Vehmas. *Routledge Handbook of Disability Studies*. Routledge, 2013. <https://doi.org/10.4324/9780203144114-10>.
- Wilkerson, Abby L. “Normate Sex and Its Discontents.” In *Sex and Disability*, edited by Robert McRuer and Anna Mollow, 183–207. Durham: Duke University Press, 2012.
- Wong, Alice, ed. *Disability Visibility: First-Person Stories from the Twenty-First Century*. New York: Vintage Books, 2020.
- Yeo, Rebecca. “Disability, Poverty and the ‘New’ Development Agenda: A Report to the KaR Programme,” 2005.