

**Queer, Crip, Rights? Establishing a new Identity Approach to Disability for a  
post- Convention on the Rights of Persons with Disabilities World**

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## **Abstract**

Disability offers unique challenges concerning human rights conceptualisation and implementation, as persons with disabilities (PWDs) experience barriers and disadvantages in society not felt by their non-disabled peers. The Convention on the Rights of Persons with Disabilities (CRPD) fills the gaps left by pre-existing general human rights instruments, establishing a structure of disability-centric rights. However, the concept of disability is fluid and lacks a precise definition, making interpreting the Convention difficult. Methods to interpret and understand disability are still open for debate, generating academic discourse through the lens of disability models. These models generally fall under moral, medical, and social headings. Moral models perceive disability as a tragedy, relying on religious understandings of humanity. Medical models utilise pathology to generate a standardised biological classification of the human body, where disability becomes an ailment needing treatment. Social models emphasise disablement through barriers preventing available and equal access to society. Each model focuses on different aspects of the disability experience, and each carries strengths and weaknesses.

This thesis argues that these weaknesses cause more problems than they solve. Instead, the disability rights discourse would benefit from a new perspective and model of disability. Identity provides this new perspective. By affording individuals the agency to dictate how and whether they identify with the term disability, the discourse surrounding human rights gains a new dimension. This thesis will use queer theory and crip theory as foundational bases to establish an identity approach. In highlighting how a queer identity contributes positively to the disability rights discussion, it will demonstrate how a postmodern and post-structural reading of the CRPD prioritises PWDs and ensures greater tangible access to human rights protections.



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This thesis is dedicated to Dr Michael Watson, my loving grandfather, who sadly passed away during my research. He supported me in every step of my journey through higher education, avidly reading drafts of all my essays. It breaks my heart that he will never be able to read this thesis. However, I hope that I continue to make him proud.

“Elementary, my dear Watson.”

## **Abbreviations**

ACHR	American Convention on Human Rights
ACHPR	African Charter on Human and People's Rights
ADRDM	American Declaration on the Rights and Duties of Man
AHC	Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities ('Ad Hoc Committee')
AU	African Union
CEDAW	Convention on the Elimination of All Forms of Discrimination Against Women
CERD	Convention on the Elimination of All Forms of Racial Discrimination
CJEU	Court of Justice of the European Union
CmRPD	Committee on the Rights of Persons with Disabilities
COE	Council of Europe
CRC	Convention on the Rights of the Child
CESCR	Committee on Economic, Social, and Cultural Rights
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disabled Persons Organisation
DRDP	Declaration on the Rights of Disabled Persons
DRMRP	Declaration on the Rights of Mentally Retarded Persons
ECHR	European Convention on Human Rights and Fundamental Freedoms
ECtHR	European Court of Human Rights

EU	European Union
HRC	Human Rights Committee
IACPD	Inter-American Convention on the Elimination of all Forms of Discrimination Against Persons with Disabilities
IACmHR	Inter-American Commission on Human Rights
IACtHR	Inter-American Court on Human Rights
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social, and Cultural Rights
ICF	International Classification of Functioning, Disability, and Health
ICIDH	International Classification of Impairment, Disabilities, and Handicaps
IOM	Institute of Medicine
IYDP	International Year of Disabled Persons
LGBTQ+	The Lesbian, Gay, Bisexual, Transgender, and Queer Community
LSN	Landmine Survivors Network
NCMRR	National Centre for Medical Rehabilitation and Research
NGO	Non-Governmental Organisation
NHRI	National Human Rights Institutions
OAS	Organisation of American States
OAU	Organisation of African Unity
PWD	Person with a Disability
UDHR	Universal Declaration of Human Rights

UN	United Nations
UNCHR	United Nations Commission on Human Rights
UNESCO	United Nations Economic and Social Council
UNGA	United Nations General Assembly
UNSR	United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities
WFD	World Federation of the Deaf
WHO	World Health Organisation
WPA	World Programme of Action concerning Disabled Persons

# Table of Contents

<b>INTRODUCTION</b> .....	<b>10</b>
OVERVIEW.....	10
RESEARCH FOUNDATIONS.....	13
THESIS STRUCTURE.....	16
<b>ONE: THE CRPD CONTEXT</b> .....	<b>20</b>
1.1 INTRODUCTION.....	20
1.2 THE INTERNATIONAL CONTEXT.....	23
1.2.1 <i>Shoehorning Disability into Human Rights Instruments</i> .....	24
1.2.2 <i>The 1970s Human Rights Shift</i> .....	32
1.2.3 <i>A Global Development</i> .....	41
1.3 NOTHING ABOUT US WITHOUT US.....	44
1.3.1 <i>Who? Party Guests and Interested Parties</i> .....	45
1.3.2 <i>What? Substantive Convention Topics</i> .....	47
1.3.3 <i>Where? Accessibility and Realism</i> .....	52
1.3.4 <i>When? Convention in Context</i> .....	53
1.3.5 <i>Why? Of Purposes and Focuses</i> .....	54
1.3.6 <i>How? Convention(al) Models</i> .....	56
1.4 A NEW AGE OF DISABILITY RIGHTS.....	57
1.4.1 <i>Defining Disability?</i> .....	58
1.4.2 <i>Key CRPD Principles</i> .....	61
1.4.3 <i>The "Social" Context</i> .....	66
1.5 CONCLUSION.....	70
<b>TWO: QUEERING DISABILITY</b> .....	<b>72</b>
2.1 INTRODUCTION.....	72
2.2 SHAKESPEARE’S RIGHTS AND WRONGS.....	74
2.2.1 <i>Understanding Shakespeare</i> .....	74
2.2.2 <i>Critiquing Shakespeare</i> .....	82

2.3	DEFINING QUEER.....	96
2.3.1	<i>Putting ‘Queer’ in Theory.....</i>	97
2.3.2	<i>Putting ‘Theory’ in Queer.....</i>	99
2.4	BUTLER AND THE QUEERING OF THINGS.....	106
2.4.1	<i>Performative Acts.....</i>	106
2.4.2	<i>Gender Trouble.....</i>	111
2.4.3	<i>Bodies That Matter.....</i>	116
2.5	CONCLUSION.....	120
<b>THREE: MAKING QUEER DISABILITY WORK .....</b>		<b>122</b>
3.1	INTRODUCTION.....	122
3.2	CRIPPING THE QUEER.....	123
3.2.1	<i>Queering Disablement.....</i>	123
3.2.2	<i>Compulsory Able-Bodiedness.....</i>	128
3.2.3	<i>Ability Trouble.....</i>	132
3.3	QUEER LEGAL THEORY .....	135
3.3.1	<i>Queering the Law.....</i>	135
3.3.2	<i>Queering Human Rights.....</i>	141
3.4	CONCLUSION.....	146
<b>FOUR: MODELLING DISABILITY .....</b>		<b>147</b>
4.1	INTRODUCTION.....	147
4.2	BIOLOGY: LOCATING DISABILITY IN THE BODY.....	149
4.2.1	<i>Biomedical Overview .....</i>	151
4.2.2	<i>Regulating Bodies.....</i>	156
4.2.3	<i>Diagnosing the Fatal Flaws .....</i>	163
4.3	GOVERNANCE: ABILITY AND POPULATION CONTROL .....	176
4.3.1	<i>Exploring Social Models.....</i>	177
4.3.2	<i>Flaws of Governance.....</i>	184
4.4	RESCUE: SOCIETY’S HERO SYNDROME .....	196
4.4.1	<i>Saving You from Yourself.....</i>	197

4.4.2	<i>Saving You from Society</i> .....	202
4.5	CONCLUSION.....	208
<b>FIVE: FORMULATING QUEER/CRIP IDENTITY .....</b>		<b>211</b>
5.1	INTRODUCTION.....	211
5.2	UNDERSTANDING A QUEER/CRIP IDENTITY.....	212
5.2.1	<i>An Identity Overview</i> .....	213
5.2.2	<i>Approaching a Queer Identity</i> .....	217
5.3	ESTABLISHING THE IDENTITY APPROACH.....	226
5.3.1	<i>Foundations</i> .....	227
5.3.2	<i>Deviations</i> .....	234
5.4	CONCLUSION.....	240
<b>SIX: POWER DYNAMICS IN THE CRPD.....</b>		<b>242</b>
6.1	INTRODUCTION.....	242
6.2	RIGHTS AND RELATIONSHIPS.....	244
6.2.1	<i>Duty-Holders: Third Parties</i> .....	245
6.2.2	<i>Rights-Holders: Collective Identity</i> .....	251
6.3	INDIVIDUAL AGENCY.....	257
6.3.1	<i>Curating the Guest List</i> .....	258
6.3.2	<i>The Right to Choose</i> .....	266
6.3.3	<i>Power to the People</i> .....	275
6.4	CONCLUSION.....	283
<b>SEVEN: INCLUSIVE RIGHTS FOR ALL .....</b>		<b>284</b>
7.1	INTRODUCTION.....	284
7.2	INCLUSIVE: TRUE DISABILITY INCLUSION .....	286
7.2.1	<i>What is Inclusion?</i> .....	287
7.2.2	<i>Education: An Inclusive Example?</i> .....	294
7.2.3	<i>Who Is Included?</i> .....	304
7.3	REASONABLE: THE FAILURES OF ACCOMMODATION.....	311

7.3.1	<i>Developing Disability Education</i> .....	311
7.3.2	<i>Accommodation or Participation?</i> .....	320
7.4	CREATIVE INTERPRETATIONS OF RIGHTS.....	325
7.4.1	<i>Equal Recognition</i> .....	327
7.4.2	<i>Independent Living</i> .....	333
7.4.3	<i>Habilitation and Rehabilitation</i> .....	339
7.5	CONCLUSION.....	345
	<b>CONCLUSION</b> .....	<b>348</b>
	<b>BIBLIOGRAPHY</b> .....	<b>353</b>



## Introduction

“Where, after all, do universal human rights begin? In small places, close to home – yet so close and so small that they cannot be seen on any maps of the world. Yet they are the world of the individual person; the neighbourhood he lives in; the school or college he attends; the factory, farm, or office where he works. Such are the places where every man, woman, and child seek equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere. Without concerted citizen action to uphold them close to home, we shall look in vain for progress in the larger world”.<sup>1</sup>

## Overview

In Eleanor Roosevelt’s speech to the United Nations on the tenth anniversary of the UDHR, she outlines the importance of the individual in the human rights conversation. With their conception, the international community sought to provide general human rights universally. They wanted all persons across the globe to live on an equal basis with each other, with equal opportunities and justice. As such, the UDHR gave broad ideological rights yet lacked tangible application modes. Roosevelt’s call to action highlights that gap, explaining the futility of the human rights movement if it failed the individual. Since the passing of the UDHR, the UN has passed nine core international human rights treaties. Each one expands upon the principles underpinning both the UN and the UDHR. Over those subsequent 70 years, the treaties developed both in

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<sup>1</sup> Excerpt from a speech by Eleanor Roosevelt at the presentation of ‘In Your Hands: A Guide for Community Action for the Tenth Anniversary of the Universal Declaration of Human Rights’ (United Nations, New York, 27 March 1958).

their content and intended application. The most recent treaty caters to disability-specific human rights to provide the plaster to fill in the existing gaps human rights network to dismantle the wall which held PWDs back from the “equal justice, equal opportunity, equal dignity without discrimination” outlined by Roosevelt.

The CRPD was desperately needed. At the point of CRPD ratification, only a third of the world’s nations had passed anti-discriminatory disability legislation.<sup>2</sup> PWDs are “the world’s largest minority”,<sup>3</sup> yet the “rights-based perspective on disability is relatively new”.<sup>4</sup> PWDs were left out of the conversation for so long, as before the CRPD, they needed to either “fall under a universal provision that by inference includes [them] as a person or possess a separately protected characteristic in addition to [their] disability”.<sup>5</sup> The CRPD fills the gaps left by pre-existing general human rights instruments, establishing a structure of disability-centric rights. PWDs are involved in the human rights movement on their terms rather than as an afterthought.

At the time of writing, the CRPD is roughly fifteen years old. The international community has had over a decade to unpack the treaty, understand how it affords rights to PWDs, and establish State-level methods to realise said rights for individuals.

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<sup>2</sup> United Nations Department of Public Information, ‘Backgrounder: Disability Treaty Closes a Gap in Protecting Human Rights’ (*United Nations*, May 2008) <<https://www.un.org/development/desa/disabilities/backgrounder-disability-treaty-closes-a-gap-in-protecting-human-rights.html>> (accessed 22 June 2021).

<sup>3</sup> United Nations Enable, ‘Fact Sheet on Persons with Disabilities’ (*United Nations*) <<https://www.un.org/disabilities/documents/toolaction/pwdfs.pdf>> (accessed 19 August 2021).

<sup>4</sup> Gerard Quinn & Charles O’Mahony, ‘Disability and Human Rights: A New Field in the United Nations’ in Catarina Krause & Martin Scheinin (eds), *International protection of Human Rights: A Textbook* (2<sup>nd</sup> edn, Institute for Human Rights 2012), 265.

<sup>5</sup> Michael A Stein & Janet E Lord, ‘Future Prospects for the United Nations Convention on the Rights of Persons with Disabilities’ in Oddný Mjöll Arnadóttir & Gerard Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities* (Martinus Nijhoff 2009), 19.

There has been immense progress in developing disability rights, bringing them towards the level of other existing treaties. Nevertheless, disability offers unique challenges concerning human rights conceptualisation and implementation, as PWDs experience barriers and disadvantages in society not felt by their non-PWD peers. As such, there is still a great deal of work.<sup>6</sup> Disability is a fluid concept and lacks a precise definition, making interpreting the Convention difficult. Methods to interpret and understand disability are still open for debate, generating academic discourse through the lens of disability models. These models generally fall under moral, medical, and social headings. Moral models perceive disability as a tragedy, relying on religious understandings of humanity. Medical models utilise pathology to generate a standardised biological classification of the human body, where disability becomes an ailment needing treatment. Social models emphasise disablement through barriers preventing available and equal access to society. There are benefits to each model, as they all focus on different aspects of the disability experience. Nevertheless, each model also exhibits weaknesses resulting from its epistemological foundations and focuses. This thesis argues that this discordance creates several practical problems for each model. Therefore, it suggests that a new approach, one using identity as an alternative lens through which to understand disability, would aid the conversation on human rights. This approach is a blend of a queering of Tom Shakespeare's interaction approach with Degener's human rights model, utilising a deconstructive analysis through postmodernism and post-structuralism.

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<sup>6</sup> For example, see Peter Bartlett, 'Benefitting from Hindsight: What the Mental Capacity Act and its Implementation can Teach us about CRPD Implementation' in Kay Wilson et al (eds), *The Future of Mental Health, Disability and Criminal Law* (Routledge 2023).

## **Research Foundations**

This thesis maintains four key research questions. First, what are the key components of existing models of disability? This thesis needs to analyse both the existing human rights legislation and the current models of disability if it intends to offer anything new to the academic discussion in this field. Second, how do existing models of disability hold up to analysis from queer theory and crip theory? Going beyond mere descriptive analysis, it will critique the current models through the deconstructive lenses of these methodological approaches. Third, what would disability look like through a postmodernist and post-structuralist lens of identity? Each model theorises a different source of disability, a different door to open and look behind. Identity offers another perspective from which to assess disability and its impacts. Fourth, how would the resulting identity approach of disability interact with the CRPD? This thesis will ask whether the new approach alleviates any of the concerns raised by the existing disability models. This thesis will attempt to answer these four questions within seven chapters. Chapter One outlines the historical foundation of disability in international human rights law. Chapters Two and Three provide a development of theory: Chapter Two summarises and critiques Shakespeare's research, whilst providing an overview of queer theory' Chapter Three then fetters queer by introducing crip theory and queer legal theory. Chapter Four provides a critical analysis of the existing models of disability. Chapter Five establishes the queer/crip identity approach to disability. Finally, Chapters Six and Seven will demonstrate how said model functions and interprets aspects of the CRPD. In their totality, the subsequent seven chapters follow a four-part narrative of disability modelling in an international human rights context through foundation, commentary, establishment, and demonstration.

The CRPD understands that PWDs “continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world”.<sup>7</sup> The key objective, therefore, is to define and understand disability within the human rights context and to ascertain how human rights can reduce or remove these barriers. When referring to individuals, this thesis uses the term Persons with Disabilities (PWDs). The debate surrounding the correct language to refer to this category of people has become incredibly contentious, with several reasons provided by both the advocates of PWDs and the advocates of ‘Disabled Persons’. The author of this thesis lacks personal lived experience, so choosing the correct language to use is essential to avoid speaking over individuals’ voices.

Several voices in the disability rights sphere advocate for the use of ‘Disabled Persons’. Series & Nilsson argue that ‘disabled people’ “reflects the theory and terminology of the disabled people’s movement in the UK”.<sup>8</sup> They acknowledge the risk of imposing an identity upon individuals, which they do not claim, especially regarding users and survivors of psychiatry. Spandler, Anderson, and Sapey suggest that there are “implications of the distress [and] disability conundrum for people with mental health problems”.<sup>9</sup> In particular, ‘disabled persons’ acknowledges the specific difficulties they experience because of their disability, as they may struggle for “an identity that provides them with adequate support and protection, [and] those seeking a collective home in disability studies or the wider disabled people’s movement”.<sup>10</sup> Therefore,

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<sup>7</sup> Convention on the Rights of Persons with Disabilities (adopted 24 January 2007, entered into force 3 May 2008) A/RES/61/106 (‘CRPD’), Preamble, (k).

<sup>8</sup> Lucy Series & Anna Nilsson, ‘Article 12: Equal Recognition before the Law’ in Ilias Bantekas, Michael A. Stein, & Dimitris Anastasiou (eds), *The UN Convention on the Rights of Persons with Disabilities* (OUP 2018), 342, footnote 7.

<sup>9</sup> Bob Sapey, Helen Spandler, & Jill Anderson, ‘Introduction’ in Helen Spandler, Jill Anderson, & Bob Sapey (eds), *Madness, Distress, and the Politics of Disablement* (Polity Press 2015), 1.

<sup>10</sup> *Ibid.*

subsequent chapters note the implications of including psychiatry within the discussion of disability identity.

In 1994, CESCR produced their fifth general comment, discussing disability rights within ICESCR. They stated that following “the approach adopted in the Standard Rules, [the] general comment uses the term ‘persons with disabilities’ rather than the older term ‘disabled persons’”.<sup>11</sup> On the one hand, using the term ‘disabled persons’ may suggest that the disability is external to the person and is imposed on them through failure to accommodate them. In contrast, the use of ‘person with disabilities’ implies that the disability is intrinsic to the person. On the other hand, CESCR suggested a possible misinterpretation to “imply that the ability of the individual to function as a person has been disabled”.<sup>12</sup> The debate around the correct label for people engaged in discussions on disability and disablement is understandably contentious, given the implications of personal lived experience. As such, human rights conventions must use accurate and acceptable terminology.

Therefore, when engaging with the *travaux préparatoires* of the CRPD, it becomes clear that there was a considerable debate between ‘PWDs’ and ‘disabled persons’ as labels. During the drafting stages, several countries argued for the use of PWD. For example, Israel argued that such language was essential to maintaining an “emphasis on the individual”.<sup>13</sup> Additionally, PWD features in Nordic person-first languages and,

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<sup>11</sup> Committee on Economic, Social, and Cultural Rights, ‘General Comment No. 5 (1994) on Persons with Disabilities’ (9 December 1994) E/1995/22(SUPP)/4760/E (‘CESCR GC5’), para 4.

<sup>12</sup> Ibid.

<sup>13</sup> Rehabilitation International, ‘UN Convention on the Human Rights of People with Disabilities: Ad Hoc Committee Seventh Session - Daily Summaries’ (*United Nations*, 31 January 2006) <<https://www.un.org/esa/socdev/enable/rights/ahc7sum31jan.htm>> (accessed 7 May 2021).

therefore, within Scandinavian commentaries on international human rights.<sup>14</sup> Many States use language where the person is given priority over their identity characteristic. In these instances, PWD is preferred to disabled persons as the latter suggests that disability is the only significant feature of the person in the discussion is that they have a disability. Based on the above, this thesis chooses to use the term PWD. The title and Article 1 of the CRPD both use PWD.<sup>15</sup> When analysing a treaty, it would be irregular to use different terminology than that used within the document. Further, the thesis focuses on identity, which places the individual first in a similar vein to the Nordic person-first language.

## **Thesis Structure**

Chapter One looks at the development of disability-focussed rights in the international sphere. It provides an analysis of the historical development of disability rights to help explain the reason why the community decided to develop the CRPD. Over seventy years, international human rights transitioned from broad overarching documents loosely applicable to everyone to multiple specialised documents specifically designed for a category of individuals. The chapter then describes the AHC process, documenting a shift away from broad human rights provisions which generally apply to broad classifications of people. It details the process of creating the CRPD and demonstrates the principles it uses as a foundation for the rights within the human rights movement. It finally provides an overview of several factors of post-CRPD human rights with importance to PWDs.

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<sup>14</sup> See Oddný Mjöll Arnardóttir and Gerard Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities – European and Scandinavian Perspectives* (Martinus Nijhoff, 2009).

<sup>15</sup> CRPD (n7), Art. 1.

Chapter Two achieves two purposes. It describes disability through the lens of Tom Shakespeare, and establishes the thesis' foundation by outlining queer theory. This thesis is a doctrinal research project with an interdisciplinary approach. By utilising sociological theories to analyse legal issues critically, this thesis intends to contribute new perspectives to these debates. Shakespeare views disability through a critical realist lens to consider it as an interaction between the impaired person and disabling society. The interaction element is sound, yet a queer approach fundamentally rejects critical realism. As such, this chapter will also outline queer theory, a deconstructive methodology that aims at the mechanisms that establish social constructions.

Chapter Three tries to rein in queer, constructing it within the confines of the present debate in international human rights law and disabilities. To achieve this, it first considers crip theory, the result of the queering of disability studies. Crip attempts to highlight ablism by rejecting normalcy and disablement. The chapter also discusses queer legal theory, the application of queer theory to the law.

Chapter Four marks a transition from foundation to critique by assessing the leading models of disability. It considers three broad categories of disability models – the moral models, the medical models, and the social models. Each model of disability maintains their conceptualisations and functions. However, there are extensive overlaps between these categories, meaning that segregated assessments of models, considering each model in a vacuum, would be unwise. Instead, the chapter will assess all models in tandem through three dedicated pillars - biology, governance, and rescue. A biological perspective relies on a medical diagnosis of impairment or disability. It,



therefore, places power in professionals, arguing that intervention through medicine, therapy, or treatment, is the correct path to life with a disability.

Meanwhile, some models focus on governance, the notion that States use disability to control the populace. Such models label social segregation and control as disability's exclusive feature, suggesting individuals live despite disability rather than with it. Finally, many models articulate disability as requiring rescue, positioning PWDs as individuals incapable of helping themselves and requiring support. The goal is to rescue individuals from harm, themselves, or society. Chapter Three will assess each of these, in turn, to understand how to craft a successful disability model by highlighting the strengths and weaknesses of each approach.

In Chapter Five, the thesis intends to introduce the identity approach to disability as an alternative to the models discussed in the previous chapter. Broderick argues that many view disability “through the lens of equality and human dignity”.<sup>16</sup> The CRPD marks a shift towards respecting the human rights of PWDs. Human rights should respect the unique attributes of individuals to protect dignity and equality. Echoing Roosevelt's words at the start of this introduction, human rights should appreciate how policies impact different identities and consider the importance of rights at the individual level. This chapter provides an overview of identity theories, highlighting how they intrinsically connect an identity to the social structures around it as the product of an individual or collective reacting to external forces. An identity does not form within a vacuum, instead reflecting a need to find meaning and uniqueness within a

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<sup>16</sup> Andrea Broderick, *The Long and Winding Road to Equality and Inclusion for Persons with Disabilities* (Intersentia 2015), 21.

created social environment. Subjects tell themselves apart from everything else, giving themselves meaning and purpose. However, there is a need to blend this understanding of identity with the postmodernism and post-structuralism built within queer. The chapter then outlines the identity approach and demonstrates how it differs from the models in current disability discourse.

Chapters Six and Seven will offer a peek behind the hypothetical door, demonstrating how the identity approach may work in practice. The former considers the power dynamics within the CRPD, whilst the latter looks at the inclusion of PWDs. Reading the CRPD through an identity lens highlights the power of PWDs in two distinct ways. First, the interactions and relationships between the PWD and the State in exercising their rights, understanding the distinction between and the obligations placed upon duty holders and rights holders. Second, the agency afforded to PWDs in exercising their rights, placed on a sliding scale between choice and power, from informed consent towards participation and support. Further, identity offers a new perspective on the inclusion of PWDs in society. The CRPD maintains inclusion as a core pillar of rights implementation. However, several States articulate rights application through reasonable accommodation. Identity creates a space to critique these concepts, demonstrating a need to transition from reasonableness to inclusivity in the form of universal design and creative rights interpretation. Through this process of foundation, critique, creation, and application, this thesis will demonstrate the impact that identity can have on the academic discussion of the human rights of PWDs.

## One: The CRPD Context

"Disability is a human rights issue...Those of us who happen to have a disability are fed up [with] being treated by society and our fellow citizens as if we did not exist or...were aliens from outer space. [Rather,] we are human beings with equal value, claiming equal rights".<sup>17</sup>

### 1.1 Introduction

Disability is a wide-reaching concept with grand application to many of the global populace. When the UN established the AHC, approximately ten per cent of the population had a disability.<sup>18</sup> However, in 2021, the UN published figures that globally, over one billion people experience a form of disability, corresponding to roughly fifteen per cent of the world's population.<sup>19</sup> It is "the one minority anyone can join at any time due to an accident, a disease, or simply by growing older".<sup>20</sup> However, the human rights framework mainly failed to reflect the needs of PWDs, allowing disability-specific violations to manifest; disability discrimination has been "one of the black holes of UN equality law".<sup>21</sup>

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<sup>17</sup> Bengt Lindqvist, 'Speech at the nineteenth Congress of Rehabilitation International' (2000), quoted in Gerard Quinn & Theresia Degener, *Human Rights and Disability: The current use and future potential of United Nations Human Rights Instruments in the Context of Disability* (United Nations 2002), 13.

<sup>18</sup> Gerard Quinn & Thereisa Degener, 'Executive Summary' in Gerard Quinn & Theresia Degener (eds), *Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability* (United Nations 2002) HR/PUB/02/01, 1.

<sup>19</sup> World Health Organisation, 'Fact Sheet: Disability and Health' (*WHO*, 24 November 2021) <<https://www.who.int/news-room/fact-sheets/detail/disability-and-health>> (accessed 23 November 2022).

<sup>20</sup> Michael Rembis, Catherine Kudlick, & Kim E. Nielsen, 'Introduction' in Michael Rembis, Catherine Kudlick, & Kim E. Nielsen (eds), *The Oxford Handbook of Disability History* (OUP 2018), 1.

<sup>21</sup> Wouter Vanderhole, *Non-Discrimination and Equality in the View of the UN Human Rights Treaty Bodies* (Intersentia 2005), 2.

In the early 2000s, the UN drafted a disability-centric human rights convention to tackle the significant inconsistencies experienced, entering the CRPD into force in May 2008. As a human rights convention, it is "historic and pathbreaking on several levels".<sup>22</sup> It provides international protection for PWDs and their human rights. It also reflects an "unprecedented level of civil society input and engagement in the negotiation process".<sup>23</sup> It is the culmination of decades of advocacy and research. It marks a turning point in the history of disability rights.

The CRPD is a product of its time, the by-product of decades of advocacy, negotiation, and legal development. It is also the first international human rights convention to utilise a user-led approach involving NGOs, DPOs, and other civil society organisations in negotiating and drafting. Therefore, it is essential to discuss the CRPD's contextual place in the broader human rights framework and disability rights history. Such a discussion "lends itself to a broad array of topics and concepts, precisely because [disability] defies easy definition".<sup>24</sup> Disability covers many experiences, meaning a succinct definition drifts out of reach. However, the CRPD overtly avoids a definition for several purposeful reasons. First, generating a cohesive system that accurately provides human rights based on disability is a tall order. Second, there is a high chance of leaving swathes of experiences and categories of people behind. Third, the unstable nature of the human body and society undoubtedly adds to the turmoil.<sup>25</sup> Finally, there are "deeply entrenched attitudes and stereotypes about disability" which have

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<sup>22</sup> Tara J Melish, 'The UN Disability Convention: Historic Process, Strong Prospects, and Why the US Should Ratify' (2007) 14(2) *Human Rights Brief* 1, 1.

<sup>23</sup> *Ibid.*

<sup>24</sup> Rembis, Kudlick, & Nielsen (n20), 2.

<sup>25</sup> *Ibid.*

"rendered many of the most flagrant abuses of the rights of persons with disabilities invisible from the mainstream human rights lens".<sup>26</sup> In general terms, therefore, the debate on PWD rights reflects an extensive discussion regarding the place of difference in society.<sup>27</sup> This chapter seeks to generate an overview of the pre-CRPD disability rights protections enshrined in existing UN documents. It shall then provide a contextual understanding of the development process of the CRPD before discussing a select number of key provisions within the CRPD. The aim is to establish a holistic image of the CRPD and the international community's intentions for respecting the rights of PWDs.

From the outset, it should be noted that the perspective forming the foundations of the push towards a disability-specific convention rely on a problematic categorisation of disability. For example, the UN data on the sheer quantity of PWDs globally and the is based on the number of people who fall within definitions of disability meeting the ICIDH. As will be discussed in section 4.2.2, there are several concerns with relying on overly-medicalised classifications of disability to justify rights protections. The primary issue is that, as will be clear throughout this thesis, many individuals with rights protection under the CRPD will not necessarily be medically disabled. Further, relying on such data may not account for cultural and social factors that impact disability identification and access to resources, and may ignore the diverse experiences of people with disabilities and may perpetuate stereotypes. However, the data is based on a standardised criteria that has received broad universal acceptance, and so can lend credibility to the discussion on expanding definitions of and protections for

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<sup>26</sup> Melish (n22), 6.

<sup>27</sup> Quinn & Degener (n18), 1.

disability. It can be helpful as a starting point to identify areas where further research is needed.

In summation, the framing provides proper context, and it is understandable why the international community still views disability through this lens. This thesis introduces a new conceptualisation of disability, but the overall focus cannot be lost. Starting the analysis and conversation with the UN data is advantageous. It is valuable to recognise that the international community recognises the vulnerability of those with disabilities and the need for greater human rights protection. However, the current definition of disability is unnecessarily limiting. While there may be some overlap between the two perspectives, shifting the conversation from a medical perspective to an identity perspective is essential.

## **1.2 The International Context**

This section will take a chronological journey through international human rights documents. It will first discuss attempts to interpret existing broad legislation to include PWDs. It will then analyse early attempts to draft disability-specific instruments and note the improvements and problems they present. Finally, it will also track the legislative developments at a regional level.

### **1.2.1 Shoehorning Disability into Human Rights Instruments**

From its inception, the UN focused on the rights and status of persons with disabilities.<sup>28</sup> The UN Charter contains specific articles that provide the foundations upon which disability rights have developed. Article 1 identifies the purposes of "promoting and encouraging respect for human rights and fundamental freedoms for all without distinction",<sup>29</sup> and Article 55 emphasises "universal respect for and observance of human rights".<sup>30</sup> The UNGA, in particular, must promote "international co-operation in the economic, social, cultural, educational, and health field, and assisting in the realisation of human rights and fundamental freedoms for all".<sup>31</sup> Though these provisions do not explicitly provide for disabilities as a protected characteristic, it is apparent that these provisions and "for all" are non-exhaustive. The UDHR is the foundational document for international human rights, acting as a broad framework from which other documents have taken inspiration and developed rights provisions. It provides for the "recognition of the inherent dignity and...the equal and inalienable rights of all",<sup>32</sup> ensuring their "universal and effective recognition and observance".<sup>33</sup> Everyone shares equal recognition of dignity.<sup>34</sup> Access to rights must be without distinction.<sup>35</sup> The right to life,<sup>36</sup> the freedom from torture,<sup>37</sup> and the right to legal recognition<sup>38</sup> are all PWD-relevant rights. The UDHR matches the UN Charter's

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<sup>28</sup> Ad Hoc Committee established by UNGA Res 56/168, 'International Norms and Standards Relating to Disability' (Updated October 2003) A/AC.265.CRP.1, Introduction.

<sup>29</sup> Charter of the United Nations (adopted 26 June 1945, entered into force 24 October 1945), 1 UNTS XVI ("UN Charter"), art. 1(3).

<sup>30</sup> *Ibid*, art. 55(c).

<sup>31</sup> *Ibid*, art. 1(3).

<sup>32</sup> Universal Declaration of Human Rights (adopted 10 December 1948) UNGA Res 217 A(III) ("UDHR"), preamble.

<sup>33</sup> *Ibid*.

<sup>34</sup> *Ibid*, Art. 1.

<sup>35</sup> *Ibid*, Art. 2.

<sup>36</sup> *Ibid*, Art. 3.

<sup>37</sup> *Ibid*, Art. 5.

<sup>38</sup> *Ibid*, Art. 6.

non-discrimination foundations with equal protection of the law.<sup>39</sup> However, the UDHR deviates by providing specific reference to disability within the right to an adequate standard of living.<sup>40</sup>

The ICCPR maintain similar provisions. The right to life,<sup>41</sup> the freedom from torture,<sup>42</sup> and the right to legal recognition<sup>43</sup> all echo previous declarations. Though these intend to provide rights and assistance to PWDs, they fail to mention specific protections which reflect the needs of PWDs, especially those with mental disabilities. Provisions regarding the death penalty make no mention of competency assessments for relevant *mens rea* requirements of crimes for which the death penalty is a sentence. Given the public outcry in cases such as David Bentley and the debate surrounding mental blame for another's death, this omission is deeply problematic.<sup>44</sup> Modern international human rights principles generally approve of abolishing the death penalty through the second optional protocol of the ICCPR.<sup>45</sup> Further, States must not impose the death penalty on a person suffering from "any form of mental disorder" if they have not abolished the death penalty.<sup>46</sup> This perspective appears nationally, where courts understand that "mentally retarded defendants in the aggregate face a special risk of wrongful execution".<sup>47</sup> The Privy Council references the death penalty's unconstitutionality for

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<sup>39</sup> Ibid, Art. 7.

<sup>40</sup> Ibid, Art. 25(1).

<sup>41</sup> International Covenant on Civil and Political Rights (adopted 16 December 1966, entered into force 23 March 1976) 999 UNTS 171 ('ICCPR'), Art. 6.

<sup>42</sup> Ibid, Art. 7.

<sup>43</sup> Ibid, Art. 16.

<sup>44</sup> R v Craig and Bentley (1952) The Times, 10 December

<sup>45</sup> UNGA Res 44/128 (15 December 1989) A/Res/44/128.

<sup>46</sup> UNCHR Res 2003/67 (24 April 2003) E/CN.4/Res/2003/67, para 4(g).

<sup>47</sup> Atkins v Virginia 536 U.S. 304 (2002), at 321.



those who suffer "significant mental abnormality".<sup>48</sup> Instead, the prerogative of mercy applies to avoid this "cruel and unusual punishment", which is unjustifiable.<sup>49</sup>

Conversely, the freedom from inhuman treatment explicitly refers to the need for "free consent to medical or scientific experimentation",<sup>50</sup> which may apply to PWDs and enforced treatment. Nevertheless, debates on therapeutic care and best interests fall outside the remit of this research. Additionally, the ICCPR recognises access to justice,<sup>51</sup> most notably with the right to access an interpreter in court.<sup>52</sup> These rights are imperative to allow access to the legal system for anyone who cannot fully comprehend the content of the courtroom, be it due to barriers of communication or capability. Finally, persons have the right to "take part in the conduct of public affairs, directly or through freely chosen representatives" and have equal access to public services".<sup>53</sup> Under its Optional Protocol, the HRC has considered a handful of individual claims against States for violations of the ICCPR principles. For example, poor prison conditions that disproportionately affect PWDs violate Article 10(1) on deprivation of liberty and dignity.<sup>54</sup> Moreover, differentiation on the grounds of dwarfism violates Article 26 on autonomy and equality.<sup>55</sup> Finally, the deportation of a PWD to a county without adequate means to treat the individual violates Article 7 on inhuman and

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<sup>48</sup> *Pitman v Trinidad and Tobago* [2017] UKPC 6, per Lord Hughes, 50.

<sup>49</sup> *Ibid.*

<sup>50</sup> ICCPR (n41), Art. 7.

<sup>51</sup> *Ibid.*, Arts. 14-15.

<sup>52</sup> *Ibid.*, Art. 14(1)(f).

<sup>53</sup> *Ibid.*, Art. 25(a)-(c).

<sup>54</sup> HRC, *Hamilton v Jamaica* (28 July 1999) Communication No. 616/1995.

<sup>55</sup> HRC, *Wackenheim v France* (26 July 2002) Communication No. 854/1999.

degrading treatment.<sup>56</sup> These are notable exceptions, as the HRC has generally “yielded little tangible benefits for [PWDs]”.<sup>57</sup>

Regarding economic, social, and cultural rights, the provisions within the ICESCR must be “exercised without discrimination of any kind”, including language, social origin, birth, or another status,<sup>58</sup> all of which are relevant to persons with disabilities. General Comment No. 3 emphasises that actions taken by States under the ICESCR must be “deliberate, concrete, and targeted” in meeting their obligations.<sup>59</sup> Additionally, even “in times of severe resource constraint”, society must protect its vulnerable members by adopting “relatively low-cost targeted programmes”.<sup>60</sup> Further, CESCR General Comment 5 explains State obligations regarding PWDs. Modern society has entrenched *de jure* and *de facto* discrimination on the grounds of disability.<sup>61</sup> Both take a range of forms, from subtle to unfair means. However, they emphasise that PWDs often face barriers to exercising their economic, social, and cultural rights equally.<sup>62</sup> These barriers emanate from “neglect, ignorance, prejudice and false assumptions, as well as through exclusion, distinction or separation”.<sup>63</sup> Accordingly, State parties are “required to take appropriate measures...to enable [PWDs] to seek to overcome any

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<sup>56</sup> HRC, *C v Australia* (13 November 2002) Communication No. 900/1999.

<sup>57</sup> Colm O’Cinneide, ‘Extracting Protection for the Rights of Persons with Disabilities from Human Rights Frameworks: Establishing Limits and New Possibilities’ in Oddný Mjöll Arnadóttir and Gerard Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009), 173.

<sup>58</sup> International Covenant on Economic, Social, and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 UNTS 3 (‘ICESCR’), Art. 2(2).

<sup>59</sup> Committee on Economic, Social, and Cultural Rights, ‘General Comment No. 3: The Nature of States Parties’ Obligations (Art. 2, Para. 1 of the Covenant)’ (14 December 1990) E/1991/23 (CESCR GC3), para 2.

<sup>60</sup> *Ibid*, para 12.

<sup>61</sup> CESCR GC5 (n11), para. 15.

<sup>62</sup> *Ibid*, para. 15.

<sup>63</sup> *Ibid*.

disadvantages, in terms of the enjoyment of the rights...flowing from their disability".<sup>64</sup> Measures include support services to assist in increasing independence and their access to and exercise of their rights.<sup>65</sup> In addition, State parties must "reduce structural disadvantages and give appropriate preferential treatment to people with disabilities to achieve the objectives of full participation and equality within society for all persons with disabilities".<sup>66</sup> Note, however, these provisions are subject to available resources.

The remaining Conventions deal with disabilities differently. CEDAW intends to cover all women, irrespective of their status or ability. Women with disabilities face compounding discrimination based on both their gender and their disability status. Likewise, CERD intends to limit compounding discrimination by various marginalised characteristics such as race, disability, and gender. Though there is little reference to disability, the Committee for CERD has acknowledged the impact of double discrimination in gender-related racial discrimination.<sup>67</sup> By analogy, this principle should cover disability-based racial discrimination.<sup>68</sup>

In contrast, the CRC explicitly references children with disabilities, ensuring they "should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community".<sup>69</sup> Still, the

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<sup>64</sup> Ibid, para. 5.

<sup>65</sup> Ibid, para. 3.

<sup>66</sup> Ibid, para. 9.

<sup>67</sup> Committee on the Elimination of Racial Discrimination, 'General Recommendation No. 25: Gender-Related Dimensions of Racial Discrimination' (20 March 2000) A/55/18 Annex V, 152.

<sup>68</sup> AHC (n28), Introduction.

<sup>69</sup> Convention on the Rights of the Child (adopted 30 November 1989, entered into force 2 September 1990) 1577 UNTS 3 ('CRC'), Art. 23(1).

Committee for the CRC has demonstrated that one cannot construe Article 23 as the only provision on disability. Instead, the rest of the Convention applies equally to children with disabilities.<sup>70</sup> This theme of universality has been echoed by the UNCHR, with resolutions discussing violations of fundamental principles of equality as infringements of the human rights of persons with disabilities.<sup>71</sup> The UNCHR also encourages States and NGOs to actively promote the protection of these rights by working together and working with United Nations Treaty Committees.<sup>72</sup>

Concurrently, several regional bodies developed their human rights instruments between the 1940s and 1980s. Organisations in Europe, the Americas, and Africa passed laws to provide a broad human rights framework in their respective regions. In Europe, the COE adopted the ECHR in 1950, which entered into force in 1953. The Convention covers several rights that hold significant value to PWDs; these include the right to privacy<sup>73</sup> and the prohibition of torture, one of only two absolute rights under the ECHR.<sup>74</sup> The person's right to liberty and security refers to restrictions on the "lawful detention of...persons of unsound mind",<sup>75</sup> noting the importance of liberty to PWDs and the historic pathologisation of mental health. Article 14 relates to non-discrimination and is not exhaustive, applying equally to all human beings regardless of ability.<sup>76</sup> Protocol 1 affords the right to "education and teaching in conformity with [an individual's] own...philosophical convictions".<sup>77</sup> This principle resonates with

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<sup>70</sup> Committee on the Rights of the Child, 'General Comment No. 9: The Rights of Children with Disabilities' (27 February 2007) CRC/C/GC/9.

<sup>71</sup> UNCHR Res 1998/31 (17 April 1998) E/CN.4/1998/31, para 1.

<sup>72</sup> *Ibid*, para 7.

<sup>73</sup> Convention for the Protection of Human Rights and Fundamental Freedoms (adopted 4 November 1950, entered into force 3 September 1953) ("ECHR"), Art. 8.

<sup>74</sup> *Ibid*, Art. 3.

<sup>75</sup> *Ibid*, Art. 5(1)(e).

<sup>76</sup> *Glor v Switzerland*, App no. 13444/04 (30 April 2009).

<sup>77</sup> ECHR (n73), Protocol 1 Art. 2.

established social communities based on disability, such as Deaf culture. Protocol 12 grants general prohibitions of discrimination or derogation of rights based on individual status.<sup>78</sup> Meanwhile, the EU passed the Charter of Fundamental Rights of the European Union 2000, which follows the same principles of dignity and equality as the ECHR. The ECHR now explicitly permits the EU to accede to the Convention,<sup>79</sup> and signing the ECHR is now a requirement of EU membership.<sup>80</sup>

Within the Americas, the OAS Charter is binding on all OAS Members. Though there is no overt mention of disability, it mentions respect for fundamental rights without distinction.<sup>81</sup> It also affords general economic and social development provisions echoing the ICESCR, such as employment, education, medicine, and housing.<sup>82</sup> The OAS adopted the ADRDM in April 1948, making it the first international human rights document.<sup>83</sup> The IACtHR and IACmHR maintain the Charter's binding precedent over OAS Members. It matches subsequent general international human rights documents by referencing the equality of the right to life, liberty, and the security of the person without distinction.<sup>84</sup> However, it explicitly refers to disability as part of the right to social security. States must protect individuals from the consequences of "any disabilities arising from causes beyond [their] control that make[s] it physically and mentally impossible for [them] to earn a living".<sup>85</sup> Finally, the OAS also produced the

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<sup>78</sup> Ibid, Protocol 12 Art. 1(1).

<sup>79</sup> Ibid, Art. 59(2) as amended by Protocol 14, Art. 17(1).

<sup>80</sup> Consolidated Version of the Treaty on European Union (as amended by the Treaty of Lisbon) (adopted 13 December 2007, entered into force 1 January 2009) 2008/C 115/01, Art. 6(2).

<sup>81</sup> Charter of the Organization of American States (adopted 30 April 1948, entered into force 13 December 1953) 119 UNTS 48, Art. 2.

<sup>82</sup> Ibid, Art. 31.

<sup>83</sup> American Declaration on the Rights and Duties of Man (adopted April 1948, entered into force 2 May 1948), OAS Res XXX.

<sup>84</sup> Ibid, Arts. 1 & 2.

<sup>85</sup> Ibid, Art. XVI.

American Convention on Human Rights,<sup>86</sup> which is binding on signatories. Though it does not mention PWDs, all rights within apply equally without discrimination.<sup>87</sup>

Within Africa, the OAU passed the ACHPR,<sup>88</sup> establishing the most recent regional human rights framework. The name reflects a unique recognition of collective rights, following a vital tenet of the African human rights system that links individual rights and peoples' rights. The Convention lists several rights relevant to PWDs, such as the right to equality,<sup>89</sup> personal dignity and integrity,<sup>90</sup> and liberty and security.<sup>91</sup> It also explicitly references disability in the right to special protection measures in "keeping with their physical or moral needs".<sup>92</sup> Finally, the AU passed their Constitutive Act as a successor of the OAU. Their remit includes promoting human rights under the ACHPR and maintaining the Region's human rights framework.<sup>93</sup>

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<sup>86</sup> American Convention on Human Rights "Pact of San José, Costa Rica" (adopted 22 November 1969, entered into force 18 July 1978), 1144 UNTS 123.

<sup>87</sup> *Ibid.*, Art. 24.

<sup>88</sup> African (Banjul) Charter on Human and People's Rights (adopted 27 June 1981, entered into force 21 October 1986) CAB/LEG/67/3 rev.5, 21 I.L.M. 58.

<sup>89</sup> *Ibid.*, Art. 3.

<sup>90</sup> *Ibid.*, Art. 5.

<sup>91</sup> *Ibid.*, Art. 6.

<sup>92</sup> *Ibid.*, Art. 18(4).

<sup>93</sup> Constitutive Act of the African Union (adopted 11 July 2000, entered into force 26 May 2001) 2158 UNTS 3, Art. 3(h).

### 1.2.2 The 1970s Human Rights Shift

The latter half of the 20<sup>th</sup> Century brought a transitional period shifting “from a pure welfare perspective to a social welfare approach”.<sup>94</sup> Quinn and Degener published a study in 2002 on UN human rights instruments in a disability context.<sup>95</sup> They provide an excellent overview of this historical shift towards a human rights framework to protect PWDs. Though bodies continued to publish broad instruments that generally apply to PWDs, they also created PWD-focussed documents. They “re-evaluated their disability policy in the 1960s, leading to a wave of de-institutionalisation and a demand for fuller participation by disabled persons in an integrated society”.<sup>96</sup> The UNGA and UNESCO adopted several resolutions from the 1950s dealing mainly with prevention and rehabilitation.<sup>97</sup> For example, the UNESCO adopted a significant report in 1950 on “Social Rehabilitation of the Physically Handicapped”.<sup>98</sup> Suggestions for a programme of action should include three principles: preventing disease and disability, limiting the effects of disability and rehabilitation, and respecting a right to a place in society.<sup>99</sup> Likewise, the UNGA issued the Declaration on Social Progress and Development in 1969 as a broad declaration on various aspects of disability rights. It protects the rights of PWDs and the “physically and mentally disadvantaged”.<sup>100</sup>

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<sup>94</sup> Broderick (n16), 47.

<sup>95</sup> Gerard Quinn & Theresia Degener (eds), *Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability* (United Nations 2002) HR/PUB/02/01.

<sup>96</sup> Broderick (n16), 47.

<sup>97</sup> Gerard Quinn & Theresia Degener, ‘The Application of Moral Authority: The Shift to the Human Rights Perspective on Disability through United Nations “Soft” Law’ in Gerard Quinn & Theresia Degener (eds), *Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability* (United Nations 2002) HR/PUB/02/01, 29.

<sup>98</sup> Economic and Social Council, ‘Social Rehabilitation of the Physically Handicapped: Report of the Secretary General’ (22 March 1950) E/CN.5/197.

<sup>99</sup> *Ibid*, para. 15.

<sup>100</sup> UNGA Res 2542 (XXIV) (11 December 1969) A/RES/2542(XXIV), Art. 11(c).

The 1970s marked the start of a shift from a "caring" to a "rights-based" approach,<sup>101</sup> adopting several resolutions on disability-specific rights principles. The first disability-oriented rights document was the DRMDP in 1971,<sup>102</sup> whose name identifies the focus clearly on mental disability rather than other forms of disability. Moreover, the name demonstrates the archaic perspective held by the international sphere on mental disability, which is still prevalent in society. "Mentally retarded" was an accepted term within pathology at the time, but due to a pejorative shift in the meaning of the phrase in society, it is no longer acceptable.

The DRMRP emphasises "the necessity of assisting mentally retarded persons [in developing] their abilities in various fields of activities and...promoting their integration as far as possible in normal life".<sup>103</sup> "Normal" is a problematic concept. The reliance on a pathologised interpretation of lived experience identifies that a non-disabled person is the 'standard' expected from humanity, and anyone who deviates is considered abnormal. Such reliance on the medicalisation of lived experience means society requires treatment or correction of PWDs. Therefore, PWDs are segregated from the rest of society and placed into care or support structures independently of the community. This wording further emphasises the social divide between PWDs and non-disabled persons. A stigma<sup>104</sup> is attached to identifying one status as the norm, implying abnormalities in other statuses. By comparing people's perceived abilities

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<sup>101</sup> Quinn & Degener (n97), 30.

<sup>102</sup> UNGA Res 2856 (XXVI) (20 December 1971) A/RES/2856(XXVI).

<sup>103</sup> Ibid, Preamble.

<sup>104</sup> This thesis follows Goffman's account of stigma as a dynamic characteristic attached to the bearer; see Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (Prentice Hall 1963). Greater discussion of this understanding of stigma is found at section 3.2.3.



against each other, society permits establishing a tiered structure to human existence as if one person's status is comparable to another's.

The DRMMP affords persons with mental disabilities the same rights as others "to the maximum degree of feasibility".<sup>105</sup> Rights also include the right to proper medical care and physical therapy,<sup>106</sup> economic security,<sup>107</sup> living with family and engaging in community life,<sup>108</sup> and the freedom from exploitation, abuse, and degrading treatment.<sup>109</sup> The Declaration uses a capacity-based assessment of the restriction of liberty.<sup>110</sup> States must provide legal safeguards against abuse, such as the opportunity for periodic review and the right of appeal. This assessment must evaluate the "social capability" of the PWD conducted by medical experts.<sup>111</sup> There are several issues with the phrasing of this provision. First, a point specifically relevant to those with a disability of the mind is the lawful removal or restriction of human rights based on capacity. Though the DRMMP is a product of its time, and capacity-based decision-making was an appropriate arrow in the Medical Practitioner's quiver, it violates PWD's rights to liberty and integrity of the person. Second, the DRMMP language on "social capability" places the burden on the PWD to fit within society, not on society, for failing to support their individual experience. Third, reference to "qualified experts" assents to the medicalisation of assessment. However, a considerable amount of the experience of PWDs falls outside the scope of medicalisation.

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<sup>105</sup> UNGA Res 2856 (n102), Art. 1.

<sup>106</sup> Ibid, Art. 2.

<sup>107</sup> Ibid, Art. 3.

<sup>108</sup> Ibid, Art. 4.

<sup>109</sup> Ibid, Art. 6.

<sup>110</sup> Ibid, Art. 7.

<sup>111</sup> Ibid.

In 1975, the Economic and Social Council passed a resolution on preventing disability and the rehabilitation of PWDs, requesting States develop measures to integrate PWDs into society better.<sup>112</sup> In response, the UNGA passed the DRDP as a development of the principles in the DRMRP. The DRDP establishes a basis and frame of reference for disability rights<sup>113</sup> to enable PWDs to "become as self-reliant as possible."<sup>114</sup> The DRDP appears to have formulated rights in four different ways. First, some provisions appear to replicate principles found in the conventions found in 1.2.1, such as the "inherent right to respect for their human dignity"<sup>115</sup> and the principle of civil and political rights equality.<sup>116</sup> Second, the DRDP replicates DRMRP provisions, for example, the right to a united family<sup>117</sup> and freedom from exploitation.<sup>118</sup> Third, some conditions appear to be pre-existing rights but with additional aspects or parameters. Examples include the right to medical treatment and rehabilitation, which "will hasten the processes of their social integration or reintegration",<sup>119</sup> and the right to economic and social security, which includes a "decent level of living".<sup>120</sup> A vital aspect of these additions is promoting higher living standards within the community for PWDs, which Schulze identifies as one of the "first indicators of reasonable accommodation".<sup>121</sup> However, there is no definition for both "reintegration" and "decent" within the DRPD.

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<sup>112</sup> Economic and Social Council, 'Prevention of Disability and Rehabilitation of Disabled Persons' (7 May 1975) E/RES/1921(LVIII), para. 2(c).

<sup>113</sup> UNGA Res 3447 (XXX) (9 December 1975) A/RES/3447(XXX), Preamble.

<sup>114</sup> Ibid, Art. 5.

<sup>115</sup> Ibid, Art. 3.

<sup>116</sup> Ibid, Art. 4.

<sup>117</sup> Ibid, Art. 9.

<sup>118</sup> Ibid, Art. 10.

<sup>119</sup> Ibid, Art. 6.

<sup>120</sup> Ibid, Art. 7.

<sup>121</sup> Marianne Schulze, *Understanding the UN Convention on the Rights of Persons with Disabilities: A Handbook on the Human Rights of Persons with Disabilities* (3<sup>rd</sup> edn, Handicap International 2010), 16.

Fourth, a few provisions appear to be new or substantially different from the rights accessible until this point. These include rights to legal aid - not merely in criminal or human rights settings but also in protecting persons and property.<sup>122</sup> This point seems to function insofar as PWDs should understand any legal matters and have a means of protecting their assets and autonomy if necessary. The DRDP also issues States with an obligation to consider the rights and needs of PWDs at every stage of economic and social planning,<sup>123</sup> seemingly starting a trend of blurring the distinction between positive and negative obligations and between political and social rights. Finally, the DRDP was the first instrument to define disability. It used a manifestly pathologised definition of “deficiency, either congenital or not, in [their] physical or mental capabilities”.<sup>124</sup> Stein notes the “possessed vestiges of the medical model by assuming individuals are disabled due to special medical problems that require segregated social services and institutions as remedies”.<sup>125</sup> Despite the clear transition towards a social welfare approach, contemporary thinking still maintained a modicum of pathology.

The UNGA proclaimed 1981 as the International Year of Disabled Persons,<sup>126</sup> running with the theme of “full participation and equity”.<sup>127</sup> The five objectives included: (1) helping PWDs with their physical and psychological adjustment to society; (2) providing proper facilities to enable access to employment; (3) encouraging research projects into PWD inclusion; (4) educating the public on PWD inclusion; and (5) preventing

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<sup>122</sup> UNGA Res 3447 (n113), Art. 11.

<sup>123</sup> Ibid, Art. 8.

<sup>124</sup> Ibid, Art. 1.

<sup>125</sup> Michael A Stein, ‘Disability Human Rights’ (2007) 95 *California Law Review* 75, 88.

<sup>126</sup> UNGA Res 31/123 (16 December 1976) A/RES/31/123.

<sup>127</sup> UNGA Res 34/154 (17 December 1979) A/RES/34/154, Art. 1.

disability and promoting rehabilitation.<sup>128</sup> States needed to include PWDs in actions stemming from the International Year of Disabled Persons.<sup>129</sup> The UNGA established the Advisory Committee for the International Year of Disabled Persons,<sup>130</sup> with provisions for a balanced composition of representatives from the States and allowance of resources.<sup>131</sup> The first session provided recommendations regarding the Plan of Action for the IYDP,<sup>132</sup> and the fourth session created the WPA.<sup>133</sup>

The aims of the WPA are threefold: (i) prevention, (ii) rehabilitation and (iii) equalisation of opportunities. The first two aims are traditional for the "caring" model. The third also functions as "a central pillar to the document"<sup>134</sup> and evidences the slow but sure shift towards a rights-based model discussed by Quinn and Degener. It defines "equalisation of opportunities" as "the process through which the general system of society...are made accessible to all".<sup>135</sup> The achievement of equality of opportunity necessitates measures that go beyond the "traditionally rehabilitative".<sup>136</sup> The environment has the most significant effect on impairment or a disability and a person's daily life.<sup>137</sup> The WPA also recognises no homogeneity between PWDs, as society generates different barriers for PWDs depending on their disability.<sup>138</sup> Subsequent policies on PWD inclusion must allow for various disabilities and

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<sup>128</sup> UNGA Res 31/123 (n126), para. 2.

<sup>129</sup> UNGA Res 35/133 (11 December 1980) A/RES/35/133, Art. 2.

<sup>130</sup> UNGA Res 32/133 (16 December 1977) A/RES/32/133.

<sup>131</sup> UNGA Res 33/170 (20 December 1978) A/RES/33/170.

<sup>132</sup> Advisory Committee for the International Year for Disabled Persons, 'Report of the Secretary-General' (13 June 1979) 1/34/158 and Corr. 1, Annex.

<sup>133</sup> UNGA Res 37/52 (8 September 2011) A/RES/37/52.

<sup>134</sup> Broderick (n16), 50.

<sup>135</sup> United Nations, *World Programme of Action concerning Disabled Persons* (United Nations 1983) ('UN WPA'), para. 12.

<sup>136</sup> Quinn & Degener (n97), 31.

<sup>137</sup> *Ibid.*

<sup>138</sup> UN WPA (n135), para. 8.

experiences rather than collating PWDs into one confused and convoluted category. Hendriks describes the WPA as “an important first step in the global recognition of the equal rights of [PWDs]”.<sup>139</sup>

Further requests by the UNGA required States to implement the WPA,<sup>140</sup> and all UN organs, organisations, and agencies, to aid States in said implementation.<sup>141</sup> Before the adoption of the WPA, disability was an individual issue. State action on disability care was event-based, and “activities mainly involved medical treatment, rehabilitation and social welfare services to enable the person with a disability to fit better into so-called normal societal structures”.<sup>142</sup> As a result, the community ignored the “ways in which policies and institutions might create obstacles to full and effective participation of persons with disabilities as development agents and beneficiaries”.<sup>143</sup> To rectify this directly, the WPA “established a direct link between the UN human rights machinery and the disability rights agenda”,<sup>144</sup> generating more political power in NGOs to help promote and enact change.

Broderick indicates the WPA “marked a new beginning of sorts – one which recognised the role played by social and environmental barriers in hindering full and effective

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<sup>139</sup> Aart Hendriks, ‘The Significance of Equality and Non-Discrimination for the Protection of the Rights and Dignity of Disabled Persons’ in Theresia Degener & Yolán Koster-Dreese (eds), *Human Rights and Disabled Persons: Essays and Relevant Human Rights Instruments* (Martinus Nijhoff 1995), 56.

<sup>140</sup> UNGA Res 37/53 (3 December 1982) A/RES/37/53, para. 2.

<sup>141</sup> *Ibid*, para. 10.

<sup>142</sup> Ad Hoc Committee established by UNGA Res 56/158, ‘Report of the Secretary General on Issues and Emerging Trends related to Advancement of Persons with Disabilities’ (16-27 June 2003) A/AC.265/2003/1.

<sup>143</sup> *Ibid*.

<sup>144</sup> Broderick (n16), 51.

participation”.<sup>145</sup> Equally, there was slow but steady progress towards a rights-based approach. To help facilitate the changes required by the WPA, the UNGA proclaimed 1983-1992 as the United Nations Decade of Disabled Persons.<sup>146</sup> The Decade sought to generate a timeline for these changes and create frameworks necessary for full realisation. They established the Voluntary Fund to run over the Decade for this exact purpose,<sup>147</sup> to ensure economic factors did not reduce representation or hinder progress. Two examples stand out as disability activism meeting legislation during the Decade. First are the 1989 Tallinn Guidelines,<sup>148</sup> which aimed to improve the development of the PWD human rights resources to enable better inclusion, especially within employment.<sup>149</sup> Second, in 1991 the UNGA adopted the Principles on Mental Illness,<sup>150</sup> a collection of twenty-five fundamental rights for individuals with Mental Health conditions. The Principles served as a guide for institutions to investigate barriers to rights and freedoms<sup>151</sup> and echo earlier sentiments of treatment with humanity and respect for dignity.<sup>152</sup> The Decade concluded with the formation of bodies and committees to localise disability policy implementation and further guidelines on enacting change effectively.<sup>153</sup> Again, this demonstrates that the international community realised it had rested on its laurels for too long. It evidences a general trend towards genuine change in the human rights discourse for PWDs.

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<sup>145</sup> Ibid.

<sup>146</sup> UNGA Res 37/53 (n140), para. 11.

<sup>147</sup> UNGA Res 32/133 (n130), para. 7.

<sup>148</sup> UNGA Res 44/70 (8 December 1989) A/RES/44/70, Annex.

<sup>149</sup> Quinn & Degener (n97), 34.

<sup>150</sup> UNGA Res 46/119 (17 December 1991) A/RES/46/199.

<sup>151</sup> Broderick (n16), 51-2.

<sup>152</sup> UNGA Res 46/119 (n150), para. 1.

<sup>153</sup> UNGA, *Guidelines for the Establishment and Development of National Coordinating Committees on Disability or Similar Bodies* (6 November 1991) A/C.3/46/4, annex 1.

This progressive trend highlights how the 1990s became the “banner period for disability law”,<sup>154</sup> following a surge in regional and national legislation on disability rights. The Vienna Declaration and Programme of Action, resulting from the UN’s Second World Conference on Human Rights, confirmed that “all human rights...are universal and thus unreservedly include [PWDs]”.<sup>155</sup> The Programme of Action culminated in the UNSR,<sup>156</sup> which sought to establish standard rules in the international sphere to equalise opportunities for PWDs. Described as “the most significant instrument...[concerning] access and participation of [PWDs]”,<sup>157</sup> it followed several attempts by Italy, Sweden, Mexico, and others to introduce a binding convention on the rights of PWDs.<sup>158</sup> The UNSR framework “hinges on the twin concepts of equality and non-discrimination”.<sup>159</sup> The needs of everyone “are of equal importance”.<sup>160</sup> Those needs are “the basis for the planning of societies...to ensure that every individual has [an] equal opportunity for participation”.<sup>161</sup> Moving away from pathologisation, the UNSR distinguishes between disability and handicap, acknowledging the implications of external factors.<sup>162</sup> It shifts from “a medical-assistance perspective towards an approach focussing on rights with an interdisciplinary focus, emphasising the psychosocial, environmental and contextual

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<sup>154</sup> Theresia Degener, ‘International Disability Law – A New Legal Subject on the Rise: The Interregional Experts’ Meeting in Hong Kong, December 13-17, 1999’ (2000) 18 *Berkley Journal of International Law* 180, 184.

<sup>155</sup> World Conference on Human Rights, ‘Vienna Declaration and Programme of Action’ (12 July 1993) A/CONF.157/23, para. 63.

<sup>156</sup> UNGA Res 48/96 (4 March 1994) A/RES/48/96.

<sup>157</sup> Melinda Jones, ‘Inclusion, Social Inclusion and Participation’ in Marcia H Rioux, Lee A Basser & Melinda Jones (eds), *Critical Perspectives on Human Rights and Disability Policy* (Martinus Nijhoff 2011), 78.

<sup>158</sup> Broderick (n16), 52-3.

<sup>159</sup> Ibid, 53.

<sup>160</sup> UNGA Res 48/96 (n156), para. 25.

<sup>161</sup> Ibid.

<sup>162</sup> Ibid, paras. 17-18.

perspective in its broadest sense".<sup>163</sup> Therefore, many groups perceive the UNSR as "of major importance" to developing modern disability rights.<sup>164</sup> The rules stood as the core principles to consider when applying rights to PWDs and establishing a hive mind of growth in the field until the drafting and adoption of the CRPD. For example, the UNCHR resolution on PWD rights acknowledges the importance of the UNSR and understands the impact of violations of the rules on the rights of PWDs.<sup>165</sup>

### **1.2.3 A Global Development**

The global shift towards a rights-based approach generated ripples in international legal policy felt across the globe. Regional organisations followed suit and developed their rights frameworks to relate to PWDs more accurately. Recognising the "value of human dignity" served as "a powerful reminder that [PWDs] have a stake in and a claim on society that must be honoured".<sup>166</sup> As dignity is "the anchor norm of human rights",<sup>167</sup> the leap towards a dedicated rights approach fits the new goal.

Though the EU began in 1952 as a trade organisation, its growth and political positioning allowed expansion into human rights enforcement. The EU references disability within a provision of the EC Treaty to combat discrimination.<sup>168</sup> The Treaty of Amsterdam explicitly refers to disability as a characteristic subject to

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<sup>163</sup> María Soledad Cisternas Reyes, 'Standard Rules on Equality of Opportunities for Persons with Disabilities: Legal View of Provisions on Support Services, Auxiliary Resources and Training/View from Latin America' in Marcia H Rioux, Lee A Basser & Melinda Jones (eds), *Critical Perspectives on Human Rights and Disability Policy* (Martinus Nijhoff 2011), 419.

<sup>164</sup> CESCR GC5 (n11), para. 7(b).

<sup>165</sup> UNCHR Res 1998/31 (n71).

<sup>166</sup> Quinn & Degener (n97), 14.

<sup>167</sup> *Ibid.*

<sup>168</sup> Consolidated Version of the Treaty Establishing the European Community [2002] OJ C325/33, Art. 11(1).



discrimination<sup>169</sup> to consider the needs of PWDs.<sup>170</sup> Within the Charter of Fundamental Rights of the European Union, principles prohibit discrimination based on any grounds, including disability.<sup>171</sup> The Charter also recognises the right of PWDs to benefit from measures designed to ensure their independence.<sup>172</sup> A primary EU focus is employment rights. EU recommendations identify the principle of fair opportunity as access to training, employment, and opportunities for promotion.<sup>173</sup> Additionally, a 2000 directive on Equal Treatment in Employment covers, among other things, disability.<sup>174</sup>

The EU also proclaimed 2003 as the European Year of the People with Disabilities, intending to raise awareness of the rights of people with disabilities to protection against discrimination and full and equal enjoyment of their rights. Finally, in 2010 the European Commission published the European Disability Strategy for 2010-2020, listing eight areas for action: Accessibility, Participation, Equality, Employment, Education, Social Protection, Health, and External Action.<sup>175</sup> Separately, the COE has passed several recommendations related to PWDs, such as refocusing legislation on the "Mentally Ill"<sup>176</sup> and ensuring that society considers the needs of PWDs, in light of

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<sup>169</sup> Treaty of Amsterdam Amending the Treaty on European Union, the Treaties Establishing the European Communities and Certain Related Acts (signed 2 October 1997, entered into force 1 May 1999), art. 7.

<sup>170</sup> Ibid, Declaration 22.

<sup>171</sup> Charter of Fundamental Rights of the European Union (adopted 2 October 2000, entered into force 7 December 2000) OJ C 326/396, Art. 21.

<sup>172</sup> Ibid, Art. 26.

<sup>173</sup> European Community Recommendation 86/379/EEC (24 July 1986) OJ L 255 P.43, para. 1.

<sup>174</sup> Council Directive 2000/78/EC of 27 November 2000 establishing a General Framework for Equal Treatment in Employment and Occupation [2000] OJ L303/16.

<sup>175</sup> European Commission, *European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe* (15 November 2010) COM(2010) 636, 4.

<sup>176</sup> Council of Europe, 'Situation of the Mentally Ill' (8 October 1977) Recommendation 818(1977).

the IYDP.<sup>177</sup> Moreover, within the European Social Charter, there is a reference to the rights of PWDs to access training, employment, and rehabilitation<sup>178</sup>

The OAS has also taken several steps to promote the rights of PWDs. At numerous OAS Summits, States agreed to "review national legislation affecting people with disabilities"<sup>179</sup> and consider "acceding to...all universal and hemispheric human rights instruments" relating to, among other things, PWDs.<sup>180</sup> In 2001 they reaffirmed their "commitment to protect the human rights and fundamental freedoms of all, including those vulnerable, marginalised, disabled or require special protection".<sup>181</sup> This commitment included eradicating discrimination and achieving full participation in society. In 2005, they drafted a Plan of Action to declare a Decade of the Americas for Persons with Disabilities.<sup>182</sup> They reported the Decade between 2006-2016.<sup>183</sup> During the Decade, they took steps to promote the "full participation and inclusion [of PWDs] in the development of [their] societies",<sup>184</sup> including involving PWDs in their "social, political, economic, and cultural development processes".<sup>185</sup> The OAS adopted the IACPD in 1999 as the first disability-centric human rights treaty. It defines disability as "a physical, mental, or sensory impairment, whether permanent or temporary, that

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<sup>177</sup> Council of Europe, 'Rehabilitation Policies for the Disabled' (7 May 1992) Recommendation 1185(1992), para. 6(1).

<sup>178</sup> Council of Europe, *European Social Charter* (3 May 1996) ETS 163, Art. 15.

<sup>179</sup> OAS, *First Summit of the Americas: Plan of Action* (OAS, 9-11 December 1994), para. 2.6.

<sup>180</sup> OAS, *Third Summit of the Americas: Plan of Action* (OAS, 20-22 April 1998), para. 29.

<sup>181</sup> OAS, *Third Summit of the Americas: Declaration of Quebec* (OAS, 20-22 April 1998), para. 26.

<sup>182</sup> OAS, *Fourth Summit of the Americas: Plan of Action* (OAS, 5 November 2005), para. 59.

<sup>183</sup> OAS Permanent Council Committee on Juridical and Political Affairs, *Program of Action, Decade of the Americas for Persons with Disabilities (2006-2016)*, OEA/Ser.G, CP/CAJP-2362/06 corr.1 (2006).

<sup>184</sup> OAS, *Fifth Summit of the Americas: Declaration of Port of Spain* (OAS, 19 April 2009), para. 40.

<sup>185</sup> OAS, *Mandates Arising from the Sixth Summit of the Americas: Poverty, Inequality, and Inequity* (OAS, 14-15 April 2012), para. 10.

limits the capacity to perform one or more essential" daily activities.<sup>186</sup> Economic and social environments can cause or aggravate these impairments.<sup>187</sup> It also defines discrimination as "any distinction, exclusion, or restriction based on a disability...which has the effect or objective of impairing or nullifying the recognition, enjoyment, or exercise" of an individual's rights.<sup>188</sup> Echoing previous human rights instruments, it focuses on the inclusion of PWDs in society. However, tangible steps to realise this goal include preventing all preventable disabilities<sup>189</sup> and promoting NGOs and DPOs in developing policies.<sup>190</sup> Completing the late 20<sup>th</sup> Century trend of Decades of Disability, the OAU declared 2000-2009 as the Africa Decade of Persons with Disabilities. Based on the success of the first Decade and furthering the cause, the AU issued a second Decade between 2010-2019 and a Plan of Action.<sup>191</sup> Within Asia, the Asian and Pacific Decade of Persons with Disabilities ran between 1993-2002.

### **1.3 Nothing About Us Without Us**

Despite the instruments discussed in 1.2.2 and 1.2.3 having "considerable potential" in the disability rights field, they remained woefully underused to protect PWDs.<sup>192</sup> Broderick notes that despite these limitations, they "acted as a precursor to future UN instruments designed to foster increased participation and inclusion of [PWDs] in

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<sup>186</sup> Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities (adopted 7 June 1999, entered into force 14 September 2001) AG/RES. 1608 (XXIX-O/99), Art. 1(1).

<sup>187</sup> Ibid.

<sup>188</sup> Ibid, Art. 1(2)(a).

<sup>189</sup> Ibid, Art. 3(2)(a).

<sup>190</sup> Ibid, Art. 5(1).

<sup>191</sup> AU Commission Department of Social Affairs, 'Continental Plan of Action for the African Decade of Persons with Disabilities 2010-2019' (AU, 7 October 2013) <[https://au.int/sites/default/files/pages/32900-file-cpoa\\_handbook.\\_audp.english\\_-\\_copy.pdf](https://au.int/sites/default/files/pages/32900-file-cpoa_handbook._audp.english_-_copy.pdf)> (accessed 1 June 2021).

<sup>192</sup> Quinn & Degener (n18), 2.

society”<sup>193</sup>. Along this vein, PWDs began actively framing grievances and injustices through human rights and equality; PWDs not only "possess inestimable inherent self-worth but are also inherently equal in terms of self-worth, regardless of their difference".<sup>194</sup> "Isolated injustices" are no longer isolating;<sup>195</sup> they unite under human rights. Therefore, in 2002 the UNGA established the AHC to "consider proposals for a comprehensive and integral international convention" to protect the rights of PWDs.<sup>196</sup>

Additionally, in 2002 the Commission for Social Development produced a report containing a draft resolution for adoption by the UNESC, which concerned the "further promotion of equalisation of opportunities by, for, and with persons with disabilities and protection of their human rights".<sup>197</sup> The draft acknowledged the AHC and UNSR as essential in promoting dignity and equal opportunities for persons with disabilities.<sup>198</sup>

### **1.3.1 Who? Party Guests and Interested Parties**

The AHC began with an understanding that although there were efforts to increase awareness of issues relating to disability and access to appropriate rights, these had been insufficient in promoting the full and effective participation of persons with disabilities in various aspects of human rights. In ensuring that PWDs were at the forefront of the Convention, the AHC deviated from the drafting process of previous

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<sup>193</sup> Broderick (n16), 49.

<sup>194</sup> Quinn & Degener (n97), 16.

<sup>195</sup> Quinn & Degener (n18), 2.

<sup>196</sup> UNGA Res 56/168 (26 February 2002) A/RES/56/168, para. 1.

<sup>197</sup> Economic and Social Council, 'Report on the fortieth session of the Commission for Social Development' (27 February 2002) E/CN.5/2002/6, para 41.

<sup>198</sup> Ibid.

conventions in three crucial ways. First, the Committee involved NGOs and DPOs at various stages of the drafting process. The UN realised "the necessity of civil society participation in all treaty-related processes, [as] official UN delegations, composed largely of career diplomats, lacked specialised expertise in disability issues and hence were not well-positioned to make meaningful drafting proposals".<sup>199</sup> Second, Member States were formally encouraged to incorporate PWDs and other experts into their official delegations and consult with them in the preparatory processes.<sup>200</sup> Some States, including Bosnia and Herzegovina, Chile, Serbia, South Africa, Thailand, and Yemen, appointed PWDs as heads of their delegations. Third, the AHC established a UN Voluntary Fund on Disability to support civil society experts' participation. It assisted in covering travel and accommodation expenses to ensure the audibility of PWD voices. These changes ensured that NGOs "became full and active partners in the negotiation process",<sup>201</sup> placing tangible and practical policies in action and actively breaking down the barriers to entry. Melish notes that "under the motto 'Nothing about us, without us,' NGOs responded with enthusiasm, commitment, and a high degree of organisation".<sup>202</sup> In addition, many NGOs and DPOs banded together to form a broad Disability Caucus to mobilise their groups and "ensure common lobbying positions, a shared agenda, and hence an efficient and effective presence".<sup>203</sup> As such, the CRPD marked a "historic break from a State-centric model of treaty negotiation...toward a participatory approach".<sup>204</sup>

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<sup>199</sup> Melish (n22), 4.

<sup>200</sup> Ibid, 5.

<sup>201</sup> Ibid, 4-5.

<sup>202</sup> Ibid, footnote 9.

<sup>203</sup> Ibid.

<sup>204</sup> Ibid, 1-2.

The involvement of civic society did not begin with the CRPD – both CEDAW and the CRC involved relevant NGOs in their drafting process.<sup>205</sup> After, however, the CRPD broke records on the level of participation, with hundreds of civil society representatives and a myriad of diverse Member State delegations.<sup>206</sup> The General Assembly encouraged States to "hold meetings or seminars to contribute to the work of the [AHC]."<sup>207</sup> Interested parties would provide "suggestions and possible elements to be considered in proposals for a convention".<sup>208</sup> As civic society groups were "a key part of negotiating and drafting the Convention", the resultant text seeks to ensure States maintain a "high level of participation at the domestic level".<sup>209</sup>

### **1.3.2 What? Substantive Convention Topics**

Several parties attended the first AHC session with concrete plans and drafts. The EU identified that it was "prepared to take an active and engaged part in the work of the AHC on all practical and procedural issues" stemming from the Committee's mandate to develop a convention, including the substantive form of the document, which houses the purported rights.<sup>210</sup> The paper suggested that "the ultimate shape and content of [the] legal instrument" need not have fit a set narrative; instead, various forms were plausible.<sup>211</sup> These alternatives included a "general instrument focusing on the transcendent norm of equality and non-discrimination [concerning] human rights in

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<sup>205</sup> Broderick (n16), 66.

<sup>206</sup> Melish (n22), 5-6.

<sup>207</sup> UNGA Res 57/229 (18 December 2002) A/RES/57/229, para. 4.

<sup>208</sup> Ibid, para. 7.

<sup>209</sup> Mental Disability Advocacy Center, *Building the Architecture for Change: Guidelines on Article 33 of the UN Convention on the Rights of Persons with Disabilities* (MDAC, March 2011) <[http://mdac.org/sites/mdac.org/files/Article\\_33\\_EN.pdf](http://mdac.org/sites/mdac.org/files/Article_33_EN.pdf)> (accessed 2 June 2021), 14-15.

<sup>210</sup> Ad Hoc Committee established by UNGA Res 56/168, 'Position Paper by the European Union' (29 July-9 August 2002) A/AC.265/WP.2.

<sup>211</sup> Ibid.

the context of disability" or a collection of optional protocols to pre-existing international human rights conventions and instruments.<sup>212</sup> However, the paper also acknowledged that a general human rights convention would be appropriate. Firstly, the contents of such a convention could have provided for "both civil and political as well as economic, social and cultural rights tailored to disabilities".<sup>213</sup> Secondly, they could have focussed on one category of rights, forming a narrower scope. Finally, they could have been broader general principles, opening up the "possibility of subsequent optional protocols containing progressively greater details", for which the EU demonstrated a preference.<sup>214</sup> The content and purpose of the above forms are similar. They provide greater awareness of rights for PWDs and ensure that either the application of pre-existing rights to the setting of disabilities or establishing new rights for the same environment are made available in the international sphere. Even though the General Assembly resolution explicitly sought a comprehensive international convention, the interpretation from the EU was that the resulting document or documents did not have to mirror the Conventions and Covenants that predate the final product of the AHC.

From the second session onwards, the AHC sought to deal with the definition of disability. Again, the panel argued that the "discussion concerning contextual variables is essential".<sup>215</sup> The discussion proceeded on two fronts regarding the construction of a definition and whether the Convention should provide a concrete definition. Several

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<sup>212</sup> Ibid.

<sup>213</sup> Ibid.

<sup>214</sup> Ibid.

<sup>215</sup> Ad Hoc Committee established by UNGA Res 56/158, 'Panel III of the Second Session: New and Emerging Approaches to Definitions of Disability: Conceptual Frameworks, Varying Context of Definition and Implications for Promotion of the Rights of Persons with Disabilities' (*United Nations*, 23 June 2003) <<https://www.un.org/esa/socdev/enable/rights/ahc2panel3.htm>> (accessed 27 November 2019).

States and NGOs rejected defining disability. Some felt that creating a definition created a "risk [of] becoming exclusive instead of inclusive".<sup>216</sup> Others believed that the CRPD should leave the definition of disability to individual States.<sup>217</sup> However, many organisations favoured creating a definition, as they "feared that some governments would define disability according to their...preferences" if the Convention lacked a definition.<sup>218</sup> For example, China supported an article on definitions "but covering only the important terms", including minimum disability and discrimination.<sup>219</sup> Japan argued that a definition of disability "should be flexible to accommodate different national systems".<sup>220</sup> Australia believed it should identify "the people entitled to protections under the Convention", including "physical, mental, intellectual disabilities as well as future, past and imputed disabilities".<sup>221</sup> They also argued that a definition should follow various impairment and functional limitation forms.<sup>222</sup>

The debate on the content of this theoretical definition generated two main factions. The first faction promoted a hybrid approach between medicine and social commentary. Despite the trend towards a social perspective noted in section 1.2, many

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<sup>216</sup> Landmine Survivors Network, 'Daily Summary of Discussions related to Article 3: Definitions' (*United Nations*, 23 August 2004), <<https://www.un.org/esa/socdev/enable/rights/ahc4sumart03.htm>> (accessed 7 May 2021).

<sup>217</sup> Ibid.

<sup>218</sup> Rehabilitation International (n13).

<sup>219</sup> Landmine Survivors Network, 'Daily Summary of Discussions related to Article 3: Definitions' (*United Nations*, 23 August 2004), <<https://www.un.org/esa/socdev/enable/rights/ahc4sumart03.htm>> (accessed 7 May 2021).

<sup>220</sup> Ibid.

<sup>221</sup> Disabled Peoples' International, Handicap International and the International Service for Human Rights, 'UN Convention on the Human Rights of People with Disabilities: Ad Hoc Committee Fourth Session - Daily Summary' (*United Nations*, 23 August 2004) <<https://www.un.org/esa/socdev/enable/rights/ahc4sum23aug.htm>> (accessed 7 May 2021).

<sup>222</sup> Ad Hoc Committee established by UNGA Res 56/168, 'Proposed Modifications by Governments: Australia' (*United Nations*, January 2006) <<https://www.un.org/esa/socdev/enable/rights/ahc7australia.htm>> (accessed 7 May 2021).



were cautious about leaving pathology behind. They acknowledged that a social understanding of disability offers a unique theoretical framework. However, there was a risk that once society removed barriers, the State may avoid further obligation toward the PWD.<sup>223</sup> By establishing a clear framework of obligations on States, delegates feared that States would achieve set goals by performing the bare minimum necessary and calling it a day. In the eyes of some delegates, leaving it open for interpretation whilst still respecting the tangible nature of pathology ensured that States remained accountable. For example, Yemen noted a “connection with the medical field”, as some psychiatric illnesses are not disabilities.<sup>224</sup> Thus, they argued that the CRDP needed a disability definition for clarity.<sup>225</sup> Further, Syria endorsed a clear-cut definition incorporating elements from medical and social models.<sup>226</sup> Moreover, WHO reported that the ICF definition accounted for “aspects of both social and medical models,” achieving a synthesis of the two.<sup>227</sup> Pathology maintained a stronghold on specific aspects of disability, necessitating involved parties to advocate for its maintenance. However, social perspectives on disability still grew in voice, resulting in their partial promotion.

The second collective advocated for a purely social approach to eliminate the medical model.<sup>228</sup> Proponents acknowledged the interpretation of disability in the UNSR, which the CRPD should reflect or echo,<sup>229</sup> as an attempt to purposely avoid pathology in the

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<sup>223</sup> Rehabilitation International (n13).

<sup>224</sup> Ibid.

<sup>225</sup> Ibid.

<sup>226</sup> Ibid.

<sup>227</sup> World Health Organisation, ‘The International Classification of Functioning, Disability and Health’, (paper submitted to the Ad Hoc Committee’s Eighth Session in ‘Contributions from UN System Agencies’) <<https://www.un.org/esa/socdev/enable/rights/ahc8contagency.htm>> (accessed 7 May 2021).

<sup>228</sup> Disabled Peoples’ International (n221).

<sup>229</sup> Rehabilitation International (n13).

final draft rather than as advocacy for a social definition. Any included definition must be broad.<sup>230</sup> This argument was consistent throughout later sessions.<sup>231</sup> For example, New Zealand rejected a definition of disability, as it could be unintentionally exclusive. However, if the CRPD provided a disability, it "should reflect the social model of disability [and] be as broad as possible".<sup>232</sup> There needed to be a transition from pathology towards a discourse on the social implications of disability.

Australia demonstrated an intense drive for a definition of disability, promoting its definition in multiple AHC sessions. Lord argues that the final placement of language reflecting the social model in the CRPD came primarily due to Australian Disabled Persons Organisations working together with their government delegation".<sup>233</sup> Australia argued that the CRPD should "clearly signal a change in understanding", recognising "a profound shift away from an understanding of disability as an individual pathology towards one that recognises the disabling impact of inaccessible social structures and processes" on [PWDs].<sup>234</sup> They believed this definition was consistent with the social model. However, they described the social model as incorporating impairment as the physiological function, disability as the interaction with the environment, and handicap as the disadvantage created by the impairment or disability.<sup>235</sup> This approach reflects the ICIDH model rather than the UPIAS/DPI model, which makes no such distinction. Lawson and Beckett argue that the

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<sup>230</sup> Disabled Peoples' International (n221).

<sup>231</sup> Rehabilitation International (n13).

<sup>232</sup> Ibid.

<sup>233</sup> Janet E Lord, 'Preamble' in Ilias Bantekas, Michael A Stein & Dimitris Anastasiou (eds), *The UN Convention on the Rights of Persons with Disabilities* (OUP 2018), 5.

<sup>234</sup> People with Disability Australia et al, 'Submission to the Ad Hoc Committee – Preamble' (July 2004), referenced in Janet E Lord, 'Preamble' in Ilias Bantekas, Michael A Stein & Dimitris Anastasiou (eds), *The UN Convention on the Rights of Persons with Disabilities* (OUP 2018), 13.

<sup>235</sup> Rehabilitation International (n13).

UPIAS/DPI model instead uses the notion of disability to reference the "disadvantage and oppression caused by environmental, legal, attitudinal and other factors external to individuals with impairments".<sup>236</sup> A detailed discussion of these disability models occurs in Chapter Two; however, it is interesting that AHC participants did not share a shared understanding of what comprised a "social" model of disability.

### **1.3.3 Where? Accessibility and Realism**

As discussed previously, the AHC marked a systematic shift in convention drafting. By joint agreement, the AHC sessions maintained "transparency, enthusiasm, lack of politicisation, and co-operation unparalleled in UN treaty negotiations or general meetings".<sup>237</sup> There was clear symbolism behind the physical accessibility of the AHC, as "the participatory process is relevant to the vision of equality advanced by the Convention".<sup>238</sup> The article debates took place in the plenary of the AHC, in the UN building's single wheelchair-accessible large conference room.<sup>239</sup>

Persons with disabilities are some of the most marginalised people in modern society; the position paper issued by the People's Republic of China emphasises that persons with disabilities "constitute a vulnerable group [and that] in general their existence continues to be marked by rejection and marginalisation".<sup>240</sup> Therefore, the Convention must "safeguard the rights of persons with disabilities and create a better

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<sup>236</sup> Anna Lawson & Angharad E Beckett, 'The Social and Human Rights Models of Disability: Towards a Complementarity Thesis' (2021) 25(2) *International Journal of Human Rights* 348, 353.

<sup>237</sup> Melish (n22), 3.

<sup>238</sup> Broderick (n16), 66-67.

<sup>239</sup> Melish (n22), 5-6.

<sup>240</sup> Ad Hoc Committee established by UNGA Res 56/168, 'Position Paper by the People's Republic of China' (29 July-9 August 2002) A/AC.265/WP.3, 3.

system of legislation to ensure equality, participation and sharing".<sup>241</sup> Nevertheless, the efficacy and realism of the Convention are of paramount importance. As the EU's paper explains, a "poorly drafted instrument could end up reinforcing a segregationist tendency in law and policy",<sup>242</sup> so the AHC must draft the convention with care, accuracy, and consistency. As the Convention purports to cover some of the most vulnerable people in society, the rights must be clear and not undermine or duplicate pre-existing rights. They also must not fall below any human rights standard that exists. If there are inconsistencies with existing rules, these are to improve or clarify them within the context of disability. In turn, the Committee must not make "utopian proposals" which have failed in other contexts.<sup>243</sup>

#### **1.3.4 When? Convention in Context**

The High Commissioner had issued a resolution in the wake of establishing the AHC, in which PWDs have protection under the existing international human rights conventions. Nevertheless, the community needed to ensure that PWDs had access to specific rights and opportunities to allow for the equality of persons.<sup>244</sup> Accordingly, "all United Nations organisations and specialised agencies address[ed] the problems that exist[ed] in creating equal opportunities for [PWDs] at all levels".<sup>245</sup> States must also "report on how these problems are...solved".<sup>246</sup>

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<sup>241</sup> Ibid.

<sup>242</sup> AHC (n210).

<sup>243</sup> Ibid.

<sup>244</sup> UNCHR Res 2002/61 (25 April 2002) E/CN.4/2002/200.

<sup>245</sup> Ibid, para 35.

<sup>246</sup> Ibid.

The momentum for a significantly better future for the rights of PWDs is clear. The 2002 "Human Rights Are For All" Study, presented to the Commission on Human Rights, was an attempt by the Office of the High Commissioner to demonstrate "the current use and future potential of the United Nations human rights instruments in the specific field of disability".<sup>247</sup> Further, the AHC took a thematic approach to its work, analysing the Convention drafts against various sources of international human rights principles.<sup>248</sup> For example, China argued that the UNSR and the WPA should form "an integral part of the indispensable guiding principles."<sup>249</sup> Additionally, the EU advocated for the refining and updating of the UNSR and that "any future legal instrument must be mutually supportive" with the rules.<sup>250</sup> AHC participants came to the table with a keen focus on collating documents promoting disability rights and using them as stepping stones to an applicable convention.

### **1.3.5 Why? Of Purposes and Focuses**

During the AHC, participants discussed the purported target of the CRPD, the entity (or entities) subject to the primary focus of the convention. They debated the needs of the individual and the responsibilities of the State. China was notably vocal about the balance of power and responsibility. In their position paper, they suggested that "all countries should take the specific characteristics and needs of persons with disabilities fully into account and ensure [the reflection of] issues relating to such

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<sup>247</sup> UNCHR Res 2002/18 Add.1 (12 February 2002) E/CN.4/2002/18/Add.1, Annex, 3.

<sup>248</sup> Ad Hoc Committee established by UNGA Res 56/168, 'Report of the First Session' (29 July-9 August 2002) A/57/357.

<sup>249</sup> AHC (n242), 7.

<sup>250</sup> AHC (n210).

persons."<sup>251</sup> However, they also highlighted the importance of resource allocation and respect for State capacity. Realising human rights can take considerable time and resources, which can become an issue for some countries. As such, China suggested that the convention "should focus on the special situation and difficulties of persons with disabilities in developing countries and should reflect the just demands of the developing countries."<sup>252</sup> China intended for a tiered approach to the practical realisation of rights under the CRPD, where some States could avoid or negate some of their obligations based on resource allocation. The fact that such provisions are absent from the CRPD demonstrates that this mentality does not translate to the final version.

Further, AHC participants argued that developing the CRPD would not provide a solution to the problems faced by PWDs in accessing human rights. The EU, for example, noted that the community should develop the CRPD "in parallel with concrete efforts to further mainstream the disability perspective into the monitoring mechanisms" of the other Conventions.<sup>253</sup> As noted in section 1.2, several existing human rights instruments have already purported to provide rights or protections to PWDs. Disability often overlaps with other categories of marginalisation, and both CEDAW and the CRC refer to disabilities. It would be remiss of the international community to rely solely on the CRPD to advocate for PWD rights moving forward. Moreover, Panel II considered "how the rights of persons with disabilities are protected and promoted based on the principle of non-discrimination and equality

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<sup>251</sup> AHC (n242), 4.

<sup>252</sup> *Ibid*, 9.

<sup>253</sup> AHC (n210).

within the existing human rights framework".<sup>254</sup> It focussed on where the principle of equal opportunities has been ineffective in the past and what to consider when trying to combat this moving forward. The panel promoted alternative responses such as anti-discrimination measures and reasonable accommodation.

### **1.3.6 How? Convention(al) Models**

The final complex subject for consideration was the overall model for CRPD. The AHC needed to decide whether the CRPD would create disability-specific rights or merely re-articulate existing rights with disability in mind. From the outset, the AHC mandate required that the CRPD did not confer new rights.<sup>255</sup> Don McKay, the AHC Chairman, indicated the Convention would focus on implementation – that “without creating...new rights, the Convention sets out a detailed code of implementation” and spells out the practical application of individual rights.<sup>256</sup> Nevertheless, the AHC debated the model and form of the Convention.<sup>257</sup>

They generated three different models of human rights treaties. First is a Holistic Rights Model, which would provide a "broader scope" based on a holistic and

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<sup>254</sup> Ad Hoc Committee established by UNGA Res 56/158, ‘Panel II of the Second Session: The Principle of Non-Discrimination and Equality from Disability Perspective: Critical Issues concerning Special Measures and Disability’ (*United Nations*, 17 June 2003) <<https://www.un.org/esa/socdev/enable/rights/ahc2panel2.htm>> (accessed 27 November 2019).

<sup>255</sup> Broderick (n16), 65.

<sup>256</sup> UN Press Releases, ‘Chairman says draft convention sets out detailed code of implementation and spells out how individual rights should be put into practice’ (*UN*, 15 August 2005) <<https://www.un.org/press/en/2005/soc4680.doc.htm>> (accessed 2 June 2021).

<sup>257</sup> UNGA Res 57/229 (n207).

comprehensive nature.<sup>258</sup> Second is a Non-Discrimination Model, which "guarantees that [PWDs] could exercise their general human rights".<sup>259</sup> Third, a Hybrid Model would combine "non-discrimination and equality with separate statements of existing rights guarantees, tailored to [the] specific situations" of PWDs.<sup>260</sup> The CRPD follows the hybrid model. During the drafting process, there was a consensus that the CRPD should not create new rights as the aim was to promote equality within the existing system.

#### **1.4 A New Age of Disability Rights**

The CRPD ushered in a new wave of disability rights discourse. As Kayess and French explain, "virtually absolute emphasis [is] placed by the substantive human rights articles on [removing] barriers and provision of accommodations".<sup>261</sup> As illustrated in section 1.3, the conversation shifted towards a human-rights focus on disability rather than pathology. In this respect, the Convention represents "a global consensus that the architecture of the current human rights regime — despite its universal application to persons with disabilities and clear prohibitions of discrimination [based on] disability — has proved ineffective in ensuring equal rights for persons with disabilities in practice".<sup>262</sup> At the point of adoption, there were grand expectations for the rate of signatures and ratifications for the CRPD.<sup>263</sup> Over a decade of enforcement, the CRPD now boasts 182 ratifications and nine additional signatures, making it the third-highest adopted international convention behind the CRC and CEDAW. The "extraordinary

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<sup>258</sup> Ad Hoc Committee established by UNGA Res 56/168, 'Panel I of the Second Session: Typology of International Conventions and Options for a Convention on the Rights of Persons with Disabilities' (*United Nations*, 16 June 2003) <<https://www.un.org/esa/socdev/enable/rights/ahc2panel1.htm>> (accessed 27 November 2019).

<sup>259</sup> *Ibid.*

<sup>260</sup> *Ibid.*

<sup>261</sup> Rosemary Kayess & Phillip French, 'Out of Darkness into Light: Introducing the United Nations Convention on the Rights of Persons with Disabilities' (2008) 8(1) *Human Rights Law Review* 1, 24.

<sup>262</sup> Melish (n22), 7.

<sup>263</sup> *Ibid.*, 2.



success” of the CRPD's participatory methodology “ensured that it...reflected in the implementation and monitoring methodologies envisioned under the Convention”.<sup>264</sup> Articles 4 and 33 require States Parties to “closely consult with and actively involve” persons with disabilities.<sup>265</sup> This next section will discuss a few impactful aspects of the CRPD in its final adopted form.

### **1.4.1 Defining Disability?**

Section 1.3.2 demonstrates the extensive debates around defining disability in the CRPD. Ultimately, there is no precise definition of disability in the CRPD, reflecting the difficulty of reaching a consensus among the AHC members.<sup>266</sup> After much negotiation, the parties agreed not to include disability as a listed definition in Article 2.<sup>267</sup> However, the CRPD provides a “description, rather than a definition” in two instances.<sup>268</sup> Firstly, there is guidance on the meaning of disability in paragraph (e) of the preamble, distinguishing ‘disability’ from ‘impairment’ like the UPIAS/DPI model. Paragraph (e) reads as follows:

“...recognising that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.”<sup>269</sup>

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<sup>264</sup> Ibid, 6.

<sup>265</sup> CRPD (n7), Art. 4(3) and 33.

<sup>266</sup> Lord (n233), 12.

<sup>267</sup> Anna Nilsson, ‘Article 2: Definitions’ in Ilias Bantekas, Michael A Stein & Dimitris Anastasiou (eds), *The UN Convention on the Rights of Persons with Disabilities* (OUP 2018), 64.

<sup>268</sup> Emily Kakoullis & Yoshikazu Ikehara, ‘Article 1: Purpose’ in Ilias Bantekas, Michael A Stein & Dimitris Anastasiou (eds), *The UN Convention on the Rights of Persons with Disabilities* (OUP 2018), 36.

<sup>269</sup> CRPD (n7), Preamble, para (e).

This wording is remarkably similar to China's proposal during the Eighth Session<sup>270</sup> and provides "a certain measure of flexibility" in an application.<sup>271</sup> Identifying that disability is "an evolving concept", together with avoiding discussing disability in Article 2, shows "the difficulty of agreeing on a common definition of disability".<sup>272</sup> Lord notes that this articulation of disability "falls squarely within a socio-contextual frame",<sup>273</sup> placing heavy emphasis on a holistic, multitudinal perspective on disability. As such, the wording remains open and "does not lock into the treaty a fixed and static understanding of disability; rather, it embraces a more nuanced approach to the conceptual boundaries of disability".<sup>274</sup>

Second, the CRPD discusses defining 'disability' as a classification. Within Article 1, the CRPD defines an individual with a disability as including:

"...those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".<sup>275</sup>

This definition is important for several reasons. To begin, article 1 ensures that the CRPD is only the second human rights convention to define its target demographic.<sup>276</sup> Providing examples of who is protected by the Convention helps establish a core

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<sup>270</sup> Ad Hoc Committee, 'Proposed Modifications by Governments: Ad Hoc Committee Eighth Session - China' (*United Nations*, 23 August 2006) <<https://www.un.org/esa/socdev/enable/rights/ahc8gpcapreamble.htm>> (accessed 4 June 2021).

<sup>271</sup> Lord (n233), 14.

<sup>272</sup> *Ibid*, 12.

<sup>273</sup> *Ibid*.

<sup>274</sup> *Ibid*, 14.

<sup>275</sup> CRPD (n7), Art. 1.

<sup>276</sup> For the first, see CRC (n69), Art. 1.

commonality between different individual categories under the same banner of 'disability'. The fact that the CRPD references physical and mental statuses as aspects of disability are imperative to reduce stigma and stratification of disability. Too readily does society place disability on a totem pole, as if one disability is more disabling than another.

Moreover, the list provided by Article 1 is non-exhaustive. Though the provision aims to demonstrate who is included, it avoids explicitly excluding individual categories. With inclusivity as a key consideration of the CRPD, it would be untoward to begin the document by drawing lines in the sand and restricting access. Conversely, the CRPD also serves as a specialist human rights treaty. State parties must understand where legislation and policy should apply to ensure workability and accurate allocation of resources. It is, therefore, no surprise that multiple countries and activist groups contributed ideas to the composition of this definition. Ultimately, Article 1 was arguably the most controversial during the drafting process,<sup>277</sup> with the final version only finalised during the last AHC session.<sup>278</sup>

These two references, when read together, ensure the CRPD "will facilitate participation and inclusion of [PWDs] within society".<sup>279</sup> However, the CRPD does not reference "every widely-experienced abuse suffered [PWDs], including many of those pressed in negotiations. Nor does it include detailed accessibility standards or concrete benchmarks of achievement in distinct social fields".<sup>280</sup> Further, the AHC

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<sup>277</sup> Kayess & French (n261), 23.

<sup>278</sup> Kakoullis & Ikehara (n268), 36.

<sup>279</sup> Kayess & French (n261), 24.

<sup>280</sup> Melish (n22), 9.

"carefully avoided 'shopping lists' and over-specification of details and standards," achieving two purposes.<sup>281</sup> First, it ensured that the CRPD would "remain relevant and vital over time and space, capable of responding to new challenges and modes of abuse as they arose."<sup>282</sup> Second, it avoids the "negative inference" caused by failing to list every abuse, leaving the unintended option of reading omissions as a tacit agreement to acceptable violations.<sup>283</sup>

#### **1.4.2 Key CRPD Principles**

The final text of the CRPD preamble "gives a flavour for nearly all of the core conceptual issues arising during the negotiation of the Convention".<sup>284</sup> Melish notes that, by design, one must read the CRPD as one united piece of holistic discourse:

"None of [the] provisions can...be read in isolation from the broader themes and shared tenets that gave rise to them in the [AHC]. [They] must remain front and centre in efforts to construe the scope and meaning of the Convention and to understand the intent behind certain drafting choices; attempts to single out and find fault in isolated provisions risk losing the broader vision of what the Convention does as a whole".<sup>285</sup>

The CRPD intends for States to read its provisions in line with a core set of beliefs. Each article discusses different topics. However, very few can exist independently of others. The rights within the CRPD are integral to PWDs to ensure they can fully access

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<sup>281</sup> Ibid.

<sup>282</sup> Ibid.

<sup>283</sup> Ibid, 9-10.

<sup>284</sup> Lord (n233), 5.

<sup>285</sup> Melish (n22), 4.

society. Said society has been developed and cultivated with able-bodiedness in mind (a fact considered at great length in Chapter Two). Melish is correct to note that all provisions under the CRPD must work in unison to protect PWDs in all areas of life, rather than specific areas. Using this logic, therefore, the CRPD deviates from the DRMMP, and Mental Health Principles as much of its content no longer reflects modern values. As noted below, the CRPD takes disability holistically in context, expanding the coverage of protections to include disability outside of the mental and psychosocial. There is a lack of reference to reasonable accommodation or the promotion of universal design in the DRMMP, both of which are key tenets of the CRPD. Further, the theoretical foundation of the DRMMP rests squarely in a medical model understanding of mental health, whereas the CRPD relies on an entirely different model of disability.

The CRPD defines several concepts important to understanding disability in context. Article 2 features the majority of these explanations. The Convention refuses to treat principles as trite, making sure to “clarify the scope of State obligations laid down...and thereby contribute to the effective implementation of the treaty”.<sup>286</sup> First, the CRPD defines communication as “different means for imparting, exchanging and accessing information” commonly used by PWDs.<sup>287</sup> Communication includes “languages, display of text, Braille, tactile communication, large print, accessible multimedia” and “written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication”.<sup>288</sup> Nilsson provides an excellent explanation of each aspect of the CRPD definition.<sup>289</sup> There is an overlap between communication and language, another concept defined in Article 2. However, the purpose of including

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<sup>286</sup> Nilsson (n267), 64.

<sup>287</sup> *Ibid*, 68.

<sup>288</sup> CRPD (n7), Art. 2.

<sup>289</sup> Nilsson (n267), 68-69.

communication “was not to establish a definition for the understanding of what communication means, but rather to ensure [inclusion of] specific forms of communication”.<sup>290</sup> Communication takes various forms, with PWDs often creating unique ways of communicating outside of the speaking/hearing “norm” set by society. Avoiding a concrete definition in preference towards a broad list provides that general coverage.

Second, the CRPD affords protection for different languages, including “spoken and signed languages and other forms of non-spoken languages”.<sup>291</sup> During the negotiation process, several countries suggested that sign languages “should be viewed merely as modes of communication” and therefore are not languages in their own right.<sup>292</sup> However, Kauppinen and Jokinen suggest that such attitudes “fail to understand Deaf culture, the concept of sign languages, and how critically important these are to one’s social and psychological development”.<sup>293</sup> Sign languages are independent “with [their] own vocabulary, grammar, and structure”.<sup>294</sup> The WFD were at the forefront of non-spoken language advocacy and ensured their inclusion in the final version. They promoted the “right to be different” and the “explicit recognition of sign language as natural languages”. Non-spoken languages lack a clear definition in Article 2’s definition. AHC members agreed to include sign language. Nevertheless, there is ambiguity regarding tactile language. Nilsson suggests, “tactile sign languages constitute a sub-category of signed languages and thus enjoy the status of being a

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<sup>290</sup> Rehabilitation International (n13).

<sup>291</sup> CRPD (n7), Art. 2.

<sup>292</sup> Liisa Kauppinen & Marku Jokinen, ‘Including Deaf Culture and Linguistic Rights’ in Maya Sabatello & Marianne Schulze (eds), *Human Rights and Disability Advocacy* (University of Pennsylvania Press 2013), 133.

<sup>293</sup> Ibid.

<sup>294</sup> Nilsson (n267), 69.

language” under the CRPD.<sup>295</sup> She continues that this may reflect “a desire among drafters to be inclusive” of future non-spoken languages, ensuring they maintain equal protection under the CRPD.

Third, Article 2 discusses the principle of non-discrimination. During the drafting process, The Netherlands (on behalf of the EU) sought an article on non-discrimination as “it is a key concept in the Convention and is not yet sufficiently defined in international law”.<sup>296</sup> They argued that a definition of “discrimination on the ground of disability” must include “both direct and indirect discrimination”.<sup>297</sup> Article 2 of the CRPD defines discrimination as “any distinction, exclusion, or restriction [based on] disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms”.<sup>298</sup> It includes “all forms of discrimination, including denial of reasonable accommodation”.<sup>299</sup> It is also one of the most important concepts within the CRPD, appearing in nine provisions in the treaty text.<sup>300</sup> However, the CRPD is not merely a non-discrimination treaty. Its “motivating purpose is gap-filling and substantive: to make existing human rights law relevant to persons with disabilities by comprehensively elaborating...from a disability perspective”.<sup>301</sup> PWDs experience violation of their human rights “in ways directly tied to their disabilities or in ways...justified by them”<sup>302</sup>

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<sup>295</sup> Ibid, 71.

<sup>296</sup> Landmine Survivors Network (n219).

<sup>297</sup> Ibid.

<sup>298</sup> CRPD (n7), Art. 2.

<sup>299</sup> Ibid.

<sup>300</sup> Nilsson (n267), 71.

<sup>301</sup> Melish (n22), 7.

<sup>302</sup> Ibid.

Fourth, the CRPD defines reasonable accommodation as the “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden...to ensure to [PWDs] the enjoyment or exercise [of rights] on an equal basis with others”.<sup>303</sup> It “builds on the idea that it takes more than restrains of biased and ignorant behaviour to ensure equal enjoyment of human rights”.<sup>304</sup> The AHC debates on accommodation involved two main questions – whether “failure to undertake such accommodations [is] a form of discrimination” and, if so, how “the duty to accommodate [is] formulated and demarcated”.<sup>305</sup> At the AHC fourth session, there was an agreement to include a duty to accommodate in the definition of disability-based discrimination.<sup>306</sup> Moreover, the ECtHR incorporated refusal to make reasonable accommodations into its definition of disability-based discrimination.<sup>307</sup> Many CRPD obligations use reasonable accommodation to promote PWD equality, such as Article 4 on various assistive technologies<sup>308</sup> and Article 9 on access to the constructed environment.<sup>309</sup> Reasonable accommodation can also take multiple forms, and the Article 2 definition is purposely broad to facilitate interpretation.

Finally, the CRPD defines universal design as the “design of products, environments, programmes and services to be usable by all people”.<sup>310</sup> The CRPD recognises that

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<sup>303</sup> CRPD (n7), Art. 2.

<sup>304</sup> Nilsson (n267), 78.

<sup>305</sup> Ibid, 66.

<sup>306</sup> Landmine Survivors Network, 'Daily Summary of Discussions related to Article 2: General Principles' (*United Nations*, 23 August 2004), <<https://www.un.org/esa/socdev/enable/rights/ahc4sumart03.htm>> (accessed 7 May 2021).

<sup>307</sup> *Çam v Turkey*, App No 51500/08 (23 February 2016), paras. 65-67.

<sup>308</sup> CRPD (n7), Art. 4(f) and (g).

<sup>309</sup> Ibid, Art. 9(1).

<sup>310</sup> Ibid, Art. 2.



some PWDs will require aids to alleviate discomfort or facets of their disabilities. Therefore, the definition does not exclude specialist assistive devices. This definition echoes the CUD's definition.<sup>311</sup> The CUD list seven principles: equitable use, flexibility, simple and intuitive use, perceptible information, tolerance for error, low physical effort, and size and space for approach and diverse abilities.<sup>312</sup> Universally designed devices must avoid stigma and segregation and accommodate many abilities. Nilsson notes that universal design is a relatively new concept in human rights law.<sup>313</sup> It acts as a perfect representation of the community's shift towards a holistic rights perspective. It considers various principles such as language, communication, discrimination, and accommodation, as discussed above, and pulls them into a modern interpretation of disability. Universal design is the ultimate goal of the CRPD, that we design every facet of the socially constructed world with various statuses in mind. Accessibility should not be an afterthought. Actual equal access is not a wheelchair ramp hastily bolted to the side of an existing building; it includes wheelchair access in the initial design process for that building.

### **1.4.3 The "Social" Context**

As noted in section 1.3.2, the AHC broadly interpreted the social model during the drafting process of the CRPD. Early preamble proposals “did not specifically address the framing of disability [following] the social model”.<sup>314</sup> One example of its usage is in a draft proposal by Venezuela in response to the original Mexican proposal,

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<sup>311</sup> Center for Universal Design, ‘About UD’ (*NC State University*, 2008) <[https://projects.ncsu.edu/ncsu/design/cud/about\\_ud/about\\_ud.htm](https://projects.ncsu.edu/ncsu/design/cud/about_ud/about_ud.htm) > (accessed 14 June 2021).

<sup>312</sup> Bettye Rose Connell et al, ‘The Principles of Universal Design’ (*NC State University*, 1 April 1997) <[https://projects.ncsu.edu/ncsu/design/cud/about\\_ud/udprinciplestext.htm](https://projects.ncsu.edu/ncsu/design/cud/about_ud/udprinciplestext.htm) > (accessed 14 June 2021).

<sup>313</sup> Nilsson (n267), 82.

<sup>314</sup> Lord (n233), 5

discussing the “structural or functional absence or impairment...in respect of human beings’ relationship to their environment”.<sup>315</sup> The LSN noted in 2003, “none of the documents specifically call for the preamble to acknowledge the paradigm shift in thinking about disability that has occurred over the last few decades”.<sup>316</sup> However, it is clear that the AHC drafted the Convention with the social model in mind, and its impact is evident in the language used in the final version of the CRPD. Kayess and French suggest the social model exercised an “enormous influence” over the treaty,<sup>317</sup> which assists in illuminating the “limitations of traditional theories of equality” concerning PWDs.<sup>318</sup> Traustadóttir argues it provided the “knowledge base which...informed” the CRPD,<sup>319</sup> whilst Degener likens the model to the “motto of the international disability movement,” suggesting “it served as a powerful tool to demand legal reform”.<sup>320</sup> As discussed in section 1.4.2, some argue that the preamble is a “non-radical” version of the model,<sup>321</sup> culminating in the negotiation process discussed in section 1.3.2.

The Secretary-General Report on Trends mentions the apparent, progressive changes sought in the drafting process. A principal difference noted is “the shift in emphasis from biomedical and social welfare service approaches to [PWDs] to the recognition of [PWDs] as agents and beneficiaries of the development of the societies in which

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<sup>315</sup> Ad Hoc Committee established by UNGA Res 56/168, ‘Draft submitted by the Government of the Bolivarian Republic of Venezuela’ (*United Nations*, 18 June 2003), A/AC.265/2003/WP.1 Annex, Preamble.

<sup>316</sup> Landmine Survivors Network, ‘Comparative Analysis Commentary, December 2003’ cited in Lord (n233), 13.

<sup>317</sup> Kayess & French (n261), 7.

<sup>318</sup> *Ibid*, 8.

<sup>319</sup> Rannveig Traustadóttir, ‘Disability Studies, the Social Model and Legal Developments’, in Oddný Mjöll Arnardóttir & Gerard Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities – European and Scandinavian Perspectives* (Martinus Nijhoff, 2009), 16.

<sup>320</sup> Theresia Degener, ‘Disability in a Human Rights Context’ (2016) 5(3) *Laws* 35, 48.

<sup>321</sup> Paul Harpur, ‘Embracing the New Disability Rights Paradigm: The Importance of the Convention on the Rights of Persons with Disabilities’, (2012) 27(1) *Disability and Society* 1, 3.

they live".<sup>322</sup> The discussion of accessible environments, vulnerability, technologies, and new practices proves that using a social model enfranchises PWDs to make their own decisions and get the necessary support to live equally with others. Shifting the discussion within the Convention to non-discrimination and equality further demonstrates the rejection of the medical model.<sup>323</sup>

The social model was an underpinning frame of reference throughout the AHC meetings. Participants drew attention to the distinction between "experiences of impairment and experiences of disability" during the AHC's second session.<sup>324</sup> During the third session, India, Jordan, and Yemen proposed the preference for the social model over the medical model.<sup>325</sup> In the seventh session, Costa Rica noted that society had left the medical model behind, favouring the social model.<sup>326</sup> It "emphasises that [PWDs] are prevented from reaching their full potential, not because of their impairment, but because of legal, attitudinal, architectural, communications and other discriminatory barriers".<sup>327</sup> Finally, during the eighth session, China proposed a passage for the Preamble of the Convention:

"Recognising an evolving concept of disability where disability is a state of participation restriction result[ing] from [the] interaction

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<sup>322</sup> AHC (n142).

<sup>323</sup> Degener (n320), 49.

<sup>324</sup> Ad Hoc Committee established by UNGA Res 56/158 'Report of the Ad Hoc Committee Promotion of the Rights and Dignity of Persons with Disabilities' Second Session (UN, 3 July 2003) A/58/118 & Corr 1, Annex II.

<sup>325</sup> Landmine Survivors Network, 'UN Convention on the Human Rights of People with Disabilities: Ad Hoc Committee Third Session - Daily Summaries' (United Nations, 24 May 2004), <<https://www.un.org/esa/socdev/enable/rights/ahc3sum24may.htm>> (accessed 14 June 2021).

<sup>326</sup> Rehabilitation International (n13).

<sup>327</sup> Ibid.

between an individual with impairments and environmental barriers."<sup>328</sup>

This implied reference to the social model was also missing from the final version of the Convention. The CRPD lacks an overt reference to the social model. However, it laces subtle references throughout, as noted in section 1.3, concerning society and the definition of disability.

The Convention represents a fundamental paradigm shift in how we conceptualise disability nationally and internationally.<sup>329</sup> Melish notes that it marks a transition away from a medical or social welfare model based on “sorting and separating persons with disabilities onto parallel tracks or exclusive living spaces” toward a social or human rights model that “focuses on capability and takes inclusion, individual dignity, personal autonomy and social solidarity as the principal points of departure.”<sup>330</sup> Further, the “disability problematic” ceases to be how to “provide for those deemed unable to integrate into mainstream society, but rather how to make society accessible to all persons, on an equal, non-separate basis.”<sup>331</sup> States must “rethink the underlying assumptions [of] their policies and practices”.<sup>332</sup> It refocuses the aim onto the social barriers barring PWDs from full participation and inclusion, rather than resigning persons with disabilities to institutionalised living arrangements, segregated education, sheltered employment and qualified income support”.<sup>333</sup>

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<sup>328</sup> Ad Hoc Committee established by UNGA Res 56/158 ‘Proposed Modifications by Governments submitted to the Eighth Session of the Ad Hoc Committee: Preamble’ (UN, 23 August 2006) <<https://www.un.org/esa/socdev/enable/rights/ahc8gpcapreamble.htm>> (accessed 25 August 2021).

<sup>329</sup> Melish (n22), 8.

<sup>330</sup> Ibid.

<sup>331</sup> Ibid.

<sup>332</sup> Ibid.

<sup>333</sup> Ibid.

## 1.5 Conclusion

This chapter demonstrates the gradual shift towards the modern human rights framework and highlights where disability fits within that development. The transition, which Mégret refers to as the “pluralisation of human rights”,<sup>334</sup> extends human rights to consider the “specific experience” of PWDs.<sup>335</sup> Within the context of the overall thesis, it highlights the transition away from ignorance of PWDs within the international human rights context towards active inclusion of PWDs in human rights documents. The UDHR began the rights discourse with broad generalisations, and the CRPD concludes a seventy-year-long march towards a human rights document specifically for PWDs.

Section 1.2 provides the crucial pre-AHC context for disability rights. Disabilities were shoehorned into the existing rights structure with little practical consideration for the PWD experience. Over the 20th Century, the UN created several documents to promote PWD rights, each moving the boundary slightly further and increasing the scope of the movement. However, these documents maintained an archaic language and discriminatory policies, limiting their impact. Viewed holistically, this provides the impetus for establishing the AHC and drafting the CRPD.

Section 1.3 discusses the actions of the AHC through the CRPD writing phases. Framed through the ‘Five Ws’ (and the additional *how*), it highlights aspects of the drafting process which differ from other treaties. These differences consider the prior failings

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<sup>334</sup> Frédéric Mégret, ‘The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights?’ (2008) 30 *Human Rights Quarterly* 494, 495.

<sup>335</sup> *Ibid*, 494.

of the human rights framework and show the steps the community took to avoid such mistakes. PWDs actively engaged in the AHC, with physical and interactional inclusion a vital consideration when establishing the AHC. Broderick suggests that this demonstrates that the CRPD represents the “first binding normative framework that seeks to ensure the promotion and protection of the human rights of [PWDs] on an equal basis with others”.<sup>336</sup>

Finally, section 1.4 highlights several features of this “dawn of a new era”, heralded by the UN, in which PWDs “no longer have to endure...discriminatory practices and attitudes”.<sup>337</sup> It contextualises some imperative features of post-CRPD rights for PWDs, explaining the implications of creating the CRPD and outlining important considerations for future debate. This chapter sets the scene for the disability rights conversation, paving the way for subsequent chapters to debate models, rights, and interpretation. In the broader narrative of this thesis, it works in tandem with the next chapter to establish the foundations of the answers to the research questions. Whilst Chapter One highlights the important legal considerations of modelling disability in human rights discourse. Chapter Two will outline the methodological foundations that the thesis will use, both to critique current models of disability and to help establish an identity approach to disability.

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<sup>336</sup> Broderick (n16), 67.

<sup>337</sup> UN Secretary-General, ‘Secretary General Hails Adoption of Landmark Convention on Rights of People with Disabilities’ (UN, 13 December 2006) <<https://www.un.org/press/en/2006/sgsm10797.doc.htm>> (accessed 1 June 2021).

## Two: Queering Disability

“What follows is a kind of anti-encyclopaedia entry: queer theory is not the theory of anything in particular, and [it] has no precise bibliographic shape. We can say that queer commentary has been animated by a sense of belonging to a discourse world that only partly exists”.<sup>338</sup>

### 2.1 Introduction

Chapter One contextualised the international nature of disability law. However, the CRPD still requires interpretation, and continuing discussions of conceptualisations of disability within human rights shape the narrative of disability. Current discourse is eclectic and confused, with myriad voices offering different perspectives on how best to steer this ship. This seems a hypocritical assessment, given that this thesis attempts to provide yet another voice, taking a radically social constructivist approach to the emergence of disability as a social category, using a postmodernist and post-structuralist grounding to develop the idea of disability as a social element of an individual’s identity. However, this is not evidence of too many cooks spoiling the broth. Instead, international human rights law and disability studies is in desperate need of an understanding of what these perspectives can offer, both in unison and in opposition.

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<sup>338</sup> Lauren Berlant & Michael Warner, ‘What Does Queer Theory Teach Us about X?’ (1995) 110(3) *PMLA* 343, 344.

Despite the prospects offered by the CRPD, it has not been a miraculous saviour of PWD rights. Broderick and Ferri note that “linguistic stereotyping and the use of negative terms relating to disability have long been a focus of scholarly attention and criticism”,<sup>339</sup> and the official French text of the CRPD retains the term “handicap” through “*personnes handicapées*”.<sup>340</sup> Clearly, more needs to be done to shift the conversation and promote an inclusive interpretation of the CRPD. The intention of this thesis, therefore, is to consider the best approach to interpret “disability” within a human rights context, and then how said interpretation impacts the provision of rights within the CRPD.

To this end, this chapter will begin a double-feature of theory. It will present the work of Tom Shakespeare, a vitally important voice in the disability studies sphere. However, as Shakespeare is a critical realist (whereas this thesis maintains a social constructivist perspective), this chapter will proceed to deviate from Shakespeare’s work. By utilising theorists such as Foucault and Butler, this thesis shall attempt to queer Shakespeare’s interaction approach, asking what the outcome would be from framing disability as interaction squarely within a queer and crip lens. Chapter Two shall outline the queer elements, and Chapter Three shall consider the perspectives on fettering queer. In distancing himself from cultural disability studies, Shakespeare questions the use of ‘queer’ for disability. He argues that “while activists can self-identify in whatever way they choose, it is harder to see how a queer theory perspective will illuminate medicine or social policy”.<sup>341</sup> This appears to be an academic challenge;

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<sup>339</sup> Andrea Broderick & Delia Ferri, *International and European Disability Law and Policy* (Cambridge UP 2019), 5.

<sup>340</sup> Mamoud Zani, ‘La Convention d I’O.N.U relative aux droits des personnes handicapées’ (2008) 3 *Revue de droit international et de droit compare* 551.

<sup>341</sup> Tom Shakespeare, *Disability Rights and Wrongs Revisited* (2<sup>nd</sup> edn, Routledge 2014), 49.



Shakespeare is almost theoretically goading cultural disability scholarship to prove him wrong. This chapter seeks to do just that.

## **2.2 Shakespeare's Rights and Wrongs**

In his work *Disability Rights and Wrongs* and *Disability Rights and Wrongs Revisited*, Shakespeare sought to create a shockwave within disability studies scholarship. Utilising a critical realist approach, he views disability as an interaction between an impaired individual and a disabling society.<sup>342</sup> He assumes that there is a truth and real object separate from a social reality and independent of the observer. In turn, he accuses cultural disability studies fail to consider the practical relevance of law on PWDs, risking ossification “into a fascination with theory for its own sake”.<sup>343</sup> Shakespeare's interaction approach shows great promise yet does not go far enough. Likewise, Shakespeare's criticisms of post-structuralism and cultural disability studies are disingenuous and lack sufficient grounding.<sup>344</sup> The identity approach to disability advocated within the rest of this thesis is a queering of Shakespeare's interaction approach, one which utilises a postmodernist and post-structuralist approach through queer theory.

### **2.2.1 Understanding Shakespeare**

A large portion of Shakespeare's research relies on a rejection of a strong British social model of disability. Commentary and criticism of said model of disability will occur in Chapter Four. However, as a brief overview to help frame this discussion, the social

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<sup>342</sup> Tom Shakespeare, *Disability Rights and Wrongs* (Routledge 2006), 55.

<sup>343</sup> Shakespeare (n341), 71.

<sup>344</sup> See Dan Goodley, 'Disability Rights and Wrongs Revisited' (2014) 29(4) *Disability & Society* 659.

model identifies societal barriers as the disabling factor for people with impairments. These barriers can be environmental, attitudinal or legislative.<sup>345</sup> Traditionally attributed to the “Big Idea” of the UPIAS, they argue that:

“In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group.”<sup>346</sup>

The UPIAS, therefore, acknowledge a difference between an impairment (the physical, biological manifestation of difference) and disability (the social reaction to the person with an impairment). This concept grew into the social model, a dominant paradigm of disability research. The social model exists in direct opposition to individual and medical models, which “perceive and classify disability in terms of a meta-narrative of deviance, lack, and tragedy, and assume it to be logically separate from and inferior to ‘normalcy’”.<sup>347</sup> If the social model keeps impairment and disability as distinctly separate, then a medical model maintains these concepts as one and the same.

Corker and Shakespeare argue that these characteristics and dichotomies fit “the kinds of epistemologies or knowledge systems generated by modernism”.<sup>348</sup> As will be noted further below, Shakespeare is critical of the social model. However, he still maintains distrust for medical model. The frequent implication of anti-individual model debates is that “diagnostic labels cannot be trusted, because they are changeable:

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<sup>345</sup> Broderick & Ferri (n339), 20.

<sup>346</sup> Union of Physically Impaired Against Segregation, *Fundamental Principles of Disability* (The Disability Alliance 1975), 3.

<sup>347</sup> Marian Corker & Tom Shakespeare, ‘Mapping the Terrain’ in Marian Corker & Tom Shakespeare (eds), *Disability/Postmodernity: Embodying Disability Theory* (Continuum 2002), 2.

<sup>348</sup> Ibid.

different professionals do not agree about a particular individual's diagnosis, and diagnoses change with fashions".<sup>349</sup> Areheart argues that impairments are understood as "the physical trait associated with disabilities, seen little more than diagnoses".<sup>350</sup> In commenting on the development of genetics as a source of human advancement and the impact on PWDs, Kerr and Shakespeare suggest that "in order to achieve legitimacy, the new biology had to develop the alibi of health and social improvement as the potential benefits of genetic research".<sup>351</sup> Medicine is in a position of scientific power, endorsed by society as the source of evidence-based truth on health. The "narrative of improving health is mainly on the basis of removing disabled people from the world",<sup>352</sup> as they deviate from traditional able-bodied standards on health. Kerr and Shakespeare note that "scientists are often ignorant about the experiences and views of disabled people",<sup>353</sup> because the bias towards disability as an illness to cure leaves disabled voices out of the narrative. Nevertheless, healthcare is not an inherently evil villain, and "it would be wrong to single out scientists as apart from culture".<sup>354</sup> Medicine provides considerable support for those who need it, and Shakespeare intends on finding this healthy balance.

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<sup>349</sup> Shakespeare (n341), 58.

<sup>350</sup> Bradley Areheart, 'Disability Trouble' (2011) 29(2) *Yale Law & Policy Review* 347, 362.

<sup>351</sup> Anne Kerr & Tom Shakespeare, *Genetic Politics: From Eugenics to Genome* (New Clarion Press 2002), 104.

<sup>352</sup> *Ibid*, 105.

<sup>353</sup> *Ibid*.

<sup>354</sup> *Ibid*.

Many scholars argue that the CRPD only exists courtesy of the social model,<sup>355</sup> whilst others advocate for its abandonment.<sup>356</sup> As someone firmly in the latter camp, Shakespeare argues first and foremost that the social model fails to undo the damage caused by medical models:

“Perhaps only the most powerful counter-claim could have effectively dislodged the deep-seated idea that disabled people are defined by their incapacity. So from one extreme – the cultural assumption that disability is equated with dependency, invalidity, and tragedy – the disability movement swung to another – the political demand that disability be defined entirely in terms of social oppression, social relations, and social barriers”.<sup>357</sup>

Finding a viable comparison to feminism, Shakespeare argues that the social model creates a “conceptual distinction between disability and impairment, similar to the feminist distinction between gender and sex”.<sup>358</sup> He notes the issues that face marginalised groups within a modernist society; modernism is “complicit in the creation of social inequalities and systems of privileging and power based on the axes of disability, gender, race, class, sexuality, and age”.<sup>359</sup> However, whilst feminism has developed post-modern perspectives to deconstruct labels and structural inequalities, disability studies has not done the same; “whereas theorists of race, gender, and sexuality have embraced and explored the contributions of postmodernism, disability

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<sup>355</sup> For example, Weller argues that the CRPD follows the social model. See Penelope Weller, *New Law and Ethics in Mental Health Advance Directives: The Convention on the Rights of Persons with Disabilities and the Right to Choose* (Taylor & Francis 2012).

<sup>356</sup> For example, see Tom Shakespeare & Nicholas Watson, ‘The Social Model of Disability: An Outdated Ideology?’ (2001) 2 *Research in Social Science and Disability* 9; Shaun Grech, ‘Disability, Poverty, and Development: Critical Reflections on the Majority World Debate’ (2009) 24(6) *Disability & Society* 771.

<sup>357</sup> Shakespeare (n342), 31.

<sup>358</sup> Corker & Shakespeare (n347), 3.

<sup>359</sup> *Ibid*, 2.

theorists have proved reluctant to take on board new perspectives”.<sup>360</sup> He laments that the social model “still seems to hold sway. Indeed the crude dichotomies of the British Social Model also strongly influenced international thinking on disability” such as in the CRPD.<sup>361</sup>

In response, Shakespeare suggests that “the global experience of [PWDs] is too complex to be rendered within one unitary model or set of ideas”.<sup>362</sup> Instead of putting forward his own model, he takes pieces from several perspectives to blend into his own approach. With this, he hopes to avoid “the danger of trying to fit the complexities and the nuances of life into an over-rigid structure or system”.<sup>363</sup> The resulting articulation understands disability as a complex interaction between the individual and society. He suggests that models of disability cannot eliminate the “problems associated with disability” entirely by “any imaginable form of social arrangements”.<sup>364</sup> Instead, the “priority for a progressive disability politics is to engage with impairment, not ignore it”.<sup>365</sup> Therefore, Shakespeare argues that the social model unnecessarily limits itself through contextual essentialism, reducing disability to external barriers and oppression.<sup>366</sup> PWDs experience limitations “as an interplay of impairment with particular contexts and environments”.<sup>367</sup> This perspective does not indicate that impairment takes centre stage or the primary focus. Shakespeare is a non-reductionist, suggesting that people are disabled both by society and by their bodies. An analysis

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<sup>360</sup> Ibid, 13.

<sup>361</sup> Shakespeare (n341), 3.

<sup>362</sup> Corker & Shakespeare (n347), 15.

<sup>363</sup> Shakespeare (n341), 54.

<sup>364</sup> Ibid, 56.

<sup>365</sup> Ibid.

<sup>366</sup> Ibid.

<sup>367</sup> Ibid.

of disability should make considerations for both. Impairment is “a necessary but not sufficient factor in the complex interplay of issues which result in disability”.<sup>368</sup>

Shakespeare further argues that a disability model should focus on the intrinsic and extrinsic factors which comprise the person's experience rather than on the definition of disability from the perspective of deficit or structural disadvantage. An interaction between two parties relies on both intrinsic and extrinsic factors. Within a disability context, intrinsic factors include the nature and severity of the impairment, the person's attitudes to the impairment, individual qualities and capabilities of the person, and their overall identity and personality. In comparison, extrinsic factors include the attitudes of others, any barriers placed by society, any enabling features of that society, and the economic, social, and cultural factors evident within that society as they relate to disability.

Shakespeare uses critical realism as his foundational basis for interaction. He argues that “while different cultures have different views or beliefs or attitudes to disability, impairment has always existed and has its experiential reality”.<sup>369</sup> Perspectives on disability will differ between groups, but there is an aspect of disability which transcends society and exists independent of any social impact. As a concept, disability persists worldwide, and society will always have perspectives on responding to the myriad statuses of being. Shakespeare's critical realist perspective distinguishes between ontology and epistemology, arguing that objects exist independent of social knowledge – “labels describe, rather than constitute, disease”.<sup>370</sup>

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<sup>368</sup> Ibid.

<sup>369</sup> Ibid, 54.

<sup>370</sup> Shakespeare (n342), 54.

In defining what critical realism means to disability, Shakespeare cites Williams' perspective of disability as "an emergent property, located, temporally speaking, in terms of the interplay between the biological reality of the physiological impairment, structural conditioning (i.e. enablements/constraints) and socio-cultural interaction".<sup>371</sup> Meanwhile, Danermark and Gellerstedt attempt to balance multiple points of view at once:

"...injustices to disabled people can be understood neither as generated by solely cultural mechanisms (cultural reductionism) nor by socio-economic mechanisms (economic reductionism) nor by biological mechanisms (biological reductionism). In sum, only by taking different levels, mechanisms and contexts into account, can disability as a phenomenon be analytically approached".<sup>372</sup>

Shakespeare takes this as a way to avoid the arguments between the medical model and the social model, demanding an approach that "gives weight to different causal levels in the complex disability experience".<sup>373</sup> Impairment has always existed regardless of the social labels attributed to them via diagnosis.

Despite co-editing a collection on disability and postmodernity,<sup>374</sup> Shakespeare argues that "the cultural version of disability studies, which also espouses political commitment, has become fatally contaminated by post-structuralist and postmodernist theory, and thus failed to provide helpful analysis or evidence".<sup>375</sup>

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<sup>371</sup> Simon J Williams, 'Is Anybody There? Critical Realism, Chronic Illness, and the Disability Debate' (1999) 21(6) *Sociology of Health & Illness* 797, 810.

<sup>372</sup> Berth Danermark & Lotta Coniavitis Gellerstedt, 'Social Justice: Redistribution and Recognition – A Non-Reductionist Perspective on Disability' (2004) 19(4) *Disability & Society* 339, 350.

<sup>373</sup> Shakespeare (n342), 55.

<sup>374</sup> Corker & Shakespeare (n347).

<sup>375</sup> Shakespeare (n341), 1.

Corker and Shakespeare understand postmodernity as an “attempt to label contemporary society, and suggests that we are living through the transition from a modern to a postmodern age”.<sup>376</sup> In turn, post-structuralism argues that “subjects are not the autonomous creators of themselves or their social worlds. Rather, subjects are embedded in a complex network of social relations. These relations in turn determine which subjects can appear, where, and in what capacity”.<sup>377</sup> In his view, disability studies has gone down an unsatisfactory path. Between the 2002 collection and his own works, Shakespeare has seen what postmodernism and post-structuralism have to offer and is underwhelmed.

Shakespeare argues that we need to reconceptualise disability studies and chart a new course. Whilst there are similarities between disability studies and feminism, an over-reliance on post-structuralism does not work for the former as it does for the latter. He argues that “gender, race, and sexuality have minimal biological underpinning. However, disability always has a biological dimension that usually entails limitations or incapacity, and sometimes frailty and pain”.<sup>378</sup> Further, “these aspects of disability can be modified or mitigated by environmental change or social interventions, but often cannot be entirely removed. They are not just a matter of culture or language”.<sup>379</sup> The balance Shakespeare attempts between biology and society, between impairment and disability (as noted earlier in this section) means that he rejects the application of post-structuralism onto disability. Shakespeare argues that gender, race, and sexuality are not biological, but rather they are social; whereas, disability always carries a biological component. This explains why he finds cultural disability studies “over-

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<sup>376</sup> Corker & Shakespeare (n347), 3.

<sup>377</sup> Ibid.

<sup>378</sup> Shakespeare (n341), 49.

<sup>379</sup> Ibid.



theoretical [without offering] much in the way of practical help in understanding the lives of [PWDs], let alone changing them for the better".<sup>380</sup> From a critical realist perspective, both queer and crip provide little value to the disability studies discourse.

The question arises, therefore, whether queer and critical realism could function in tandem. Queer is reductionist by nature, understanding that the social world has an ontological connection to the natural world but that there are 'true' social elements which are purely socially generated and therefore do not exist naturally. Queer seeks to look at the mechanisms which create/cause those social structures to understand how they exist, why they exist, and why specific parameters define them. Queer also seeks to reject these structures, arguing that the parameters inherently impact development and inclusion. The problem becomes that society relies on structures to function. Structures exist everywhere and are necessary for everyday life. As noted in Chapter Two, queer must remain practical and functional. It has to 'queer' the system without rendering it defunct or void. One can accept that there is a source for the system which cannot be rejected and that society must respond in some form. Nevertheless, queer can keep society in check by balancing its responses against a queer goal, similar to Shakespeare's use of critical realism.

### **2.2.2 Critiquing Shakespeare**

In 2007, Sheldon, Traustasdóttir, Beresford, Boxall, and Oliver – all dominant names in the disability studies sphere – penned a review symposium for Shakespeare's *Disability Rights and Wrongs*.<sup>381</sup> Sheldon begins by suggesting that Shakespeare's book

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<sup>380</sup> Ibid, 3.

<sup>381</sup> Alison Sheldon et al, 'Disability Rights and Wrongs?' (2007) 22(2) *Disability & Society* 209.

“appears to launch an attack on British disability studies and the disabled people’s movement”, and that the “instinctual response will no doubt be to launch a defensive counter-attack, whilst the rest of the world looks on in bemusement”.<sup>382</sup> This attempt at humour is purposely and moderately flippant, as Shakespeare is known to be “provocative and entertaining” in his own work.<sup>383</sup> It also suggests a collective understanding that the correct approach is to consider Shakespeare’s viewpoints and provide a measured response. After all, becoming overly-defensive in commenting on Shakespeare’s work would “distract attention away from what should be the real point of disability studies – defending not oneself and one’s peers, but the disadvantaged of the world”.<sup>384</sup> Across the rest of the symposium, the authors each provide their own interpretations of Shakespeare’s book, which range from cautiously optimistic, to frustratedly despondent, to openly chagrined. Nevertheless, they all provide points of critique, which shall be considered below.

A key issue present in Shakespeare’s work is his use of theory. In both books, he looks at various theoretical perspectives on the source of disability, before resiling himself to use critical realism to justify his interactionist approach. The problem is not merely that he chooses critical realism over another theoretical perspective, but that he seems to do so without sufficient reasoning. As Sheldon notes:

“In *Disability Rights and Wrongs*, we are often told that British disability studies is too reliant on ideology. Whilst the term ‘ideology’ is not clarified, a pejorative view is clearly taken. The suggestion is

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<sup>382</sup> Ibid.

<sup>383</sup> Goodley (n344), 659.

<sup>384</sup> Sheldon et al (n381), 209.

that anything ‘ideological’ is unreasonable and unfounded and cannot therefore be scrutinised in a mature and critical manner”.<sup>385</sup>

Shakespeare argues that the source of “current fruitless and frustrating debate[s]” on disability and the social model is the overreliance of an “increasingly ideological definition of disability”.<sup>386</sup> Shakespeare is interested in the tangible application to PWDs now, what gets PWDs their necessary accommodations, adjustments, and medical interventions. Therefore, he believes that disability scholarship is becoming a rigid and unimaginative structure of “crude dichotomies” which are “ultimately misleading”.<sup>387</sup> Current discourses do not serve their purpose and leave out the practical application of debate. Shakespeare is partially correct here, that decades of debate on the social model of disability have not resulted in utopia. PWDs continue to face oppression and marginalisation. However, he underestimates the value of postmodern and post-structural theory and alternative viewpoints to the discussion. The rest of this chapter will provide said alternative theories, in the hopes of patching these gaps in an otherwise reasonable argument.

The result of highlighting his displeasure in “the disability rights ideology” in the first book is a lack of explanation of what the ideology *is*. McLellan defines ideology as “someone else’s thought, seldom our own,” suggesting that labelling something as ideological is to instinctively reject the notion “lest the foundations of our most cherished conceptions turn out to be composed of more shifting sand than we would like”.<sup>388</sup> Sheldon uses this idea to argue that Shakespeare fails to properly balance his views and provide sufficient analytical depth – “it would have been more helpful to give

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<sup>385</sup> Ibid, 212.

<sup>386</sup> Shakespeare (n342), 13.

<sup>387</sup> Ibid.

<sup>388</sup> David McLellan, *Ideology* (2<sup>nd</sup> edn, Open University Press 1995), 1.

proper consideration to the actual arguments that are being made”.<sup>389</sup> It becomes difficult to critique Shakespeare’s logic if he does not provide it. In turn, it is suggested that Shakespeare conflates the social model with a legalistic rights model. Though the social model “embraces the notion of rights”,<sup>390</sup> Finkelstein argues “it is not a rights model”.<sup>391</sup> Instead, it was a “political tool”,<sup>392</sup> to help PWDs “who could be angry at discriminatory societal arrangements instead of being ashamed of their own shortcomings”.<sup>393</sup> By treating ideology as abstraction, it is argued by Sheldon that Shakespeare misses the point of the social model. This argument is unconvincing, yet speaks to some truth.

Importantly, Shakespeare does not appear to rectify his ideological issue, as he remains rather pejorative and conflatory to ideology in his later works. Goodley reviewed Shakespeare’s second bite of the apple in *Disability Rights and Wrongs Revisited*. He notes that Shakespeare mentions several cultural approaches, yet the criticism provided was “too simplistic”.<sup>394</sup> Almost echoing Sheldon’s concerns about Shakespeare bludgeoning his way through theory he sees as ineffective, Goodley argues that Shakespeare accuses “materialist social modelists of holding a Stalinist line while arguing that cultural disability studies are interested only in discourse rather than the real stuff of everyday life”.<sup>395</sup> These are quite harsh and polarising comments to make about entire bodies of scholarship. As such, Shakespeare displays “an oddly ambivalent relationship with disability theory and the act of theorising”, leading to

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<sup>389</sup> Sheldon et al (n381), 212.

<sup>390</sup> Ibid, 209.

<sup>391</sup> Vic Finkelstein, ‘The Social Model of Disability Repossessed’ (2002) *The Coalition*, February 10-16.

<sup>392</sup> Sheldon et al (n381), 215.

<sup>393</sup> Ibid.

<sup>394</sup> Goodley (n344), 659.

<sup>395</sup> Ibid, 659-660.

disingenuous anti-intellectualism.<sup>396</sup> His idea that post-structuralists like Butler and McRuer fail to contribute anything helpful to the discussion loses strength and ceases to be a useful contribution itself: “Come on, he argues in Chapter Two, there can never be universal architectural design that will include all disabled people, get real!”.<sup>397</sup> The mere fact that there cannot be a one-size-fits-all approach to modelling disability, should not inherently preclude cultural disability studies from throwing their hats into the ring and contributing something novel and new. Goodley proceeds to advocate for utopian ideals, a wistful chastisement of Shakespeare for ignoring that many theorists and activists enter this space to advocate for an idealised future. This is true, disability studies has thrived on advocacy and political engagement from people who want real idyllic change. A similar sentiment can be applied to queer, which will be discussed further in later sections of this chapter. In essence, Shakespeare is selling “ideology” short, unduly casting it aside as impractical, when in reality a post-structuralist queering of disability may provide unique commentary and a new path down which to tread.

A second problem arises in Shakespeare’s conceptualisation of the location of disability. Boxall acknowledges that a defining feature of the social model is “the separation of disability, which is viewed as socially created, from impairment which is taken as located within the individual”.<sup>398</sup> However, Shakespeare argues that the distinction between the two is unclear – “impairment is always already social, while disability is almost always intertwined with impairment effects”.<sup>399</sup> He argues that the social model perspective is unduly restrictive, and a more pragmatic approach would

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<sup>396</sup> Ibid, 660.

<sup>397</sup> Ibid.

<sup>398</sup> Sheldon et al (n381), 225.

<sup>399</sup> Shakespeare (n342), 35.

understand that PWDs experience both pain and discrimination simultaneously. Boxall takes issue with this assessment within the context of learning difficulties. A considerable portion of individuals who experience learning difficulties demonstrate no bio-medical cause.<sup>400</sup> As such, Boxall argues that “it is considered unlikely that social factors alone have caused the difficulties they experience; for others, their learning difficulties will be attributed to social, rather than biological causes”.<sup>401</sup>

This complication around impairment versus perceived impairment,<sup>402</sup> caused by a disagreement on the source, challenges Shakespeare’s view on bio-medical reference for impairment, since “whether or not impairment is biologically based or socially produced, disability...is imposed ‘on top of’ people with learning difficulties’ perceived impairment”.<sup>403</sup> Shakespeare is correct that there is an inherent physicality to a notable number of disabilities, but becoming reliant on diagnoses to indicate all impairments to treat is a dangerous path to take. Shakespeare does not go so far as to endorse a medical model approach, but as noted in the previous section, he does argue that “gender, race, and sexuality have minimal biological underpinning” as a justification for treating disability differently.<sup>404</sup> Attempting to rationalise a distinction between disability and these “usual suspects in cultural studies”,<sup>405</sup> seems to fall back on medicine as the evidential truth.

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<sup>400</sup> See Eric Emerson et al, *Learning Disabilities: The Fundamental Facts* (Foundation for People with Learning Disabilities 2001).

<sup>401</sup> Sheldon et al (n381), 225.

<sup>402</sup> See Colin Barnes, ‘The Social Model of Disability: A Sociological Phenomenon Ignored by Sociologists?’ in Tom Shakespeare (ed), *The Disability Reader: Social Sciences Perspectives* (Cassell 1998), 78.

<sup>403</sup> Sheldon et al (n381), 225.

<sup>404</sup> Shakespeare (n341), 49.

<sup>405</sup> Lennard Davis, ‘Disability Rights and Wrongs Revisited’ (2015) 17(1) *Scandinavian Journal of Disability Research* 95, 96.

This focus on social identity, ironically, leads to Shakespeare militantly rejecting the notion of blending social and biological for certain categories but not others. Despite his argument that disability maintains biological elements, it would be incorrect to state that race, gender, and sexuality are purely social. To say there is minimal foundation of these concepts in the physical reality of humanity is unnecessarily reductive. All four of these concepts are fluid social constructions depending on the internal perspectives of those who ascribe identity. There is an overlap of biological, physical reality with construction of social categories. His argument that deconstructivists reduce impairment to diagnosis, conflating the two, misses the point that both concepts are grounded in social construction. Our understanding of a diagnosis is socially and culturally contingent, and society can only ever understand physical, mental, or psychosocial conditions through the lenses it has created itself. As will be noted in Chapter Three, the overreliance of the term “impairment” by the social model allows the medical model in through the back door, and Shakespeare is guilty of doing the same here. It also demonstrates the lack of consideration to the distinction between lack and loss: PWDs will experience their disability depending on whether they were born with it or whether they developed it over time. Both the social model and Shakespeare’s critique do not provide sufficient answers to this issue.

This debate extends further to what disability means for PWDs. Shakespeare uses the term to describe “the whole interplay of different factors which make up the experience of people with impairments”,<sup>406</sup> which Sheldon argues makes “explanatory critiques of disabled people’s maltreatment hard to formulate, and thus undermines any

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<sup>406</sup> Shakespeare (n342), 58.

attempts at social change”.<sup>407</sup> Sheldon seems to believe that Shakespeare’s definition is far too loose to be practical, and that a return to a stricter understanding of impairment and disability is more appropriate. These debates have arguably existed since the development of the UPIAS’s Big Idea; Beresford notes “the tensions that have emerged between on the one hand disability studies and its associated academics and researchers and, on the other, disability politics and activists”.<sup>408</sup> The notion here is that parties with vested interests in this discourse all approach disability with different perspectives. Interestingly, a post-structural queering of disability would agree with Shakespeare in expanding the understanding of disability to cover a variety of sources. In particular, Butler’s theories on performativity and citationality (as discussed at section 2.3 below), which McRuer develops within disability studies into “ability trouble” (as discussed at section 2.4 below),<sup>409</sup> see the socialisation of disability as a symptom of an expansive collection of referential material in society. A social world manifests an increasing number of points of comparison for PWDs, entrenching their perspective on their disability further. Where this deviates from Shakespeare’s logic is the location and source of disability, with Shakespeare arguing that an impaired person will always exist outside of a society, while Butler and McRuer would argue that society has created disability before the subject is even aware of the impairment.

Traustasdóttir agrees with Shakespeare on “the dangers of polarisation”,<sup>410</sup> as “UK disability studies, and the social model of disability in particular, has been criticised

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<sup>407</sup> Sheldon et al (n381), 210.

<sup>408</sup> Ibid, 217.

<sup>409</sup> Robert McRuer, ‘Compulsory Able-Bodiedness and Queer/Disabled Existence’ in Donald E. Hall et al (eds), *The Routledge Queer Studies Reader* (Routledge 2013), 492.

<sup>410</sup> Sheldon et al (n381), 214.



for not including certain groups of people such as people with learning difficulties...and mental health issues”.<sup>411</sup> Shakespeare despairs for the ‘us versus them’ mentality, as the ‘us’ in the narrative is not a homogenous collective all seeking the same thing. The experience of PWDs consists of factors both intrinsic to the individual and extrinsic from wider context.<sup>412</sup> Shakespeare is correct in this instance; however, given his reliance on critical realism, his theoretical foundations unduly restrict him. The factors that impact PWDs are limited to what can be labelled and identified as tangible or real. As will be explained in the later sections of this chapter, a post-structuralist queer perspective can deconstruct these labels further, highlighting the myriad of ways in which PWDs are forced to perpetuate specific categories of restriction through performance of socially-constructed categories and identities.

Along a similar vein, Shakespeare takes issue with a forced disability identity and shared community:

“It is paradoxical that the identification of people with impairment as members of a disabled collective is generally viewed positively, whereas the ascription of group membership – in the form of labelling – is generally viewed negatively in the disability community”.<sup>413</sup>

In his second book, Shakespeare suggests that the majority of PWDs do not identify with a common “disability identity” under the banner of the social model.<sup>414</sup> As such, an attempt to “organise or analyse on the basis of impairments becomes redundant” if forced to view disability as a shared identity in the face of oppression.<sup>415</sup> He sees no

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<sup>411</sup> Ibid, 215.

<sup>412</sup> Ibid, 216.

<sup>413</sup> Shakespeare (n341), 95.

<sup>414</sup> Ibid, 97-99.

<sup>415</sup> Shakespeare (n342), 31.

value in forcing an identity label on a group that does not itself identify with it. Further, given the lack of homogeneity, it is impossible in his eyes for a communal disabled identity to organically develop. Shakespeare uses the Deaf community as an example of a rejection of a communal 'disability identity', as they see themselves as a linguistic minority instead.<sup>416</sup> This example achieves another purpose – highlighting a situation where the specific lived experiences of a community prevent other groups of people from empathising with their plight, and vice versa. After all, what overlap exists between Deaf people and psychiatric system survivors?

Nevertheless, this has not stopped PWDs from continuing to rally together in order to enact change. As explained in Chapter One, with the mantra of “nothing about us without us” (which seems to have shifted during the AHC to become “without us, nothing”), DPOs and NGOs banded together to create a custom human rights convention for PWDs. This is in spite of the fact that “there does not seem to be any consensus in relation to the social model of disability among mental health service users”.<sup>417</sup> As will be discussed in Chapter Six, mental health service users (also sometimes referred to as psychiatric system survivors) reject the label of disability on mental health. Whether the word “disability” is the correct name for the community is an entirely different debate from whether a community and shared identity could form.

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<sup>416</sup> Ibid, 75.

<sup>417</sup> Sheldon et al (n381), 221.

Further, others mental health service users have developed links and shared activities with DPOs and disability-based NGOs.<sup>418</sup> Additionally, the discourse around the CRPD, which same after the publication of the first book but before the second, demonstrates an acknowledgement of the myriad of different disabilities people experience and the varied restrictions to realisable engagement. For instance, Boxall notes the significant barriers that people face in participating in academic debate,<sup>419</sup> with Docherty et al providing examples of pictures and large print as necessary accessibility concessions for certain PWDs to be able to study the social model themselves.<sup>420</sup> Given that the social model was borne from political activism and subsequently shifted into academic discourse, individuals with lived experience have a stake in the development of said discourse. As noted in Chapter One, the AHC made multiple adjustments to ensure DPOs and NGOs were involved in the CRPD's development process. A collective identity around broad conceptions of disability ensured tangible and impactful inclusion.

Ultimately, Shakespeare's concerns read as distrust of identity politics, with entire chapters dedicated to debunking the application of identity to disability discourse.<sup>421</sup> There is a justification for wanting to avoid identity politics, given that it can "create conflicts between social groupings who have much to gain from forming alliances".<sup>422</sup> Davis agrees with Shakespeare that "life is not all about the panopticon; it is also about

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<sup>418</sup> For example, several participants in the AHC meetings were representatives of mental health-based NGOs. See further Ad Hoc Committee established by UNGA Res 56/158, 'List of Participants' (*United Nations*, 16-27 June 2003) <[https://www.un.org/esa/socdev/enable/rights/a\\_ac265\\_2003\\_inf\\_1.htm](https://www.un.org/esa/socdev/enable/rights/a_ac265_2003_inf_1.htm)> (accessed 11 April 2024).

<sup>419</sup> Kathy Boxall, Iain Carson, & Daniel Docherty, 'Room at the Academy? People with Learning Difficulties and Higher Education' (2004) 19(2) *Disability & Society* 99.

<sup>420</sup> Daniel Docherty et al, 'This is What We Think' in Dan Goodley & Geert Van Hove (eds), *Another Disability Studies Reader? People with Learning Difficulties and a Disabling World* (Garant 2005), 34.

<sup>421</sup> See Shakespeare (n342), 68-82; Shakespeare (n341), 92-110.

<sup>422</sup> Sheldon et al (n381), 210.

the pharmacy, personal assistants, protection and other positive things”.<sup>423</sup> This all relies on Shakespeare’s fundamental premise that there is meaning to be found emerging at the level of interaction between the self and society. As will be explained in subsequent sections, queer theory adopts a different approach to the location of things that carry social meanings; it does not seem possible for Shakespeare to agree with Derrida or Foucault, for example. However, there is sufficient overlap in the existence of the person as a subject and as a foundation for social development.

Finally, Shakespeare discusses the location of non-disabled people within the disability studies discourse,<sup>424</sup> suggesting that “allies, advocates, assistants and interpreters seem to lose their status as non-disabled people, enjoying the temporary privilege of membership to the disabled world”.<sup>425</sup> Boxall disagrees, citing “the power dynamics of such relationships and people with learning difficulties’ frequent lack of recourse to ‘higher authority’ when they disagree with those who support them”.<sup>426</sup> This is a key issue of queer legal theory – how to understand the structure of power dynamics without relying on unhelpful separation based on labels. Zanghellini notes the limitations of focusing on distinct categories or labels as justification for specific rights provisions; ‘it may be generally desirable that, wherever possible, rights should not be claimed – or granted – on the ground of membership to a group identified by a purported shared identity’.<sup>427</sup> Attempting to consolidate the construction of identity along some definite lines is a concerning and problematic endeavour, as it contributes

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<sup>423</sup> Davis (n405), 96.

<sup>424</sup> Shakespeare (n342), 187.

<sup>425</sup> Ibid, 194.

<sup>426</sup> Sheldon et al (n381), 228.

<sup>427</sup> Aleardo Zanghellini, ‘Queer, Antinormativity, Counter-normativity and Abjection’ (2009) 18 *Griffith Law Review* 1, 1.

to the promulgation of binary modes of thinking.<sup>428</sup> The remaining sections of this chapter shall explain how queer tries to retain its post-structural deconstructive perspective in the face of categories, and Chapter Four will demonstrate how an identity approach can hope to maintain fluidity whilst recognising the practical application of such labels.

Moreover, in Chapter Seven, there is a discussion of the outer boundaries of rights within the CRPD, and whether the convention affords those without disabilities with rights protections. There are examples of situations where non-disabled people receive protections under the CRPD, such as in *Bellini*, where a non-disabled caregiver has rights under Article 28(2)(c) to an adequate standard of living.<sup>429</sup> However, these situations are hyper-specific to nuanced situations, and Shakespeare has been accused multiple times of painting with too broad a brush.<sup>430</sup> The best approach to take is one that can navigate these nuanced situations, and a critical realist perspective cannot achieve this due to its inability to let go of seemingly entrenched bio-medical justifications to impairment.

As a postscript to this critical commentary, the authors of the symposium can be justifiably accused of pushing their criticism too far. Though Traustasdóttir welcomes Shakespeare's book as "an important contribution to the international forum on disability",<sup>431</sup> several of the symposium's comments still come across as bitter and vengeful. Sheldon suggests that readers of *Disability Rights and Wrongs* will find it "of

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<sup>428</sup> Aleardo Zanghellini, 'Lesbian and Gay Identity, the Closet and Laws on Procreation and Parenting' (2007) 16 *Griffith Law Review* 107, 111-114.

<sup>429</sup> *Bellini v. Italy* (2018) CRPD/C/27/D/51/2018.

<sup>430</sup> See Davis (n405), 96; Goodley (n344), 660.

<sup>431</sup> Sheldon et al (n381), 213.

no more use than the wheelchair depicted on the front cover”,<sup>432</sup> notably, the wheelchair on the front cover of *Disability Rights and Wrongs* is made entirely of stainless steel and has kitchen knives for handles. Oliver echoes this sentiment, arguing that Shakespeare “has taken some of the truths of disability studies and turned them into something I can hardly recognise. If that’s the best that an emergent disability studies can do, I’m glad I’ve retired”.<sup>433</sup> It is difficult to not perceive these comments as a departure from enthusiastic and constructive criticism, towards the jaded in-fighting that Sheldon attempts to allay with mild humour in her opening paragraph. Perhaps their intention is to use the knife handles of the wheelchair on the cover of *Disability Rights and Wrongs* to aid in this backstabbing.

It is important to understand how theory develops and progresses. Theory ebbs and flows, it progresses not in step with society, but ahead of it, leading us into increasingly progressive ages of understanding. Shakespeare argues that the strong social model was useful for a time, but disability studies must move on to greener pastures. This is the correct approach to take, and his attempts are admirable. The entirety of section 2.2 demonstrates what Shakespeare gets right, and what can be improved. However, if disability theory sits on a spectrum, and staunch believers in a strong social model sit at one end of the spectrum, Shakespeare does not sit at the other end. If the entrenched approach to disability is the disablement of impaired people by society, to swing the pendulum in the complete opposite direction is not to follow a critical realist approach. Instead, disability studies scholarship should push the boundaries further, dispense with the painful shackles of restrictive conceptualisations of disability, and strive for something more inclusive.

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<sup>432</sup> Ibid.

<sup>433</sup> Ibid, 234.

In summary, Shakespeare's interaction approach is an interesting and engaging perspective on the location and practicalities of disability. However, there are several shortcomings within his work. The rest of this chapter will provide an overview of queer theory and the accompanying ideas of crip theory. Together, these perspectives will help queer Shakespeare's work into a new identity approach to disability.

### **2.3 Defining Queer**

The previous section outlines and critiques Shakespeare's work on critical realism and an interactionist approach to disability. Throughout, there is mention of and comparison to queer theory. Queer attempts to understand the mechanisms of reality and how these mechanisms have developed structures within the socially-constructed world. It aims to achieve "desystematisation, anti-definition, and opposition to normalisation".<sup>434</sup> Queer's general position within critical discourse is in opposition to the norm. What currently exist as trite structures and definitions are, in fact, statements of 'normal' by a hegemonic, able-bodied, heteronormative society. As such, they alienate and restrict access and representation for those who do not conform to these restrictions.

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<sup>434</sup> C. Heike Schotten, 'To Exist Is to Resist: Palestine and the Question of Queer Theory' (2018) 47(3) *Journal of Palestine Studies* 13, 15.

### 2.3.1 Putting 'Queer' in Theory

An appropriate place to start on this journey of queer discovery, therefore, is to define queer. Decades of contextualising, restructuring and redefining can be attributed to the journey from 'queer' to current queer legal theory. The Oxford English Dictionary tracks the use of the term 'queer' as an adjective to the United States in 1914, where it was used as a derogatory colloquialism towards homosexuality or association with homosexual people.<sup>435</sup> In recent years, however, the term has seen a shift. Jagose notes that 'queer' has been 'used differently, sometimes as an umbrella term for a coalition of culturally marginal sexual self-identifications and at other times to describe a nascent theoretical model which has developed out of more traditional lesbian and gay studies'.<sup>436</sup> The LGBTQ+ community, having undergone characteristic shifts over the last half-Century, has utilised 'queer' as an umbrella term to their various identities, reclaiming the term alongside gay rights activism. At the same time, academics engaged in studies of 'gay' experiences, such as the impact of sexuality and gender within the AIDS crisis.<sup>437</sup> This blending of discourse within the spheres of academia and political activism has led to the corpus we now know as 'queer studies' or 'queer theory'.

Halperin attributes the creation of the term 'queer theory' to Teresa de Lauretis, coining the term to title a conference at the University of California, Santa Cruz in February 1990.<sup>438</sup> It was a cognisant blend of the 'scurrilous term' of 'queer' with the

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<sup>435</sup> Oxford English Dictionary, 'queer, adj.' (OED, December 2023) <[https://www.oed.com/dictionary/queer\\_adj1?tab=meaning\\_and\\_use#27444388](https://www.oed.com/dictionary/queer_adj1?tab=meaning_and_use#27444388)> (accessed 13 March 2024).

<sup>436</sup> Annamarie Jagose, *Queer Theory: An Introduction* (New York UP 1996), 1.

<sup>437</sup> OED (n435).

<sup>438</sup> David Halperin, 'The Normalization of Queer Theory' (2003) 45(2) *Journal of Homosexuality* 339, 339.



'academic holy word' of 'theory' to be deliberately disruptive.<sup>439</sup> After all, queer was a pejorative term used to label sexual deviants as abnormal and sick, and was only starting to be used by rights activists in an attempt to take ownership and ameliorate it. Using the term 'queer theory' also sought to consolidate several bodies of research under one umbrella. Sociological research into sex, gender, identity, and society existed in different locales, and were conflated to be equal, when in reality, 'lesbian and gay studies' took primacy. Further, experiences of homosexuality differed between lesbians and gay men, leading to discordance within the field. Accordingly, de Lauretis notes that the term 'queer theory' was chosen 'in the effort to avoid all of these fine distinctions in our discursive protocols, not to adhere to any one of the given terms, not to assume their ideological liabilities, but instead to both transgress and transcend them – or at the very least problematise them'.<sup>440</sup> The aspirations of queer became twofold,

...both to make theory queer (that is, to challenge the heterosexist underpinnings and assumptions of what conventionally passed for "theory" in academic circles) and to queer theory (to call attention to everything that is perverse about the project of theorising sexual desire and sexual pleasure).<sup>441</sup>

This two-stage approach attacked different levels of the social structure of things. Not only the normative assumptions made by society about categorising people, but also the very notion that seemingly trite concepts as sex, gender and sexuality were still up for debate.

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<sup>439</sup> Ibid, 339-340.

<sup>440</sup> Teresa de Lauretis, 'Queer Theory: Lesbian and Gay Sexualities, An Introduction' (1991) 3(2) *differences: A Journal of Feminist Cultural Studies* iii, v.

<sup>441</sup> Halperin (n438), 340.

Queer theory, as Halperin argues, was thus ‘a placeholder for a hypothetical knowledge–practice not yet in existence, but whose consummation was devoutly to be wished’.<sup>442</sup> The title existed before scholars had a chance to define its parameters; it is an excellent example of the cart coming before the horse. Queer theory became the poster child of emergent identity politics studies. It blazed a trail through existing feminist and gay studies, leaving behind questions such as Berlant and Warner’s ‘What Does Queer Theory Teach Us about X?’.<sup>443</sup> Two key texts, Sedgwick’s *Epistemology*<sup>444</sup> and Butler’s *Gender Trouble*<sup>445</sup> predate the development of queer as a theory, with scholars retroactively applying queer to the former and Butler publishing updated editions to incorporate queer for the latter. The result is a rich, postmodernist/post-structuralist oeuvre on the subject of identity and antinormativity, crafted over three decades, and formed of a variety of different voices.

### **2.3.2 Putting ‘Theory’ in Queer**

Queer is ‘a continuing moment, movement, motive – recurrent, eddying, troublant’.<sup>446</sup> It is constantly shifting, progressing along the road of deconstructing existing notions of identity. Sullivan acutely summarises the epistemological foundation of queer theory as such,

sexuality is not natural but...discursively constructed. Moreover, sexuality...is constructed, experienced, and understood in culturally

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<sup>442</sup> Ibid.

<sup>443</sup> Berlant & Warner (n338).

<sup>444</sup> Eve Kosofsky Sedgwick, *Epistemology of the Closet* (University of California Press 1990).

<sup>445</sup> Judith Butler, *Gender Trouble* (Routledge 1990).

<sup>446</sup> Eve Kosofsky Sedgwick, *Tendencies* (Duke University Press 1993), xii.

and historically specific ways. Thus, we could say there can be no true or correct account of heterosexuality, homosexuality, bisexuality, and so on.<sup>447</sup>

Queer takes a postmodernist focus on reality, highlighting the constructed nature of society. It considers the mechanisms of reality, purporting to understand the causes for societal differences between individuals based on their characteristics. By making theory queer and queering theory, it embraces the 'utilitarian mix of activism and academia' afforded to it by its beginnings.<sup>448</sup> It unapologetically flexes its activist muscles, highlighting the inequalities caused by entrenched normative values attributed to specific identities; in turn, this paves the way for queer to assess the causes of said normative values, addressing the root cause of discrimination.

If queer maintains origins in lesbian and gay studies, the regulation of sexuality and gender identity is a helpful example of its function. Through the first political activism under the notion of non-conformity in the 1960s, homosexuality began to be more commonly accepted as a state of being not appropriately regulated by medicine.<sup>449</sup> In 1974, homosexuality was removed from the Diagnostic Statistical Manual, yet transsexuality was added;<sup>450</sup> this marked the beginning of the depathologisation of homosexuality, but the pathologisation of trans- identities. This also showed a divergence between the goals of the 'homosexual' and the 'transsexual',<sup>451</sup> as the

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<sup>447</sup> Nikki Sullivan, *A Critical Introduction to Queer Theory* (Edinburgh UP 2003), 1.

<sup>448</sup> Stephen Whittle, 'Gender Fucking or Fucking Gender' in Richard Ekins & Dave King (eds), *Blending Genders: Social aspects of cross-dressing and sex-changing* (Routledge 1996), 201.

<sup>449</sup> *Ibid*, 197.

<sup>450</sup> Rick Mayes & Allan Horwitz, 'DSM-III and the Revolution in the Classification of Mental Illness' (2005) 41(3) *Journal of the History of the Behavioural Sciences* 249, 258-9.

<sup>451</sup> The use of the term 'transsexual' is contextually accurate, though it is acknowledged that the term is considered outdated and overly-medicalised. Other references to non-cisgender identities in this thesis use the umbrella term 'trans-' instead.

former elected to 'float with the current', trying to fit in as equal in a mainstream which fetishises the normal and holds heterosexual ideals as the goal.<sup>452</sup> As Dubermann notes, this focus on reformism and respectability originated 'in fierce anger and [was] initially marked by broad-gauged demands for social change, then rapidly evolve[d] into well-behaved self-protective associations...pressing for narrow assimilationist goals'.<sup>453</sup> Homosexuality was understood and (to an extent) accepted, whereas trans-identities were not. These two categories overlap and interact but are not the same; marginalised individuals regarding sexual orientation and gender identity have sought refuge within each other's communities yet exhibit several differences which cause their cohabitation to be problematic. Debates of trans-identities persist, however the shift away from 'gender identity disorder' towards 'gender incongruence' in the ICD-11 highlights a progression similar to the depathologisation of homosexuality in the 1970s.<sup>454</sup>

The obvious outcome from the above discussion is the knowledge that queer takes aim at restrictive social constructions. Historically, its focus has targeted the entrenchment of normativities of gender and sexuality. As a social construct, gender has been instigated to apply categorical definitions and parameters to identity, and queer intends to analyse and dissect them critically. The body is 'a statement of gender from the moment of birth',<sup>455</sup> with society creating the categories of 'male' and 'female' to apply to individuals based on a myriad of characteristics. Though these categories seem to function in society broadly, these binary terms fail to reflect the

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<sup>452</sup> Berlant & Warner (n338), 345.

<sup>453</sup> Martin Dubermann, *About Time: Exploring the Gay Past* (Penguin Books 1991), 392.

<sup>454</sup> World Health Organisation, *International Statistical Classification of Diseases and Related Health Problems* (11<sup>th</sup> edn, WHO 2019).

<sup>455</sup> Ibid.

uniqueness of individual bodies, creating a group of individuals who do not conform. Queer seeks to undo this disparity. Further, as Jagose notes that ‘demonstrating the impossibility of any ‘natural’ sexuality, it calls into question even such...unproblematic terms as ‘man’ and ‘woman’’.<sup>456</sup> Its position in general discourse is that of critique of the norm: what is seen as normal, common, or trite was dictated as such by the heteronormative mentality of society. Whittle, through a personal account, explains that he is gendered not just by himself but by everybody who knows him, meaning he ‘cannot escape the hegemony of gendering’.<sup>457</sup> The cyclical nature of gender within society demands that it be enforced on its subjects, who then repeat the process on others and themselves. Gender is entrenched as it has become the status quo, accepted as truth by the echo chamber of society. Queer is tasked with ‘desystematisation, anti-definition, and opposition to normalisation’<sup>458</sup> to deconstruct societal understandings of gender and reconstruct a paradigm which lacks hard, restrictive definitions. By refusing to systematise the world, queer is a ‘resistance to being an apparatus for falsely translating systematic and random violence into normal states’,<sup>459</sup> a means of ceasing the problematic normal.

Finally, it may be helpful to position queer as it relates to feminism. Feminist legal theory has existed in several different forms (or ‘waves’) for more than a century. From Mary Wollstencraft in the 18<sup>th</sup> century to the modern day, academic discourse has seen several versions of feminist theory.<sup>460</sup> Feminism is an attempt ‘to critique, to disrupt,

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<sup>456</sup> Jagose (n436), 3.

<sup>457</sup> Whittle (n448), 197.

<sup>458</sup> Schotten (n434), 15.

<sup>459</sup> Berlant & Warner (n338), 348.

<sup>460</sup> Susannah Gibson, *Bluestockings: The First Women’s Movement* (John Murray 2024).

to question, to render problematic the objective, the neutral and the normal'.<sup>461</sup> To be feminist is to understand the inherent partiality of society towards the male; to be a feminist legal theorist is to identify the biases against women in the law. Smart argues that 'it is not that law fails to apply objective criteria when faced with the feminine subject, but precisely that it does apply objective criteria and these criteria are masculine...to insist on equality, neutrality and objectivity is thus, ironically, to insist on being judged by the values of masculinity'.<sup>462</sup> Further, as Sachs and Wilson note within the context of English common law, though it 'had so often been extolled as being the embodiment of human freedom', it maintained precedent that 'provided the main intellectual justification for the avowed and formal subordination of women'.<sup>463</sup> However, a common critique of several feminist movements is an inherent expectation of a homogeneity within oppressed groups. Advocating for women means advocating for *all* women, yet individuals experience womanhood in a myriad of different ways. Connell suggests that the differences between the conceptual and the political had become broader and more distinct and that feminism was not offering anything academically new.<sup>464</sup> As such, queer involves an acknowledgement of intersectionality, without which 'we would be left with the false sense that all members of a particular category of people...are affected equally by various social forces'.<sup>465</sup>

Crenshaw coined the term 'intersectionality' to label the unique discrimination faced by Black women, and to highlight 'subordination as disadvantage occurring along a

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<sup>461</sup> Alison Diduck & Katherine O'Donovan, 'Feminism and Families: Plus Ça Change?' in Alison Diduck & Katherine O'Donovan (eds), *Feminist Perspectives on Family Law* (Taylor & Francis 2007), 1.

<sup>462</sup> Carol Smart, *Law, Crime and Sexuality: Essays in Feminism* (Sage 1995), 189.

<sup>463</sup> Albie Sachs and Joan Hoff Wilson, *Sexism and the Law: A Study of Male Beliefs and Judicial Bias* (Martin Robertson 1978), 40-41.

<sup>464</sup> Robert Connell, *Gender and Power* (Polity Press 1987), 38.

<sup>465</sup> Stephanie G Guittar and Nicholas A Guittar, 'Intersectionality' in James D Wright (ed), *International Encyclopedia of the Social & Behavioural Sciences* (2<sup>nd</sup> edn, Elsevier 2015), 657.

single categorical axis'.<sup>466</sup> By ignoring the ways in which race *and* gender impact someone simultaneously, feminism erased Black women in 'the conceptualisation, identification and remediation of race and sex discrimination, by limiting inquiry to the experiences of otherwise-privileged members of the group'.<sup>467</sup> An intersectional perspective, therefore, acknowledges the diversity of society. Andersen and Collins take this further, in an attempt to understand what a diverse society means for critique of structural discrimination. Due to increased heterogeneity in the general public, 'diversity has become a buzzword – popularly used, but loosely defined. People use diversity to mean cultural variety, numerical representation, changing social norms, and the inequalities that characterise the status of different groups'.<sup>468</sup> Though this has led to previously invisible groups gaining more overt recognition – for example, marginalised groups based on sexual orientation or gender identity, – these groups are still understood as 'other'. We see this clearly in relation to disabilities; comparing people based on their physical or mental difference highlights the discrimination they face, but still maintains these stigmatising barriers – the social chasm between normal and abnormal.

Therefore, in justifying her establishment of queer theory, de Lauretis suggests the 'differences made by race in self-representation and identity argue for the necessity to examine, question, or contest the usefulness and/or the limitations of current discourses'.<sup>469</sup> Existing frameworks provided insufficient scope and leverage to

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<sup>466</sup> Kimberle Crenshaw, 'Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics' (1989) 140 *University of Chicago Legal Forum* 139, 140.

<sup>467</sup> Ibid.

<sup>468</sup> Margaret L Andersen & Patricia Hill Collins, 'Why Race, Class, and Gender Still Matter' in Margaret L Andersen & Patricia Hill Collins (eds), *Race, Class & Gender: An Anthology* (8<sup>th</sup> edn, Wadsworth 2013), 8.

<sup>469</sup> Lauretis (n440), x.

sufficiently critique the structural oppression faced by marginalised groups. The scope of queer ensures respect of the universality of existence, as ‘fundamentally, race, class, and gender are intersecting categories of experience that affect all aspects of human life; thus, they simultaneously structure the experiences of all people in this society’.<sup>470</sup> Further, these concepts fluctuate, their applicability and functionality are fluid over time; ‘at any moment, race, class, or gender may feel more salient or meaningful in a given person’s life, but they are overlapping and cumulative in their effects’.<sup>471</sup>

Ultimately, as Andersen and Collins note, recognising diversity involves ‘understanding race, class, and gender [as] simply a matter of recognising the plurality of views and experiences in society – as if race, class, and gender were benign categories that foster diverse experiences instead of systems of power that produce social inequalities’.<sup>472</sup> This echoes the sentiments of De Lauretis, who concludes thus,

Finally, it is because sexuality is so inevitably personal, because it so inextricably entwines the self with others, fantasy with representation, the subjective with the social, that racial as well as gender differences are a crucial area of concern for queer theory, and one where critical dialogue alone can provide a better understanding of the specificity and partiality of our respective histories, as well as the stakes of some common struggles.<sup>473</sup>

Queer differs from feminism, as instead of attempting to undo injustices and prejudices based on gender by advocating equality of treatment within the current

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<sup>470</sup> Andersen & Collins (n468), 4.

<sup>471</sup> Ibid.

<sup>472</sup> Ibid, 8.

<sup>473</sup> Lauretis (n440), xi.



sociological framework, it critiques that framework and seeks a fairer system overall. Suppose feminism critiques from within, queer critiques from without.

## **2.4 Butler and the Queering of Things**

With an understanding of what queer is, it is important to turn now to discussions of how to queer. Judith Butler is seen as the foremost theorist of the current queer movement; academics in the early 1990s were in awe of “the productive impact their dense and even imposing work has had on the recent development of queer theory and reading”,<sup>474</sup> and their work is “cited more persistently and pervasively than any other queer theorist”.<sup>475</sup> Therefore, this section shall provide an overview of Butler’s work in feminism and queer theory. As preliminary framing, Butler discusses queer through gender, sex, and sexuality. This thesis seeks to contribute to disability studies scholarship. Chapter Three shall demonstrate how subsequent theorists such as McRuer and Kafer have shifted disability studies scholarship under the queer theory umbrella. Nevertheless, the rest of this section shall look in particular at gender, sex, and sexuality as the lens of study.

### **2.4.1 Performative Acts**

Within their earlier works, Butler considers the performativity of societal interactions. In *Performative Acts and Gender Constitution*, Butler argues that gender, as a social construction, is inherently performative; it is not a static identity, but a set of acts that can evolve over time:

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<sup>474</sup> Sedgwick (n446), 1.

<sup>475</sup> Rosemary Hennessey, ‘Queer Theory: Left Politics’ (1994) 7(3) *Rethinking Marxism* 85, 94.

“...if gender is instituted through acts which are internally discontinuous, then the appearance of substance is precisely that, a constructed identity, a performative accomplishment which the mundane social audience, including the actors themselves, come to believe and to perform in the mode of belief”.<sup>476</sup>

For Butler, the sources of gender are socially constructed expectations, meaning the entire concept of gender is constructed. Given that society had predetermined the parameters of gender, all individuals seeking to engage in society would perform their gender based on these definitions. There are biological components to this performance, the existence of the body as both canvas and vehicle as the prime example, but the remainder is socially-produced. As such, Butler argues that “the more mundane reproduction of gendered identity takes place through the various ways in which bodies are acted in relationship to the deeply entrenched or sedimented expectations of gendered existence”.<sup>477</sup> Individuals perform social expectations of gender upon their bodies, shaping their understanding of gender and entrenching these notions within the individual’s sense of self and existence. Further, the social production does not stop at the body - it is “not merely matter but a continual and incessant materialising of possibilities”.<sup>478</sup> The boundary between biology and sociology blurs, creating space for the constructed to permeate what we know as physical truth.

This is not to say that gender is the same for everyone. Butler notes that “one is not simply a body, but in some very key sense, one does one’s body and, indeed, one does

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<sup>476</sup> Judith Butler, ‘Performative Acts and Gender Constitution: An Essay in Phenomenology and Feminist Theory’ (1988) 40(4) *Theatre Journal* 519, 520.

<sup>477</sup> *Ibid*, 524.

<sup>478</sup> *Ibid*, 521.

one's body differently from one's contemporaries and from one's embodied predecessors and successors as well".<sup>479</sup> Given that the body is a vessel, the point of interaction between the self and the social, there are entrenched codes for actors to follow. However, the ways in which performers experience gender for themselves, the way they see it envelop their body and roll off of the tongue are distinctly unique to themselves. However, these performances are not autonomous or inertly constructed:

"Gender is not passively scripted on the body, and neither is it determined by nature, language, the symbolic, or the overwhelming history of patriarchy. Gender is what is put on, invariably, under constraint, daily and incessantly, with anxiety and pleasure, but if this continuous act is mistaken for a natural or linguistic given, power is relinquished to expand the cultural field bodily through subversive performances of various kinds".<sup>480</sup>

Butler is clear in locating the power squarely within society and not the individual. It is not for the person to dictate what their gender is and how it should be performed. Society retains this power, given the established definitions and parameters which predate the creation of the individual body. Gender constructs exist before an individual is born, and they will continue after they die. The sole agency the individual has is how they experience the gender they wear.

As a nod to the brief intersectional considerations in the previous section, Butler also provides a commentary on the binary nature of feminist discourse, critiquing the "reifications that tacitly serve as substantial gender cores" within feminism.<sup>481</sup> They do

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<sup>479</sup> Ibid.

<sup>480</sup> Ibid, 531.

<sup>481</sup> Ibid, 530.

not argue that these concepts are completely separate from each other, but that their overlaps are oversold by feminism. Butler posits that “if gender is the cultural significance that the sexed body assumes, and if that significance is codetermined through various acts and their cultural perception, then it would appear that from within the terms of culture it is not possible to know sex as distinct from gender”.<sup>482</sup> Actors see the physical elements of sex and use those in supporting their understanding and performance of gender.

However, by relying on the entrenched gender ideals found within gender binaries, feminism perpetuates the restrictive narratives it seeks to undo. Feminism’s status of knowledge around gender posited that it was a status of power; it sought to “uncover and claim as valid the experience of women, the major content of which is the devaluation of women's experience”.<sup>483</sup> Several early versions of feminism, such as Difference Feminism and Radical Feminism, navigated a version of sex-role theory, arguing that sex underpins gender and that men maintain power to place roles on women as subservient. Feminism, therefore, resisted gender, attempting to defy the societal norms and expectations set, arguing that people were not attributable purely to their biological sex.

Other commentators have agreed with Butler. Instead of attacking the “dimorphism of gender and sex roles”, feminism arguably tasked itself with upholding “the idea of women as a separate/different gender and in doing so were reinforcing these very

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<sup>482</sup> Ibid, 524.

<sup>483</sup> Catherine McKinnon, ‘Feminism, Marxism, Method and the State: Towards Feminist Jurisprudence’ (1983) 8(4) *Signs* 635, 638.

binary divisions”.<sup>484</sup> It took the concept of lived experience as a way of differentiating men and women, showing power in the experiences faced by those labelled as female or woman. Feminism often conflated sex and gender into synonymous and non-negotiable categories; for radical feminists such as Catherine Millot, gender is an “insuperable barrier” allocated to an individual at birth.<sup>485</sup> Yet, Beauvoir formulates that “one is not born, but rather becomes, a woman”; one assumes a role and develops it within the confines of a constructed society.<sup>486</sup> It is “a purposive and appropriative set of acts, the gradual acquisition of a skill”.<sup>487</sup> What we become and what we already are, are inherently separate and not causally linked; gender is separate from sex, and their attributes are distinguishable from the cultural connotations they entail.<sup>488</sup> Moreover, it explains the issues faced but does not offer a reconstruction of theory; it “fail[ed] to situate sex roles within a structural explanation of their origin”.<sup>489</sup> Connell suggested that the conceptual and political differences had become broader and more distinct, and radical feminism was not offering anything academically new.<sup>490</sup> As gender and sex are not synonymous, gender studies required a reconstructionist theory that allowed for the understanding of identities separate from sex. This realisation led to a queerer reading of the field.

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<sup>484</sup> Whittle (n448), 203.

<sup>485</sup> Catherine Millot, *Horsexe: Essays on Transsexuality* (Autonomea 1990), 15.

<sup>486</sup> Simone de Beauvoir, *The Second Sex* (Constance Borde and Sheila Malovany-Chevallier trs, Vintage 2011), 293.

<sup>487</sup> Judith Butler, ‘Variations on Sex and Gender: Beauvoir, Wittig and Foucault’ in Seyla Benhabib & Drucilla Cornell (eds), *Feminism as Critique: Essays on the Politics of Gender in Late-Capitalist Societies* (Polity 1987), 128.

<sup>488</sup> Ibid.

<sup>489</sup> James. W Messerschmidt, *Masculinities and Crime, Critiques and Reconceptualisation of Theory* (Rowman & Littlefield Publishers 1993), 28.

<sup>490</sup> Connell (n464), 38.

### 2.4.2 Gender Trouble

Butler continued this trajectory of questioning the naturalness of gender in *Gender Trouble*, which “came to be read by many as foundational to the project of queer theory and the advancing of dissident sexual practices”.<sup>491</sup> The book is an example of postmodern feminist discourse, commenting on the use of the label “woman” in debating narratives of gender. Butler builds on the development of sex and gender as social constructions by Beauvoir and Merleau-Ponty, who featured heavily in the text discussed in the previous section.<sup>492</sup> They start with passages from psychoanalytic feminist theorists on subjects of sex and gender: Wittig argues that “the category of sex is the political category that founds society as heterosexual”,<sup>493</sup> and Foucault posits that “the deployment of sexuality, with its different strategies, was what established this notion of sex”.<sup>494</sup> To this end, they highlight society’s gender trouble, asking “what happens to the subject and to the stability of gender categories when the epistemic regime of resumptive heterosexuality is unmasked as that which produces and reifies these ostensible categories of otology?”.<sup>495</sup> The result is a commentary of feminism’s greatest flaw, to endorse woman as its own discrete category; feminist critique ought to “understand how the category of ‘women’, the subject of feminism, is produced and restrained by the very structures of power through which emancipation is sought”.<sup>496</sup> Because feminism sees ‘woman’ as a common collective identity, and because the term carries immense political baggage, feminism perpetuates the problems it tries to undermine.

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<sup>491</sup> Anthony Elliott, *Psychoanalytic Theory: An Introduction* (2<sup>nd</sup> edn, Palgrave 2002), 150.

<sup>492</sup> See Maruice Merleau-Ponty, *The Phenomenology of Perception* (Colin Smith tr.) (Routledge & Kegan Paul 1962); Beauvoir (n486).

<sup>493</sup> Monique Wittig, ‘The Category of Sex’ (1982) 2 *Feminist Issues* 63, 66.

<sup>494</sup> Michel Foucault, *The History of Sexuality, Volume 1: An Introduction* (Robert Hurley tr.) (Pantheon Books 1976), 157.

<sup>495</sup> Butler (n445), viii.

<sup>496</sup> *Ibid*, 2.

The book engages in a queering of Foucault's 'docile body' to create performativity. In *Discipline and Punish*, Foucault argues that society engages in various levels of coercive power to shape a capable but domesticated populace; "a body is docile that may be subjected, used, transformed, and improved".<sup>497</sup> Individuals are malleable and capable of manipulation given sufficient power and strength exerted by an external force. Within the context of discipline, Foucault argues that society "dissociates power from the body; on the one hand, it turns it into an 'aptitude', a 'capacity', which it seeks to increase; on the other hand, it reverses the course of the energy, the power that might result from it, and turns it into a relation of strict subjection".<sup>498</sup> These changes occur across multiple social arenas, slowly shaping norms. It is "a multiplicity of often minor processes, of different origin and scattered location, which overlap, repeat, or imitate one another, support one another, distinguish themselves from one another according to their domain of application, coverage, and gradually produce the blueprint of a general method".<sup>499</sup> It is subliminal a restrained, yet manipulative and malevolent. Society functioning as both Big Brother and Little Brother, seeing everything individuals do and telling on them in the process. There is a level of conformity expected within society, and when opposing forces abrade, there is fallout.

Therefore, Butler engages with performativity to explain gendered behaviour. They suggest that there is "no gender identity behind the expressions of gender; that identity is performatively constituted by the very 'expressions' that are said to be its

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<sup>497</sup> Michel Foucault, *Discipline & Punish: The Birth of the Prison* (Alan Sheridan tr) (2<sup>nd</sup> edn, Vintage Books 1995), 136.

<sup>498</sup> Ibid, 138.

<sup>499</sup> Ibid.

results”.<sup>500</sup> They argue that “there is no subject who is ‘free’ to stand outside norms or to negotiate them at a distance; on the contrary, the subject is retroactively produced by these norms on their repetition”.<sup>501</sup> What many call ‘agency’ is in fact a “specific political prerogative that is produced” by the system,<sup>502</sup> and only exists within the confines of what society allows. Though the individual performs certain gendered behaviours, these function in justifying a gendered identity, rather than generating one. Ultimately, if the gendered body is performative, this suggests that it “has no ontological status apart from the various acts which constitute its reality”.<sup>503</sup> The body exists, but it is only gendered by society; gender has no natural reality.

As an example, Butler suggests that drag “fully subverts the distinction between inner and outer psychic space and effectively mocks both the expressive model of gender and the notion of a true gender identity”.<sup>504</sup> The performance highlights the “three contingent dimensions of significant corporeality: anatomical sex, gender identity, and gender performance”.<sup>505</sup> What the viewer, an external party to the performance, perceives of the performer is a blend of the three in a purposeful confusion of social structures. By imitating gender, drag “implicitly reveals the imitative structure of gender itself”.<sup>506</sup> Given that society tries to justify gender as a true reality, drag is an example of deconstructing the interactions between these three dimensions. Further, Butler uses Jameson’s postmodern ideas of pastiche to identify how drag undermines the notion of true gender. Pastiche is “the imitation of a peculiar or unique style, the

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<sup>500</sup> Butler (n445), 25.

<sup>501</sup> Judith Butler, ‘Critically Queer’ in Donald E. Hall et al (eds), *The Routledge Queer Studies Reader* (Routledge 2013), 22.

<sup>502</sup> Ibid.

<sup>503</sup> Butler (n445), 136.

<sup>504</sup> Ibid, 137.

<sup>505</sup> Ibid.

<sup>506</sup> Ibid.



wearing of a stylistic mask” through a “neutral practice of mimicry, without parody’s ulterior motive”.<sup>507</sup> In turn, drag mimics gender without engaging in mockery. The aim is not to suggest that drag is a parody, a performance thriving on schadenfreude. Nor is it a timid peek behind the curtains of social construction. It is an “imitation that mocks the notion of [the] original”, revealing that gender is an “inevitably failed” copy that no one can embody.<sup>508</sup>

Nevertheless, the *trouble* alluded to within the title is not expressly with gender, but with society’s responses to gender. By reading the above through the lens of questioning substance and bringing dynamic power into the equation, it is clear that the above performance is not autonomous. A performer may believe they are exercising agency by deciding to defy societal norms and present as a different gender to the one assigned to them. In fact, performativity is not a matter of choice of which gender to present as, but a mere repetition of the norms by which gender has been established. It is not “a radical fabrication of a gendered self”.<sup>509</sup> Instead, it is an individual’s attempt at “copying images of sexuality in order to create the effect of the natural, the original, and the actual”.<sup>510</sup> It reflects a feminine aspect to the individual’s masculinity or maleness; delineating a boundary between the ‘real’ woman and the ‘drag’ woman presupposes “a formula for gender constitution in which social woman is equated with genital woman”,<sup>511</sup> it would be as if “without genital reconstruction,

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<sup>507</sup> Fredric Jameson, ‘Postmodernism and Consumer Society’ in Hal Foster (ed), *The Anti-Aesthetic: Essays on Postmodern Culture* (Bay Press 1983), 114.

<sup>508</sup> Butler (n445), 138-9.

<sup>509</sup> Butler (n501), 22.

<sup>510</sup> Elliott (n491), 151.

<sup>511</sup> Anne Bolin, ‘Transcending and Transgendering: Male-to-Female Transsexuals, Dichotomy and Diversity’ in Gilbert Herdt (ed), *Third Sex, Third Gender: Beyond Sexual Dimorphism in Culture and History* (Zone Books 1996), 460.

personal gender roles could not be changed and even with it, that reconstruction s provide[s] the point of change”.<sup>512</sup>

This is not an attempt by Butler to undermine the *existence* of gender, but to understand the application of it, and highlight the over-reliance on rigid binaries. Performativity is an intersectional theory, given that “there is no gender performance more authentic than any other reckoning of gender”.<sup>513</sup> Traditional feminism maintained a strict adherence to a sex and gender binary, of male and female, of man and woman. Butler does not merely lament the rigidity of the definitions of these two seemingly opposing concepts, but also questions the logic of positing both sex and gender as a binary:

“The presumption of a binary gender system implicitly retains the belief in a mimetic relation of gender to sex whereby gender mirrors sex or is otherwise restricted by it. When the constructed status of gender is theorised as radically independent of sex, gender itself becomes a free-floating artifice, with the consequence that *man* and *masculine* might just as easily signify a female body as a male one, and *woman* and *feminine* a male body as easily as a female one.”<sup>514</sup>

The question posed, therefore, is *why* society forcefully attaches labels of *man* and *woman* to specific bodies along a binary when such a rigid binary does not adequately explain the intricacies of lived experience. In expanding on Foucault and Wittig, Butler highlights the problem with both the power and location of identity, what they consider as the “substance” of a self-identical being. An identity is self-referential, justifying its

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<sup>512</sup> Whittle (n448), 204.

<sup>513</sup> Elliott (n491), 151.

<sup>514</sup> Butler (n445), 6.

existence and entrenchment by using itself as the definition. Gender, as they conclude, is “not a noun, but neither is it a set of free-floating attributes, for we have seen that the substantive effect of gender is performatively produced and compelled by the regulatory practices of gender coherence”.<sup>515</sup>

As if pushing deconstructivism to its absolute limit, Butler poses that “perhaps this construct called ‘sex’ is as culturally constructed as gender; indeed, perhaps it was always already gender, with the consequence that the distinction between sex and gender turns out to be no distinction at all”.<sup>516</sup> If the realm of postmodern feminism, which has morphed and developed towards a queer theory, is willing to deconstruct the reality of gender, then what is stopping us from deconstructing seemingly biologically true concepts such as sex?

### **2.4.3 Bodies That Matter**

Within *Bodies That Matter*, Butler bolsters the conversation of performativity with citationality. Their intention seems to have been to maintain the understanding of the repetitive nature of gender, but pull the conversation away from the ambiguity of performance. In iterating on gender, actors reference established definitions, concepts which have been pre-approved by society. If there is agency, Butler argues it is to be found “in the possibilities opened up in and by that constrained appropriation of the regulatory law”.<sup>517</sup> The freedom to self-determine exists purely within the confines set by society. Norms take hold to the extent that they are cited as such, but

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<sup>515</sup> Ibid, 24.

<sup>516</sup> Ibid, 7.

<sup>517</sup> Judith Butler, *Bodies That Matter: On the Discursive Limits of Sex* (Routledge 1993), 12.

they also derive power through the citations they compel. To perform, therefore, is to sustain an idea by way of imitation, by citing predetermined social constructions.

Butler grounds their understanding of iterances through the work of Derrida, and in particular the notion of *différance*. Derrida asks whether “a performative utterance succeed if its formation did not repeat a ‘coded’ or iterable utterance...if it were not then identifiable in some way as a ‘citation’”.<sup>518</sup> Butler considers the application of reiterations to the self, suggesting that if a performance succeeds, it is “not because an intention successfully governs the action of speech, but only because that action echoes a prior action, and accumulates the force of authority, through the repetition or citation of a prior, authoritative set of practices”.<sup>519</sup> Derrida appears concerned with the “ways of thinking about how meanings are established, specifically that meanings are organised through difference in a dynamic play of presence and absence”.<sup>520</sup> In turn, conferring meaning includes both identity, namely what something *is*, and difference, namely what something *is not*, which is continuously being deferred.<sup>521</sup> Deutscher notes that “in relation to the opposition between ‘presence’ and ‘absence’, *différance* is neither present, nor absent. Instead, it is a kind of absence that generates the effect of presence. Further, *différance* is “neither identity, nor difference. Instead, it is a kind of differentiation that produces the effect of identity and of difference between those identities”.<sup>522</sup> Derrida denies ‘reality’ in favour of ‘words’ and ‘text’; “to say there is nothing outside of text is to say there is always relationality and

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<sup>518</sup> Jacques Derrida, ‘Signature Event Context’ in Gerald Graff (ed), *Limited Inc* (Samuel Weber & Jeffrey Mehlman trs.) (Northwestern University Press 1988), 18.

<sup>519</sup> Butler (n501), 20.

<sup>520</sup> Corker & Shakespeare (n347), 7.

<sup>521</sup> *Ibid.*

<sup>522</sup> Penelope Deutscher, *How to Read Derrida* (Granta Books 2005), 29.

differentiation. No matter what we imagine as 'reality', it could be argued that differentiation is critical to it".<sup>523</sup>

Applying *différance* to gender, Butler argues that gender is the fluctuation between states, found at the mirror's edge between the psyche and appearance. The power of a citation gives a performance its binding power. If the performance succeeds, if the actor successfully utilises gender to navigate a social situation, it is "not because an intention successfully governs the action of speech, but only because that action echoes a prior action, and accumulates the force of authority through the repetition or citation of a prior, authoritative set of practices".<sup>524</sup> Gender is not an identity, but a means of producing identity and manifesting a difference between gendered identities.

This alteration to performativity results in five key elements. Firstly, Butler argues that gender cannot be read as separate from the "forcible and reiterative practice of regulatory sexual regimes".<sup>525</sup> Secondly, the "account of agency conditioned by those very regimes of discourse/power cannot be conflated with voluntarism or individualism, much less with consumerism, and in no way presupposes a choosing subject".<sup>526</sup> Third, the "regime of heterosexuality operates to circumscribe and contour the materiality of sex", which is formed and maintained through a heterosexual hegemony.<sup>527</sup> Fourth, norms require identificatory processes by which they are assumed, and these processes both precede and enable the formation of a subject, yet are not performed

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<sup>523</sup> Ibid, 34.

<sup>524</sup> Butler (n501), 20.

<sup>525</sup> Butler (n517), 15.

<sup>526</sup> Ibid.

<sup>527</sup> Ibid.

by said subject. Finally, the “limits of constructivism are exposed at those boundaries of bodily life where abjected or delegitimated bodies fail to count as bodies”.<sup>528</sup>

Butler wrote *Critically Queer*, in part as a retrospective analysis of both *Gender Trouble* and *Bodies That Matter*. One of the aims of this article was to respond to general misunderstandings on their theory of gender performativity. Butler notes that many read their theory as “a voluntarist account of gender which presumes a subject, intact, prior to its gendering”.<sup>529</sup> This is undoubtedly due to their choice of drag as an example of how a performance of gender undoes the entrenched values of truth society has bestowed upon gender. As drag is a purposeful artistic performance, commentators likely read a level of control into performativity that Butler did not intend. Rather, Butler makes clear that gender is only performative insofar as it is “the effect of a regulatory regime of gender differences in which genders are divided and hierarchised”.<sup>530</sup> Performativity is not a matter of choosing gender. It is a matter of “reiterating or repeating the norms by which one is constituted”.<sup>531</sup>

Repetition creates uniformity, a stability within society. As such, gender is not an active choice, and it is clear that Butler did not intend performativity and citationality to confer agency to the subject. They argue that there is no subject “free to stand outside these norms or to negotiate them at a distance; on the contrary, the subject is retroactively produced by these norms in their repetition”.<sup>532</sup> An individual is created within a gendered society and is always gendered. Accepting and leaning into this

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<sup>528</sup> Ibid.

<sup>529</sup> Butler (n501), 22.

<sup>530</sup> Ibid.

<sup>531</sup> Ibid.

<sup>532</sup> Ibid.

gendering grants individuals with citizenship; “this citation of the gender norm is necessary in order to qualify as a ‘one’, to become viable as a ‘one’ , where subject-formation is dependent on the prior operation of legitimating social norms”.<sup>533</sup> Society places obligations and expectations upon actors. To deviate is not to go against the grain, but stand out and lose citizenship. In all, Butler sees performativity “not as self-expression or self-presentation, but as the unanticipated resignifiability of high invested terms”.<sup>534</sup> It is self-preservation.

Therefore, in bringing these deconstructions of gender back into the substantive theory of queer, Butler argues that gender trouble becomes queer trouble, society’s inability to include queer experiences. The force of queer stems “precisely through the repeated invocation by which it has become linked to accusation, pathologisation, insult”.<sup>535</sup>

## **2.5 Conclusion**

This chapter transfers the conversation of disability from the realm of international human rights law into the world of the theoretical. If the goal of this thesis is to provide novel interpretations of the CRPD, it is important to explain the foundations of the perspectives taken on disability as a concept. Section 2.2 provides an overview of Shakespeare’s commentary on disability studies, his concerns with existing models of disability, and the parameters of his interactional approach. It also highlights several of the shortcomings within this approach, the primary concern being his foundation

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<sup>533</sup> Ibid, 23.

<sup>534</sup> Ibid, 28.

<sup>535</sup> Ibid, 19.

within critical realism. An interactional approach, finding disability in the interaction between the impaired person and society, shows great promise; however, it suffers from Shakespeare's reliance on impairment and his belief that disability has a reality. The perspective taken by this thesis is that of deconstruction through postmodernism and post-structuralism, refusing the notion that both impairment and disability experience some natural reality. Therefore, the intention is to apply this perspective to Shakespeare's interaction approach.

To achieve this, sections 2.3 and 2.4 provide an overview of queer theory. Section 2.3 discusses the history of queer, considering its sources and development as a corpus of research. It explains how LaRetis coined the term queer theory, the logic behind her decision, as well as some of the important boundaries and goals of the theory. Section 2.4 then considers the work of Butler, given the importance of their research in developing the field of queer theory. By methodically considering their work between *Performative Acts* and *Bodies That Matter*, this chapter highlights how queer functions as a deconstructive methodology. Chapter Three shall provide the other necessary theory to apply queer to disability rights law – specifically crip theory and queer legal theory. Read together, these two chapters will provide the necessary resources to queer Shakespeare.



## Three: Making Queer Disability Work

“...arguably, able-bodied identity is at this juncture even more naturalised than heterosexual identity. At the very least, many people not sympathetic to queer theory will concede that ways of being heterosexual are culturally produced and culturally variable, even if and even as they understand heterosexual identity itself to be entirely natural. The same cannot be said, on the whole, for able-bodied identity”.<sup>536</sup>

### 3.1 Introduction

If Chapter Two intends on demonstrating how this thesis views disability and provides an overview of queer, then this chapter demonstrates how to fetter and rationalise queer within a disability and international human rights law context. Crip Theory is an extension of queer. It seeks to “redefine individual and group identities...to envision a more accessible, radically democratic public sphere”.<sup>537</sup> Spearheaded by Robert McRuer, it lies at the intersection of queer and Disability Studies. It rejects perceiving able-bodiedness as normalcy, pushing towards inclusive legal systems for PWDs through “cultural redefinition, depathologisation, and revaluation of an ethos of community and care”.<sup>538</sup>

The discussion in sections 2.3 and 2.4 closely relied upon gender and sex as narrative discourses in demonstrating the function of queer. However, this thesis intends to

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<sup>536</sup> McRuer (n409), 490.

<sup>537</sup> Robert McRuer & Abby Wilkerson, ‘Introduction’ (2003) 9:1-2 *GLQ* 1, 4.

<sup>538</sup> *Ibid.*

comment on the CRPD. Though gender is a relevant aspect of several provisions within the CRPD, the main focus is on disability itself as the minority category. Therefore, considerations of theory on queering disability would benefit the analysis found in later chapters in this thesis. As such, section 3.2 shall look at crip theory, the theoretical movement to understand disability studies under the queer umbrella. Further, given that queer is continuously moving and inherently deconstructive, it may prove challenging to see how such a methodology could be used in critiquing the law – a system beholden to rigid structure, clear definitions, and absolute rules. Therefore, section 3.3 shall consider queer legal theory, discussing how to successfully use a queer methodology to address legal structure.

## **3.2 Crippling the Queer**

Given that, as discussed in the previous chapter, the CRPD lends a key focus to the human rights of PWDs, it is prudent to utilise Crip Theory as an extension of queer commentary analysis. McRuer has attempted to consolidate much of the work conducted under these two banners and develop the realm of Crip Theory, where disability and queer intersect. Within a queer discussion of disability rights, using Crip Theory facilitates a queer use of disability studies. Further, when critiquing existing models of disability, Crip Theory allows for an additional deconstructive layer.

### **3.2.1 Queering Disablement**

McRuer saw the chance for disability studies to develop down a new path under the protection of the queer umbrella:

“Queering disability studies or claiming disability in or around queer theory...helps create critically disabled spaces overlapping with the

critically queer spaces that activists and scholars have shaped during the recent decades, in which we can identify and challenge the ongoing consolidation of heterosexual, able-bodied hegemony”.<sup>539</sup>

Seemingly inspired by the inclusivity built into queer theory, Crip seeks to identify methods of marginalisation at the intersection of disability with other minority identities, such as race, sex, gender, and economic status. Queer and disability studies are adamantly against norms imposed by society.<sup>540</sup> They also view history as a history of injustices through pathology and demonisation. Cameron and Swain go so far as to suggest that “there is a similar coming out process for disabled people as for queer people”.<sup>541</sup> As a collaborative effort of queer and disability, Crip respects the specialisations of each theory. It is an opportunity for disability studies to challenge the social hegemony against perceived abnormality and deviance through the lens of inclusivity and acceptance.

Waldschmidt poses the three basic questions that Crip aims to tackle. The first asks, “how many people have a disability”.<sup>542</sup> As discussed in section 1.1, roughly one billion people live with a disability. Further, disability is a status condition that an individual can accrue or attain during their lifetime. Such a proportion with a flexible membership demonstrates the importance of critically analysing societal oppression, establishing Crip’s mandate for study. The second question asks, “how disability [is] distributed

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<sup>539</sup> Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability* (NYU Press 2006), 19.

<sup>540</sup> Carrie Sandahl, ‘Queering the Crip or Crippling the Queer?: Intersections of Queer and Crip Identities in Solo Autobiographical Performance’ (2003) 9:1-2 *GLQ* 25, 26.

<sup>541</sup> John Swain & Colin Cameron, ‘Unless Otherwise Stated: Discourses of Labelling and Identity in Coming Out’ in Mairian Corker & Sally French (eds), *Disability Discourse* (Open University Press 1999), 68.

<sup>542</sup> Anna Waldschmidt, ‘Disability as a Social Problem’ in George Ritzer (ed), *The Blackwell Encyclopedia of Sociology* (Blackwell 2007), 1168.

within the population”.<sup>543</sup> Disability does not discriminate, as anyone can be born with or develop a disability, regardless of geopolitical or socioeconomic status. However, the societal impact of disability disproportionately impacts minorities and the lowest economic groups. This disparity is due to national and international wealth disparities and the general allocation of resources to support PWDs centralising around certain groups and classes of individuals. Crip seeks to highlight these disparities and help undo the damage caused. The third question asks, “what...the major causes” are.<sup>544</sup> This question takes two forms, asking what causes the existence of a disability and what causes the limitations faced by PWDs. Regarding the former, disability manifests through lack and loss, a difference in the human condition between the individual and others. The individual may lack something from birth which society takes for granted. The individual may also lose that standard something during their life. Regarding the latter, society responds to these differences in alternative fashion depending on multiple factors, many of which manifest in the answers to the previous question. It is the job of Crip to acknowledge the diversity of sources of disability and critically analyse society’s responses. Section 3.3.2 will tackle the first of these issues, addressing sources of individual disability by criticising normalcy. This section will continue to address the latter.

Disablement is a core element of Crip Theory. Oliver argues that “disability as a category can only be understood within a framework, which suggests that it is culturally produced and socially structured”.<sup>545</sup> Society defines disability and applies it to individuals based on their characteristics. According to Oliver, disablement is “the

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<sup>543</sup> Ibid.

<sup>544</sup> Ibid.

<sup>545</sup> Michael Oliver, *The Politics of Disablement* (Macmillan Press 1990), 22.

product of social organisation rather than personal limitation”,<sup>546</sup> a perspective he maintained throughout his career. Enforced limitations on PWDs come from societal prejudices against their character and identity. Accordingly, to define disability requires “(i) the presence of an impairment; (ii) the experience of externally-imposed restrictions; and (iii) self-identification as a disabled person”.<sup>547</sup> Crip ensures that an individual can self-determine; if an individual experiences limitation and identify with the label of disability, the community under the queer and Crip umbrella welcomes them with open arms.

Nevertheless, decisions on whether an individual experiences disablement often results from external restrictions and limitations. Such restrictions highlight conflicts between the second and third principles above, between the individual experience and their self-identification. Edgerton notes that “some cultures regard [disability] as seriously troublesome and others do not”.<sup>548</sup> How a society has constructed itself will dictate how it perceives certain types of disability. Regardless of self-determination, an individual or group may receive the disability label from society. Deafness is a clear example where two separate cultures have different perspectives. Society disables the Deaf community because of “our failure to learn how to communicate with them, not their inability to communicate with us”.<sup>549</sup> Humanity has built a broader society with foundations of speech and hearing-based communication. Its reliance on speaking/hearing means that an inability to use that form carries a label of disabled. The Deaf community may reject the disability label yet still experience discrimination and restriction.

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<sup>546</sup> Michael Oliver, *Understanding Disability: From Theory to Practice* (Macmillan Press 1996), 1.

<sup>547</sup> *Ibid*, 5.

<sup>548</sup> Robert Edgerton, *Deviance: A Cross-Cultural Perspective* (Benjamin/Cummings 1976), 62-3.

<sup>549</sup> Oliver (n545), 17.

As Oliver notes, PWDs experience limitations “from individual prejudices to institutional discrimination, from inaccessible public buildings to unsuitable transport systems, from segregated education to excluding work arrangements”.<sup>550</sup> Disablement causes a wealth of restrictions, preventing PWDs from fully accessing society. However, disablement also leaves PWDs in a state of limbo. Murphy notes that “the long-term physically impaired are neither sick nor well, neither dead nor alive, neither out of society nor wholly in it. They are human beings, but their bodies are warped or malfunctioning, leaving their full humanity in doubt”.<sup>551</sup> In a medicalised world, an individual with illness experiences social suspension until they recover. However, PWDs with permanent impairment will never medically ‘recover’. Their body is not normal, so they remain in situ and stasis.

In a controversial research project, Miller and Gwynne argue that “to lack any actual or potential role that confers a positive social status in wider society is tantamount to being socially dead”.<sup>552</sup> The controversy comes from a prejudiced view of psychiatric system users and their perceived social utility. Measuring an individual’s worth according to their participation in a system built to restrict them is a gross injustice. Instead, Morris argues that “social death comes about because of the non-disabled world’s reaction to disability rather than being an inevitable consequence of even a high functional limitation”.<sup>553</sup> Society removes a person’s opportunity to engage on an

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<sup>550</sup> Oliver (n546), 33.

<sup>551</sup> Robert Murphy, *The Body Silent* (Dent 1987), 112.

<sup>552</sup> Eric J Miller & Geraldine V Gwynne, *A Life Apart: A Pilot Study of Residential Institutions for the Physically Handicapped and the Young Chronic Sick* (Tavistock Publications 1972), 80.

<sup>553</sup> Jenny Morris, *Pride Against Prejudice: Transforming Attitudes to Disability: A Personal Politics of Disability* (Women’s Press 1991), 132.

equal platform to others based on disability. As such, a queer approach to disability studies seeks to remove such barriers to inclusion.

### **3.2.2 Compulsory Able-Bodiedness**

Within Crip Theory, disability covers a range of experiences, including yet not limited to an individual's physical, mental, and psychosocial health. Taking a queer approach to defining disability, the concepts of 'crip' and 'disabled' "cannot easily be accepted as a self-evident phrase referring to a discrete group of particular people".<sup>554</sup> They are "fluid and ever-changing", having "expanded to include not only those with physical impairments but those with sensory or mental impairments as well".<sup>555</sup> McRuer argues that "in a nutshell, you either have an able body or you don't".<sup>556</sup> Society perpetuates this dichotomy as a binary truth, and that creates problems for all, not just for PWDs.

Society manifests a state of "compulsory able-bodiedness",<sup>557</sup> with emphasis on "soundness of health, ability to work, [and] robustness" of body.<sup>558</sup> Able-bodiedness is a socially constructed 'ideal', a state of being that is either considered a standard to maintain or an ideal to attain. From the outset, promoting a gold standard of health seems admirable and humane. Society should seek the best for everyone to promote peak health and strive for the highest possible standard of living. These often appear in international treaties, including within the principles of the CRPD. However, the result includes an 'othering' of experiences; ability is an antonym to disability.

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<sup>554</sup> Alison Kafer, 'Compulsory Bodies: Reflections of Heterosexuality and Able-bodiedness' (2003) 15:3 *Journal of Women's History* 77, 78.

<sup>555</sup> Sandahl (n540), 27.

<sup>556</sup> McRuer (n409), 491.

<sup>557</sup> Oliver (n545), 2.

<sup>558</sup> *Ibid*, 7.

Just as to be heterosexual is not to be homosexual, so too is able-bodiedness considered with disability. Society consistently posits a dichotomy where one does not exist to conceptualise perceived differences easily. This dichotomy goes beyond mere normative forces to establishing characterisations of individuals or groups. Being able-bodied allows for “normal relations”, the ability to engage with society and work in the “normal” way.<sup>559</sup> It becomes compulsory through society’s need to strive for and repeat this as an idea. Within discussions of queer identities, heterosexual identities are “performatively constituted through an imitation that sets itself up as the origin and the ground of all imitations”,<sup>560</sup> and McRuer argues that able-bodiedness suffers the same ailment within the Crip realm. Being able-bodied is a performance, and though society requires the repetition of this performance, it is ultimately doomed to fail as individuals cannot achieve the ideal able-bodied identity.<sup>561</sup>

McRuer notes that, like compulsory heterosexuality, “compulsory able-bodiedness functions by covering over, with the appearance of choice, a system in which there actually is no choice”.<sup>562</sup> A system built upon compulsory able-bodiedness “repeatedly demands that [PWDs] embody for others an affirmative answer to the unspoken question, yes, but in the end, wouldn’t you rather be more like me?”.<sup>563</sup> This focus on the normal leads to people within the normate to see PWDs as inherently lesser. Warner

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<sup>559</sup> Ibid, 7-8.

<sup>560</sup> Judith Butler, ‘Imitation and Gender Insubordination’ in Diana Fuss (ed), *Inside/Out: Lesbian Theories, Gay Theories* (Routledge 1991), 21.

<sup>561</sup> Oliver (n546), 9.

<sup>562</sup> McRuer (n409), 491.

<sup>563</sup> Ibid, 491-2.



notes that many PWDs internalise these ableist narratives, which leads to PWDs striving to be ‘normal’”

“...nearly everyone wants to be normal. And who can blame them, if the alternative is being abnormal, or deviant, or not being one of the rest of us? Put in those terms, there doesn’t seem to be a choice at all, especially in places where normal probably outranks all other social aspirations”.<sup>564</sup>

Garland-Thompson coins the “normate”, which “usefully designates the social figure through which people can represent themselves as definitive human beings”.<sup>565</sup> It is “the constructed identity of those who, by way of bodily configurations and cultural capital they assume, can step into a position of authority and wield the power it grants them”.<sup>566</sup> Society labels “ability” as the standard and overall goal, an aspiration to attain. The most central perceived ideal identity is the cis, straight, white, able, middle-class male. Moreover, by having an able body and exhibiting characteristics that afford privilege, one can enter the echelons of power and exert control in ways others may not – one faces fewer barriers.

Davis continues by deconstructing normalcy, stating that “the problem is not the person with disabilities; the problem is how normalcy is constructed to create the problem of the disabled person”.<sup>567</sup> The concept of a norm means that “the majority of the population must or should somehow be part of the norm”.<sup>568</sup> The culture of

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<sup>564</sup> Michael Warner, *The Trouble with Normal: Sex, Politics, and the Ethics of Queer Life* (Harvard UP 1999), 53.

<sup>565</sup> Rosemarie Garland-Thompson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (Columbia University Press 1997), 8.

<sup>566</sup> *Ibid.*

<sup>567</sup> Lennard Davis, *Enforcing Normalcy: Disability, Deafness, and the Body* (Verso 1995), 24.

<sup>568</sup> *Ibid.*, 29.

asking questions indicating able-bodiedness as preferable to the alternative assumes that “able-bodied identities, able-bodied perspectives are preferable” and what we all collectively aim for.<sup>569</sup> People who identify as the normate need validation, not only of their own identity but that theirs is superior; in the end, “wouldn’t you rather be me?’ they say to the other<sup>570</sup> and failing that, “wouldn’t you rather die?”.<sup>571</sup>

Akin to a discussion of the timing of identity in section 3.2 above, to assume the role of the normate is merely a matter of dates; in the early 20<sup>th</sup> Century, “heterosexuality was not equated with the normal sex, but with perversion”, a syndrome that assumes “feelings had a biology”.<sup>572</sup> Reproduction and desire were considered independent, and only “the coming out of the homo provoked the coming out of the het”,<sup>573</sup>. In much the same way, able-bodiedness has been “cast as separate from politics, as a universal ideal and as a normal way of life”,<sup>574</sup> the rise of the Crip causes the exertion of the dominance of the abled.

The instigation of a standard is problematic as it allowed heterosexuality to be “institutionalised as the normal relations of the sexes”.<sup>575</sup> The inclusion of normalcy creates a compulsion to establish a system of supposed choice where none exists. Likewise, it establishes that disability is purely a physical enterprise. If someone does not appear disabled, they are assumed not to be, which restricts their ability to engage

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<sup>569</sup> Oliver (n546), 9.

<sup>570</sup> Ibid.

<sup>571</sup> Kafer (n554), 81.

<sup>572</sup> Jonathan Ned Katz, ‘The Invention of Heterosexuality’ (1990) 20 *Socialist Review* 21, 21.

<sup>573</sup> Jonathan Ned Katz, *The Invention of Heterosexuality* (Dutton 1995), 24.

<sup>574</sup> Kafer (n554), 79.

<sup>575</sup> Oliver (n546), 6.

with society and access support.<sup>576</sup> This restriction is not only an issue for those with disabilities, but it also harms those who consider themselves part of the normate – Wendell argues that “idealising the body prevents everyone, able-bodied and disabled, from identifying with and loving [their] real body”.<sup>577</sup>

### **3.2.3 Ability Trouble**

Before progressing to queer legal theory, it is important to note the interactions between crip theory and content discussed earlier in this thesis. At section 2.4.2, Butler discusses society’s gender trouble – an inability for social structures to fully comprehend the ramifications of gender and incorporate myriad individuality. McRuer takes this concept and applies it to disability:

“Butler’s theory of gender trouble might be resignified in the context of queer/disability studies as what we could call ‘ability trouble’ – meaning not the so-called problem of disability but the inevitable impossibility, even as it is made compulsory, of an able-bodied identity”.<sup>578</sup>

The problem facing society is its over-reliance on a clearly defined standard, and therefore a rejection of any deviation as a flaw. As gender troubles society, so too does disability. Further, with Butler moving the needle away from trouble towards performativity and citationality, it is clear how McRuer’s understanding of queer/crip

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<sup>576</sup> Ellen Jean Samuels, ‘My Body, My Closet: Invisible Disability and the Limits of Coming-Out Discourse’ (2003) 9:1-2 *GLQ* 233.

<sup>577</sup> Susan Wendell, ‘Towards a Feminist Theory of Disability’ in Lennard Davis (ed), *The Disability Studies Reader* (Routledge 1997), 267.

<sup>578</sup> McRuer (n409), 492.

ability develops along the same battle lines. Society has created a standard of ability from which everyone must cite and perform.

An excellent example of this ability trouble manifests through stigma, highlighted in passing in section 1.2.2 within the discussion of the DRMRP. Within his account of stigma, Goffman sees it as dynamic. He notes that “society establishes the means of categorising persons and the complement of attributes felt to be ordinary and natural for members of each of these categories”.<sup>579</sup> Individuals rely on social capital to navigate life, and so any negative associations will limit their access and inclusion. The term ‘stigma’ refers to an attribute that is deeply discrediting, a characteristic which is considered abnormal. This attribute then ‘spoils’ their identity. Society justifies this by relying on the foundations of the status quo that justify the assertion of stigma; “by definition, of course, we believe the person with a stigma is not quite human”, exercising varying levels of discrimination.<sup>580</sup> The parallels between Goffman’s and McRuer’s theory are evident. Society creates an account of a ‘healthy’ or ‘standard’ body, and applies stigma to anything or anyone caught in non-conformance. This means that anyone with a disability lacks social value. However, the application of stigma to disability occurs at an additional micro- level. Because society maintains an idea of what PWDs should be, should act, or should look like, there will be further stigmatisation of PWDs who do not conform to these expectations. A perfect example can be found in individuals with invisible disabilities, those who don’t “look disabled”, and so must be faking it.

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<sup>579</sup> Goffman (n104), 2.

<sup>580</sup> Ibid, 5.

Goffman notes that there are several ways in which a stigmatised person can respond. First, they can attempt to “correct what [they] see as the objective basis of [their] failing”.<sup>581</sup> Second, they can “attempt to correct [their] condition indirectly by devoting much private effort to the mastery of areas of activity ordinarily felt to be closed on the incidental and physical grounds to one with [their] shortcoming”.<sup>582</sup> Finally, they can “break with what is called reality, and obstinately attempt to employ an unconventional interpretation of the character of [their] social identity”.<sup>583</sup> Importantly, language of stigma should be relative: “an attribute that stigmatises one type of possessor can confirm the usualness of another, and therefore is neither creditable nor discreditable as a thing in itself”.<sup>584</sup> Applying this to PWDs, the options available to decouple themselves from this stigma are to ‘fix’ or ‘cure’ their disability, to hide their disability, or to accept their disability as a part of them and refuse to conform. The first two are methods to conceal their characteristic to gain social capital, and the final method requires an alteration of social behaviour to compensate for their spoiled identity. Either way, the stigma is always interactive and changes how individuals present themselves.

A final thought on crip theory is an application of normalcy to the CRPD. By drafting a convention dedicated to the advancement of PWDs as equal members of society, does the CRPD itself promote compulsory able-bodiedness? This is a risk associated with the stratification of rights along roads of identity, and is covered as a potential issue in section 3.3 below. Given that compulsory able-bodiedness is prevalent in society, it is unsurprising that aspects of the CRPD may not be as progressive as one might

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<sup>581</sup> Ibid, 9.

<sup>582</sup> Ibid, 10.

<sup>583</sup> Ibid.

<sup>584</sup> Ibid, 3.

assume, and may in fact reinforce problematic neoliberal subjectivities of ability. This thesis attempts to avoid this negative perpetuation. In Chapter Four, there is commentary on existing models of disability, and Chapter Five formulates the Identity Approach to disability. Further, by using a queer lens to recontextualise provisions within the CRPD, Chapters Six and Seven demonstrates how an alternative interpretation can undo these entrenched values of compulsory able-bodiedness.

### **3.3 Queer Legal Theory**

It is pertinent to understand *how* both queer theory and crip theory can perform as lenses of human rights law commentary and critique. Queer theory may be a ‘broad church’,<sup>585</sup> but it is important to locate the law within the congregation. In his 2019 book, Gonzalez-Salzberg undertakes a critical analysis of human rights from queer theory perspective.<sup>586</sup> The remaining sections of this paper follow a similar methodology.

#### **3.3.1 Queering the Law**

Queering legal theory is not a novel or new enterprise. In 2009, Zanghellini proposed that the law requires a deft and queer hand:

“A call to queer the voice of the law therefore seems to require, substantively, that law and law reform open up to the concerns of a broader range of gender and sex outsiders than lesbians and gay men

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<sup>585</sup> Aleardo Zanghellini. ‘Antihumanism in Queer Theory’ (2020) 23(4) *Sexualities* 530, 533.

<sup>586</sup> Damian A Gonzalez-Salzberg, *Sexuality and Transsexuality under the European Convention on Human Rights: A Queer Reading of Human Rights Law* (Hart 2019), 2.

— and, methodologically, that in doing so the law remain sensitive to the contingency of gender and sexual identity categories”.<sup>587</sup>

The law is “far more implicated in its social, political and cultural contexts than this jurisprudential ideal would have us believe”.<sup>588</sup> We like to think of the law as a rigid, neutral source of factual information, structure, and rule. However, the law maintains its own foundations within the social and cultural, a self-referential development and progression. As such, Conaghan argues that the “law thus took its modern shape and form not under conditions of gender-neutrality but in the context of a legally sanctioned gender hierarchy”.<sup>589</sup> Extrapolating this further, understanding how marginalised communities all suffer at the hands of entrenched power, we can say the law perpetuates ableist narratives against PWDs in a similar way to its enforcement of gendered stereotypes and barriers on women and gender non-conformity.

Gonzalez-Salzberg, citing Balkan, defines deconstruction as “a critical reading of texts that is specifically aimed at highlighting certain meanings that, while present in the text, do not appear as the obvious focus of attention”.<sup>590</sup> Meanwhile, Derrida suggests that deconstruction is “inventive or it is nothing at all; it does not settle for methodical procedures, it opens up a passageway, it marches ahead and leaves a trail”.<sup>591</sup> Whilst these definitions approach the subject with different levels of aggression, they demonstrate a singular purpose: to not understand the *what* but to consider the *why* and *how*. What matters in terms of the law is not just how the law is written, but how it is interpreted. Within the context of the CRPD, for example, it is beneficial to

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<sup>587</sup> Zanghellini (n427), 2.

<sup>588</sup> Joanne Conaghan, *Law and Gender* (Oxford Academic 2013), 12.

<sup>589</sup> *Ibid*, 4.

<sup>590</sup> Gonzalez-Salzberg (n586), 2.

<sup>591</sup> Jacques Derrida, *Psyche: Invention of Other* (Stanford University Press, 2007) 23.

understand the document's full potential by questioning the seemingly trite and asking where it could take us. Queer is not content with pushing against the walls of a box; queer smashes directly through them.

There are several reasons to use a deconstructive lens to critique the law. Balkan outlines three, covering the various stages of legal commentary and reform:

“First, deconstruction provides a method for critiquing existing legal doctrines; in particular, a deconstructive reading can show how arguments offered to support a particular rule undermine themselves, and instead, support an opposite rule. Second, deconstructive techniques can show how doctrinal arguments are informed by and disguise ideological thinking ... Third, deconstructive techniques offer both a new kind of interpretive strategy and a critique of conventional interpretations of legal texts”.<sup>592</sup>

Queer, by taking a deconstructive lens, demonstrates not only what the current law does (and why), but also what it could do. Stychin notes that queer theory has “paid much attention to subjecting texts--literary, legal, political--to a deconstructive analysis, seeking to uncover the incoherence of the hetero/homo binary at the heart of the construction of those texts specifically, and of sexual identities more generally”.<sup>593</sup> As such, to critically assess the normative ideas within law and understand their logics, queer is best placed to provide said analysis. After all, “deconstruction is queer’s technique *par excellence*”.<sup>594</sup>

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<sup>592</sup> Jack M Balkin, ‘Deconstructive Practice and Legal Theory’ (1987) 96 Yale Law Journal 743, 743.

<sup>593</sup> Carl Stychin, ‘Couplings: Civil Partnerships in the United Kingdom’ (2005) 8 *New York City Law Review* 543, 544.

<sup>594</sup> Gonzalez-Salzburg (n586), 2.



Valdes argues that queer legal theory is “devoted to the education and reformation of legal discourse, culture, and doctrine regarding matters of (special) concern to sexual minorities”.<sup>595</sup> A queer legal theory, therefore, is a “legal theory that is queer is legal scholarship that is oppositional or at odds with – and thus in relation to – that which is normal or dominant”.<sup>596</sup> It is a “self-conscious, self-defined, and self-sustaining body of liberational legal scholarship that voices and pursues the interests of sexual minorities and its particular contribution towards the end of sex/gender subordination”.<sup>597</sup> Halperin argues that queer refers “not [to] a positivity but [to] a positionality vis-à-vis the normative”.<sup>598</sup> By extension, therefore, and by incorporating Butler’s considerations at section 2.4, queer legal theory becomes a positionality that considers the impact of multiple marginalised categories of social identity.

By bringing law into the world of queer, its origins in interdisciplinary cultural activism can “provide the point of departure for articulating and practicing queer legal theory as a form of multidimensionalised anti-subordination praxis in sexual orientation sociological contexts”.<sup>599</sup> However, it is important to note that much of queer politics and queer theory is “suspicious of identity politics, which tend to categorise and

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<sup>595</sup> Francisco Valdes, ‘Queers, Sissies, Dykes, and Tomboys: Deconstruction of the Conflation of “Sex”, “Gender”, and “Sexual Orientation” in Euro-American Law and Society’ (1995) 83(1) *California Law Review* 1, 344.

<sup>596</sup> Adam P Romero, ‘Methodological Descriptions: “Feminist” and “Queer” Legal Theories’ in Martha A Fineman, Jack E Jackson, & Adam P Romero (eds), *Feminist and Queer Legal Theory: Intimate Encounters, Uncomfortable Conversations* (Ashgate 2009), 195.

<sup>597</sup> Valdes (n595), 349.

<sup>598</sup> David Halperin, *Saint Foucault: Towards a Gay Hagiography* (OUP 1995), 62.

<sup>599</sup> Francisco Valdes, ‘Afterword – Beyond Sexual Orientation in Queer Legal Theory: Majoritarianism, Multidimensionality, and Responsibility in Social Justice Scholarship, or Legal Scholars as Cultural Warriors’ (1998) 75(4) *Denver University Law Review* 1409, 1423.

simplify experience”.<sup>600</sup> Merely because queer discusses the interaction between multiple categories of identity and entrenched normative power structures, that does not mean that an intersectional perspective carries its own elements of segregation and political performativity.

In contextualising queer legal theory, this section must also fetter queer. Modern queer legal theory can manifest as queer liberalism, an attempt to “reconcile the radical political aspirations of queer studies’ subjectless critique”.<sup>601</sup> This follows the tendency of queer commentators to shift away from intense deconstructivist methodology due to the “contemporary liberal demands of a nationalist gay and lesbian...citizen-subject petitioning for rights and recognition before the law”.<sup>602</sup> The international community has developed human rights along the path of stratification. Certain marginalised groups have their own human rights treaties, complete with unique interpretations of supposedly shared rights values.

This seems at odds with queer. Zanghellini posits that the “failure of much queer theory to live up to its abstract antihumanistic rhetoric may be due to the intuitive cognitive appeal of humanistic principles (universalism) and concepts (the autonomous right-bearing subject)”.<sup>603</sup> Creating a set of disability rights (whether rights for PWDs or disability-specific rights) seems to go against the ethos of queer to undo structural imbalances and ensure a holistic method of inclusion. By focusing on the individual, we lose sight of the overall goal of eradicating normativities. Likewise, Romero notes

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<sup>600</sup> Romero (n596), 190-1.

<sup>601</sup> David Eng, Judith Halberstam, & José Esteban Muñoz, ‘Introduction: What’s Queer about Queer Studies Now?’ (2005) 23(3-4) *Social Text* 1, 10.

<sup>602</sup> Ibid.

<sup>603</sup> Zanghellini (n585), 533.

that the “concept of queer legal theory is something of a paradox given the tensions between ‘queer’ and ‘legal’”.<sup>604</sup> Current social and legal discourse has ‘let in’ the queer and the crip, has provided them with a modicum of the power and privilege held by the normate. Society is still centred around cis/hetero- able-bodied normativity. Nevertheless, the existence of the CRPD, the fact that PWDs comprised a large portion of the Ad Hoc Committee for the drafting of the Convention, and the fact that we are now almost two decades on from the CRPD entering into force, all mean that the position of PWDs is not the same as it was in the 1990s, when disruptive political activism fuelled the fight for crip rights.

Finally, Romero argues that “what may be queer in relation to certain things, may not be queer in relation to others. That which is normative or dominant is of course a matter of context or perspective”.<sup>605</sup> This is where queer shines: by maintaining a sense of flexibility, queer can shift and shape itself to better approach a specific situation. He suggests that “we cannot, therefore, definitely know what the project of queer legal theory is, even as the bulk of legal theories understood to be queer are critical of the place and role of sexuality within law and legal institutions”.<sup>606</sup> Romero laments that “the second you (think you) get your finger on it, a queer theoretical move registers an exception or shifts away to posture contrary to what you think you just identified”.<sup>607</sup> He gives the example of asexuality; saying that queer defines itself within sexuality rejects the research of asexual people and perpetuates the narratives of allonormativity. As soon as the parameters of queer seem clear, queer immediately

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<sup>604</sup> Romero (n596), 190.

<sup>605</sup> Ibid, 195.

<sup>606</sup> Ibid, 192.

<sup>607</sup> Ibid.

dodges, ducks, dips, and dives out of reach, throwing into contention the seemingly clear foundations from moments prior.

Rather than shrugging its shoulders and lament that ‘this is how it is’, queer must change course and acknowledge the changes in the battlefield. Conversations about progressing the rights of marginalised groups must take into consideration the new position they find themselves in. Those same conversations must also work within the confines of a human rights model that tends to “universalise historically and geographically specific sexual and gender identities and are overly reliant on the language of rights, deploying it in the service of ultimately heteronormative ends”.<sup>608</sup> Human rights are here, and they can be queer, if we try hard enough.

### **3.3.2 Queering Human Rights**

Given, then, the multiple benefits available when using queer legal theory, yet the equally numerous potential clashes with the rigid structure of the law, it seems pertinent to outline precisely *how* one can queer human rights. Gonzalez-Salzberg and Hodson argue that vast swathes of human rights research engage in purely doctrinal methodology. Though this has its value, doctrinal approaches carry baggage not-outweighed by its benefits:

“...it provides a narrow and particular lens through which to engage with a subject that has roots in philosophy, religion and ethics; the articulation of which is intimately wrapped up with historical and political forces; and the meaningful application of which has such

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<sup>608</sup> Ibid.

crucial significance for individuals and groups seeking justice, challenging structural inequality, and striving for a language through which to articulate their claims for dignity”.<sup>609</sup>

The sources of human rights are varied and rich, and a doctrinal approach cannot begin to truly appreciate them. Therefore, using a queer lens to approach the law “could help us to critically analyse and question the role played by the law” when it comes to the regulation of identity.<sup>610</sup>

However, the debate works both ways. Not only is it important to justify using queer theory to develop human rights, but it is also important to justify why human rights are valuable to undo inequalities. Some feminists are not sold. For instance, Smart argues within the context of a right to an abortion, that “the law may concede a right but if the State refuses to fund abortions...it is an empty right”.<sup>611</sup> Smart shares the sentiment of Shakespeare when debating the theoretical versus the tangible: what good is a law or a policy if there is no enforcement, no discernible benefit to those with lived experience? The main reason for the AHC and the CRPD was that existing human rights frameworks did not adequately protect the human rights of PWDs. One logical conclusion, therefore, would be that a new human rights convention focused specifically on disabled experiences would make no difference, another swing of the bat which results in yet another miss.

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<sup>609</sup> Damian Gonzalez-Salzberg & Loveday Hodson, 'Human Rights Research beyond the Doctrinal Approach' in Damian Gonzalez-Salzberg & Loveday Hodson (eds), *Research Methods for International Human Rights Law: Beyond the Traditional Paradigm* (Taylor & Francis 2019), 2.

<sup>610</sup> Damian Gonzalez-Salzberg, 'A Queer Approach to the Advisory Opinion 24/2017 on LGBT Rights' in Damian Gonzalez-Salzberg & Loveday Hodson (eds), *Research Methods for International Human Rights Law: Beyond the Traditional Paradigm* (Taylor & Francis 2019), 103.

<sup>611</sup> Carol Smart, *Feminism and the Power of Law* (Routledge 1989), 143-4.

Another issue is how to address potential conflicting interests, especially given the lack of enforcement mechanisms. Human rights documents are often the offspring of international law, which tend to have purely political enforcement methods; it is difficult to hold States to account for rights violations if those States can ignore any condemnation from treaty bodies. Munro explains that “there is nothing within rights analysis itself to provide guidance on how such tensions can be resolved, without resort to broader utilitarian calculus”.<sup>612</sup> Further, Williams argues that “the problem of rights is not that the discourse is itself constricting, but that it exists in a constricted referential universe”.<sup>613</sup> Human rights is limited in scope. In citing Derrida, Fuss warns that “to the deconstructionist, strategy of any kind is a risk because its effects, its outcomes, are always unpredictable and undecidable. Depending in the historical moment and the cultural context, a strategy can be ‘radically revolutionary or deconstructive’ or it can be ‘dangerously reactive’”.<sup>614</sup>

There is also an arbitrariness to rights, acting as “the magic wand of visibility and invisibility, of inclusion and exclusion, of power and no power”.<sup>615</sup> Karaian jests, “I find myself responding to my own inquiries, as well as those of others, with even more questions”, the metaphor of the fictional gameshow *Theoretical Jeopardy!* highlights post-structuralism’s “troubled relationship with knowledge, power, danger, and the

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<sup>612</sup> Vanessa Munro, *Law and Politics at the Perimeter: Re-evaluating Key Debates in Feminist Theory* (Bloomsbury 2017), 77.

<sup>613</sup> Patricia Williams, *The Alchemy of Race and Rights* (Cambridge University Press 1991), 159.

<sup>614</sup> Diana Fuss, *Essentially Speaking: Feminism, Nature & Difference* (Routledge 1989), 20; see also Jacques Derrida, ‘Women in the Beehive: A Seminar with Jacques Derrida’ in Alice Jardine & Paul Smith (eds), *Men in Feminism* (Methuen 1987).

<sup>615</sup> Williams (n613), 164.

destabilisation of the legal subject”.<sup>616</sup> Locating the individual has traditionally been the focus of activist-based perspectives, and the uncertainty caused by the entrenched legal power dynamics leads to a confusion of how rights can possibly empower PWDs and undo discrimination. However, Muñoz notes that “queer failure is often deemed or understood as failure because it rejects normative ideas of value...it is blatantly and irrevocably antinormative”.<sup>617</sup> Whilst the critics above demonstrate an aversion to the risks associated with the strategy required to queer the law, Muñoz argues that these risks only appear due to comparisons with existing non-queer perspectives. There will always be risks to rejecting normativities, precisely because society is heavily reliant on them. Unease is born from uncertainty, yet queer thrives within the unknown and unrestrained.

Arguably, the concerns of human rights above are misguided. A deconstructive approach to human rights does not detract from the hard-fought protections of vulnerable people, nor does it refuse to acknowledge the value of those protections in a normative society. Instead, queer seeks to *critique* the law to re-centre minorities within a discourse of power. Queer is not a rejection of the law. To be critical of the law, to *critique* it, is not to argue that the law should not exist. Queer is not undermining the activity of rights; it merely attempts to “play a different game entirely”.<sup>618</sup> Sokhi-Bulley notes that “a critique of rights, for instance, does not distance itself from rights

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<sup>616</sup> Lara Karaian, ‘The Troubled Relationship of Feminist and Queer Legal Theory to Strategic Essentialism: Theory/Praxis, Queer Porn, and Canadian Anti-Discrimination Law’ in Martha A Fineman, Jack E Jackson, & Adam P Romero (eds), *Feminist and Queer Legal Theory: Intimate Encounters, Uncomfortable Conversations* (Ashgate 2009), 375.

<sup>617</sup> José Esteban Muñoz, *Cruising Utopia: The Then and There of Queer Futurity* (NYU Press 2009), 173.

<sup>618</sup> Ben Golder, *Foucault and the Politics of Rights* (Stanford UP 2015), 117.

or dismiss rights; rather, it must use rights strategically”.<sup>619</sup> A critical attitude understands that “before you can break the rules, you have to know what the rules are”.<sup>620</sup>

Therefore, a marriage of queer theory and law through human rights offers new possibilities. Several feminists and queer theorists have sought to “deconstruct international law norms to expose their structural biases and to question the value systems that underlie the privileging and prioritising of certain issues over others”<sup>621</sup> Nedelsky suggests that rights discourse promotes equality in dynamics of power.<sup>622</sup> Given that queer shares this quality, this should make them natural bedfellows. Likewise, Palmer argues that human rights offer an opportunity for marginalised voices to have a platform in situations they have otherwise been disenfranchised from, such as the courtroom.<sup>623</sup> The discussion in Chapter One highlights the ways in which PWDs have been ostracised and kept out of the purview of human rights protections. This is not a consequence of discrimination against minorities manifesting as a core quality of human rights, but a result of poor drafting and failure to include varied experiences in rights discourse. Human rights have political power, as they demonstrate a social claim to respect and support; to promote such a claim, Bilder argues, is “to vest it

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<sup>619</sup> Bal Sokhi-Bulley, ‘A Postmodern Approach to *Elisabeta Dano v Jobcenter Leipzig*’ in Damian Gonzalez-Salzberg & Loveday Hodson (eds), *Research Methods for International Human Rights Law: Beyond the Traditional Paradigm* (Taylor & Francis 2019), 72.

<sup>620</sup> Panu Minkinen, ‘Critical Legal ‘Method’ as Attitude’ in Dawn Watkins & Mandy Burton (eds), *Research Methods in Law* (Routledge 2013), 119.

<sup>621</sup> Nora Honkala, ‘International Law and Human Rights’ in Rosemary Auchmuty (ed), *Great Debates in Gender and Law* (Palgrave 2018), 88.

<sup>622</sup> Jennifer Nedelsky, ‘The Practical Possibilities of Feminist Theory’ (1993) 87 *Northwestern University Law Review* 1290.

<sup>623</sup> Stephanie Palmer, ‘Feminism and the Promise of Human Rights: Possibilities and Paradoxes’ in Susan James and Stephanie Palmer (eds), *Visible Women: Essays on Feminist Legal Theory and Political Philosophy* (Hart 2002), 97.



emotionally and morally with an especially high order of legitimacy”.<sup>624</sup> Given the symbolic power vested in human rights, feminist and queer theorists argue that movements tasked with seeking to undo oppressive systems and deconstruct barriers should take advantage of human rights.<sup>625</sup>

### **3.4 Conclusion**

This chapter provides two approaches taken by theorists to apply queer to issues relevant to the research questions of this thesis. Queer is a broad and innovative method, eager to deconstruct existing problematic structures. In order to highlight how this approach can be applied to the CRPD, this chapter brings crip theory and queer legal theory to the table. In section 3.2, it outlines the key elements of crip theory, establishing how academics such as McRuer have taken the work of Butler and applied it to disability studies. In doing so, it shows how a postmodern and post-structural methodology can apply to disabilities, further demonstrating that Shakespeare is unduly critical in his rejection. In section 3.3, this chapter highlights how queer can be applied to law and legal theory. Regardless of the fundamental differences between the fluidity of queer and the rigidity of the law, commentators such as Zanghellini and Gonzalez-Salzberg show how a queer perspective can successfully critique human rights and afford minority groups greater protections.

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<sup>624</sup> Richard Bilder, ‘Rethinking International Human Rights Law: Some Basic Questions’ (1969) *Wisconsin Law Review* 174.

<sup>625</sup> Hilary Charlesworth & Christine Chinkin, *The Boundaries of International Law: A Feminist Analysis* (Manchester University Press 2000), 212.

## Four: Modelling Disability

“These kind of standards – the religious, the moral, the work ethic, the rational, and the medical – have for a long time provided the terms for discourse...the medical model stands out as the one that offers care and help to the individual, but generally it is not a good thing to be on the wrong end of any of the other distinctions: there lies sin, corruption, immorality, inadequacy, and irrationality, these signifying in each case the opposite of what is regarded as the highest good”.<sup>626</sup>

### 4.1 Introduction

Disability equality is a core component of the various legislative documents discussed in Chapter One. The overall objective of this thesis is to re-frame 'disability' conceptually to match the needs of PWDs. To achieve this, it aims to provide an inclusive and sensible interpretation of the CRPD. In turn, the international community must be clear on equality and inclusivity concerning disability. Rioux and Riddle note that “the meaning of equality will vary depending on the perspective of disability adopted”.<sup>627</sup> We lack an internationally recognised definition of disability, causing potential issues with the interpretation and practical application of human rights principles. The reason is that disability is incredibly complex and does not open itself up to simplification or broad definition application. In Waldschmidt’s words, the “complexity, relativity, and multidimensionality of bodily, mental, and psychological

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<sup>626</sup> Derek Bolton, *What is Mental Disorder? An Essay in Philosophy, Science, and Values* (OUP 2008), xv.

<sup>627</sup> Marcia H Rioux & Christopher A Riddle, ‘Values in Disability Policy and Law: Equality’ in Marcia H Rioux, Lee A Bassar & Melinda Jones (eds), *Critical Perspectives on Human Rights and Disability Policy* (Martinus Nijhoff 2011), 42.

phenomena make it difficult to establish a clear-cut disability definition as a starting point and to agree on operational categories that meet the basic requirements of valid statistics, such as one-dimensionality, exclusiveness, and completeness".<sup>628</sup> As such, the development of an understanding of disability has been slow and incremental. As Sandland notes, the main issue which the CRPD raises is whether a 'social model' should be adopted universally within international human rights – "although I concede that Rome was not built in a day, and so [I suggest] other, less contentious, changes...whilst we patiently await 'the dawn of a new era' promised by Kofi Annan on the day the CRPD came into existence".<sup>629</sup> There has been a regular update to the collective consciousness, rather than a "new era".

Parties engaged in the PWD rights discourse have created their definitions of disability founded on various models of understanding. Some utilise morality and religion to justify confinement and segregation policies, the creation of asylums, and the perception of disability as a tragedy. Others view disability through a lens of pathology, relying on medicine to treat abnormalities in the mind and body. Additionally, social definitions are operational at a national level, including segregated specialist education for children with disabilities and the medical monopoly of pathology over disability treatment. Each model has its merits and shortcomings, each contributing to the overall historic discussion of disability and society. Importantly, though considered their own independent theories, these models often share certain foundations and features, articulating disability in unique ways to achieve different results. As such, commenting on shared overarching themes rather than discussing each model in

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<sup>628</sup> Waldschmidt (n524), 1168.

<sup>629</sup> Ralph Sandland, 'A Clash of Conventions? Participation, Power, and the Rights of Disabled Children' (2017) 5(3) *Social Inclusion* 93, 94.

isolation will produce a richer assessment of the existing literature. It will form a foundational basis upon which this thesis shall develop the queer/crip identity approach, using the commentary and critique from this chapter to establish the important features of an inclusive disability approach, which queers the interaction approach taken by Shakespeare. Therefore, this chapter will outline many of the key features of different disability models through three topics – biology, governance, and rescue. In doing so, it will also establish general foundations of models to explain their creation and function. This will allow subsequent chapters to discuss the formation of the identity approach, how identity reacts to the pre-existing models, and how it potentially answers the questions left wanting by said models.

## **4.2 Biology: Locating Disability in the Body**

To begin, some models of disability rely on biological justifications for identifying disability, as society maintains a history of locating disability in the human body. Early understandings of deviant behaviour followed a moral or religious perspective. Moral positions have included disability as a reflection of God's dismay in Ancient Greece, as evidence of intimacy with God in medieval Europe, and as a divine response to parental wrongdoing during the Renaissance.<sup>630</sup> As society transitioned into the age of industrialisation and scientific enquiry, perspectives shifted from religious tragedy to medical logic. Disability remained a bodily issue, but the location and cause changed. A Foucauldian analysis<sup>631</sup> articulates the seventeenth century as "the epoch of confinement".<sup>632</sup> Waldschmidt notes that as a "consequence of the working and

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<sup>630</sup> David T Mitchell & Sharon L Snyder, *Narrative Discourse: Disability and the Dependencies of Discourse* (University of Michigan Press 2001), 379-380.

<sup>631</sup> Michel Foucault, *History of Madness* (Jean Khalifa ed, Jonathan Murphy & Jean Khalifa trs) (Routledge 2009).

<sup>632</sup> Waldschmidt (n524), 1169.

living conditions in an early capitalist society, chronic diseases, impairments, and injuries were widespread in the nineteenth century. Poor health was one of the main causes of deprivation and pauperisation".<sup>633</sup>

Historically, disability groups have maintained caution around medicine. In discussing the Kerr and Shakespeare note that "in order to achieve legitimacy, the new biology had to develop the alibi of health and social improvement as the potential benefits of genetic research".<sup>634</sup> Narratives on medicine developed around removing disability from society,<sup>635</sup> yet Kerr & Shakespeare note that scientists are often ignorant about disability experiences.<sup>636</sup> Despite this, Kerr and Shakespeare acknowledge "it would be wrong to single out scientists as apart from culture".<sup>637</sup> Social model theorists argue disability stems from "the failure of a structured social environment to adjust to the needs and aspirations of citizens with disabilities rather than from the inability of the disabled individual to adapt to the demands of society".<sup>638</sup> As such, society has created a need for medicine, a cyclical justification for its existence.

The resulting treatment of PWDs remained the same for both moral and medical models as institutionalisation became commonplace, generating asylums for people with impairments.<sup>639</sup> Later developments of disability and the social model, though

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<sup>633</sup> Ibid.

<sup>634</sup> Kerr & Shakespeare (n351), 104.

<sup>635</sup> Ibid, 105

<sup>636</sup> Ibid.

<sup>637</sup> Ibid.

<sup>638</sup> Harlan Hahn, 'Public Support for Rehabilitation in Programs: The Analysis of US Disability Policy' (1986) 1(2) *Disability & Society* 121, 128.

<sup>639</sup> Ibid.

shifting the narrative towards societal disablement, rely on the tangible implications of impairment and the pathological evidential basis of difference in the body. As such, they leave the door open for medicine to play an active role in the commentary of PWD physiology and psychology.

#### **4.2.1 Biomedical Overview**

According to Annandale, the biomedical model comprises three characteristics. Firstly, it is reductive, assuming that “disease is a problem of the individual body, rather than a result of the interaction of the individual and the social world”.<sup>640</sup> Western science and medicine revolve around “a fundamental opposition between spirit and matter, mind and body, and...real and unreal”,<sup>641</sup> distinguishing between a legitimate quantifiable cause of disease and something merely circumstantial to the issue. In turn, it becomes commonplace to interpret “the stream of social information [from the individual] as extraneous and irrelevant to the *real* biomedical diagnosis”.<sup>642</sup>

Secondly, it follows the doctrine of specific aetiology, that “physiological stresses are...regarded as specific causes of disease”.<sup>643</sup> The notion of specificity is “typically interpreted in terms of a monocausal view in which particular diseases have single main causal factors”,<sup>644</sup> all diseases have a central cause which can be determined through medical, scientific rigour and assessment. An inability to understand the

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<sup>640</sup> Ellen Annandale, *The Sociology of Health and Medicine* (2nd edn, Polity Press 2014), 4.

<sup>641</sup> Nancy Scheper-Hughes & Margaret M Lock, ‘The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology’ (1987) 1(1) *Medical Anthropology Quarterly* 6, 8.

<sup>642</sup> *Ibid.*

<sup>643</sup> René Dubos, *Mirage of Health: Utopias, Progress, and Biological Change* (Harper Colophon 1979), 102.

<sup>644</sup> Lauren N Ross, ‘The Doctrine of Specific Etiology’ (2018) 33:37 *Biology & Philosophy* 36, 37.

cause of disease should be attributed to the limited technology used to measure health, which can continually improve accuracy. Nevertheless, Dubos suggests that searching for the cause “may be a hopeless pursuit because most disease states are the indirect outcome of a constellation of circumstances rather than the direct result of single determinant factors”.<sup>645</sup>

Thirdly, it claims scientific neutrality, that it “can be rational, objective, and value-free, treating each individual, treating each individual according to their need, irrespective of imputed moral worth”.<sup>646</sup> Medicine takes an objective stance on assessing an individual's health, ignoring any social factors that may cause a bias during an assessment. In practice, however, the medical model “focuses on the health status or biological characteristics of the individual and on attempt to cure the functional limitations of the [PWD] in question, in order to bring the individual in line with the non-disabled norm”.<sup>647</sup> Decisions during assessments may be made through a lens of normativity: Nurok and Henckes’ study on pre-hospital resuscitation suggests that social factors sometimes constitute competing values, causing some level of prejudice or predisposition towards a particular decision.<sup>648</sup> However, no one ‘true’ version of the medical model exists. Instead, different methods of interpreting the general model ideas manifest throughout history.

Nagi, who saw “fundamental distinctions” between conceptually different conditions, outlined a framework separating phenomena into five different yet overlapping

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<sup>645</sup> Dubos (n643), 102.

<sup>646</sup> Annandale (n640), 5.

<sup>647</sup> Broderick & Ferri (n339), 19.

<sup>648</sup> Michael Nurok & Nicholas Henckes, ‘Between professional values and the social valuation of patients: the fluctuating economy of pre-hospital emergency work’ (2009) 68 *Social Science & Medicine* 504.

categories.<sup>649</sup> First is Active Pathology, the state of mobilising “the body’s defences and coping mechanisms”.<sup>650</sup> This category involves not only the establishment of disease and the disruption it causes to the body but also the body’s attempts to ‘recover’, to return to the previous state. Disease is, therefore, “not merely the surrender of the body to an abnormal state of affairs, but also the fight for health”.<sup>651</sup> In other words, “unless there is fight, there is no disease”.<sup>652</sup> There must be an interaction or conflict between the body and the altered state of being. Second is Impairment, the “anatomical and physiological abnormalities and losses”.<sup>653</sup> Though disease often involves some element of deviation, they are not always causally linked or reliant on each other to exist, such as impairments which outlast the treatment of a disease. As such, “every disease involves an impairment, but not every impairment involves a disease”.<sup>654</sup> The third is Functional Limitation, how impairments impact the performance of regular activities. Of note is that “the degree of limitation is not dependent only on the type of impairment but also on the nature and requirements of these...activities”.<sup>655</sup> There are situations in which an impairment will cause more or less of a burden or barrier. Nagi, therefore, justifies the use of ‘functional’ as a determiner, suggesting that “not every impairment results in functional limitations”.<sup>656</sup>

Fourth is Behaviour, the visible reaction of the individual when a disease manifests. Behaviour generates three different forms: individual characteristics of the

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<sup>649</sup> Saad Nagi, ‘Some Conceptual Issues in Disability and Rehabilitation’ in Marvin Sussman (ed) *Sociology and Rehabilitation* (American Sociological Association 1965), 100.

<sup>650</sup> Ibid, 101.

<sup>651</sup> Ibid.

<sup>652</sup> Hans Selye, *The Stress of Life* (McGraw-Hill 1956), 11.

<sup>653</sup> Nagi (n649), 101.

<sup>654</sup> Ibid, 102.

<sup>655</sup> Ibid.

<sup>656</sup> Ibid.



pathological condition and the definition of the situation by both the individual and third parties. Finally, fifth is Disability, defined as “a pattern of behaviour that evolves in situations of long-term or continued impairments associated with functional limitations”.<sup>657</sup> These often manifest themselves in performing socially defined roles and actions or exercising tasks within the local environment. However, correlation does not equal causation; while disability “indicates the existence of an impairment which limits the individual’s functioning, it may not be associated with the presence of a disease”.<sup>658</sup>

Subsequently, other organisations and scholars took the Nagi model and developed it further, hoping to create a deeper mode. One of the key groups in the United States of America to use the Nagi model was the IOM.<sup>659</sup> It defined disability as “the interaction of...physical or mental limitations with social and environmental factors”.<sup>660</sup> Further, it describes these risk factors as “independent variables that exist at all stages of the process”.<sup>661</sup> Of note is the reliance on the directional aspect of the Nagi model, the compounding and development of impairment, and “the need for identifying risk factors whose control would facilitate the prevention of disability”.<sup>662</sup> Second, the NCMRR “adds emphasis to the importance of environment”.<sup>663</sup> It adds “societal

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<sup>657</sup> Ibid, 103.

<sup>658</sup> Ibid.

<sup>659</sup> Arie Rimmerman, *Social Inclusion of People with Disabilities: National and International Perspectives* (CUP 2012), 26.

<sup>660</sup> Institute of Medicine, *Disability in America: Toward a National Agenda for Prevention* (Alvin R. Tarlov & Andrew M Pope eds) (National Academies Press 1991), 81.

<sup>661</sup> Institute of Medicine, *Enabling America: Assessing the Role of Rehabilitation Science and Engineering* (Edward N Brandt Jr & Andrew M Pope eds) (National Academy Press 1997), 64.

<sup>662</sup> Ibid, 67.

<sup>663</sup> Ibid, 64.

limitations" as a category to the Nagi model,<sup>664</sup> covering "restrictions attributable to social policy or barriers, which limit the fulfilment of roles or deny access to services and opportunities".<sup>665</sup> Through this addition, biomedical models seek to appreciate and understand the points of interaction between the body and society, the internal and external. They drift close to a biosocial understanding yet never reach it.

Townsend's construction of disability maintains similar features.<sup>666</sup> Disability comprises five concepts: abnormality or loss, clinical condition, functional limitation, deviance, and disadvantage.<sup>667</sup> The first two are primarily the same; where Nagi uses 'active pathology', Townsend uses 'clinical condition'. Townsend goes as far as to suggest that, conceptually, one could combine these two under an umbrella term of "impairment".<sup>668</sup> Townsend also builds on the deviance of behaviour, which "can be determined by an impairment or pathological condition" and may be irregular.<sup>669</sup> Behaviour need not be reduced purely to the physiological impairment but can consist of "a mixture of what society expects of someone in certain situations and what the individual falls into doing".<sup>670</sup> Townsend differentiates this from functional limitation, suggesting that due to the potential for irregularity and the nature of behavioural and social deviance, "activity might not necessarily be limited or only limited, but

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<sup>664</sup> National Center for Medical Rehabilitation Research, *Research Plan for the National Center for Medical Rehabilitation Research* (National Institutes of Health 1993), 25.

<sup>665</sup> *Ibid.*

<sup>666</sup> Peter Townsend, *Poverty in the United Kingdom: A Survey of Household Records and Standards of Living* (Penguin Book 1979), 686.

<sup>667</sup> Michael Oliver, Bob Sapey, & Pam Thomas, *Social Work with Disabled People* (4<sup>th</sup> edn, Palgrave Macmillan 2012), 11-2.

<sup>668</sup> Townsend (n666), 688.

<sup>669</sup> *Ibid.*, 686.

<sup>670</sup> *Ibid.*, 686-7.

different”.<sup>671</sup> Finally, concerning disadvantage, Townsend focuses on the socially-defined class and status afforded to persons with Disabilities.

#### **4.2.2 Regulating Bodies**

WHO developed the ICIDH model to classify disease, consequence, and individual impact. The foreword to the 1993 reprint of the ICIDH outlines the purpose of the Classification:

“...the ICIDH is intended to offer a conceptual framework for information; the framework is relevant to the long-term consequences of disease, injuries, or disorders, and applicable both to personal health care, including early identification and prevention and to the mitigation of environmental and societal barriers...a primary application of the ICIDH has been in describing the circumstances of individuals with disabilities across a wide range of settings”.<sup>672</sup>

The ICIDH acknowledges that “difficulties arise because of the limited scope of the medical model of illness”.<sup>673</sup> As such, the document establishes separate categories of Disease/Disorder, Impairment, Disability, and Handicap; each stage is different and focuses on a different element of disability, yet the ICIDH proposes multiple links between the stages than following a more linear progression like the Nagi model.

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<sup>671</sup> Ibid, 686.

<sup>672</sup> WHO (n454), 2.

<sup>673</sup> Ibid, 10.

Concerning Disease and Disorder, the State must deviate from the ascribed norm and occur within the individual. As the ICIDH notes:

“...a chain of causal circumstances, the aetiology, gives rise to changes in the structure or functioning in of the body, the pathology. Pathological changes may or may not make themselves evident; when they do, they are described as manifestations, which...are usually distinguished as symptoms and signs”.<sup>674</sup>

From this stems three additional events in the individual’s experience: the individual becomes aware of the state, their behaviour and performance becomes altered, and subsequent disadvantage becomes evident. These phases of exteriorisation, objectification, and socialisation reflect the aspects of Impairment, Disability, and Handicap, respectively. The multiple links between these stages become evident with an understanding that a handicap may result from an impairment without evidence of a disability or that a state of active pathology gives rise to socialised disadvantage without a disability being attributed to that connection. Moreover, each stage is severable from one another, and each experience may be interrupted at any category; there can be “striking disparities in the degree to which the various elements of the sequence depart from their respective norms, and, as a result, one cannot assume consonance in degrees of disability and handicap”.<sup>675</sup>

The ICIDH considers an impairment “concerned with abnormalities of body structure and appearance and organ or system function, resulting from any cause”.<sup>676</sup> Impairment reflects a “deviation from some norm in the individual’s biomedical

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<sup>674</sup> Ibid, 25.

<sup>675</sup> Ibid, 30.

<sup>676</sup> Ibid, 14.

status”.<sup>677</sup> It “represents disturbances at the organ level”.<sup>678</sup> It is the exteriorisation of disease. Impairment is “not contingent upon aetiology, how the state arose or developed; both ascribed and achieved status...are included”<sup>679</sup> and includes losses rather than mere lack. Impairment “does not necessarily indicate that disease is present or that the individual should be considered sick”.<sup>680</sup> Disability ultimately reflects “the consequences of impairment in terms of functional performance and activity by the individual; disabilities thus represent disturbances at the level of the person”.<sup>681</sup> Where an impairment is a loss or lack of psychological, physiological, or anatomical function, a disability is an action or function that the impairment inhibits. The performance of daily actions for the individual may be impacted by the change in status, as a restriction of actions objectifies the lived experience.

Finally, Handicap is “concerned with the disadvantages experienced by the individual as a result of impairments and disabilities; handicaps thus reflect interaction with and adaption to the individual’s surroundings”.<sup>682</sup> The 1993 reprint emphasises that the structure of ‘handicap’ is “more problematic” than the other two classifications, given that it is “radically different from all other ICD-related classifications”.<sup>683</sup> The ICIDH focuses on “the circumstances in which people with disabilities are likely to find themselves, circumstances that can be expected to place such individuals at a disadvantage concerning their peers when viewed from the norms of society”.<sup>684</sup> There are three features of handicap – first, that “some value is attached to departure

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<sup>677</sup> Ibid, 27.

<sup>678</sup> Ibid, 14.

<sup>679</sup> Ibid, 27.

<sup>680</sup> Ibid.

<sup>681</sup> Ibid, 14.

<sup>682</sup> Ibid.

<sup>683</sup> Ibid.

<sup>684</sup> Ibid.

from a structure, functional, or performance norm”, second that “the valuation is dependent on cultural norms, so that a person may be handicapped in one group and not in another”, and finally that “the valuation is usually to the disadvantage of the affected individual”.<sup>685</sup>

One additional note regarding Handicap relates to terminology. The ICIDH acknowledges the need for an umbrella term to govern impairment, disability, and handicap. The official French version uses handicap as the overarching term for the three stages, “stressing that it does not cover a monolithic reality but is the result of different experience levels”.<sup>686</sup> Other versions suggest disadvantage or disablement, but neither are universally accepted. At this stage, there appears to be no single agreed term.<sup>687</sup> This debate has led to a complicated understanding of this final stage, especially regarding the “normal social roles”. Handicap is arguably an assessment of conformity, penalising those who do not match the preconceived societal expectations. Section 2.3 deals with the governance of the person in greater detail. It is telling that the subsequent ICF definition/model completely dropped handicap as a concept.

The ICF model, approved by the World Health Assembly in 2001, sought to build upon the ICIDH. It takes a multidimensional approach based on a “biopsychosocial perspective on health”.<sup>688</sup> The origin of disability remains the health of the individual – a condition of either disorder or disease. However, the model differentiates between

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<sup>685</sup> Ibid, 29.

<sup>686</sup> Ibid, 6.

<sup>687</sup> Ibid.

<sup>688</sup> Janette McDougall, Virginia Wright & Peter Rosenbaum, 'The ICF model of functioning and disability: Incorporating quality of life and human development' (2010) 13(3) *Developmental Neurorehabilitation* 204, 205.

functioning and disability based on three individual facets: the bodily functions and structures of the individual, their activity limitations, and their participation restrictions. Other contextual matters relate to factors both environmental and personal.<sup>689</sup> Disability combines medical terminology, activity limitations, and participation restriction. The ICF provides a "coherent view of different perspectives of health: biological, individual and social".<sup>690</sup> The academic community met this change with general approval, as "the use of the participation concept as well as the reference to environmental factors are important novelties in contrast to the ICIDH".<sup>691</sup> Grech argues that the ICF maintains "the ambitious aim of becoming a unified, universal framework for defining and quantifying disability in a culturally neutral way", attempting to "bridge the medical and social models...[and] seeking to achieve a synthesis" between original perspectives.<sup>692</sup>

Further, regulating bodies provides space to approach the matter from the perspective of capability. Commonly attributed to the writings of Amartya Sen,<sup>693</sup> it establishes an alternative method of medicalising the human body by assessing the ability of an individual to perform tasks. Broderick notes that it distinguishes "functionings" from "capabilities".<sup>694</sup> Functionings are the "various states of human beings and activities that a person can undertake", and capabilities are the "innate potential of each human being".<sup>695</sup> As such, people's capabilities determine the freedom to achieve well-being

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<sup>689</sup> World Health Organisation, *International Classification of Functioning, Disability, and Health* (WHO 2001).

<sup>690</sup> World Health Organisation, *ICF: Towards a Common Language for Functioning, Disability and Health* (WHO 2002), 9.

<sup>691</sup> Waldschmidt (n542), 1168.

<sup>692</sup> Shaun Grech, 'Disability in the folds of Poverty: Exploring Connections and Transitions in Guatemala' (DPhil Thesis, Manchester Metropolitan University 2011), 13.

<sup>693</sup> See Amartya K Sen, *Development as Freedom* (OUP 2001).

<sup>694</sup> Broderick (n16), 28.

<sup>695</sup> Ibid.

and, thus, the kind of life they can lead effectively.<sup>696</sup> The path individuals can take, and the life they wish to lead are inherently restricted based on the physiological aspects of their bodies. What people can do and what they can be are pre-determined by biology.<sup>697</sup> Such is the nature of life and humanity, and society should use technological advances to support individuals in reaching their potential within the confines of their capability. One must note that this deviates from the traditional ‘medical’ models of disability as purported by social model advocates. A capabilities approach blends elements of medicalisation of the body with an acknowledgement of the social ramifications of functional limitations. However, differentiating between functionings and capabilities means that the approach relies in part on finding disability in the body. This chapter will consider the social aspect of this dynamic with discussions of the social models at section 4.3. However, to clarify – this chapter is not aligning the capabilities approach with the medical model of disability. Instead, this is a commentary on how a perspective that traditionally relies on a social model understanding can actually perpetuate a reliance on pathology to justify labels and treatment.

Nussbaum takes this idea further and establishes a comprehensive list of “central human capabilities”<sup>698</sup>. This classification includes direct physical aspects of the individual’s body of life, bodily health, and bodily integrity. It includes mental considerations, such as senses, imagination, thought, and emotions. Further, it includes aspects of social interaction which rely on these individual classifications, such as affiliation, the nature of other species, play, and control over one’s

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<sup>696</sup> Ibid, 29.

<sup>697</sup> Martha C Nussbaum, *Women and Human Development* (CUP 2001), 5.

<sup>698</sup> Martha C Nussbaum, *Creating Capabilities: The Human Development Approach* (Harvard UP 2011), 33.



environment.<sup>699</sup> This mix of sources culminates in the individual's capability, their potential within the social context. Proponents of this perspective suggest that understanding capability as a baseline ensures "a notion of the basic heterogeneity of human beings, such that human diversity is essential to [this] approach to equality".<sup>700</sup> Advocates of this perspective have developed the notion of capability further in understanding the concepts of agency<sup>701</sup> and arguing how capability relates to human rights.<sup>702</sup> Such discussions have contributed to the extension and development of welfare models, promoting the investment of State resources in supporting those within society afflicted with reduced capability.

This perspective bleeds, metaphorically and literally, into national laws relying on a biomedical analysis of disability. The UK's national law is such an example. The Disability Discrimination Act describes a disabled person as "anyone with a physical or mental impairment, which has a substantial and long-term adverse effect upon their ability to carry out normal day-to-day activities".<sup>703</sup> It will only acknowledge a mental impairment if it is a "clinically well-recognised illness".<sup>704</sup> Importantly, it states that an impairment must last between 12 months and the rest of the individual's life to classify as a long-term effect.<sup>705</sup> This logic continues through subsequent legislation, especially in statutes intended to update the law and bring it into modern thinking. The Equality Act 2010 defines disability as a "physical or mental impairment" that has "a

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<sup>699</sup> Ibid, 33-34.

<sup>700</sup> WR Woodward and L Barbour, 'Beyond Universalism: Capabilities Approach for Improving Women's Quality of Life' (2009) 3(2) *Journal of Human Ontogenetics* 75, 77.

<sup>701</sup> See further, David A Crocker & Ingrid Robeyns, 'Capability and Agency' in Christopher Morris (ed), *Amartya Sen* (OUP 2009).

<sup>702</sup> See, for example, Martha C Nussbaum, 'Capabilities and Human Rights' (1997) 66(2) *Fordham Law Review* 273.

<sup>703</sup> Disability Discrimination Act 1995, s.1 (1).

<sup>704</sup> Ibid, Schedule 1, s.1 (1).

<sup>705</sup> Ibid, Schedule 1, s.2 (1) (a-c).

substantial and long-term adverse effect on [an] ability to carry out normal day-to-day activities”.<sup>706</sup> The Care Act 2014 mentions disability or impairment “which gives rise, or which the authority considers may in the future give rise, to needs for care and support” regarding individuals registering as disabled with a local authority.<sup>707</sup> These statutes provide a practical example of policies which defer power to medical professionals, relying on their knowledge to adjudicate over the legal interaction between PWD and the State. They demonstrate a State’s reliance on third parties to approve or deny an individual access to support, with a State refusing to afford individual support if they do not meet the requirements of the statutory test.

### **4.2.3 Diagnosing the Fatal Flaws**

This final section critiques the biological approach taken by various models of disability. A history of pathology means that the power to control the disability narrative rests beyond the reach of PWDs. Individuals and institutions have afforded themselves the authority to navigate the development of disability research, often at the expense of PWD voices. A queer assessment of the two previous sections generates four problems with a biological analysis of disability. Each creates an impasse of unfairness and injustice. Taken together, they render the approach unworkable as a predominant model.

First, a medical perspective of disability ignores the social barriers PWDs experience daily. Disability studies scholars, and proponents of the social model in general, tend to blame the medical model for discrimination, as the model focuses solely on the

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<sup>706</sup> Equality Act 2010, s.6 (1).

<sup>707</sup> Care Act 2014, s.77.

impairment itself. Broderick notes that impairment's consequence is the individual's inability to participate in society,<sup>708</sup> which a biological assessment of disability explicitly ignores. Disability covers a wealth of experiences, meaning too great a focus on one stone leaves another stone unturned. At best, it reduces the potential impact of research, where professionals tasked with offering support to PWDs suffer from tunnel vision. At worst, it risks medical model subscribers becoming apologists for the most problematic layers of the intersection. Bolton notes a further issue within the context of mental health, the “negative values associated with the medical model specifically has to do with the ambiguous nature of the mental illness attribution”.<sup>709</sup> He argues that “on the one hand, it excuses by reason of illness, but on the other it does so by apparently disqualifying the person’s mental life and agency”.<sup>710</sup> There is an inherent inconsistency, a double-standard that limits an individual’s ability to advocate for themselves and seek respect. Any malady or misstep from PWDs are labelled as an obvious consequence of ill-health.

Broderick and Ferri argue that “structural inequalities and inaccessibility are not taken into account, nor are they addressed as possible factors in the process of disablement” by the medical model,<sup>711</sup> and that it requires the individual to “fit into society rather than requiring society to adapt to the individual”.<sup>712</sup> Though this argument carries some validity, it should be fettered and applied to general practice. Often, the individual is not expecting unique treatment. The result of this approach is segregation from society, as “those who are considered deviant from the norm and incompetent

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<sup>708</sup> Broderick (n16), 23

<sup>709</sup> Bolton (n626), xv.

<sup>710</sup> Ibid.

<sup>711</sup> Broderick & Ferri (n339), 19.

<sup>712</sup> Ibid.

are excluded”.<sup>713</sup> It is “disempowering and reinforced stigmatisation as well as unequal structures in society”.<sup>714</sup> It has been criticised for its debilitating emphasis on physical limitations and low expectations.<sup>715</sup> When legislators rely on medical definitions, the result is a “‘labelling’ approach, segregated structures and alternative services”.<sup>716</sup> It is often considered a ‘charity’ model due to State responsibility to PWDs being achieved through welfare payments.<sup>717</sup> This critique appears to highlight the need for society to create specialist support structures at great expense for a drastic minority. However, as noted in the Introduction, disability affects a considerable portion of the public and the accessibility changes sought are broad and would benefit non-disabled persons as well. Later chapters will discuss how these changes would work in practice.

Further, even when aspects of social discrimination and segregation feature in medical modelling, they are woefully underrepresented. Waldschmidt notes that despite the changes brought by the ICF, “the social model of disability was only half-heartedly implemented”.<sup>718</sup> Any reference to divested disability sources has shaky foundations, as the biopsychosocial perspective is still heavily reliant on knowledge of the body. It sees disability as “an umbrella term for impairment, activity limitations and participation restriction”.<sup>719</sup> However, most of those are still bodily observations – the body's status compared to itself and others. When considering the social, it is a mere footnote of what the body can do when navigating society’s obstacle course. All three

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<sup>713</sup> Ibid.

<sup>714</sup> Ibid.

<sup>715</sup> See Simon Brisenden, ‘Independent Living and the Medical Model of Disability’ (1986) 1(2) *Disability and Society* 173, 177.

<sup>716</sup> Broderick & Ferri (n339), 19.

<sup>717</sup> Gerard Quinn & Eilionóir Flynn, ‘Transatlantic Borrowings: The Past and Future of EU Non-Discrimination Law and Policy on the Ground of Disability’ (2012) 60(1) *American Journal of Comparative Law* 23.

<sup>718</sup> Waldschmidt (n542), 1168.

<sup>719</sup> Dan Goodley, *Disability Studies: An Interdisciplinary Introduction* (2nd edn, Sage 2017), 20.

theoretical perspectives outlined in chapter two promote an understanding and respect for various sources. Queer seeks the mechanical sources of issues, which in this instance rest partially in the social. As a queer extension of disability studies, Crip also aims at the social elements of disability, rejecting an overly medicalised view of the human condition. As such, the identity approach proposed in Chapter Five will consider multiple sources, rejecting an over-emphasis on pathology.

Secondly, focusing on pathology generates a biological binary, promoting an “us versus them” mentality. This approach manifests in welfare legislation, which often holds resources out of reach from those who need them. For example, the UK law referenced in section 4.2.2 merges impairment and disability as synonymous concepts.<sup>720</sup> Medicalisation “looks mainly for the deficit” and creates an “inferior role for persons with a disability in our society”.<sup>721</sup> In turn, this orients the law as a gatekeeper; to access the support of the State; PWDs “have to demonstrate that they are *really* impaired”.<sup>722</sup> There is a rift in society where mistreatment justified legislation that justified mistreatment, in a vicious circle. By sowing mistrust of disability within the general populace, legislation pathologising disabled existences creates a divide and scope for State-run ostracisation and individual vigilante regulation. As Davis notes, “those whose disabilities are invisible may have to convince other people that they really are disabled, not seeking some special – unfair – advantage”.<sup>723</sup> Linking back to the discussion of compulsory able-bodiedness and stigma at section 3.2.3, PWDs must prove their worthiness to funds for care, medical treatment, disabled parking, or seats on public transport to hawkish onlookers who see accommodations as luxuries rather

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<sup>720</sup> Ibid, 6.

<sup>721</sup> Rimmerman (n659), 23.

<sup>722</sup> Goodley (n719), 6.

<sup>723</sup> N Ann Davis, ‘Invisible Disability’ (2005) 116(1) *Ethics* 153, 154.

than necessities. Not only does this perpetuate a society built around unaccommodating structures, forcing all members to navigate an imperfect world built without physical and mental wellbeing in mind, it persuades the broader normate membership that the down-trodden PWDs are the real villain in this faux war. In essence, such laws pit these two groups against each other. In the red corner is the normate, those blessed to experience the perfect human condition. In the blue corner are the abnormal, whose bodies differ substantially to deserve different treatment. The normate holds power and resources and expects PWDs to bend to their will to access them.

Queer and Crip agree, in this instance, that such a binary is an unnecessary reduction and oversimplification of the topic. Society cannot resolve the debate on the source of disability, the source of PWD exclusion and isolation, through such internal strife. Binaries do not promote healthy debate, and PWDs often need support to interact with society. A rejection of binaries is a core tenet of Butler's work, as noted extensively in section 2.4. Placing PWDs at odds with the broader non-disabled populace causes more harm than it solves. It is to the benefit of all to improve the standards of living in society. Further, reducing the argument to 'us versus them' also ignores the other individual characteristics which may impact the disability experience. Shildrick notes that what counts as a disabling anomaly varies greatly according to the socio-historical context, and so "to speak of the problematic of disability in theoretical terms must both respond to, as well as take apart, the dominance of binary thinking".<sup>724</sup> She continues to note that binary modes of thinking often prevent us from fully understanding the boundaries imposed by society in acceptability. This causes a

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<sup>724</sup> Margrit Shildrick, *Dangerous Discourses of Disability, Subjectivity and Sexuality* (Palgrave Macmillan 2009), 3.

limitation in conceptualising the difference of ability. She notes that the “most influential and taken-for-granted boundary of all is the one that separates those who count as able-bodied from those who are marked as disabled, and yet, like the definitions of subjectivity and sexuality, neither of those terms is as self-evident as they appear to be”.<sup>725</sup>

The obvious question in response to this is ‘how can we avoid this?’. Shildrick argues that “the separation and distinction between diverse morphologies is at best a convenience, and at worst a violent imposition, both literally and metaphorically, of epistemic power”.<sup>726</sup> Therefore, in relying on binary dichotomies, existing models of disability have unduly sold themselves short. The correct approach is to reject rigid definitions entrenched in identity politics or reliant on pathologisation:

“In rejecting the conservative agenda that disabled people are a distinct group who nevertheless are entitled to all the rights and benefits of their particular society, or at least to compensation where those cannot be accessed, many theorists now subscribe both to the notion of difference, and to the blurring of boundaries at the edges, in such a way that problematises the whole categorical distinction”.<sup>727</sup>

We must engage with society’s ability trouble and understand what disability means to the individual. It is at the intersections of disability and other facets of identity where commentary is the most productive. Therefore, when considering a new approach of disability, one needs to consider the multiple aspects and layers which contribute to the whole. Identity comprises multiple separate features. These features work in

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<sup>725</sup> Ibid, 7.

<sup>726</sup> Ibid.

<sup>727</sup> Ibid.

tandem to generate an identity unique to the individual. In this regard, a postmodern and post-structural identity appears on its face to be able to avoid a binary us versus them mentality.

Third, scholars highlight that the human body has no innate history and that disability development follows multiple diverging avenues. Goodley argues that "individualisation shrinks the socially, historically, economically and culturally constituted human being",<sup>728</sup> and such reductionism "fails to capture the complexity of life".<sup>729</sup> The history of disability, considered in detail both in Chapter One and section 3.4 below, extends beyond the boundaries of the biological. However, tracing disability history solely through medicine paints an incomplete picture. Longmore identifies this issue, that society traditionally defines disability as "individual limitation in social functioning due to medical and social pathology" and that medicine has already written this story.<sup>730</sup> Medicine forcibly gained a monopoly over the matter, as society allocated disability as an "objectively measurable clinical entity" and an "appropriate subject for applied academic fields such as medicine, rehabilitation, special education".<sup>731</sup> Pathology gained access to disability purely because society allowed it. Society saw disability as a problem with the body, and medicine gladly offered a solution.

Modern perspectives of disability now trend away from a medical monopoly. As noted in section 1.3, the *travaux préparatoires* indicate a considerable discussion within the AHC about the sources of disability. Instead, a more accurate perspective of disability

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<sup>728</sup> Goodley (n719), 8.

<sup>729</sup> Ibid.

<sup>730</sup> Paul K Longmore, 'Making Disability an Essential Part of American History' (2009) 23(3) *OAH Magazine of History* 11, 11.

<sup>731</sup> Ibid.



is as “a historically contingent panoply of social identities and roles, socio-political classifications, and cultural metaphors”.<sup>732</sup> It does not start and end in the body but bleeds through all experiences and interactions, individual and collective. To fully appreciate disability history, a model of analysis must consider this diversity. As with the discussion on a biological binary, all three theories agree that disability maintains a diverse and rich history which must be respected. To be queer is to critique hegemonic thinking and reject it if another perspective offers greater inclusion and respect for discriminated minorities. Crip exists as a queer development of disability studies through rejecting normalcy. It establishes a safe space for critical thinking under the queer umbrella, appreciating the stratification of disability sources and understand how they interact with each other. When offering a queered model of disability, Chapter Four will acknowledge the sources ignored by society’s historical overindulgence in biology.

Finally, a biological perspective generates stigma, suggesting that disability manifests something wrong with someone. The medical model, as Broderick argues, suggests that disability was a biological lack that directly resulted from an impairment. The models focus on “attempts to ‘cure’ the functional limitations of the disabled person...in order that they can conform to the non-disabled ‘norm’”.<sup>733</sup> PWDs often need support to engage in society and overcome the various barriers in a non-disabled world. They also may seek support to deal with the potential consequences of the disability. A physical disability may cause pain, limited movement, and fatigue, so that PWDs may seek medication and therapy. A mental or psychological disability may bring unwanted thoughts, feelings, and hallucinations which the individual may seek to allay

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<sup>732</sup> Ibid.

<sup>733</sup> Broderick (n16), 22.

or alleviate. Creating stigma makes it harder for PWDs to access support. Stigma places fault on the person rather than society, creating a sense of shame or brokenness. It facilitates the creation of barriers to entry and hoops to jump through before accessing support, such as paternalistic welfare legislation and policies. In these cases, States provide support based on perceived need rather than actual need. Stigma also results in the binary divide discussed above of norms and deviations, separation and otherness.

Throughout the history of medicine, practitioners have not always treated disability with such benevolence. Instead, evidence of abnormality from good social health invited intervention. Queer maintains roots in rejecting historical attempts to establish a binary of gender and sex and eradicating a medicalisation of deviance.<sup>734</sup> It seeks to remove the power of theories which undermine individual experience outside of the binary. Such theories intertwined gender identity and sexual orientation, with Ulrich articulating homosexuality as a “congenital abnormality by which a female soul had become united with a male body”.<sup>735</sup> The medicalisation of homosexuality served as a weapon for society to explore its opposition to the “hermaphroditism of the soul”.<sup>736</sup> However, through social development, political activism, and sociolegal research,<sup>737</sup> homosexuality transitioned to a status outside medical regulation.<sup>738</sup> Such political advocacy and social reform originated “in fierce anger and [was] initially marked by broad-gauged demands for social change, then rapidly evolve[d] into well-behaved self-protective associations...pressing for narrow assimilationist goals”.<sup>739</sup> This

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<sup>734</sup> Whittle (n448), 202.

<sup>735</sup> Havelock Ellis, *Studies in the Psychology of Sex, Volume 7* (F.A. Davies & Co. 1938), 66.

<sup>736</sup> Foucault, (n494), 43.

<sup>737</sup> See, for example, Richard von Krafft-Ebbing, *Psychopathia Sexualis* (F. R. Davis & Co. 1893).

<sup>738</sup> Whittle (n448), 197.

<sup>739</sup> Dubermann (n453), 392.

development culminated in the DSM removing homosexuality in 1974.<sup>740</sup> At each stage, queer activists used their position to rebel against the stigma and shame placed upon them through the 'othering' by pathology. In the same way, a queered perspective on disability rejects the shame of diagnosis and fights the resulting power imbalance between individuals and medical practitioners.

Kleinmann articulates diagnosis as "a semiotic act in which the patient's experienced symptoms are reinterpreted as signs of particular disease states".<sup>741</sup> As such, those who diagnose significantly influence whether a condition is labelled an ailment requiring treatment. Many biomedical professionals posit that impairment has a traumatic impact on the person, stopping them from achieving a reasonable quality of life.<sup>742</sup> This impact opens the door for treatment in the patient's best interests. That is not to say that medicine is always harmful. There are positive experiences available with medicine, as "medicine, rehabilitation, and therapy have given life" to many who need it.<sup>743</sup> In discussing her personal experiences with the biological implications of her disabilities, Kellgren-Fozard indicates that "if you could wave a magic wand and take away all the pain...I would one hundred per cent say yes".<sup>744</sup> However, this does not detract from her sense of pride and personal agency. Society should be careful when setting medicine as the default viewpoint to assess the human condition. Power should remain in the individual to seek medical support should they wish.

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<sup>740</sup> Mayes & Horwitz (n450), 258-9.

<sup>741</sup> Arthur Kleinmann, *Rethinking Psychiatry: From Cultural Category to Personal Experience* (Free Press 1988), 8.

<sup>742</sup> Colin Barnes, *Disabled People in Britain and Discrimination: A Case for Anti-Discrimination Legislation* (Hurst & Co. 1991), ix.

<sup>743</sup> Goodley (n719), 8.

<sup>744</sup> Jessica Kellgren-Fozard, 'Proud To Be Disabled?' (YouTube, 15 July 2017) <<https://www.youtube.com/watch?v=u-fUm32Qaxo>> (accessed 11 March 2019).

To this end, there are several potential rebuttals to the criticisms raised against a reliance on biology. The first is that medicine is clearly helpful. Several individuals with lived experience discuss owning the label of disability to access support. There is, of course, a difference between medicine and medicalisation, but many of the proponents of the social model struggle with that.<sup>745</sup> Secondly, labels are important to help classify experiences, identify the biological root cause of some of the impairment and stigma. Butler addresses issues of identity politics and advocates for a post-structural rejection of labels, as discussed at section 2.4. However, this does not detract from the safety and comfort they bring individuals. Is there a way of acknowledging the physiological aspect of needing a wheelchair and the problems that brings a person, whilst also acknowledging the social disablement caused by a lack of wheelchair access, all the while not undermining the impact of either on the individual? A simple answer is not forthcoming. Finally, this has an impact on tangible criteria within legislation. Disability affects various of the law, and we need to have a structure that provides a robust referential criterion against which society can set parameters. This is especially relevant to mental health, which has a less-developed assessment criteria than physical disability. The Mental Health Acts and the Mental Capacity Act attempt to outline clear parameters for the legal detention of people for assessment and treatment. The success of these statutes depends on the interpretation and identification of mental health.

A lot of work that cites and critiques the medical model are papers, books, and individuals who advocate for the use and relevance of the social or human rights

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<sup>745</sup> See, for instance Oliver (n546).

models. As such, the medical model lacks a specific source, as if it is a theoretical bogeyman. Everyone agrees that it exists, but they fail to pin it down or establish its parameters, creating the perfect scapegoat for problems with existing structures. It is deeply telling that Broderick and Ferri's textbook on disability law and policy dedicates one page to the medical model but five pages to the social model with critique.<sup>746</sup> Chapter Two considers Shakespeare's reliance on biology as a determining factor of the existence of disability, and a justification for rejecting social models of disability. Though his arguments have similar flaws to those discussed in this section, there is value to consider how important the body remains in disability discourse.

A clear example of the risks associated with staunch support of or aggression towards pathology lies within psychiatry. Kirk, Cohen, and Gomory paint a scathing report of the success of the DSM:

"In each subsequent revision of the DSM...no physiological criteria of any sort are included for any diagnosis, confirming the empirical failure of this attempt to substantiate the medical model of madness. The futile endeavour to validate countless human faults and suffering as medical diseases explains most of the 'scientific' conundrums and controversies surrounding the release of DSM-V...despite [its] insolvency, the essentially moral project of descriptive psychiatric diagnosis has today vast socio-economic ramifications that help to preserve it".<sup>747</sup>

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<sup>746</sup> Broderick & Ferri (n339), 18-24.

<sup>747</sup> Stuart Kirk, David Cohen, & Tomi Gomory, 'DSM-5: The Delayed Demise of Descriptive Diagnosis' in Steeves Demazeux & Patrick Singy (eds), *The DSM-5 in Perspective: Philosophical Reflections on the Psychiatric Babel* (Springer 2015), 63.

As will be discussed in Chapter Five, there is debate on whether mental health should be classified as disability. Nevertheless, it is clear that, as noted above in reference to Shildrick, the correct path to take would avoid a binary and attempt to include the knowledge of medicine. Guze sees the medical model as including “systematic clinical description, systematic methods of examination, and the essential ideas of diagnosis, epidemiology, aetiology, pathogenesis, response to intervention, natural history of disease, and prognosis”.<sup>748</sup> The corollary is that medicine depends increasingly upon the growing understanding of the operations of the body and mind. To this end, Sedler argues that there is a good reason to utilise the medical model as a starting point. Many problems faced by individuals represent diseases, and he argues the “medical approach is the most comprehensive way to sort them out, [and] identify appropriate opportunities for medical treatment”.<sup>749</sup> Nevertheless, medicine should not be the default. Instead, a holistic approach to disability should consider various potential sources, understand where physical or mental health manifest disability, and where personal experience or social interactions either develop or exacerbate disability independent of biology.

The argument put forward by this section is that existing models of disability place undue emphasis on pathologisation. It does not argue that biology has no relevance to the disability discussion, but that medicine should not supersede the value of lived experience, personal identity, and individual autonomy. Queer rejects the normate and uplifts the stigmatised, using its deconstructivism to seek greater inclusion in legislative alternatives. UK law has engaged in some of these developments already,

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<sup>748</sup> Samuel Guze, *Why Psychiatry is a Branch of Medicine* (OUP 1992), 129.

<sup>749</sup> Mark Sedler, ‘Medicalisation in Psychiatry: The Medical Model, Descriptive Diagnosis, and Lost Knowledge’ (2016) 19(2) *Medicine, Health Care and Philosophy* 247, 250.

such as within the Care Act, which promotes the individual's "well-being".<sup>750</sup> Relevant considerations to well-being include personal dignity, physical and mental health, participation in work and education, and the individual's contributions to society.<sup>751</sup> This echoes sentiments in aspects of the CRPD, which will be discussed in Chapter Seven. A reconstructed and queered system would, therefore, enable both the rejection of a disability label if the individual wishes, as well as the power to access support if the individual wants it. Further, Crip tackles stigma head-on, rejecting the assertion of blame and seeking justice for anyone under the disability umbrella. The identity approach suggested in Chapter Five will respect the impact of stigma and pain and aim to alleviate these issues.

### **4.3 Governance: Ability and Population Control**

Waldschmidt notes that "disability as a social problem has evolved as a product of the modern welfare State. With the beginning of modernity and, above all, during the period of industrialisation, a line was drawn between 'the disabled' and other poor and unemployed people".<sup>752</sup> As such, society views disability as an assessment of the social utility and the worth of an individual to the rest of society.<sup>753</sup> The social governance of the lower classes had explicit roles in an industrialised society, a "horizontal category of social stratification" manifested during the twentieth century.<sup>754</sup> Elements of social governance appear in the ICIDH. It suggests that "disability takes form as the

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<sup>750</sup> Care Act 2014, s.1.

<sup>751</sup> Ibid, s.1(2)(a-i).

<sup>752</sup> Waldschmidt (n542), 1168.

<sup>753</sup> See further Gary L Albrecht, Katherine D Seelman, and Michael Bury (eds), *Handbook of Disability Studies* (Sage 2001).

<sup>754</sup> Waldschmidt (n542), 1168.

individual becomes aware of a change in [their] identity".<sup>755</sup> This change demonstrates the disadvantage suffered by the individual relative to others, "either the awareness itself or [their] altered behaviour or performance".<sup>756</sup>

Population control has also followed a darker path. "Social Darwinism and degeneration theory gained influence in public and scientific discourse, and former educational institutions gradually changed into nursing and custody homes".<sup>757</sup> Treatment became locking away deviants to the norm, maintaining this as the status quo, generating a medicalised perspective of "survival of the fittest". Radical attitudes became more acceptable due to financial crises in the twentieth century. As Schmuhl argued,<sup>758</sup> this led to the internationally successful eugenics movement and nationally funded sterilisation policies.<sup>759</sup> Though such policies are considered horrific and cast to the annals of history, modern disability theory often strays into social control and the limitation of specific groups.

### **4.3.1 Exploring Social Models**

Disability studies and the Social Model of Disability both arise from articulating hardships faced by persons with disabilities using an activist lens. The social model as a critique of the governance and repression of PWDs is synonymous with British sociological theory and rights activism. As such, the social model is a central theme in

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<sup>755</sup> World Health Organisation, *International Classification of Impairments, Disabilities, and Handicaps* (4th edn, WHO 1993), 28.

<sup>756</sup> *Ibid*, 26.

<sup>757</sup> Waldschmidt (n542), 1169.

<sup>758</sup> Hans-Walter Schmuhl, *Rassenhygiene, Nationalsozialismus, Euthanasie: Von der Verhütung zur Vernichtung, lebensunwerten Lebens* (2<sup>nd</sup> edn, Vandenhoeck & Ruprecht 1992).

<sup>759</sup> Waldschmidt (n542), 1169.



British disability studies,<sup>760</sup> and using a social barriers approach to disability is considered a “very British phenomenon”.<sup>761</sup> The social model was radical for its time, marking a paradigmatic leap instead of a paradigm shift in understanding disability.<sup>762</sup> Its sources are equal parts academia and activism. Developments in disability theory in the 1990s took place alongside “the emergence of an international disabled people’s movement, campaigning for equality and full participation in all spheres of social life and human rights”.<sup>763</sup> Goodley argues that this is a “classic counter-hegemony, an alternative idea to the medical/individual tragedy that serves the aims of paramedical professions”.<sup>764</sup> Whilst existing literature equated disability with the need for treatment, as noted in section 3.2, newer voices argued that it was “the relationship between the environment, body and psyche [which] excludes certain people from becoming full participants in the social world”.<sup>765</sup> Individuals within this repressed collective had had enough and found their voice to shift the dial dramatically and ultimately redirect the development of disability studies.

Oliver coined the Social Model after work conducted by the UPIAS argued that “disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society”.<sup>766</sup> This approach purportedly “helps to clear the confusion that the experts introduce into what is basically a straightforward

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<sup>760</sup> Carol Thomas, *Sociologies of Disability and Illness: Contested Ideas in Disability Studies and Medical Sociology* (Palgrave 2007), 6.

<sup>761</sup> Goodley (n719), 11.

<sup>762</sup> See, for example, Rhoda Olkin, *What Psychotherapists Should Know about Disability* (Guildford Press 1999).

<sup>763</sup> Mark Priestly, *Disability: A Life Course Approach* (Polity Press 2003), 12.

<sup>764</sup> Goodley (n719), 11.

<sup>765</sup> Deborah Marks, ‘Dimensions of Oppression: Theorising the Embodied Subject’ (1999) 14(5) *Disability & Society* 611, 611.

<sup>766</sup> UPIAS (n346), 3-4.

issue, requiring the application of fundamental principles, drawn from the actual experience of disability, rather than the adoption of a very complicated position”.<sup>767</sup> They suggest that “the ‘experts’ in the field have never concerned themselves with the real cause at all”.<sup>768</sup> The addition of inverted commas explicitly acknowledges that they reject the medicalisation of PWDs, questioning the qualification and expertise of medical professionals. Their logic rests in misidentifying the treatment location for individual disability, suggesting that professionals concentrate on the effects of impairment rather than the actual cause of disability. In turn, the UPIAS argue that PWDs need to become their experts to see through the attempts to disguise “the traditional, clearly failed, ‘spontaneous’ struggle against aspects of disability”.<sup>769</sup>

The UPIAS model of disablement distinguishes between impairment and disability, arguing them to be two distinctly different concepts. An impairment is the “lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body”.<sup>770</sup> Whereas disability is the “disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities”.<sup>771</sup> A social model approach considers the individual to experience impairment and disability separately, arguing that disability only exists once the individual attempts to interact with a social system or construction. The significance of this model becomes its “radical challenge to the medical or individual model of

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<sup>767</sup> Oliver (n546), 22.

<sup>768</sup> Ibid.

<sup>769</sup> Ibid.

<sup>770</sup> Ibid.

<sup>771</sup> Ibid.

disability".<sup>772</sup> Therefore, they consider physical disability "a particular form of social oppression",<sup>773</sup> manifesting through barriers preventing access to social spaces and resources.

Further, the UPIAS argues that "the impoverishment of physically impaired people arises out of the fact that, as a group, we are excluded from the mainstream of social activities".<sup>774</sup> As noted in previous chapters, there is often a correlation between disability and poverty. An inability to interact with social structures can compound financial hardship and create a downward spiral into greater impoverishment. As such, the UPIAS suggest that the "particular form of poverty principally associated with physical impairment" is caused by "exclusion from the ability to earn an income on a par with our able-bodied peers".<sup>775</sup> Disablement prevents employment and income, making the gap between PWD and non-PWD greater. It is important to note that society actively tries to improve access through technological advances in accessibility, and for their part, UPIAS acknowledges this. They note that modern technological developments have improved organisations' chances to "employ even the most severely physically impaired people" and to integrate PWDs into "the mainstream of social and economic activity".<sup>776</sup> However, this also emphasises the amount of work yet to complete, as PWDs experience oppression and face barriers despite technological advancement making access easier.<sup>777</sup>

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<sup>772</sup> Colin Barnes & Geoff Mercer, 'Breaking the Mould? An Introduction to Doing Disability Research' in Colin Barnes & Geoff Mercer (eds) *Doing Disability Research* (Disability Press 1997), 1-2.

<sup>773</sup> Oliver (n546), 22.

<sup>774</sup> Ibid.

<sup>775</sup> Ibid.

<sup>776</sup> Ibid, 23.

<sup>777</sup> See Paul Abberley, 'Work, Utopia and Impairment' in Len Barton (ed) *Disability and Society: emerging Issues and Insights* (Longman 1996).

A feature of social model commentary is labelling. Labelling allows for analysing social discourses and the interaction between individuals and society. Society considers disability as “deviant behaviour” compared to systems based upon “the norms of bodily fitness, functioning at the workplace, individual capacity to self-care, and beautiful outer appearance”.<sup>778</sup> As a result, PWDs find themselves permanently marginalised, with a considerable stigma attached to their identity. In uncovering this aspect of marginalisation, Waldschmidt relies on Goffman’s Stigma Theory.<sup>779</sup> She argues that disability is “constituted in social interaction” and that “if a person has a highly visible bodily feature or behaves a particular way”, they are “negatively valued by interaction partners”.<sup>780</sup> The resulting stigma created by said interaction partners and attached to the individual results in social distance.<sup>781</sup> Concurrently, however, social rules of interaction demand the maintenance of quasi-normalcy, creating an awkward power dynamic.<sup>782</sup> Whilst social barriers generate attitudinal prejudices, the debate around PWD inclusion becomes nuanced when States and groups make evident efforts to change them. As Waldschmidt suggests, following a social model affords PWDs a voice in this conversation:

“By focussing on structural inequalities, the social model seeks to increase opportunities for participation and inclusion of persons with disabilities in all aspects of mainstream society. The social model also

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<sup>778</sup> Waldschmidt (n542), 1170.

<sup>779</sup> Goffman (n104).

<sup>780</sup> Waldschmidt (n542), 1169-1170.

<sup>781</sup> Ibid, 1170.

<sup>782</sup> Ibid.

endorses an increased role for persons with disabilities to express their experiences and views through participatory process".<sup>783</sup>

Understanding the impact of power within the social dynamic helps ensure that PWDs can engage in society. It also ensures that they have the voice to speak of their experiences. By tackling these two issues in unison, the social model hopes to unpack the disabling social barriers whilst also avoiding the problems associated with the unwanted advocacy of external voices speaking over PWDs.

Labelling theory helps unpack uneven power dynamics by understanding the interactions between the individual's life course and the rehabilitation system.<sup>784</sup> Jung suggests that disability is a label that "inaugurates consignment to an identity category, which signifies disadvantage and oppression".<sup>785</sup> Given that the social model partially manifests through activism, many consider that disability as an identity relates wholly to the social world.<sup>786</sup> This identity is shared based on individual experiences with societal barriers, regardless of how the individual perceives their impairment. Garland-Thompson argues that one can understand disability best as a sign system that, by differentiating and marking bodies and minds, produces PWDs and maintains the ideal of the inherently stable non-disabled body/mind.<sup>787</sup> Further, understanding disability as a label allows theorists to acknowledge the set of associated meanings to the term.<sup>788</sup>

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<sup>783</sup> Broderick (n16), 24.

<sup>784</sup> Waldschmidt (n542), 1170.

<sup>785</sup> Karen Elizabeth Jung, 'Chronic Illness and Educational Equity: The Politics of Visibility' (2002) 14(3) *NWSA Journal: Feminist Disability Studies* 178, 178.

<sup>786</sup> Goodley (n719), 9.

<sup>787</sup> Rosemarie Garland-Thompson, 'Integrating Disability, Transforming Feminist Theory' (2002) 14(3) *NWSA Journal: Feminist Disability Studies* 1, 5.

<sup>788</sup> Goodley (n719), 9.

Some social model theorists define disability as the adverse social reaction to perceived medical differences. For instance, Thomas argues that disablism is "a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being".<sup>789</sup> Disability is a form of population control through the establishment of limitations by society. By targeting this oppression, Bauman suggests that "one can make things better than they are and need not settle for what there is since no verdict of nature is final, no resistance is unbreakable".<sup>790</sup> Through activism and critical discourse, the movement can make things better and ameliorate disability from within.

Finally, the social model "assists in illuminating the limitations of traditional theories of equality" concerning PWDs.<sup>791</sup> Here, one should emphasise "assist", as the social and medical models might be as distinctly separate as people suggest. There is an overlap, a convergence, where both models rely on each other and work together to conceptualise disability. Alternatively, disability is such a broad and complex matter that society relies on concepts discussed by different models to try and make sense of it and is potentially muddying the waters. Broderick notes that "in line with the social model, the focus has shifted away from the disabled individual and [their] differential characteristic towards a broader re-examination of structural disadvantage".<sup>792</sup> To think about social dynamics requires acknowledging the broader issues faced by PWDs as a collective.

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<sup>789</sup> Thomas (n760), 73.

<sup>790</sup> Zygmunt Bauman, 'Identity in the Globalising World' in Anthony Elliott & Paul du Gay (eds), *Identity in Question* (Sage 2009), 2.

<sup>791</sup> Kayess & French (n261), 8.

<sup>792</sup> Broderick (n16), 24.

### **4.3.2 Flaws of Governance**

Nevertheless, articulating disability through a lens of social governance manifests several problems. The existence of multiple sub-theories to the social model of disability demonstrates that it is unworkable in its current form. To begin, the British-centric nature of the social model creates friction when attempting to apply it on an international level. To some, “the social model promoted debates that were unnecessarily aggressive and in some cases anti-intellectual”.<sup>793</sup> The social governance of individuals based on perceived ability is a tranquilising molasses on individual development – slow, unyielding, and deeply uncomfortable to experience. However, this does not accurately translate to other legal jurisdictions and social perspectives. In advocating for a human rights model of disability, Degener suggests that the disability rights movement has featured the dichotomy of the medical and social models for several decades. Nevertheless, now disability studies are discussing “new, less dichotomist models”.<sup>794</sup> She provides a non-exhaustive list of examples, including the economic model, the minority group model, the universality model, the Nordic relational model, and the capabilities model.<sup>795</sup> Each carries its strengths and weaknesses, providing alternative options to the worlds of academia and international human rights in formulating and applying PWD rights.<sup>796</sup>

Individualising disability from the perspective of power creates a fault line where disability becomes an essentialist condition. A governance approach treats PWDs as

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<sup>793</sup> Goodley (n719), 12.

<sup>794</sup> Degener (n320), 35-6.

<sup>795</sup> Ibid, 36.

<sup>796</sup> See Theresia Degener, ‘A Human Rights Model of Disability’ in Peter Blanck & Eilionóir Flynn (eds.), *Routledge Handbook of Disability Law and Human Rights* (Routledge 2017).

objects rather than authors of their own lives. Their disabilities and experiences become data points in a rebellion against the system. The individual ceases to be relevant to the conversation. Language relating to the 'fight for oppression' becomes militant, as if the battle against social disablement is an armed revolution. Everyone must fall in line and agree as a single collective conscience, as "unpredictability breeds anxiety and fear".<sup>797</sup> Bauman argues that "the world is full of accidents and surprises", so "one must never let vigilance lapse and should never lay down arms".<sup>798</sup> Further, Stevens notes that society represents PWDs as "monstrous, inspirational, undesirable, asexual, dependent, and pitiful".<sup>799</sup> This summation is accurate regarding some media depictions of PWDs, often type-casting disability as a problem requiring a solution. However, focusing on this perspective with absolute vigour and disregarding other perspectives eradicates all possibilities for nuance. Degener argues that "whereas the social model merely explains disability, the human rights model encompasses the values for disability policy that acknowledges the human dignity of disabled persons".<sup>800</sup> Using disability as a pawn in a power battle removes the humanity and dignity of the individual.

A concern arising from the above discourse is that it makes powerful claims about PWDs, but to the extent that individuals themselves do not make those claims. Instead, they are always made by professionals or academics on behalf of people with lived experience. Discourse still dehumanises PWDs. Considering Foucault and Butler on power in Chapter Two, it is clear that for PWDs to be taken seriously, they need to be

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<sup>797</sup> Bauman (n790), 2.

<sup>798</sup> Ibid.

<sup>799</sup> Bethany Stevens, 'Cripsex: Sk(r)ewed Media Representation' in Russell Shuttleworth & Teela Sanders (eds), *Sex and Disability: Politics, Identity, and Access* (The Disability Press 2010), 53.

<sup>800</sup> Degener (n320), 37.



included in the conversation, rather than spoken over. Within the relationship between PWDs and society – be that law, healthcare providers, employers, or other individuals – power manifests as a dynamic reality, an ebb and flow between parties. The social model draws particular attention to PWDs as the powerless. Shakespeare takes issue with this, as noted in section 2.2, and it is the assertion of this thesis that a queer/crip approach to Shakespeare’s understanding of the interaction between PWD and society can address these issues. Impairment should not be a prerequisite for disability, nor should it be the sole identifier for whether an individual has a voice in the conversation. It is not a box to tick or a membership pass allowing entry to a restricted club. The fight for equality of all persons is the interest of all of society, and gatekeeping access assists no one.

Furthermore, meticulously separating impairment and disability inadvertently accepts the relevance of medicalisation. For disability to be the disablement of individuals by a restrictive society, there must be a tacit agreement to the existence and treatment of impairment. Rather than advocating for interventions of context-changing, the social model allows for the existence of person-fixing measures. Sherry notes that when society medicalises impairment, the power of health and social care professionals increases and accentuates the tyranny of normality.<sup>801</sup> Further, Swain and French note that whilst the social model is “certainly totally incompatible with the view that disability is a personal tragedy, it can be argued that the social model has not, in itself, underpinned a non-tragedy view”.<sup>802</sup> It leaves the door open for the possibility that “even in an ideal world of full civil rights and participative citizenship for disabled

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<sup>801</sup> See Mark Sherry, *If I Only Had a Brain: Deconstructing Brain Injury* (Routledge 2006).

<sup>802</sup> John Swain & Sally French, ‘Towards an Affirmation Model of Disability’ (2000) 15(4) *Disability & Society* 569, 571.

people, an impairment could be seen to be a personal tragedy”.<sup>803</sup> Ultimately, conceptualising the disadvantage of disability as the consequence of societal limitations fails to capture the complete picture of the individual experience.<sup>804</sup> Speaking from experience, Morris demonstrates this clearly:

“...while environmental barriers and social attitudes are a crucial part of our experience of disability – and do indeed disable us – to suggest that this is all there is, is to deny the personal experience of physical and intellectual restrictions, of the fear of dying”.<sup>805</sup>

The common example of social disablement is that a wheelchair user is disabled by the lack of ramp access into a building.<sup>806</sup> However, the question remains whether the individual is already disabled by their own body. Someone who experiences either lack or loss of function within their limbs faces barriers before they interact with society; living with a body part that does not function or functions differently to other parts of their body (or other individual’s relevant body parts) can cause anguish and pain. An individual experiencing harmful voices due to psychosis or paranoid schizophrenia may also consider that disabling, regardless of their interactions with social structures. There is a point where an individual’s experiences go beyond our current conceptualisation of impairment and constitute a disability. As such, a model of disability must take into consideration a variety of elements, as the human experience is unique and complicated. Therefore, the discussion in Chapter Five on the identity approach will reflect this broad perspective, utilising the power of the queer/crip to create a lens of analysis featuring many characteristics.

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<sup>803</sup> Ibid.

<sup>804</sup> See Paul Abberley, ‘The Concept of Oppression and the Development of a Social Theory of Disability’ (1987) 2(1) *Disability, Handicap & Society* 5.

<sup>805</sup> Morris (n553), 10.

<sup>806</sup> Broderick & Ferri (n339), 19-22.

From the outset, advocates for the social model understood the slippery slope of such an analysis, but for different reasons. Oliver posited that there is “a danger in emphasising the personal at the expense of the political because most of the world still thinks of disability as an individual, intensely personal problem”.<sup>807</sup> He argued that “many of those who once made a good living espousing this view would be only too glad to come out of the woodwork and say that they were right all along”.<sup>808</sup> Shakespeare takes this further, arguing that:

“...the achievement of the disability movement has been to break the link between our bodies and our social situation and to focus on the real cause of disability (i.e., discrimination and prejudice). To mention biology, to admit pain, to confront our impairments has been to risk the oppressive seizing of evidence that disability is ‘really’ about physical limitations after all”.<sup>809</sup>

Metaphorically speaking, this perspective cuts off its nose to spite its face. Arguing against respecting the impact of biology willingly ignores the harmful experiential elements of the body or mind out of fear of a nefarious society weaponizing that experience against PWDs. To show no weakness out of fear of losing valuable progress is a toxic mentality. Crow notes that “an impairment such as pain or chronic illness may curtail an individual’s activities so much that the restriction of the outside world becomes irrelevant”.<sup>810</sup> As noted in section 3.2, there are benefits to medical intervention, and an individual may seek treatment to alleviate pain or reduce the

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<sup>807</sup> Oliver (n546), 5.

<sup>808</sup> Ibid.

<sup>809</sup> Tom Shakespeare, ‘A Reply to Liz Crow’ (1992) *September Coalition*, 40.

<sup>810</sup> Liz Crow, ‘Renewing the Social Model of Disability’ (1992) *July Coalition* 5, 9.

impact of their impairment. The existence of the impairment can disable them just as much, if not even more, than any social barrier. Further, for many PWDs, “personal struggles relating to impairment will remain even when disabling barriers no longer exist”.<sup>811</sup> Disability can manifest outside social situations and can be an incredibly personal experience. To suggest that disability exists purely within the social context invalidates these experiences. The identity approach to disability will respect this, taking a queer approach to the lived experience of PWDs to understand the different levels of impact disability has on their lives.

Shifting focus, it is essential to understand how researchers have attempted to expand or reshape the social model. Within a minority model approach, PWDs are a minority, ostracised from society. This logic follows parallel to the original social model, as it perceives disability in part as discriminatory barriers placed by society. However, it differs from the work of Oliver and the UPIAS by acknowledging the state of collective identity for PWDs. Influenced by American black civil rights and LGBTQ+ political movements in the 1960s-1970s, this model tries to establish a positive minority identity as a basis for commentary.<sup>812</sup> The term PWD originates with people-first language and aims to "recognise humanity and diversity beyond the narrow confines of labour and consumption".<sup>813</sup> According to a minority model approach, PWDs constitute a minority position in society, similar to other oppressed groups based on identity characteristics. Said groups are devalued, stigmatised, discredited and

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<sup>811</sup> Liz Crow, 'Including All Our Lives: Renewing the Social Model of Disability' in Jenny Morris (ed), *Encounters with Strangers: Feminism and Disability* (Women's Press 1996), 209.

<sup>812</sup> See Robert McRuer, 'Compulsory Able-Bodiedness and Queer/Disabled Experience' in Sharon L Snyder, Brenda J Brueggemann, & Rosemarie Garland-Thompson (eds), *Disability Studies: Enabling the Humanities* (Modern Languages Association 2002).

<sup>813</sup> Goodley (n719), 13.

discounted by society. PWD comprise a minority group that has been denied its civil rights, equal access, and protection.

The minority model involves the “categorisation of classes of individuals into distinct groups in order to determine their entitlement to protection from discrimination and to positive measures to redress the effects of the disadvantage suffered by that class of individuals”.<sup>814</sup> Much like racial minorities, “disabled people are also characterised as a discrete and insular minority, who have suffered from a history of discrimination and who are relatively powerless politically and are socially excluded”.<sup>815</sup> Within the context of disability, the minority model emphasises the “political and social aspect” of the experience of PWDs.<sup>816</sup> Therefore, in focusing on a shared collective identity, proponents claim that the minority model challenges ablism. Society prejudices those whose bodies perform differently from those regarded as normal due to discrimination-serving attitudes and behaviours stemming from and reacting to these biases.<sup>817</sup> Again, this model tries to tackle the same issues as the original social model but does so through a different approach. By steering away from conversations of power that see disability as a pejorative, advocates of the minority model hope to improve overall social perspectives of disability. Further, it rejects the “cutthroat individualism” of the dominant societies and perspectives heavily present in the original social model discourse.<sup>818</sup> By uniting with other minority groups against a

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<sup>814</sup> Broderick (n16), 25.

<sup>815</sup> Sandra Fredman, ‘Disability Equality and the Existing Paradigm’ in Anna Lawson and Caroline Gooding (eds), *Disability Rights in Europe: From Theory to Practice* (Hart 2005), 204-5.

<sup>816</sup> *Ibid*, 205.

<sup>817</sup> Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (Routledge 1996).

<sup>818</sup> McRuer & Wilkerson (n537) 4.

greater goal of reducing the control of the normate over society, they hope to challenge able-bodied privilege, just as racial minorities seek to challenge white privilege.

The goal of deconstructing ableism is admirable, and the identity approach in Chapter Five aspires to this level of intersectionality. However, the minority approach is not without its flaws. Fredman and Broderick argue that such an approach is “problematic both legally and socially”,<sup>819</sup> as “an individual must prove that they fall into a particular minority category before they can claim the protection of the law against discrimination”.<sup>820</sup> Legal definitions of protected classes are often purposely narrow, making using the minority approach difficult. Moreover, the remains of the power dynamic analysis from the social model linger. The minority approach emphasises “difference and deviance from what is deemed normal, rather than emphasising human diversity”.<sup>821</sup> There is still a benefit to acknowledging individualism, respecting the difference between individual and collective identity and individuals rejecting a collective identity whilst advocating for their rights and goals.

The universalist approach is another example of social model proponents attempting to expand the coverage of the social model by patching over its weaknesses. From a universalist perspective, disability is “not a fixed construction inherent to one particular group but is rather a fluid construction and a universal characteristic of the human condition”.<sup>822</sup> As such, universalist disablement policy is “not the policy for

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<sup>819</sup> Fredman (n815), 206.

<sup>820</sup> Broderick (n16), 25.

<sup>821</sup> Ibid.

<sup>822</sup> Ibid, 26.

some minority groups, it is policy for all”.<sup>823</sup> It travels in the opposite direction to a minority perspective, arguing for the promotion of full and equal participation without limitations or prescribed caveats. It emphasises “universal access to society for all individuals, regardless of personal characteristics”.<sup>824</sup> PWDs do not deserve rights because they are a minority experiencing discrimination. Instead, they deserve rights because they are humans, equal to all. Broderick suggests that “laws, policies and social structures based on the universalist maxim should reflect this concept of maximum accessibility”.<sup>825</sup> Through a macro lens, this perspective is an admirable end goal to see all human beings access human rights based on equality.

However, from a micro lens, it completely ignores the current discriminatory barriers and marginalisation that PWDs experience. As such, Kayess and French note that “the universalist approach has enormous transformative potential for all persons who experience disadvantage and discrimination”,<sup>826</sup> but “its Utopian aspirations may prove impossible to operationalise”.<sup>827</sup> This thesis agrees with Kayess and French that now is not the time for the universalist argument for PWD rights implementation. However, this also reflects the limitations that queer experiences when shifting between the purely theoretical and the feasibly tangible. Often, broad and sweeping theoretical perspectives struggle in their application to existing strict social structures. Nevertheless, the work of Zanghellini and Gonzalez-Salzberg noted in section 3.3 highlights that a fettered queer can still critique law and human rights. Further,

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<sup>823</sup> Jerome E Bickenbach, ‘Minority Rights or Universal Participation: The Politics of Disablement’ in Melinda Jones and Lee A Bassler (eds), *Disability, Divers-Ability and Legal Change* (Martinus Nijhoff 1999), 112.

<sup>824</sup> Broderick (n16), 26.

<sup>825</sup> Ibid.

<sup>826</sup> Kayess & French (n261), 10, footnote 43.

<sup>827</sup> Ibid.

McRuer's work in crip theory, discussed in section 3.2, demonstrates that maintaining a clear positionality of disability incentivises inclusion and enables critique. Therefore, when articulating an identity approach, Chapter Five will note the end goal of true inclusion whilst maintaining an understanding of how to implement the theory within the current social structure. The queering of Shakespeare is the refined queer of Zanghellini and Gonzalez-Salzburg, not the utopian queer of Muñoz or the idealised aspirations of universalism.

Another perspective on the socialisation of disability considers ability as a part of the life course. Often, the physical manifestations of bodily difference that society labels disability are merely consequences of the progression of time. Disability is a commonality which "transcends class, age, gender, nation, wealth, and national borders".<sup>828</sup> Anyone can transition from non-PWD to PWD at any time in their life. The chance of accruing disability increases with age, and "in Western industrialised societies, [most PWDs] are over retirement age".<sup>829</sup> Moreover, 97 per cent of impairments are acquired rather than congenital.<sup>830</sup> In creating the life course approach, Priestly identifies an "apparent lack of critical debate about disability issues in old age".<sup>831</sup> Therefore, a life course approach argues that non-PWDs are temporarily able-bodied.<sup>832</sup> This approach shifts the perspective from social disablement to the interaction between the individual, their body, and their place in society.

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<sup>828</sup> Goodley (n719), 2.

<sup>829</sup> Priestly (n763), 5.

<sup>830</sup> Goodley (n719), 2.

<sup>831</sup> Priestly (n763), 5.

<sup>832</sup> Deborah Marks, *Disability: Controversial Debates and Psychosocial Perspectives* (Routledge 1999), 18.



Priestley posits that a life course approach examines the “ways in which disabled lives are understood, organised and governed within societies, from regulation of birth and reproduction to the social organisation of death and dying, and all points in between”.<sup>833</sup> The construction of generation extends further than mere age. Instead, a life course approach considers how relations and social institutions govern the boundaries and transitions between generations.<sup>834</sup> He argues that the weakness of other social models is “a tendency to focus on a fairly narrow range of issues, often those affecting adults of working age”.<sup>835</sup> Again, a significant flaw in the current social models is the habit of narrowly defining disability as disablement through a particular category of individuals. Queer studies were borne from a rejection of feminist literature for its ignorance of marginalised women's struggles. Queer attempts to undo the social stratification of individuals into specific classes and Crip brings this mentality to the table in expanding disability studies. The life course approach tries to broaden the social model regarding age and the manifestation of biological impairment.

For the purpose of this thesis, this attempt is admirable and could be expanded upon. Nevertheless, some theorists may be critical of following a life-course approach. Priestly relies on a teleological normative understanding of the body, the assumption that disability becomes more likely with age. Notable commentators already mentioned in this chapter, Shildrick and Degener, would argue against this for different reasons. Shildrick perceives disability as inscribed within, purposefully blurring the binary.<sup>836</sup> Degener notes the difference between “acquired and congenital impairment”, given that “to be born blind or deaf or physically or intellectually impaired is very different

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<sup>833</sup> Priestly (n763), 4.

<sup>834</sup> Ibid, 5.

<sup>835</sup> Ibid, 4.

<sup>836</sup> Shildrick (n724), 3.

from becoming disabled through illness, accident, violence, or poverty”.<sup>837</sup> A commonality here is the varied sources of disability and the inability to restrain it to a confined (albeit temporal) category. Further, Kafer may agree with Priestly’s temporal considerations of disability, but would veer away from normative values to approach a post-structural understanding of disability within the context of time. She understands disability in terms of “frequency, incidence, occurrence”.<sup>838</sup> Though Degener’s distinctions between acquired and congenital are temporal, Kafer notes that “we rarely recognize or discuss them as such”, collating them under the rubric of “crip time.”<sup>839</sup> Therefore, blending Kafer’s queer approach to temporality with Priestly’s life-course approach would acknowledge the relevance of time (both age and stage), whilst avoiding an unduly limited perspective of causality and explanation of phenomena.

There are also dangers in “over-simplifying the collective experience when we know that disabling societies affect different people” differently.<sup>840</sup> A common theme of disability studies is the unique nature of a disability identity; there is no specific way to have a disability or a specific shared lived experience. Instead, there are many possibilities and infinite unique lives with a disability. A functional critical model must use an intersectional lens to understand the impact of uniqueness on disability and afford the greatest protection to PWDs as a category. Nevertheless, Priestly respects that “our understanding of the roles and responsibilities of adulthood tells us a great deal about why people with perceived impairments have been so often excluded from full citizenship in modern societies”.<sup>841</sup> Social models have made progress in

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<sup>837</sup> Degener (n796), 42.

<sup>838</sup> Alison Kafer, *Feminist, Queer, Crip* (Indiana UP 2013), 26.

<sup>839</sup> *Ibid.*

<sup>840</sup> Priestly (n763), 5.

<sup>841</sup> *Ibid.*

highlighting and reducing barriers through the “collective experiences of disabled people as an oppressed group”.<sup>842</sup> Therefore, the identity approach in Chapter Five will consciously consider the impact of age in a holistic manner. It will borrow Priestley’s respect of the life course and deviation away from prescriptive understandings of social disablement. However, it will not ignore the positives gained by the works of social model theorists such as Oliver.

#### **4.4 Rescue: Society’s Hero Syndrome**

Finally, a theme common throughout the social models discussed above is the notion of rescue. Various models position PWDs as individuals needing rescue from their disability and the original cause. PWDs are damsels in distress, and the creators behind these models are the knights in shining armour, rescuing them from the gatekeeper dragon, which disables them. As Goodley notes, PWDs are “ignored, pitied, patronised, objectified, hated, mocked and fetishised”.<sup>843</sup> They are objects for society to interact with and use for their resulting gain. Hero Syndrome is a media term for individuals who create harmful or dangerous situations to resolve for adulation and pride. There is a double meaning to the term “Society’s Hero Syndrome”. Firstly, society often creates harmful scenarios for PWDs by labelling them in specific ways. Society also attempts to uplift or fix the situation placed on PWDs. This scenario is analogous to firefighters who start fires to extinguish to get the resulting adulation, the phenomena after which “Hero Syndrome” is named. Secondly, all models attempt to rescue PWDs by casting them as victims needing protection and treatment.

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<sup>842</sup> Ibid.

<sup>843</sup> Goodley (n719), 2.

#### **4.4.1 Saving You from Yourself**

To begin, positioning PWDs as powerless victims manifests a desire within society to save the individual from themselves, suggesting that there is an inherent illness found within. Moral models of disability perceive it as a mark of the devil and a tragedy fit to befall that individual. As Waldschmidt notes, “until the early modern age, the treatment of bodily differences and health conditions was characterised by religion and magic as well as exclusion and charity”.<sup>844</sup> Hindsight enables us to judge those who sought to ‘fix’ disability through religion or magics, as modern views of science give us a better understanding of human biology and psyche. However, modern medicine shares much with moral and religious approaches, especially concerning treatment with exclusion and perceptions of charity. The victimisation of PWDs stems from paternalism, a feature of multiple models. For instance, “while the church benefitted from the moral position, the paramedical professions benefit from the medical model”,<sup>845</sup> with both relying on a prescriptive idea of an ideal state of living. The former perceives disability as an act of God, punishment for actions conducted in a previous life or incarnation. The latter argues that disability is an illness to be treated or cured. Whilst they differ in logic, their foundational reasoning is similar. Disability is “a personal tragedy inflicting damage upon the mind and body, requiring treatment, rehabilitation or...cure”.<sup>846</sup> It is an unacceptable standard of living, requiring intervention to resolve.

Goodley argues that disability has become “the flawed tragedy of an isolated person treatable through the interventions of religious charities and healthcare professionals”.<sup>847</sup> Society uses a negative perspective of disability to justify its

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<sup>844</sup> Waldschmidt (n542), 1169.

<sup>845</sup> Goodley (n719), 6.

<sup>846</sup> Ibid.

<sup>847</sup> Ibid.

paternalism. In turn, this manifests equally paternalistic laws and practices. As noted in section 1.2, the recent history of international human rights instruments shows aspects of infantilisation and a rejection of individual capacity. The DRMRP and DRDP “were significant steps in raising awareness about the human rights of [PWDs], but they reflected medical and charity models of disability and were heavy-laden with paternalism”.<sup>848</sup> The pejoration of a disability identity manifests not just through the ableist and derogatory language but also through the medicalisation of the human condition. They were examples of society making progress with mixed intentions, a bold effort which ultimately fell flat. Within medicine, the ICIDH uses the term ‘disadvantage’, defining it as “a result of his being unable to conform to the norms of his universe”.<sup>849</sup> An individual accrues a disadvantage, which can “arise when the individual deviates [despite] his wishes, but it can also develop when the deviation is inadvertent or the product of his own choice”.<sup>850</sup> Further, Rimmerman explains that “one of the popular expressions by psychotherapists is God would not give you this cross to bear unless you could handle it”.<sup>851</sup> It is meant as a positive to demonstrate such desirable qualities as courage, power, and bravery. Instead, it cements that disability is considered a moral issue, given to those who deserve it or are strong enough to bear it. It also emphasises a disconnect between the presumed disability and society’s impact on its manifestation.

These examples demonstrate a continued effort by society to moralise and medicalise PWD experiences, to suggest that treatment of the human condition will resolve unwanted abnormality. As such, disability became synonymous with “the identification

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<sup>848</sup> Stein & Lord (n5) 21.

<sup>849</sup> WHO (n755), 29.

<sup>850</sup> Ibid.

<sup>851</sup> Rimmerman (n659), 24.

of a pathology or impairment”.<sup>852</sup> In turn, medicine conceptualises disability as “a distinct pathology rather than a place on a continuum of disease or of capacities and strengths”.<sup>853</sup> By establishing an exact problem, society opened the gates to a solution. Therefore, the “primary role of the physician was to assess and determine the medical deficit associated with the impairment”.<sup>854</sup> Medicine sees disability as a problem within the body necessitating treatment. For example, the ICIDH argues that disability concerns “compound or integrated activities expected of the person or of the body as a whole, such as are represented by tasks, skills, and behaviours”.<sup>855</sup>

This understanding of disability creates several issues in terms of conceptualisation and application. Firstly, “in providing the link between impairment and handicap, it is fairly easy for the concept of disability to appear somewhat vague, variable, or arbitrary”.<sup>856</sup> As such, there is disagreement on the precise labelling of this mixed moral/medical perspective. Goodley suggests that there is a distinction between a medical model of disability and mere medicalisation of experience. A medical model “refers to a general use of knowledge and practices associated with medicine,” while medicalisation “views the world solely through medical discourses”.<sup>857</sup> However, Oliver argues that “there is no such thing as the medical model of disability”.<sup>858</sup> Instead, he identifies “an individual model of disability of which medicalisation is one significant component”.<sup>859</sup> An individual model focuses on the individual’s perspective of disability, locating it within the interaction between their impairment and lived

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<sup>852</sup> Ibid, 25.

<sup>853</sup> Goodley (n719), 8.

<sup>854</sup> Rimmerman (n659), 25.

<sup>855</sup> WHO (n755), 28.

<sup>856</sup> Ibid.

<sup>857</sup> Goodley (n719), 23, footnote 45.

<sup>858</sup> Oliver (n546), 31.

<sup>859</sup> Ibid.

experience. Oliver's assertion of the existence and interpretation of an individual model of disability is agreeable. However, there is a risk that rejecting the existence of medicalisation, as is a reality for many PWDs. It runs the risk of blending medicine and medicalisation into one entity. Medicalisation is problematic as it implies the patient as passive. By itself, medicine does no such thing.

Second, conceptualising disability as a mixture of medicalisation and moralisation devalues the impact of impairment on the individual. Some PWDs "experience the onset of impairment as a personal tragedy which, while not invalidating the argument that they are being excluded from a range of activities by a disabling environment, does mean it would be inappropriate to deny that impairment can be experienced in this way".<sup>860</sup> Lived experience does not begin at the point of social interaction, and individuals can perceive their state of ability before tackling social barriers of disablement. As Swain and French note, "the onset of impairment and disability can be experienced as a tragedy" for an individual.<sup>861</sup> This is especially the case if they had constructed their life based on being non-disabled, or if the onset of disability "is associated with the trauma of illness or accident".<sup>862</sup> They provide an example of a sighted person, "whose life is based around being sighted, who lacks knowledge of the experiences of people with visual impairments, whose identity is founded on being sighted, and who has been subjected to the personal tragedy model of visual impairment".<sup>863</sup> In this instance, transitioning from non-PWD to PWD may be legitimately jarring and cause individual tragedy. Experiencing loss means having to unlearn methods of navigating life in society. Because society caters to one type of

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<sup>860</sup> Michael Oliver & Bob Sapey, *Social Work with Disabled People* (2<sup>nd</sup> edn, Macmillan 1999), 26.

<sup>861</sup> Swain & French (n802), 574.

<sup>862</sup> *Ibid.*

<sup>863</sup> *Ibid.*, 573.

person and one state of ability, deviating from that state highlights more barriers to entry.

Inversely, such a moral/medical model can generate an enforced tragedy within the individual, a potentially ironic antonym to the second concern of devaluing tragedy. Swain and French highlight this as a concern in their critique of a limited social model. They argue that “the personal tragedy view of impairment and disability is ingrained in the social identity of non-disabled people”.<sup>864</sup> Society creates situations which justify a tragedy perspective; tragedy has “a rational, cognitive basis constructed through experiences in disablist social contexts”.<sup>865</sup> Many non-PWDs fear gaining a disability for the reasons discussed above, manifesting tragedy, as they perceive disability as limiting and becoming of lesser social status. Because society is built upon being able-bodied, gaining membership to disability risks the access to society which non-PWDs enjoy. This fear highlights the barriers PWDs face in society, as non-PWDs genuinely fear having to experience said barriers for themselves. Therefore, “the tragedy model is in itself disabling”, as “it denies experiences of a disabling society, their enjoyment of life, and their identity and self-awareness as disabled people”.<sup>866</sup> In Chapter Five, the identity approach must tow the fine line between acknowledging the importance of tragedy whilst respecting personal autonomy.

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<sup>864</sup> Ibid.

<sup>865</sup> Ibid.

<sup>866</sup> Ibid, 574.



#### **4.4.2 Saving You from Society**

Social model theorists take the lack of social disability in some cultures as evidence of the social nature of disability. Despite "common sense" dictating disability as "a simple natural fact", theorists argue that "disability has to be differentiated from impairment".<sup>867</sup> As noted previously, they perceive disability as oppression by society, with Goodley remarking that "society's discriminatory response to disability...remains historically and culturally relative".<sup>868</sup> The changes in law documented in Chapter One indicate a shift in society, moving from segregation and isolationism towards PWD integration. This change marks an attempt to afford PWDs greater autonomy, with society attempting to undo the damage caused by previous social paradigms. However, such attempts often stem from a problematic ableist position, doubling down on PWDs as victims. Society continues to support PWDs "via patronage and charity, through organisations...which provided specialist services and professional intervention".<sup>869</sup>

As discussed in section 3.2, intervention is not always harmful, as medicine can provide individuals with positive support and beneficial outcomes. However, Goodley's argument here hinges on the reason for assistance and the method used to achieve it. Providing "patronage and charity" generates a power dynamic between PWDs and non-PWDs. Power is taken away from PWDs, who are framed as incapable victims. Conversely, non-PWDs retain power and engage in self-adulation to help the less fortunate. The members of the normate, the group who have created the social divide based upon perceived ability, maintain the imbalance and get to feel good about themselves for their pitiful contributions. In response, PWD groups have organised to

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<sup>867</sup> Waldschmidt (n542), 1168.

<sup>868</sup> Goodley (n719), 3.

<sup>869</sup> Ibid.

protest for their emancipation. In the face of “such negative cultural formations”, they have developed their own disability culture with a “richness in terms of creative proud slogans of liberation including 'Piss on Pity', 'Disabled and Proud' and 'People First'”.<sup>870</sup> United through a common goal, PWDs seek power and control by fighting against the system. Rather than drowning in misplaced rescue, they fight for greater autonomy and equality. In essence, their existence becomes rebellion.

Take, for instance, the slogan ‘Piss on Pity’. Musician Johnny Crescendo coined the term as part of a protest of the charity television show ‘Telethon’.<sup>871</sup> Telethon was a 24+ hour marathon to raise money for disability charities. ITV, the host network, would provide a phone number for viewers to call to donate money to the cause. This premise fits the broader ‘British Telethon’ category of media, combining visual entertainment with charity. ‘Block Telethon’ was an informal collective of disability rights activists working together to protest the show, as mentioned earlier. Their goal was to inform the public about the problematic narrative from charitable entertainment shows and try to restrict the show's duration by making filming difficult. After the protest, they formally organised the Disability Activists Network in 1993. They were part of the larger political activist movement in the UK between 1990 and 1995, which led to the passing of the Disability Discrimination Act.<sup>872</sup>

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<sup>870</sup> Ibid, 11.

<sup>871</sup> NDACA, ‘Johnny Crescendo, Block Telethon protest’ (*NDACA.org*) <<https://the-ndaca.org/resources/audio-described-gallery/johnny-crescendo-block-telethon-protest/>> (accessed 19 October 2022).

<sup>872</sup> Damon Rose, ‘When disabled people took to the streets to change the law’ (*BBC*, 7 November 2015) <<https://www.bbc.co.uk/news/disability-34732084>> (accessed 19 October 2022).

During the protest, members of Block Telethon spoke up about the meaning behind the slogan and their intentions with the protest. Alan Holdsworth, a founding member of Block Telethon, argued that such shows “portrays us as tragic, pathetic victims who long to be non-disabled, or plucky heroes who deserve a pat on the head for triumphing over adversity”.<sup>873</sup> Further, Rachel Hurst explained that pity is “one of the greatest obstacles we face in our struggle to be recognised as normal human beings”.<sup>874</sup> The goal was to remove charity from the conversation and instead focus on human rights. Further, ‘Piss on Pity’ was also the title of an art exhibition organised in 2019 in Wakefield. The aim of the exhibition echoed these goals to reject the articulation of disability as necessitating charity.<sup>875</sup> Inclusion of PWDs in education and employment on an equal basis with others is more important for growth and development than nominal financial handouts or a gold sticker.

On the surface, charity ignores potential problems by hiding under the guise of benevolence. British telethons are incredibly popular with the public and have historically been successful; for example, the BBC’s Children in Need has raised over £1 billion since its first appeal in 1980.<sup>876</sup> There is an element of generosity and altruism in charity work due to the positive trait in human nature to help others. As such, any protest of charitable work is met with shock. An individual who calls into a

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<sup>873</sup> Lisa O’Kelly, ‘Media: Another Telethon? What help is that if you’re disabled?: ITV’s fund-raising marathon does more harm than good, say critics. Lisa O’Kelly reports’ (*Independent*, 7 July 1992) <<https://www.independent.co.uk/news/media/media-another-telethon-what-help-is-that-if-you-re-disabled-itv-s-fundraising-marathon-does-more-harm-than-good-say-critics-lisa-o-kelly-reports-1531897.html>> (accessed 19 October 2022).

<sup>874</sup> Ibid.

<sup>875</sup> Gill Crawshaw, ‘Piss on Pity: Disabled artists versus Charity’ (*Disability Arts Online*, 1 October 2019) <<https://disabilityarts.online/magazine/opinion/piss-on-pity-disabled-artists-versus-charity/>> (accessed 19 October 2022).

<sup>876</sup> BBC Children in Need, ‘Frequently Asked Questions’ (*BBC Children in Need*) <<https://www.bbcchildreninneed.co.uk/about-us/faqs/>> (accessed 19 October 2022).

telethon to donate may see activism like Block Telethon and respond aghast: “But charity is always good, right?”. Further, charity leans into the promotion of principles of social utility. Individuals with kind natures can give money to sources that can put it to better use.

However, delve deeper, and it becomes clear that such charitable organisations risk alienating PWDs for several reasons. First, treating PWDs as recipients of charity separates them as an alternative individual category. Events like Telethon manifest situations where “groups of able-bodied people around the country [are] encouraged to raise money for another group they can then dissociate themselves from”.<sup>877</sup> If individuals donate money to these causes, they can feel empowered that they have made a difference without actively engaging with the topic at hand. They no longer must consider the implications of health and society on PWDs as they support a charity. They have done all that society expects of them. Pity becomes a mono-directional road, travelling from non-PWDs towards PWDs, who do not own the term nor wish to receive it; “I do not have an awful lot of self-pity because this is just my life”.<sup>878</sup>

Second, using pity as a lens through which to perceive PWDs is infantilising. Such a perspective refuses to see PWDs as equal and maintains a sense of ableism. Kellgren-Fozard explains that treating PWDs as different becomes an othering experience. It is ultimately irrelevant whether the charitable action had good intentions. She argues, “I did not choose this body. I am not brave for being in it”.<sup>879</sup> Often, the media will depict

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<sup>877</sup> O’Kelly (n873).

<sup>878</sup> Kellgren-Fozard (n744).

<sup>879</sup> Jessica Kellgren-Fozard, ‘Why Not All Disabled People Want To Be Inspirational’ (YouTube, 13 July 2018) <<https://www.youtube.com/watch?v=AAE4n1dcgQw>> (accessed 2 September 2020).

PWDs as inspirations and heroes lauded over average citizens for their perseverance in adversity. However, this perspective implies that “merely existing as a disabled person is the worst possible life and [non-PWDs] simply could not cope with it”.<sup>880</sup> Articulating existence as inspiration turns PWDs from “an equal to a secondary motivational character in the life of the person saying it”.<sup>881</sup> As such, PWDs may perceive an interaction intended to be positive and helpful as derogatory or restrictive. Listening to the voices of impacted groups is important to ensure that social change occurs for just and proper reasons.

Third, it highlights the importance of lived experience and voice. To suggest that all members of a particular group maintain a unified perspective on a topic is short-sighted. Often, critical moral debates involve interacting with several different standpoints, so it is imperative to listen to them and find a balance. Martin Lucas, the producer responsible for Telethon, explained that his experience as a PWD fed into his overall plan for the show. He understood the goals of Block Telethon but argued that the show was “a great opportunity to slip the knife in, to be subversive”.<sup>882</sup> At that time, PWDs had fewer platforms to make their voices heard, and he argued that using their available resources was essential to spreading equality. Notably, the changes he proposed to better advocate for inclusion pulled away from older iterations of the show and aligned more closely with the ethos of Block Telethon.

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<sup>880</sup> Ibid.

<sup>881</sup> Jessica Kellgren-Fozard, ‘Why not all disabled people want to be seen as an inspiration’ (*Cosmopolitan*, 13 June 2018) <<https://www.cosmopolitan.com/uk/reports/a21345034/disabled-people-inspiration-inspiring/>> (accessed 19 November 2022).

<sup>882</sup> O’Kelly (n873).

Therefore, it is historically evident that marginalised groups react to charity and pity with resistance. When society chooses charity to apply victimhood to PWDs, political discourse from activist groups forcefully rejects the notion and instead advocates for equality. Tyler argues that PWDs are "revolting subjects".<sup>883</sup> Revolting carries two distinct meanings in political discourse – as an adjective conferring a sense of causing disgust and as a verb to denote a protest or resistance. By looking at the intersection of these two meanings, Tyler seeks to understand how society labels marginalised groups as 'other'. In the process, she also highlights examples of groups manifesting their power from a scenario where they were otherwise devoid of agency. She argues that "disgust is political"<sup>884</sup> and is emblematic of society generating a "low ranking of things, people, and actions deemed disgusting and contemptible".<sup>885</sup> When PWDs engage in revolution, they are "cast out as the revolting antithesis of normative ideas about what it means to be an active citizen while also revolting against disablism through their politics".<sup>886</sup> Therefore, Tyler argues that if we "approach disgust as symptomatic of wider social relations of power, we can ascertain why disgust might be attributed to particular bodies".<sup>887</sup> Fighting socially entrenched sources of power bestows a different form of power within the oppressed class.

Such perspectives highlight the political nature of identity with disability and the resistance many show towards society's responses to their existence. In a world where PWDs have limited access to society, having a modicum of control and agency against the system which perpetuates those limitations can provide considerable solace. Non-

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<sup>883</sup> Imogen Tyler, *Revolting Subjects: Social Abjection and Resistance in Neoliberal Britain* (Bloomsbury 2013).

<sup>884</sup> *Ibid*, 24.

<sup>885</sup> William Miller, *The Anatomy of Disgust* (Harvard University Press 1997), xiv.

<sup>886</sup> Goodley (n719), 13.

<sup>887</sup> Tyler (n883), 24.

PWDs are “much more threatened and challenged by the notion that a wheelchair-user could be pleased and proud” to be themselves.<sup>888</sup> To many, disability is, therefore, “a proud identity”.<sup>889</sup> They can feel and express that pride in various unique ways. It can be a reaction to success or a response to hardship. Understanding the source of this identity can help target and alleviate burdens or highlight positive aspects of life that society can promote. Therefore, the identity approach in Chapter Five will include lived experience and a focus on the individual and collective reaction to enforced victimhood, acknowledging that resistance may contribute to identity formation. Individuality is a unique facet of identity, as it does not appear within a social or medical model’s repertoire. If existing models lack a respect for individuality and personal agency, an identity approach could offset the imbalances acknowledged in this chapter.

Assumptions legitimise “segregated families for [PWDs], such as special schools, institutions, or sheltered employment, and...guardianship laws based on the deprivation of legal capacity”<sup>890</sup>

#### **4.5 Conclusion**

To conclude, there are several different methods of understanding disability, stemming predominately from differences in foundational approach. Goodley summarises this well: "disability studies is developing in global ways reflecting distinct regional contexts across the social sciences and humanities".<sup>891</sup> Due to the vast wealth of models present

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<sup>888</sup> Swain & French (n802), 570.

<sup>889</sup> Goodley (n719), 13.

<sup>890</sup> Broderick & Ferri (n339), 19.

<sup>891</sup> Ibid, 19.

in academia, this chapter sought to analyse general themes which feature across multiple models rather than consider each model individually. In doing so, the chapter establishes important discussion topics and contentious aspects of disability. As such, the identity approach in Chapter Five tackles these points, and both echoes the positive aspects of existing models and deviate away from less constructive aspects. The added benefit to this approach is to ensure the critique of disability and establishment of the queer/crip identity comes from a position of constructive analysis of overarching issues rather than an overly subjective or prejudicial attack on specific models.

To begin, section 3.2 tackles the tendency for models to overly medicalise the human condition. Society utilises medical intervention to cure many ailments, illnesses, and injuries. Moreover, society perceives disability as a deviation from the gold standard of health. Medical professionals label different impairments as medical conditions, developing treatment methods for both the cause and the consequence. However, a recurring flaw of this perspective is that the resultant regulation of the human body creates insurmountable barriers and burdens for PWDs. Section 3.2.3 outlines four of these barriers. Medicalisation ignores the barriers PWDs face when trying to interact with society. It creates a social binary of health versus unhealth. It reduces an individual to their ailments, ignoring their personal history and experience. Finally, it contributes to the stigma PWDs regularly face in everyday life.

In turn, section 3.3 discusses the models which argue that disability is a form of social governance of PWDs. The predominant theory here is the social model, which argues that disablement is separate from impairment. Disability exists at the point of social interaction rather than within the biological narrative of the human body. This



perspective accommodates most of the discourse over the last three decades and arguably contributed to establishing the AHC and developing the CRPD. Much of the progress made for PWD rights can be attributed to the development of the social model. However, the model is not without problems. Section 3.3.2 explains how focusing purely on social disablement does not account for all PWD experiences outside of the context of British political activism. It reduces individual autonomy by taking power away from PWDs and placing it in the hands of society. It ignores the positive interactions PWDs have with their impairments or support systems. The multiple attempts by theorists to expand or restructure the model demonstrates practical issues in its rigid structure.

Finally, section 4.4 considers how specific models of disability position PWDs as powerless victims in need of rescue. An existence with a disability is a tragedy, and models must save individuals from themselves and society. Nevertheless, enforced tragedy risks undermining the lived experience of the individual. They can legitimately experience tragedy through loss or reject the notion of tragedy and pity. Therefore, the next chapter will consider these perspectives when using different theories of identity to create an identity approach to disability in the hopes of redressing these concerns.

## Five: Formulating Queer/Crip Identity

“...injustices to disabled people can be understood neither as generated by solely cultural mechanisms (cultural reductionism) nor by socio-economic mechanisms (biological reductionism). In sum, only by taking different levels, mechanisms, and contexts into account can disability as a phenomenon be analytically approached”.<sup>892</sup>

### 5.1 Introduction

Identity is a complex social construction. It is a means by which we understand the existence of an individual or a collective. It involves “knowing who we are, knowing who others are, them knowing who we are, us knowing who they think we are and so on”.<sup>893</sup> In essence, it is a multi-layered living definition of the status of being, imparting to others a vast wealth of knowledge about the subject. It has many sources; it is not located within one specific source and is not confined to a set structure. Identity can be incredibly personal, providing euphoria or dysphoria to the subject depending on various factors, including the subject’s understanding of their identity and society’s reaction to aspects of the identity. Therefore, identity is a fluid dynamic between person and external variable. An example is the idea of identity creativity. Concerning the discussion of queer in Chapter Two, definitions limit the creativity afforded to individuals in crafting actions and responses. In turn, there is debate about how creative an identity can be if society provides individuals with the same material from which to formulate their identities.

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<sup>892</sup> Danermark & Gellerstedt (n372), 350

<sup>893</sup> Richard Jenkins, *Social Identity* (4<sup>th</sup> edn, Routledge 2014), 6.

In Chapter Two, this thesis provides an overview of Shakespeare's interactional approach to disability, and offered a postmodernist and post-structuralist critique. The promise given in the introduction of Chapter Two was for a queering of Shakespeare, a discussion of what happens when queer/crip perspectives are applied to a critical realist. This Chapter seeks to make good on this promise, to demonstrate how an identity approach to disability functions as a queered interaction. To achieve this, it will first define identity as a concept, demarking the potential structure of a disability identity. It shall debate how identity functions within a methodological framework, one which has often rejected identity politics and labels. Secondly, it shall outline what an identity approach looks like and how it functions, with reference to other attempts to recontextualise models of disability. Given that queer rejects definitions and structures, it is simpler to highlight what a queer/crip approach *is not*, rather than what it *is*. Throughout, comparisons will be made through the application of biology, governance, and rescue from Chapter Four. Given that the identity approach is a departure from Shakespeare, who himself departs from existing models, it is important to note how a new approach maintains the strengths of existing perspectives whilst building on their weaknesses.

## **5.2 Understanding a Queer/Crip Identity**

Identity is “a prism through which other topical aspects of contemporary life are spotted, grasped, and examined”.<sup>894</sup> Developments in social sciences research show a “rehash and refurbish[ment] to fit the discourse now rotating around the identity

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<sup>894</sup> Bauman (n790), 1.

axis”.<sup>895</sup> Identity offers an exciting new door for legal scholars to open and peer behind when discussing disability and human rights. Nevertheless, defining identity is an important first step in developing an identity approach to disability.

### **5.2.1 An Identity Overview**

Identity originates in Latin, derived from *idem*, meaning ‘same’ or ‘sameness’. Sameness relates to the features by which individuals can empathise with each other, elements of self-echoed in others. These features enable connections through which individuals can understand one another using their shared experiences. As Plummer posits:

“[Identity] serves as a crucial bridge in social life between human beings and wider cultures; it implies a sense of meaning and a sense of categorisation and differentiation; and it marks out differences – between ourselves and others. The idea of identity speaks of locating a person within a personal and social category. It suggests an answer to the question ‘who am I?’ placing oneself and life within a framework of past...of present...and future”.<sup>896</sup>

Plummer’s distinction between sameness and difference within identity is key, as society often perceives identity as individual and unique; the notion of individuality in identity is only partially correct. Identity is both individual and shared, structured and fluid. It features several components and stems from socially constructed systems and structures generated collectively based on norms and definitions. Identity is “not a

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<sup>895</sup> Ibid.

<sup>896</sup> Ken Plummer, ‘Sexual Identities’ in George Ritzer (ed), *The Blackwell Encyclopedia of Sociology* (Blackwell 2007), 4246.

private matter and a private worry, [rather]...our individuality is socially produced.”<sup>897</sup> In forming an identity, actors then engage in a two-fold creation of an identity, first by analysing the social categories and second by internally interpreting those categories and applying them to the self. In doing so, the actor chooses which categories to apply and which to ignore – often, “identifying with one social category often goes hand-in-hand with demonstrating one’s disidentification with another.”<sup>898</sup> This choice also leads to a development cycle of identity, with continuous engagement in analysis and interpretation by the actor on their path – “who I am now is not who I was yesterday or who I will be tomorrow”.<sup>899</sup> Bauman posits that “individualisation consists in transforming human identity from a given into a task – and charging the actors with the responsibility for performing that task and the consequences...of their performance.”<sup>900</sup> Each particular facet of identity is the same for everyone, whereas the individual’s composition of those characteristics generates the uniqueness of identity. Additionally, the interpretation phase also shapes the actor’s understanding of the social categories, leading to this cyclical function manifesting differently for a particular actor compared to a different actor.

Scott aggregates several social theories of identity, defining identity as a “set of integrated ideas about the self, the roles we play and the qualities that make us unique”.<sup>901</sup> Identity seemingly begins as a grounded and constant state, internally consistent and forming a basis for social relations and interactions.<sup>902</sup> Nevertheless,

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<sup>897</sup> Zygmunt Bauman, ‘Identity in the globalising world’ (2001) 9(2) *Social Anthropology* 121, 124.

<sup>898</sup> Susie Scott, *Negotiating Identity: Symbolic Interactionist Approaches to Social Identity* (Polity Press 2015), 4.

<sup>899</sup> *Ibid.*, 1.

<sup>900</sup> Bauman (n897), 124.

<sup>901</sup> Scott (n898), 2.

<sup>902</sup> Gordon Allport, *Pattern and Growth in Personality* (Holt, Rinehart and Winston 1961).

it is instead an aggregate of social roles,<sup>903</sup> a collection of “situated selves which are averaged out to create an identity”.<sup>904</sup> These are externally sourced and generated in reaction to social experiences, which then generate a “central paradox of identity”, combining the continuity of social categories and the uniqueness of the individual generation of self.<sup>905</sup> To demonstrate the duality of identity, Kuhn and McPartland devised the Twenty Statements Test and asked students to list twenty words that describe themselves. The responses overwhelmingly included references to social categories, roles, and memberships, such as age, gender, and occupation.<sup>906</sup> These categories would be socially generated and subsequently reproduced by the participants in an attempt to understand the self. Williams distinguishes between identity and identification; the former is the sense of self, and the latter categorises the self against social parameters.<sup>907</sup> This may cause problems for queer, which rejects social structures and labels. In section 5.2.2, this chapter will expand on how Butler’s theories of performativity and citationality interact with these theories of identity.

Theorists have generated several types of identity, which actors perform at different points in time but comprise an identity. Two types of identity, social and personal, are well-received and agreed upon, though their parameters differ between theorists. Whilst Harré defines social identity as attributes which are externally applied to the actor,<sup>908</sup> Goffman argues that it features the “complement of attributes felt to be

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<sup>903</sup> Stanford M Lyman & Marvin B Scott, *A Sociology of the Absurd* (2nd edn, General Hall 1989).

<sup>904</sup> Scott (n898), 1.

<sup>905</sup> Steph Lawler, *Identity: Sociological Perspectives* (Polity Press 2008).

<sup>906</sup> Manfred H Kuhn and Thomas S McPartland, ‘An empirical investigation of self-attitudes’ (1954) 19(1) *American Sociological Review* 68.

<sup>907</sup> Robin Williams, *Making Identity Matter: Identity, Society, and Social Interaction* (Routledge 2000).

<sup>908</sup> Rom Harré, *The Singular Self: An Introduction to the Psychology of Personhood* (Sage Publications 1998).

ordinary and natural” to members of a category.<sup>909</sup> Similarly, both Tajfel<sup>910</sup> and Hewitt<sup>911</sup> perceive social identity as memberships to groups based on shared interests and values. On the other hand, personal identity is the belief an individual has in the amalgamation of selves, the generation of the characteristics of their identity.<sup>912</sup> It is the idea that “the individual can be differentiated from all others and that around this means of differentiation a single continuous record of social facts can be attached, entangled, like candy floss, becoming then the sticky substance to which still other biographical facts can be attached”.<sup>913</sup> In addition, several additional types of identity appear. With biographical identity, the self is represented in stories (similar to the linguistic self as mentioned below).<sup>914</sup> Per situational identity, the presentation or announcement of the self in specific circumstances.<sup>915</sup> Finally, per ego identity the individual’s subjective and reflexive perspective of their character and identity formation.<sup>916</sup>

Beyond this are debates on the features of identity; sociologists agree that identity is a multi-layered and multi-faceted concept, though the exact composition of identity differs between theorists. Lindesmith, Strauss, and Denzin consider identity incorporating various versions of self.<sup>917</sup> First is the internal consciousness as relating

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<sup>909</sup> Goffman (n104), 2.

<sup>910</sup> Henri Tajfel, ‘Social Psychology of Intergroup Relations’ (1982) 33 *Annual Review of Psychology* 1.

<sup>911</sup> Joph P Hewitt, *Self and Society: A Symbolic Interactionist Social Psychology* (10th edn, Allyn & Bacon 2007).

<sup>912</sup> Harré (n908).

<sup>913</sup> Goffman (n104), 57.

<sup>914</sup> Hewitt (n911).

<sup>915</sup> Gregory P Stone, ‘Appearance and the Self’ in Arnold M Rose (ed), *Human Behavior and Social Processes* (Routledge 1962).

<sup>916</sup> Goffman (n104), 106.

<sup>917</sup> Alfred R Lindesmith, Anselm L Strauss, & Norman K Denzin, *Social Psychology* (8th edn, Sage Publications 1999).

to one's location within a situation, the phenomenological self. The second is how an individual acts towards others in such situations, the interactional self. Third, the way an individual represents themselves to others, specifically through biographies and language, the linguistic self. Fourth, the commodified entity is represented through visible body parts, the material self. Fifth, the broader social definitions followed in attempting to conform to expectations, the ideological self. In unison, these five layers generate an identity which ebbs and flows through various social situations. Selfhood is reflexive, governing "experience[s] which are private, internal, and subjective" in nature.<sup>918</sup> The self, reflexive through various social interactions, is inherently different from identity, which is the unified meaning given to the individual based on those experiences.<sup>919</sup> Jenkins sees these concepts as interlinked, relying on each other to develop. Jenkins also suggests that identity comprises several features without using the lens of self.<sup>920</sup> First is similarity, the internal consistencies of identity. Second is difference, the elements of uniqueness and individuality experienced within identity. The third is reflexivity, the perceptions an individual has of themselves. Fourth is process, the liberty and agency individuals have over themselves to change and develop. In summation, selfhood generates characteristics and meanings that attach to an overarching subjective identity, which manifests itself in specific social situations.

### **5.2.2 Approaching a Queer Identity**

As examined in section 2.3, queer finds grounding within political activism and the amelioration of LGBTQ+ identities. As such, queer theorists explain many general

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<sup>918</sup> Scott (n898), 2.

<sup>919</sup> Lindesmith, Strauss, & Denzin (n917), 218.

<sup>920</sup> Jenkins (n893).



principles and approaches through the lens of gender identity and sexual orientation. Though the discussion in this thesis avoids the gender politics aspect of queer, it is an essential contextual aspect of queer history. As Mardell notes, “reclaiming ‘Queer’ has proven to be an empowering experience for many [LGBTQ+] people. They feel taking ownership of the word strips it of its previous power”.<sup>921</sup> Further, Whittle explains through a personal account how he is gendered:

“...not just by myself but by everybody who knows me, by all those who write of me and ‘my sort’, by all those who work with transgendered people, and nearly always by transgendered people themselves...I cannot escape the hegemony of gendering”.<sup>922</sup>

There are prevalent themes of empowerment in the face of adversity in queer, actively rejecting the status quo if it fails to consider inclusivity. Jagose notes that “demonstrating the impossibility of any ‘natural’ sexuality, [queer] calls into question even such apparently unproblematic terms as ‘man’ and ‘woman’”.<sup>923</sup> It critiques sex and gender as structures, open for interpretation and as a matter of choice. Similarly, identity remains open and cautious of pre-existing social structures. However, as Sokhi-Bulley notes at section 3.3.2, to critique does not mean to vehemently reject or condemn. As will become evident, the narrative of identity flows through queer and crip, albeit with a post-structuralist perspective.

At section 2.4, Butler suggests that it may seem impossible to self-determine our gender from a state outside of gender if we are already immersed within gender.<sup>924</sup>

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<sup>921</sup> Ashley Mardell, *The ABCs of LGBT+* (Mango Media 2016), 172.

<sup>922</sup> Whittle (n448), 197.

<sup>923</sup> Jagose (n436), 3.

<sup>924</sup> Butler (n487), 129.

The body is “a statement of gender from the moment of birth”,<sup>925</sup> with society creating the categories of ‘male’ and ‘female’ to apply to individuals based on various human body characteristics. Therefore, if gender is pre-determined by society, one must question how it can also be a choice one makes themselves. Butler uses the works of Sartre and Beauvoir to settle this ontological issue. Sartre argues that there is a distinction between the body and an individual’s consciousness, their sense of self. However, these are intrinsically interlinked, and their specific parameters are not always clear. Not only is identity parallel to the body, but it is also, in part, an existence extended beyond the body. He posits that we are “at once [both] a point of view and a point of departure...[the body is] a point of departure which I am and which at the same time I surpass towards what I have to be”.<sup>926</sup> The body is the locus of the establishment of experience of both the past and current states of view.<sup>927</sup> It is not merely the vessel by which persons live and experience the world but also impacts and changes how it experiences them.<sup>928</sup> Likewise, when considering identity, it is important to understand that individuals retain power and agency to determine who they are. Both disability and identity are unique to each person. In this context, however, power is a restrained and dynamic interaction. It is not a zero-sum game, where one side always loses.

As a condition of access, the body “is a being comported beyond itself, referring to the world and thereby revealing its ontological status as a referential reality”.<sup>929</sup> As Butler

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<sup>925</sup> Whittle (n448), 196.

<sup>926</sup> Jean-Paul Sartre, *Being and Nothingness: An Essay in Phenomenological Ontology*, Hazel E. Barnes (tr), (Philosophical Library 1947), 429-30.

<sup>927</sup> Ibid, 431-2.

<sup>928</sup> See Thomas W Busch, ‘Beyond the Cogito: The Question of the Continuity of Sartre’s Thought’ (1983) 60:3 *The Modern Schoolman* 189.

<sup>929</sup> Butler (n487), 130.

explains, because “all human beings strive after possibilities not yet realised, human beings are to that extent ‘beyond’ themselves. This ek-static condition is a corporeal experience; the body is thus experienced as a mode of becoming”.<sup>930</sup> Transferring this to gender and identity, Beauvoir utilises the puzzle posed by Sartre but moves beyond mere discussion of the body. Instead, she considers the juxtaposition between the natural body and the body assimilated through culture. Gender is not set at birth. Instead, it develops over time; “one is one’s body from the start, and only thereafter becomes one’s gender”.<sup>931</sup> As such, “gender as an incessant project, a daily act of reconstruction and interpretation, [which] draws upon Sartre’s doctrine of pre-reflective choice and gives that abstract epistemological structure a concrete cultural meaning”.<sup>932</sup> Likewise, disability is in constant development. Blending the content of 5.2.1 with queer and crip from Chapters Two and Three, an individual is an actor who performs their identity in different locations, learning about how society responds and how the actor reacts. As such, their experiences impact their understanding of identity and how they navigate future interactions.

As noted in section 2.4.3, Butler builds on this idea of gender by discussing “citationality”.<sup>933</sup> For them, society establishes the parameters within which gender can be found, and individuals then use this to formulate their sense of gender identity through the “symbolic prohibitions” situated within said societal parameters.<sup>934</sup> Individual identity can be represented and demonstrated in a myriad of forms, going beyond the confines of the body, as Sartre argued. Less a radical act of creation,

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<sup>930</sup> Ibid.

<sup>931</sup> Ibid, 131.

<sup>932</sup> Ibid, 131.

<sup>933</sup> Judith Butler, *Bodies that Matter: On the Discursive Limits of Sex* (Routledge 2011), xxi.

<sup>934</sup> Jay Prosser, ‘Judith Butler: Queer Feminism, Transgender, and the Transubstantiation of Sex’ in Donald E Hall et al (eds), *The Routledge Queer Studies Reader* (Routledge 2013), 37.

gender, and in turn identity, therefore, is a tacit project to renew a cultural history in one's corporeal terms".<sup>935</sup> Butler's shift from "Gender Troubles" to the "Discursive Limits of Sex" accounts for this development. Rather than manifesting out of thin air, identity forms through the progressive realisation of one's position in society and subsequent developments of the individual. Likewise, disability exists as a mixture of personal understanding of circumstance and development of identity through progressive interactions with sources both intrinsic and extrinsic to the individual.

Further writings on crip theory establish the applicability of Butler's citationality on disability. As noted at section 3.2.3, McRuer interprets Butler's theory of gender performativity and repetition as applicable to disability studies – the concept of "ability trouble", the "inevitable impossibility, even as it is made compulsory, of an able-bodied identity".<sup>936</sup> Butler's concept of citationality translates effectively to the crip. In performing their identity, actors cite ableness when engaging in social spaces. Consequently, society cites ableness when providing opportunities for individuals to interact with others. The body is another source of identity, another reference material. This perspective tends to apply with greater veracity to physical ability over psychosocial disability or the experiences of psychiatric system survivors due to the requirement of input by society. Society maintains a bias towards the obvious and visual aspects of disability, regardless of the experience and identity of the PWD.

Butler continues with a discussion of agency, or lack thereof. Despite the notion that an individual holds some choice when citing socially-constructed ideas such as gender

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<sup>935</sup> Butler (n487), 131.

<sup>936</sup> McRuer (n539), 10.

for their own identity, Butler suggests that “there is no subject who is ‘free’ to stand outside norms or to negotiate them at a distance; on the contrary, the subject is retroactively produced by these norms on their repetition”.<sup>937</sup> The choice to “assume a certain kind of body, to live or wear one’s body a certain way, implies a world of already established corporeal styles”.<sup>938</sup> Sex is not merely a static description of a person. It is “one of the norms by which the ‘one’ becomes viable at all”.<sup>939</sup> As society automatically applies categories such as sex and gender to individuals rigidly, there are obligations on individuals to conform; in fact, social constraints upon obedience and deviation are “so great that most people feel deeply wounded if they are told that they exercise their manhood or womanhood improperly”.<sup>940</sup> Therefore, Butler argues that agency rests within the person’s identity and body. It is inherent rather than developed. Personal agency is “a logical prerequisite for taking on a gender, does not presuppose that this agency is itself disembodied; indeed, it is our genders that we become and not our bodies”.<sup>941</sup> Likewise, when considering their identity, an individual must create and nurture it within the confines of society and the parameters it has already set. Though subsequent discussions of identity will relate to individual agency, it is important to acknowledge that complete agency is somewhat of a fallacy. Instead, when articulating individual agency, identity must respect the restrictions set on individuals by society.

The models in Chapter Four all maintain a key ‘premise’, a tagline to effectively impart their perspective and argument. Based on the above discussion on the interactions of

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<sup>937</sup> Butler (n501), 22.

<sup>938</sup> Butler (n487), 131.

<sup>939</sup> Butler (n933), xii.

<sup>940</sup> Butler (n487), 132.

<sup>941</sup> *Ibid*, 131.

the queer/crip and identity, the identity approach's premise becomes clear. The identity approach positions disability as a characteristic of an individual's identity. The only important definition is the one the individual uses to describe themselves. It matters not how society defines or labels the individual, though this can contribute to their identity if they find it helpful. Disability has several sources, all of which carry weight and validity to constructing identity. To truly understand how disability manifests within an individual, one must consider the various biological, economic, social, and relational contributions experienced.

Two questions arise through this new perspective. First, it is clear how identity interacts with disability, but the opposite is less certain. As noted in previous sections, contemporary social models suggest that outside of social structures, an individual does not have a disability. Instead, disability is a socially constructed label for a state of being which is assumed or presumed deviant from the normate. Without the social aspect, the person would live and experience life in their way, devoid of knowledge of difference. Once an individual enters society, there are immediate comparisons between PWDs and non-PWDs. The individual status of ability is a comparative factor, as the PWD may have shared characteristics with the non-PWD, which does not work to compound the difference. In this regard, one understands disability through social interaction. As Hughes and Paterson note, "identity is complex and problematic, and it is – in an individualistic and rapidly changing society – a precarious source of solidarity. Open recognition of this precariousness is useful. It mitigates against rather than encourages factionalism".<sup>942</sup> It is multi-faceted, providing a variety of angles from which to understand the lived experience.

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<sup>942</sup> Bill Hughes & Kevin Paterson, 'The Social Model of Disability and the Disappearing Body: towards a Sociology of Impairment' (1996) 12:3 *Disability & Society* 325, 338.

The interaction between individuals helps establish information about oneself. This interaction builds upon knowledge but does not generate or establish the disability. The disability becomes an aspect of the individual with whom the person may or may not identify. For example, they may take solace in the knowledge of difference or reject the label entirely, which is their prerogative. Continual interaction with society builds more information on disability, generating this cyclical development of identity. Notably, the power and status of the disability rest with the individual, not anyone else. Identity features through culture, where distinctions between identity and ethnicity are often blurred or disregarded altogether. It manifests in both collective and social categories, focussing on how phenomena create a common unity among individuals. It also caters to the self, providing meanings that actors apply to various roles played through social interaction.

The other question relates to why disability should be a facet of identity rather than something else. The location of disability is not wholly within society. To suggest this is to rely heavily on the perspective of society in the narrative, at the expense of dehumanising the individual. This was noted in detail in section 4.3.2 in critiquing the social model's governance over the debate on disability. In turn, this perspective enables others to shape the narrative around these characteristics. The discussion in section 4.4 on rescue provides perfect examples, as groups external to the individual suggest that they need assistance, are incapable of independence, or need to be pitied. Society takes these views regardless of the wishes of PWDs. Further, one can locate disability within the individual without an overreliance on biology. The power rests with the individual on whether they identify with the terms 'disability' or PWD. Anyone who identifies with these terms gains membership to the collective and can

use the labels that fit them without having to ascertain permission from others. To argue that disability is biological locates it within a physical space, which can be regulated and assessed.

Further, using a focal point for disability which practitioners or professionals can assess, suggests that someone knows more about an individual than themselves and ensures the existence of a gatekeeper to prevent access to support. Examples include the governance of groups by States through enacting policies on disability benefits, many of which are subject to commentary by the models discussed in section 3.3. Taking that power away from policy makers and professionals gives individuals greater autonomy to manage themselves and how they fit in society. It means that the disability is located within the individual, in whatever manner that may manifest, ensuring that all PWDs have protections. As it relates to contemporary debates on the parameters of disability, physical and psychosocial features are in the conversation by default unless an individual elects not to identify with the term.

This section highlights essential general parameters for an identity approach to disability. However, it does not provide an explicit structure. It is an active choice to reflect the functionality of queer. As noted in section 2.3, queer refuses definition and structure. Queer manifests as “a desire to create new context” rather than “professional ones in which cool work can be performed”.<sup>943</sup> Within this new context, queer can work to critique the system from without rather than within. Accordingly, identity provides an open space for those with lived experience to voice their truth and help contribute to an inclusive reformation of the social narrative. Berlant and Warner

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<sup>943</sup> Berlant & Warner (n338), 347.



explain that a crucial reason for “using the word queer in the first place was the wrenching sense of recontextualisation it gave,”<sup>944</sup> a fundamental aspect of the movement. As such, developing a new approach to disability based on queer principles should follow suit. Rather than prescribe a specific classification or structure, the above model resists rigidity and maintains flexibility for practical application.

### **5.3 Establishing the Identity Approach**

This next section seeks to establish a new disability model using identity as its foundation. It will use the content of section 5.2 and the constructive criticism of existing models in Chapter Four. It aims to follow the deconstructive logic of queer and crip discussed in Chapters Two and Three to generate an approach which seeks inclusion, respect, and agency for PWDs. Some scholars may suggest this is futile; Goodman notes the risks of too readily categorising disability analyses into models of thinking. “Mature disability studies have become increasingly eclectic. Pigeon-holing specific arguments in terms of distinct models risks stripping away the more nuanced nature of their contributions”.<sup>945</sup> Such thinking suggests that generating different models and separating schools of thought means less collaboration overall. Disability models, therefore, have flaws which function in opposition rather than in conjunction with each other. It also follows the adage that too many cooks spoil the broth, and multiple competing models confuse disability studies. However, as Bauman notes, “solids may be melted, but they are melted in order to mould new solids better shaped and better fitted for human happiness than the old ones”.<sup>946</sup> In such circumstances, the resulting solids are “also more solid and so more certain than the old solids

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<sup>944</sup> Ibid, 345.

<sup>945</sup> Goodley (n719), 17.

<sup>946</sup> Bauman (n790), 3.

managed to be”.<sup>947</sup> By constructively critiquing existing models and using the results to create a new approach, this chapter seeks to contribute positively to academia by offering a new perspective on disability. Doing so will help strengthen the discussion of human rights for PWDs. The discussion at 5.3.2 will consider the plausibility of deeper human rights discourses for PWDs.

### **5.3.1 Foundations**

In establishing his life-course approach, Priestly suggests that there are four different “headings” when approaching disability.<sup>948</sup> To begin, there is a difference between the approaches taken by a model and the principles the model holds at its core. The model’s approach considers the angle from which a model seeks to articulate disability. Priestly proposes two angles of approach models take. One axis establishes the model’s position on an individual/social dynamic, and the other axis establishes its position on a materialist/idealist dynamic, manifesting a theoretical Punnett square of intersections.<sup>949</sup> However, this articulation suggests that these are independent categories within which models can fit neatly; in theory, *model x* should be either individual or social and materialist or biological. As Chapter Four notes, models are complicated and engage in considerable overlap with each other. Segregated boxes are insufficient to consider the intricacies of disability modelling accurately. Therefore, a queer/crip approach to disability would deviate from the prescriptive nature of this approach. Though Priestly’s framework is helpful as a springboard from which to develop and compare a queered identity approach, this chapter has a deconstructivist mandate to start afresh in conceptualising disability.

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<sup>947</sup> Ibid.

<sup>948</sup> Priestly (n763), 15.

<sup>949</sup> Ibid.

A truly queer interpretation would completely reject the categorisation of disability in this way. At sections 2.4 and 5.2, this thesis makes reference to Butler's considerations of performativity and citationality. Their understanding of the gendered subject is the theoretical yet unattainable existence of an individual outside of gender, given that gender is applied historically and prospectively. The subject cannot escape gender. McRuer and Kafer translate this to disability; it is impossible for the subject to perceive themselves independent of disability. Therefore, the first problem rests in *locating* disability. Is it found in the definitions set by society, or the performance by the actor in citing those definitions? Given Halperin's understanding of queer as positionality,<sup>950</sup> it seems that disability exists in this fluid dynamic. Shakespeare attempts to articulate a similar problem by considering disability as relative.<sup>951</sup> Given that the identity approach is an attempt to queer Shakespeare, it seems that a dynamic and fluid interpretation of Priestly's headings would be a better approach, blending the 'structure' of definitions with the deconstruction of queer.

A compromise between the two could be an articulation of Priestly's headings through an intersectional graph. Along the x-axis sits considerations of location, which reflects the individual/social dynamic discussed above. This axis maintains individual characteristics of disability at one end and the social elements of disability at the other end. To sit at the individual end suggests disability is located purely within the individual; to sit at the social end suggests disability is located externally from the person through disablement by society. Along the y-axis sits considerations of the source, which reflects the materialist/idealist lens. This axis maintains the biological

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<sup>950</sup> Halperin (n598), 62.

<sup>951</sup> Shakespeare (n341), 7.

and physical aspects of disability at one end and the “negotiated aspects of individual identity and adjustment” found within psychology at the other end.<sup>952</sup> To sit at the materialist end suggests that the source of disability is medical through tangible considerations of impairment. To sit at the idealist end suggests that the source of disability is a personal experience in negotiating and navigating through social life.

It may be helpful to use the models of disability discussed in Chapter Four as examples to demonstrate the function of this intersectional graph. The medical models of disability sit squarely in the individual-materialist box as an intersection of biological assessment and the individual. Disability results from physical or mental impairment in the body, which the individual wholly experiences. Medicine can fix the ailment and the individual. Further, the moral models of disability sit at the intersection of the individual and the ideal. Since disability is a tragedy befalling the individual, external forces use their preconceived notions of what is good and bad to place assessments on the situation.

Conversely, the social models of disability vary but sit within a general intersection of a social location and a materialist source. Individuals experience disablement at the point of interaction with society through disabling social barriers preventing access and engagement. Such barriers exist based on an assessment of the individual’s capabilities. Stairs at a building entrance bar those who cannot walk. Directional signs without Braille bar for those who cannot see. Art and cultural shows without sign language or subtitled bar those who cannot hear. Nevertheless, some articulations of social models steer more towards the idealist side of the debate. When interacting

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<sup>952</sup> Priestly (n763), 15.

with society, some barriers can exist purely on social perspectives and biases rather than relying on impairment as a foundation.

Regardless of this queering of Priestly's headings, establishing an exact location for a queer/crip identity approach is troublesome. To function as a queer concept, identity must resist labels and structure. Additionally, to remain truly inclusive, a disability model must remain open and fluid, allowing for influence by those with lived experience. As such, the nature of identity lends itself to similar queer resistances. Identity uses the individual and society as locations and sees value in medical and ideal sources. Identity is unique to each person and collective, with various influences, locations, and sources. Therefore, though an identity approach generally sits within the centre of this intersectional graph, individual actors can steer identity in any given direction.

One important aspect to consider when assessing these approaches is the positioning of structural and cultural forces. Structural considerations factor into the equation the external dynamics impacting PWDs within a particular context. For example, they consider the impact of the "material relationships of power arising from the division of labour and the factory-based wage economy that excluded many people from participating in paid labour".<sup>953</sup> This impact is significant for the social model and other power-adjacent models, as disablement and exclusion feature heavily in their discourse. In comparison, cultural forces establish the lens through which to view disability. As noted in Chapter Four, theorists argue that this has changed over time. Whilst society once perceived PWDs as objects of charity and welfare, they are now

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<sup>953</sup> Ibid.

“holders of rights, entitled to exercise and enjoy human rights on an equal basis with others”.<sup>954</sup> In other words, “disability is now viewed through the lens of equality and human dignity”.<sup>955</sup> The lens of disability used will impact the understanding of disability and the approach taken by a State, a society, or by a legal instrument. In turn, the meaning of equality will “vary depending on the perspective of disability adopted”.<sup>956</sup> Ensuring a queer/crip disability has a solid foundation and approach will help establish the goals and aspirations of this venture.

Priestly continues, suggesting that there are four key facets of disability which interact within conceptual models. These interact with each other, creating a four-way Venn diagram.<sup>957</sup> At the centre sits the concept of disability, an umbrella term covering several unique facets of life. Each core aspect of disability – identity, body, culture, and structure – functions in unison to generate an interwoven system of classifying individuals and experiences. Nevertheless, these features also function in isolation, creating situations unique to the individual. The strength of these interactions between facets of disability also depends on the experience and character of the individual. Though Priestly's depiction of the interaction between facets appears symmetrical and equal, these facets will differ in size, location, and influence depending on the individual's experience and perspective on their life. The individual's understanding of disability will differ depending on whether they were born with their impairment or if they developed it during their life.

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<sup>954</sup> Broderick (n16), 21.

<sup>955</sup> Ibid.

<sup>956</sup> Rioux & Riddle (n627), 42.

<sup>957</sup> Priestly (n763), 17.

The question arises, then, on where identity should sit at these intersections. Rather than picking one of two choices in each column, this thesis argues that identity seeks to achieve all of the above. As Hughes and Paterson acknowledge, it is no accident that feminism has avoided dualistic methodologies.<sup>958</sup> This avoidance extends to theoretical developments of queer theory. To maintain a queer perspective, the identity approach cannot attempt to wedge itself into a dualistic methodology. Moreover, deviating from such a methodology is not novel. Oliver argues that both cultural and material variables impact the establishment of disability as a social construction:

“Hence disability, according to the social model, is all the things that impose restrictions on disabled people, ranging from individual prejudice to institutional discrimination, from inaccessible buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on. Further, the consequences of this failure do not simply and randomly fall on individuals but systematically upon disabled people as a group who experience this failure as discrimination institutionalised throughout society”.<sup>959</sup>

As noted in section 4.3, it is unnecessary and restrictive to suggest that disability results *only* from one source. Likewise, it would be unduly limiting for identity to locate itself within one approach over another. Many of the current models see the approaches discussed by Priestly as mutually exclusive. The identity approach seeks to demonstrate that to be a flawed perspective.

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<sup>958</sup> Hughes & Paterson (n942), 337.

<sup>959</sup> Oliver (n546), 33.

Priestly's headings help establish important considerations, but it would be un-queer to read them strictly as a recipe to adhere to. Through a combination of lenses, identity conceptualises disability as both an individual issue and a social one, with materialist and idealist perspectives contributing to the overall approach. The goal of the disability rights movement has been a transition from disablement to enablement. This goal involves the establishment of multiple models as well as multiple approaches within these models. As noted in section 4.5, the identity approach must consider all of these aspects to contribute something new and valuable while adhering to its queer roots. Again, Priestly's articulation of these considerations is a helpful platform. It does not shape the development of a queer/crip identity, rather it provides relevant prompts for the deconstruction of a historically structural and modernist concept.

Finally, recent disability rights theory has recorded a shift towards a socio-functional approach, emphasising the "role of the physical and social environment in conceptualising disability".<sup>960</sup> As argued in section 4.3.2, "in spite of its critique of the medical model," the social model "actually concedes the body to medicine and understands impairment in terms of medical discourse",<sup>961</sup> and that in reality, the status of the body plays a significant factor in bringing the situation up to the point of social inquiry. Though listed as a flaw of the social model, and section 4.2 documents several problems with an overly medical approach, researchers in the field acknowledge the perks of a multi-faceted approach. Examples include Morris' work on lived experience with medicalisation,<sup>962</sup> the human rights model perspectives from

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<sup>960</sup> Rimmerman (n659), 24.

<sup>961</sup> Hughes & Paterson (n942), 326.

<sup>962</sup> Jenny Morris, *Independent Lives: Community Care and Disabled People* (Macmillan 1993), x.



Quinn and Degener,<sup>963</sup> and various political and relational approaches.<sup>964</sup> The current debates on disability contain a rich diversity of approaches and perspectives, many of which interact and coexist. Only by respecting this variety of voices can we create a genuinely inclusive approach to disability.

### **5.3.2 Deviations**

Several principles of a queer identity approach feature in other models of disability. The first is a balance of the positive aspects of individual experience with the potentially harmful aspects of social disablement. Within academia, there have been attempts to transition towards a positive outlook on disability in response to society's attempts to position PWDs as subjects of rescue and charity. The amelioration of disability discourse is not in itself novel, and several theorists have suggested their alterations to the models of disability to include positivity. As such, this thesis needs to distinguish itself from these attempts to highlight where the similarities lie, which will also assist in setting boundaries for the identity approach in a productive queer way. It must also justify why it attempts to function within the academic space of human rights, given its application to the CRPD.

Positivity features heavily in the affirmation model proposed by Swain and French in 2000. They argue for the benefits of a “non-tragic view of disability and impairment”.<sup>965</sup> An affirmation model would encompass “positive social identities, both individual and collective” for PWDs, “grounded in the benefits of lifestyle and life

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<sup>963</sup> Quinn & Degener (n95).

<sup>964</sup> For example, see Kafer (n838).

<sup>965</sup> Swain & French (n802), 569.

experience of being impaired and disabled”.<sup>966</sup> As such, it emphasises the validity of individual experience, highlighting the positive aspects of life and the successes an individual may experience. For them, a non-tragic view is “not about ‘the problem’, but about disability as a positive personal and collective identity, and disabled people leading fulfilled and satisfying lives”.<sup>967</sup> Finding affirmation in an identity society has purposely pejorated is abrasive to the norm. It rejects socially entrenched perspectives on tragedy and “flies in the face of dominant values and ideologies” of disability conception.<sup>968</sup> As such, considering positivity helps shift the locus of power towards the individual and the collective. However, as noted above, PWD existence is complex and nuanced. To focus purely on one pathway risks ignoring equally essential aspects of lived experience. A holistic perspective considering the impact of various sources is preferable when establishing an inclusive approach to disability.

Another quirk of the disability identity discussion is the consideration of individual versus collective. Naturally, an identity approach respects individual and collective identities as important aspects of the disability experience. There is no debate on whether one ‘type’ of identity is included or restricted from the conversation. However, some theorists have argued the intricacies of individual versus collective, and so it is important to at least consider these points within the debate. On the one hand, Harré notes that “the self, as the singularity we each feel ourselves to be, is not an entity”.<sup>969</sup> Instead, identity is a “site from which a person perceives the world and a place from which to act. There are only persons. Selves are grammatical fictions, necessary

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<sup>966</sup> Ibid.

<sup>967</sup> Ibid, 571.

<sup>968</sup> Ibid, 574.

<sup>969</sup> Harré (n908), 3-4.

characteristics of person-oriented discourses”.<sup>970</sup> As such, identity is a unique individual and personal experience. Further, Erikson discusses the “sense of personal sameness and historical continuity” as an individual identity feature.<sup>971</sup> They suggest “what identity feels like when you become aware that you do undoubtedly have one...[imbues] a subjective sense of an invigorating sameness and continuity”.<sup>972</sup> These feelings manifest as identity euphoria when someone finds the means of articulating their true individual identity. It further demonstrates the impact of social barriers which reject unique identities, highlighting the bliss felt when someone lives authentically.

Nevertheless, collective identity plays a crucial role in establishing individuality. For instance, Bauman argues that “instead of talking about identities, inherited or acquired, it would be more in keeping with the realities of the globalizing world to speak of *identification*, a never-ending, always incomplete, unfinished and open-ended activity in which we all, by necessity or by choice, are engaged”.<sup>973</sup> Scott notes that identification becomes relational, as “identifying with one social category often goes hand-in-hand with demonstrating one’s disidentification with another”.<sup>974</sup> When developing their own identity, individuals consider identities different or opposite to theirs just as often as similar or similar to theirs. Further, in their work ‘Losing the Traditional’, Beck & Beck-Gernsheim aim to individualise lifestyles. They suggest that modern life turns various sources of identity into “God, nature, truth, science,

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<sup>970</sup> Ibid.

<sup>971</sup> Erik H Erikson, *Dimensions of a new identity: The 1973 Jefferson Lectures in the Humanities* (Norton 1974), 17.

<sup>972</sup> Ibid, 17-19.

<sup>973</sup> Bauman (n897), 129.

<sup>974</sup> Scott (n898), 4.

technology, morality, love, or marriage” into “precious freedoms”.<sup>975</sup> In turn, “the space in which modern subjects deploy their options is anything but a non-social sphere,” as its overall effect “is a work of art of labyrinthine complexity, which accompanies us literally from the cradle to the grave”.<sup>976</sup> Identity sources are unique and plentiful; one must respect the collective sources to understand identity wholly. Scott notes, “we understand ourselves as members of social groups...mobilized in political arenas”.<sup>977</sup> Humans are social creatures, and identity is both individual and collective.

Another consideration for a queer/crip identity approach to disability, and the subsequent application to the CRPD, is the value of human rights for PWDs. There is a discussion on the function and validity of human rights to support minorities in section 3.3.2. Commentators such as Smart identify the foundations of the law and human rights as ableist, racist, and heteronormative. One can expose the hidden biases of law by eschewing traditional doctrinal categories and reconfiguring legal doctrine around minority lives and practical experiences.<sup>978</sup> Within the context of gender, Baer notes that “conventional legal doctrines, developed by men in a society dominated by men, have a fundamental male bias even when they are ostensibly gender-neutral”.<sup>979</sup> Moreover, Chamallas and Wriggins argue that “when viewed through a wider cultural lens, the basic structure of contemporary [law] still tends to reflect and reinforce the social marginalisation of women and racial minorities and to place a lower value on

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<sup>975</sup> Ulrich Beck & Elisabeth Beck-Gernsheim, ‘Losing the Traditional: Individualisation and Precarious Freedoms’ in Anthony Elliott & Paul du Gay (eds) *Identity in Question* (Sage Publications 2009), 28.

<sup>976</sup> *Ibid.*

<sup>977</sup> Scott (n898), 4.

<sup>978</sup> See Regina Graycar & Jenny Morgan, *The Hidden Gender of Law* (Federation Press 2002).

<sup>979</sup> Judith Baer, ‘Feminist Theory and the Law’ in Gregory Caldeira *et al* (ed) *The Oxford Handbook of Law and Politics* (OUP 2008), 438.

their lives, activities, and potential”.<sup>980</sup> Further, at section 4.4, discussion on pity and charity demonstrates that the provision of welfare policy has historically infantilised PWDs.

Given, then, these laws may maintain inherent biases against minorities, it is important to demonstrate *how* a queer/crip identity approach seeks to succeed where other approaches have seemingly failed. The answer lies within a blend of queer and an enrichment of human rights. Degener argues that previous models, such as the social model, may acknowledge the importance of human rights,<sup>981</sup> however this only extends to a tangential association with a rights-based approach as opposed to needs-based approaches of welfare.<sup>982</sup> The social model extends “beyond individual rights to social relations in society to the broader system of inequality”.<sup>983</sup> In her piece on developing a new human rights model of disability, Degener takes great lengths to differentiate human rights to the social model: from an avoidance of a reliance on capacity, to valuing impairment as part of human diversity; from acknowledging identity issues, to engagement with social policy. Given that the social model fought hard for anti-discrimination legislation, the human rights model is a transition to a new legal paradigm. Degener suggests “it is thus illustrative that the global independent living movement has always phrased their demands in terms of broader human rights rather than in terms of pure anti-discrimination rights”.<sup>984</sup>

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<sup>980</sup> Martha Chamallas & Jennifer Wriggins, *The Measure of Injury: Race, Gender, and Tort Law* (NYU Press 2010), 2.

<sup>981</sup> Oliver (n546), 63.

<sup>982</sup> Degener (n796), 35.

<sup>983</sup> *Ibid.*

<sup>984</sup> *Ibid.*, 36.

Further, as noted at section 3.3.2, human rights offer valuable opportunities. Rioux and Heath argue that using human rights as the lens for policy improvement promotes reforms “as a matter of universal right rather than charity”.<sup>985</sup> Goodale and Merry agree, arguing that promoting human rights fuels “important discourse of resistance movements all over the world”.<sup>986</sup> Human rights are the system currently available to PWDs; it is the current playing field for the fight for inclusion. Though there are potential systemic issues within the foundations of rights, the work of Zanghellini and Gonzalez-Salzberg proves that it is possible to queer human rights to undo these disadvantages. Law may carry the baggage of social governance, and, as noted at section 4.3, many of the existing models tasked with fighting discrimination engage in the dehumanisation of PWDs. Therefore, a new approach should queer the law and highlight the minority voice in the narrative. An identity approach blends the queering of Shakespeare with many of the inclusive legal principles behind Degener’s human rights model. These concerns have been woven into the discussion of human rights in Chapters Six and Seven.

Finally, there is perhaps an issue of novelty and originality. The approach taken in both Chapter Four and in this chapter has been to utilise existing models of disability to craft a queer/crip identity approach. If the approach features pre-existing perspectives, it is potentially debatable how far this approach deviates from existing literature. This risk was also taken by Shakespeare in developing his approach to disability. As noted in section 2.2.1, he admits that rather than attach himself to one

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<sup>985</sup> Marcia H Rioux & Bonita Heath, ‘Human Rights in Context: Making Rights Count’ in John Swain *et al* (eds), *Disabling Barriers – Enabling Environments* (3<sup>rd</sup> edn, Sage Publications 2014), 319.

<sup>986</sup> Mark Goodale & Sally E Merry, *The Practice of Human Rights: Tracking Law Between the Global and the Local* (CUP 2007), 176.

model, he has tried to take useful elements from different theorists.<sup>987</sup> Unsurprisingly, this thesis mirrors this process. The faults in Shakespeare's argument lie in his reliance on critical realism, not in the procedural steps taken in developing his approach.

As noted in Chapter Four, to suggest that other models of disability are unique from each other and lack common ground would be a falsehood. Existing models share similar features and overlap, hence the separation of discussion into the subheadings of biology, governance, and rescue. Throughout this chapter, the discussion of a queer/crip identity refers back to these three headings, to ensure consistency in advocating for an improved approach to disability. Nevertheless, the question remains, whether the idea of melting and remaking suggests that the new perspective is inherently merely a rearticulation of pre-existing ideas. If an individual recycles plastic bottles to create a reusable bag, would it be accurate to still define the bag as a plastic bottle? Alternatively, is the correct metaphor the idea of recycling old garments into a new jumper? Using this logic, the new jumper is still an article of clothing, made of typical material, so the novelty is at least partially overstated. It is asserted that Shakespeare contributed a truly novel approach in his research, and the identity approach provided for here is equally new.

#### **5.4 Conclusion**

Chapter Five provides an overview of the identity approach of disability. It uses the commentary from the first four chapters of this thesis to construct an approach to disability which provides a more inclusive perspective. It utilises the methodological foundations of queer and crip, whilst also using the constructive critiques of existing

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<sup>987</sup> Shakespeare (n342), 54.

models of disability. Section 5.2 explains identity, demonstrating how to understand identity in relation to a postmodernist and post-structuralist deconstructive methodology in queer theory. Section 5.3 then proceeds to use these to create an identity approach. It highlights how Priestly attempted to categorise headings of disability, noting where structure is helpful whilst demonstrating the queer and crip need to start afresh. Section 5.3.2 then demonstrates how the identity approach differs from other models in important factors such as social interaction, acknowledgement of human rights, and the limitation of novelty.

The previous chapter outlines three broad issues with current models of disability. Naturally, to ensure that the identity approach is productive and valuable for discourse, it should be able to respond to these three issues. Regarding the problems with biology, identity is not located wholly within the body. Identity manifests within the person through the experience and experimentation of the individual. It is a personal understanding of oneself and, as such, cannot be gatekept by others. Regarding social governance, identity places power within the individual. It enables them to voice their experiences and dictate social interactions on their terms. In turn, identity takes power away from society. Finally, concerning rescue, identity affords the individual personal agency. Moreover, agency means PWDs no longer become the subject of pity because they have greater control of the narrative and the interaction. The final two chapters of this thesis will now demonstrate identity in practice by analysing rights within the CRPD.



## Six: Power Dynamics in the CRPD

“After the party, we now face the morning after – the bleary hangover of implementation, a process that will take many years. This is, of course, a problem with any new treaty, but the CRPD is meant to be not merely a new treaty but a new paradigm...The impetus for the CRPD was not that the existing law required consolidation; it was that existing law was not working for [PWDs] and that something new was required”.<sup>988</sup>

### 6.1 Introduction

In Chapter One, the history of disability rights demonstrates a lack of representation for PWDs in primary legal instruments. The discussion also shows the slow and impotent application of generalised policies – all bark, yet no bite. Stein argues that in contrast to “hard law treaties that do not enumerate specific disability protections, [many] soft laws expressly provide[d] for disabled individuals”.<sup>989</sup> Nevertheless, this level of inclusion was genuinely insufficient. Thus, the international community created the CRPD, heralded as a turning point. Commentators universally describe the CRPD as “representing a ‘new paradigm’ in human rights protections of [PWDs] based on an absolute prohibition of involuntary detention and non-consensual treatment”.<sup>990</sup> However, as Chapter Four notes, the application and implementation of the CRPD

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<sup>988</sup> Peter Bartlett, ‘Implementing A Paradigm Shift: Implementing the Convention on the Rights of Persons with Disabilities, in the Context of Mental Disability Law’ in Centre for Human Rights & Humanitarian Law, *Torture in Healthcare Settings: Reflections on the Special Rapporteur on Torture’s 2013 Thematic Report* (American University Washington College of Law 2014), 170.

<sup>989</sup> Stein (n125), 82.

<sup>990</sup> Phil Fennell, ‘Article 15: Protection against Torture and Cruel or Inhuman or Degrading Treatment or Punishment’ in Ilias Bantekas, Michael A Stein, & Dimitris Anastasiou (eds), *The Un Convention on the Rights of Persons with Disabilities* (OUP 2018), 429.

through the social and human rights models have failed to realise the true potential of the convention. There is an insufficient acknowledgement of the unique identity aspects of disability and how a queer approach changes how PWDs can utilise their human rights. For example, the language of Article 1 reveals a connection to the minority group approach to disability, the “identification of persons that identify as [PWDs] to be entitled to human rights protection”.<sup>991</sup> Using the identity approach in Chapter Five provides this alternative reading of the CRPD and can alleviate many of the problems discussed in Chapter Four regarding biology, governance, and rescue. Note this chapter does not argue that the CRPD was drafted from a queer perspective. Weller argues that the CRPD follows a social model perspective,<sup>992</sup> whilst Kazou suggests the descriptions of disability in the CRPD more accurately match the ICF model.<sup>993</sup> As noted in Chapter Five, Degener argues that the CRPD demonstrates a paradigm shift away from the social model towards a human rights model.<sup>994</sup> Viewing this holistically, it is clear that the CRPD engages in some form of modernism and structuralism, both of which are at odds with a queer framework. Instead, the content within the CRPD ought to be read through a queer/crip lens, to attempt the deconstruction of modernist rigidity and bolster the protections PWDs can receive.

The next two chapters provide examples of how using a queer/crip disability identity affords PWDs new and unique rights, improved access to rights, and freedom from paternalistic societal confinement. This chapter focuses on power dynamics, demonstrating identity’s impact on relationships and agency. PWD inclusion and

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<sup>991</sup> Kakoullis & Ikehara (n268), 55.

<sup>992</sup> Weller (n355).

<sup>993</sup> Katerina Kazou, ‘Analysing the Definition of Disability in the UN Convention on the Rights of Persons with Disabilities: Is it Really Based on a ‘Social Model’ Approach?’ (2017) 23 *International Journal of Mental Health and Capacity Law* 25.

<sup>994</sup> Degener (n796).

involvement are crucial considerations of the CRPD – “nothing about us without us” was not mere rhetoric. It was a plea for respect. Identity changes the typical rights relationships between individuals and the State, on the one hand providing PWDs with greater autonomy, yet, on the other hand, possibly complicating the negotiation process with more voices. However, it changes the dynamic of the phrase to “without us, nothing”. Understanding a queer/crip identity also gives PWDs more agency and autonomy, granting them rights negotiation and implementation power.

## **6.2 Rights and Relationships**

Human rights discourse considers the relationship between the duty-holder and the rights-holder. This relationship often manifests between the State and the individual rights recipient. However, within the context of the CRPD, this understanding ignores two essential facets of disability rights. Certain rights generate unique relationships between the duty-holder and the rights-holder. First, the CRPD impacts the status of the duty-holder by introducing new parties who take some responsibility for facilitating PWD rights. Second, the CRPD affects the nature of the rights-holder, shifting the focus from individual recipients to a collective identity. These changes reimagine the position PWDs find themselves in when accessing rights. Concerning biology, identity emphasizes an individual's relationship with their body, giving them the power to self-identify. It, therefore, moves the discussion location away from pathology to the individual's self-determination. Identity rejects societal governance, ignoring current systems and engaging in specific power dynamics. The State no longer solely holds power, as identity promotes disability culture over social structures which do not fit PWDs accurately. Finally, the discourse around PWD rights changes with identity, giving PWDs self-determination and individual control of their destiny. A focus on identity avoids the treatment of PWDs as needing rescue.

### **6.2.1 Duty-Holders: Third Parties**

One interpretation of human rights generates a relationship between the rights bearer and the duty holder. This relationship manifests vertically between the State and its populace in most instances. The duty holder maintains power over legislation and resources. The rights bearer negotiates the legislative framework and allocation of resources needed to ensure complete rights access, and participation in society. However, the function of some disability-specific rights exacerbates the power imbalance PWDs experience in societal interactions. In these situations, the State interacts with an independent third party, who functions as a proxy for the rights holder in their interest. However, problems manifest twofold. Firstly, PWDs cannot always actively exercise their rights. Instead, they often rely on a third party to negotiate with the State on their behalf. Secondly, the State bestows the legal policy and resources to ensure rights adherence to the third party, further solidifying the isolation of the rights holder from the negotiation process.

To begin, the CRPD requires States to support PWDs by placing support, anti-discrimination, and inclusion within the general obligations of the Convention. States have positive obligations to take “all appropriate measures to eliminate discrimination based on disability by any person, organisation, or private enterprise”.<sup>995</sup> Further, States must “promote the training of professionals and staff working with [PWDs] in the rights recognised in this Convention to provide better the assistance and services guaranteed by those rights”.<sup>996</sup> Finally, “in the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to [PWDs], State parties shall closely

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<sup>995</sup> CRPD (n7), Art. 4(1)(e).

<sup>996</sup> Ibid, Art. 4(1)(i).

consult with and actively involve [PWDs], including children with disabilities, through their representative organisations”.<sup>997</sup> These provisions demonstrate the need to eliminate discrimination by all sources, not just State-produced. It also highlights the benefits of training to facilitate rights and consult PWDs in developing legislation and policy. The CRPD prioritises involving PWDs at every step of the rights process. The right to work and employment includes “the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive, and accessible”.<sup>998</sup> Important to relationships, it also includes provisions to prohibit discrimination,<sup>999</sup> promote access to unions,<sup>1000</sup> and provide reasonable accommodation.<sup>1001</sup> These provisions rely on PWDs’ ability to interact with the various duty-holders needed to facilitate their right to employment; they are all intrinsically connected to obtaining and retaining a job. Importantly, these provisions require active participation from PWDs, echoing the article's sentiments on general obligations.

Nevertheless, some interpretations of Article 27 have rendered PWDs isolated from the discussion. The case of *Gröninger* demonstrates some of the problems currently experienced by PWDs in accessing their right to employment.<sup>1002</sup> In *Gröninger*, the applicant represented her son. She argued that the German occupation policies to support PWDs indirectly discriminated against her son. These policies only provide an employment subsidy to an employer after they make a job offer and if the disability

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<sup>997</sup> Ibid, Art. 4(3).

<sup>998</sup> Ibid, Art. 27(1).

<sup>999</sup> Ibid Art. 27(1)(a).

<sup>1000</sup> Ibid, Art. 27(1)(c).

<sup>1001</sup> Ibid, Art. 27(1)(i).

<sup>1002</sup> *Gröninger v Germany* (2014) CRPD/C/D/2/2010.

ceases to impact “full working capacity” within 36 months.<sup>1003</sup> Gröninger purported that her son was ostracised and excluded from the labour market. The policy application arguably discriminates against PWDs, citing an expert who stated that “participation in working life is practically impossible”.<sup>1004</sup> The CmRPD concluded that the scheme “served as a deterrent, rather than as an encouragement for employers”.<sup>1005</sup> They agreed with Gröninger that the German law provided inadequate protections and failed to fulfil the State obligations under Article 27(1)(h). Significantly to the discussion on rights and relationships, their judgment demonstrates several ways the German law generates imbalances between State, employer, and employee. Using identity to provide an alternative reading of the right to employment can help reduce these flaws. Significantly, the German legislation assessed in *Gröninger* predates the passage of the CRPD. Therefore, it would be disingenuous to analyse the legislation with the same rigour as legislation passed after adopting the CRPD. Also, many anti-discrimination laws in other signatories to the CRPD allow PWDs to make claims against employers to assert rights to reasonable adjustments. Nevertheless, this case demonstrates four issues with possible methods of interpreting the right to employment. The general principles of eroding discriminatory barriers to employment are present in German law.

First, the law generates a sense of isolation by hosting the entire negotiation process for subsidy provision without the input of PWDs. Despite the applicant’s son being the rights-holder and recipient of the accessibility policy, he would never functionally experience implementing his rights under the CRPD. The negotiation process would

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<sup>1003</sup> Ibid, para 6.2.

<sup>1004</sup> Ibid, para 2.8.

<sup>1005</sup> Ibid, para 6.2.

occur between the State and the employer without him. Formatting the subsidy policy as an application devoid of PWD involvement fails to create rights for the individual.<sup>1006</sup> Further, it creates ambiguity within the State, employer, and PWD relationship dynamic. The legislation gave “the right to claim such a subsidy...exclusively to the employer” rather than the PWD.<sup>1007</sup> This legislation, therefore, frames the employer as the recipient of the financial subsidy. At best, the State appoints the employer as an agent or proxy for the PWD, who had no choice or ability to voice their opinion. At worst, the State labels the employer as the right-holder, receiving the “benefit” of the CRPD right on the PWD’s behalf. This action violates the ethos of inclusion established in the CRPD, as the law must involve PWDs, so they remain the primary focus.

Second, the law pushes a narrative of disability that discriminates against entire groups of PWDs. Given the three-year capability recovery requirement, the legislation leans heavily on a transient understanding of disability. The policy relies on a medical model understanding, viewing disability as “something that is transitional and that, in consequence, can be surpassed or cured with time”.<sup>1008</sup> Moreover, the employer must claim the potential expenditure needed to employ the PWD, implying that hiring them would be an affliction. PWDs cannot demonstrate their skills “if employers and employment agencies do not provide them with the necessary reasonable accommodation”.<sup>1009</sup> PWDs cannot contribute to society and experience true inclusion if the State views them with a pathologised treatment and prospective recovery mentality. Additionally, States cannot adequately support PWD inclusion and rights

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<sup>1006</sup> Ibid.

<sup>1007</sup> Ibid.

<sup>1008</sup> Ibid.

<sup>1009</sup> Coomara Pyaneandee, *International Disability Law: A Practical Approach to the United Nations Convention on the Rights of Persons with Disabilities* (Routledge 2018), 165.

access if they focus on the possibility of “curing” an individual. The CRPD emphasises the importance of temporality and disability in Article 2; despite some disabilities demonstrating fluctuations, States must consider their often-permanent nature and establish policies for the long-term support of PWDs.

Third, the law acts as a deterrence to employing PWDs, manifesting a situation where employers have to pass several hurdles without guaranteeing subsidy or assistance. To qualify for State support, the employer must first offer a binding employment contract to the PWD before applying for subsidy eligibility review. This review carries specific requirements regarding the status of disability and additional policies, meaning the employer is not guaranteed receipt of subsidy or assistance. The intention was to encourage employers to hire PWDs since the subsidy would alleviate the financial burden on employers to hire PWDs.<sup>1010</sup> However, in reality, the scheme “requires employers to go through an additional application process, the duration and the outcome of which are not certain”.<sup>1011</sup> The policy places more burdens and processes on non-State actors, generating “administrative complexities [which] put applicants in a disadvantageous position”.<sup>1012</sup> This law exemplifies inclusive intentions but a problematic implementation of flawed logic. If Germany involved all parties and removed extraneous barriers, the law may not deter employers and indirectly discriminate PWDs.

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<sup>1010</sup> *Gröninger* (n1002), Para 6.2.

<sup>1011</sup> *Ibid.*

<sup>1012</sup> Sándor Gurbaj, ‘Beyond the Pragmatic Definition? The Right to Non-Discrimination of Persons with Disabilities in the Context of Coercive Interventions’ (2020) 22(1) *Health & Human Rights Journal* 279, 287.



The CmRPD's judgment clarifies that States "must not merely pay lip service to their responsibilities regarding the employment" of PWDs.<sup>1013</sup> Both the social and human rights models position PWDs as rights-holders vis-à-vis the State, who are duty-holders. The State, as legislators, is de facto responsible for implementing rights provisions to eradicate PWD barriers to society. However, the right to employment utilises both horizontal and vertical relationships, complicating matters. The State must ensure that private entities, who become duty-holders in the employment sphere, do not cause burdens or barriers for PWDs. This stance causes issues when assessing who the recipient of State intervention should be and the parties involved. By creating policies incentivising employing PWDs and offsetting the financial implications (such as in Gröninger), the PWD ceases to receive said incentives. The rights-holder is singled-out from the negotiation process between the duty-holders.

The resulting dilemma focuses on rectifying this imbalance. In theory and practice, State legislation must ensure that the individual is the right-holder. The legislation must also understand the unique nature of rights which rely on independent third parties and establish dedicated policies to counteract any imbalances this generates. A Foucauldian assessment of power highlights the disadvantage that a mixed horizontal/vertical relationship dynamic between the third parties causes for PWDs. A Butlerian queer narrative would argue that these imbalances are demonstrative of an unjust and unequal employment structure and human rights system. However, by crippling queer (and acknowledging the practical necessities of including third parties in this discourse), an identity approach pushes for the inclusion of PWDs at every stage. Where a social model would make strong anti-discrimination demands, a queered rights approach brings each party together at the table. Moreover, identity

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<sup>1013</sup> Pyaneandee (n1009), 165.

acknowledges the variety of conditions PWDs experience and respects the intersectional nature of disability and other identity characteristics. Maintaining a broader employment policy puts the interests of PWDs at the forefront.

### **6.2.2 *Rights-Holders: Collective Identity***

The relationship between duty-holders and rights-holders expects an interaction between the State and a person. However, as Chapter Four demonstrates, disability is an often-shared identity. By formulating identity as a collective, individuals subscribe to a group. They subsequently maintain group tenets and ideologies as foundational to their self-understanding. In turn, this subscription demonstrates the cyclical nature of identity formation and development, relying on information from others to further develop self-identity. This unique lens feeds into the development of rights in the CRPD. States have obligations to facilitate rights applicable to a broader umbrella community of disability, changing how States exercise their duties and establish policies to facilitate rights. Within the context of rights, collective identity recontextualises the State's obligations. Understanding that human rights manifest relationships between State and the rights-holder, the CRPD distinguishes between rights specific to individuals and rights afforded to a collective. The distinction depends on the point of interaction. If the right is open-ended, where States publicly establish goods or services for individuals to interact with, the CRPD treats the State obligation as facilitating a collective. Suppose the right requires a direct relationship between the person as rights-holder and the duty-holder (either the State or an obligated third party). In that case, the CRPD treats the State obligation as facilitating an individual.

Accessibility is the quintessential collective right. The CRPD establishes accessibility as a primary goal for States to achieve, to ensure various facets of society are accessible “to enable [PWDs] to live independently and participate fully in all aspects of life”.<sup>1014</sup> In their second general comment, the CmRPD tackles accessibility as “a precondition for [PWDs] to live independently and participate fully and equally in society”.<sup>1015</sup> In their General Comment, the CmRPD outline several essential facets to consider regarding implementing accessibility for PWDs. Accessibility originates primarily within a rejection of normalcy standards and discrimination of minorities. The ICCPR<sup>1016</sup> and CERD<sup>1017</sup> afford the right of every citizen to access public services basis on equality. The international human rights framework has therefore set a precedent “for viewing the right to access as a right per se.”<sup>1018</sup> As noted in the introduction, PWDs are a sizeable global minority group, hence the need for States to promote accessibility to enable inclusion of PWDs in a similar vein to other minority groups. However, the reasoning for undoing the discriminatory segregation differs depending on the affected party. For members of different ethnic groups, “the barriers to free access...were the result of prejudicial attitudes and a readiness to use force in preventing access to spaces that were physically accessible.”<sup>1019</sup> However, PWDs “face technical and environmental...barriers such as steps at the entrances of buildings, the absence of lifts in multi-floor buildings and a lack of information in accessible formats”.<sup>1020</sup>

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<sup>1014</sup> CRPD (n7), Art. 9(1).

<sup>1015</sup> Committee on the Rights of Persons with Disabilities, ‘General Comment 2 (2014) Article 9: Accessibility’ (22 May 2014) CPRD/C/GC/2, para. 1.

<sup>1016</sup> ICCPR (n41), Art. 25(c).

<sup>1017</sup> International Convention on the Elimination of All Forms of Racial Discrimination (adopted 21 December 1965, entered into force 4 January 1969) 660 UNTS 195, Art. 5(f).

<sup>1018</sup> CRPD GC2 (n1015), para. 3.

<sup>1019</sup> Ibid, para. 3.

<sup>1020</sup> Ibid, para. 3.

Accessibility relies heavily on structural equality. In promoting positive structural societal change, accessibility is a positive means of “investing in society and an integral part of the sustainable development agenda”.<sup>1021</sup> States should actively devote resources to establishing accessible public services. This requirement extends to the physical environment and access to information and communication necessary to access public services.<sup>1022</sup> Queer theory emphasizes an intersectional deconstruction of social barriers, ensuring that resulting policies and structures take into consideration as many experiences as possible. Therefore, a queer approach to State obligations would necessitate consideration of a myriad of identities and the impact laws have on different minority groups. In *Nyusti & Takács v Hungary*, the Committee considered the distinction between public and private services as they relate to accessibility.<sup>1023</sup> Both authors have severe visual impairments, and experienced problems in accessing automatic teller machines (ATMs) managed by OTP Bank, their banking provider. They paid annual fees in order to use these services, but could not, as the keypads were not marked with braille and the bank did not provide either audio description or vocalised instructions on how to use the ATMs. When bringing a claim at the national level, the Courts found that the State did not have any obligations under the CRPD to regulate private contractual relationships between legal persons or entities; given that OTP was a private bank, the authors’ claim failed.

The Committee disagreed with this assessment. States must take all appropriate measures to eliminate discrimination on the basis of disability “by any

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<sup>1021</sup> Ibid, para. 4.

<sup>1022</sup> UNGA Res 48/96 (n156), Annex, Rule 5 (a) and (b).

<sup>1023</sup> *Nyusti & Takács v Hungary* (1/2010) CRPD/C/9/D/1/2010.

person, organisation, or private enterprise”.<sup>1024</sup> Read in conjunction with Article 9 on accessibility, States must ensure that PWDs have adequate access to information, communication, and other services, which includes an obligation on States to monitor private organisations.<sup>1025</sup> The Committee emphasised “facilities and services open or provided to the public”,<sup>1026</sup> treating them as public services even when private entities offer them.

The Committee found Hungary in violation of (among other provisions) their obligations under Article 9(1)(b). For the authors, the State had to remedy the lack of accessible ATMs, either by installing new accessible ones or retrofitting reasonable adjustments to existing ATMs, and provide compensation.<sup>1027</sup> Generally, Hungary had to create minimum accessibility standards for the banking sector, create appropriate training for judges in implementing the CRPD, and draft legislative frameworks to ensure the CRPD is applied properly.<sup>1028</sup> Lewis notes that this decision renders accessibility judiciable, presumably meaning that Articles 5 and 9 are so inherently bound together that failures to provide reasonable accommodations for accessibility could be considered discrimination.<sup>1029</sup> Though the Committee does not address this directly, nor is it clear from the wording of the CRPD whether this is accurate, Lawson

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<sup>1024</sup> CRPD (n7), Art. 4(1)(e).

<sup>1025</sup> *Nyusti* (n1023), para 9.4.

<sup>1026</sup> *Ibid.*

<sup>1027</sup> *Ibid.*, para 10.1.

<sup>1028</sup> *Ibid.*, para 10.2.

<sup>1029</sup> Oliver Lewis, ‘*Nyusti and Takács v Hungary: decision of the UN Committee on the Rights of Persons with Disabilities*’ (2013) 4 *European Human Rights Law Review* 419, 421.

suggests that a reading of Articles 5 and 9 as separate provisions with considerable overlap is rather persuasive.<sup>1030</sup>

This blurring of horizontal and vertical rights relationships means that States are liable to rectify any transgressions by a private entity, rather than just account for State-run initiatives. This is well-trodden ground, given that the Committee already considered the public/private divide in their second general comment. They noted that the focus should not be on legal personality and the public or private nature of buildings and services; “as long as goods, products and services are open or provided to the public, they must be accessible to all”, regardless of ownership.<sup>1031</sup> This makes sense, given the blurring of positive and negative obligations within the Convention. It matters not who is in charge of the service, but that the person with a disability can access said service. If people with disabilities are to be included in society, this extends to *all* aspects of society, and places burdens on the State to adequately regulate private entities and ensure standards of accessibility.

However, the decision in *Nyusti* goes further: it proves that rights under the CRPD are held by all, not just by individuals. An ATM must be accessible to anyone intending to use it and account for their unique modes of communication. Therefore, States must ensure that services are ready to receive any person with any access need. Most human rights are held by individuals. For example, Article 12 relates to a specific individual’s capacity, and Article 14 ensures their liberty. Though they set general

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<sup>1030</sup> Anna Lawson, ‘Accessibility Obligations in the UN Convention on the Rights of Persons with Disabilities: *Nyusti* and *Takács v Hungary*’ (2014) 30(2) *South African Journal on Human Rights* 380, 390.

<sup>1031</sup> CRPD GC2 (n1015), para 13.

standards of how the State should treat people with disabilities, enforcement occurs through an individual exercising their right to make choices about their treatment or avoid arbitrary detention against their will. However, Article 9 on accessibility functions differently. It is not that a single individual has a right that can be enforced to a specific standard, but that the public has a broad and deep collective right that binds States to a higher standard. The general public are stakeholders, capable of enforcing rights to accessible communication. The location of the right has shifted, it has queered to reflect the specific needs of PWDs.

*Nyusti* emphasises the slow realisation of general structural improvement, “achieved through gradual implementation when necessary”.<sup>1032</sup> However, it also demonstrates that States must be proactive rather than reactive. Therefore, accessibility functions differently from reasonable accommodation. Chapter Seven considers inclusivity concerning applications of reasonableness and universality. However, as it relates to collective identity, the CmRPD notes that “accessibility is related to groups, whereas reasonable accommodation is related to individuals”.<sup>1033</sup> The CRPD provides a different layer of rights implementation. It depends on whether the right applies universally to all or if an individual will stake a claim to the right. States must “provide accessibility before receiving an individual request to enter or use a place or service”,<sup>1034</sup> as their obligations under the CRPD amount to an *ex-ante* duty. To fully realise their obligations under the CRPD, States need to understand the relationship between individual rights and collective application.

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<sup>1032</sup> Ibid, para. 27.

<sup>1033</sup> Ibid, para. 25.

<sup>1034</sup> Ibid, para. 25.

To summarise, interpretations of *Myusti* demonstrate the need for a shift in perspective. As noted above, commentators such as Lewis and Lawson consider the decision a reserved and trite assessment of accessibility obligations. However, if viewed through a queer lens, the decision achieves a greater goal of renegotiating the rights relationship. Given society's ability trouble, the instigation of compulsory able-bodiedness by designing access based on ability, interpreting accessibility through collective identity redefines State obligations. States cannot merely be reactionary, nor should they understand rights as a purely individual enterprise. By echoing the post-structural ideals of queer, defining who *is* and *is not* disabled ceases to be relevant; what matters is the inclusion of all forms of ability, and the capacity for anyone affected by inaccessibility the opportunity to exercise rights under the CRPD. Discussions in Chapter Seven will expand the notion of who is 'affected' and who has standing to make claims. For the purpose of relationships, a queer/crip identity approach changes the individual/collective/State rights dynamic.

### **6.3 Individual Agency**

Agency primarily deals with the location of power, taking it away from States and medical professionals and placing it with the individual. Using an identity framework to analyse the CRPD and disability-centric rights provisions affords PWDs the individual agency more significant control over their rights access. PWDs cease to be voiceless and powerless in the rights negotiation. Instead, they assume an active role in seeking rights protection and its application format. Agency within the context of identity enables PWDs to define their experiences on their own terms, shifting the power dynamic away from States or third parties to better centre the individual. It removes the influence of diagnosis of the body by professionals, replacing biology with the individual's personal sense of being. Agency through identity also rejects social



governance and structure, affording PWDs greater autonomy to live as they please, treating them as capable individuals rather than recipients of State rescue.

Agency manifests itself in an identity-focused analysis of the CRPD in three ways. First, through a discussion of self-identification by considering the mental versus physical debate. Debates in the disability rights sphere exist on whether users and survivors of psychiatry should be part of the rights movement, given the extent to which the campaign focuses on physical disability considerations. The identity approach attempts a balance between autonomy on the individual to decide if they fall under the umbrella community, and State obligations to ensure no one is left behind. Second, the CRPD provides a version of the right to choose, allowing PWDs to decide how to utilise their rights access, as PWDs must be involved at several stages of rights manifestation. Third, the CRPD provides PWDs with individual autonomy as States have positive obligations to facilitate disability rights and policies and support PWDs in accessing said rights and policies.

### ***6.3.1 Curating the Guest List***

In the passage introducing this chapter, Bartlett laments the ‘bleary hangover’ of implementation following the after party of passing the CRPD. Though this may be merely a literary device on first glance, it accurately highlights another issue facing the CRPD: for there to be an after party, there ought to be a guest list. After all, what good is a human rights treaty if it is unclear who benefits from its implementation? Given the discussion at 6.2.2 on collective identity, an immediate reaction would be that everyone benefits; an accessible world is an improvement for all. In Chapter Seven, a similar conversation occurs about whether non-PWDs have rights under the CRPD.

Nevertheless, in this section, it would be helpful to consider *who* falls under the category of ‘disability’.

Using an identity framework aids the debate on inclusion in the PWD umbrella. For decades, academic and activist discussions have created ambiguity on whether people with mental disabilities (also considered psychiatric system survivors) fit within the disability rights narrative. In 2015, Sapey, Spandler, and Anderson posited that “while there has been a long history of political activism and theorising, about disability on the one hand, and madness and distress on the other, these debates have tended to happen separately”.<sup>1035</sup> Focusing on identity, agency is with the individual to dictate how they identify. They can make an informed decision, choosing how disability interacts with their sense of self. Importantly, this should not impact their access to rights under the CRPD, as a queer/crip approach rejects the rigid trappings of structuralism. Over-reliance on labels has been a fatal flaw of the social model, as noted at sections 4.3 and 4.4. This section will account for reasons given by other discussants on the topic of including mental health in disability discourse. It will then use these findings to demonstrate how identity provides agency to the individual in accessing rights.

One of the most significant barriers for individuals when considering universal disability policy is the mental versus physical distinction. Many argue that the essential factors for survivors or psychiatry and those with mental health conditions are sufficiently different from the important factors for individuals with a physical disability. These differences are substantial enough to warrant alternative policies and

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<sup>1035</sup> Sapey, Spandler, & Anderson (n9), 1.

separation between mental and physical when issuing support policies. In discussing definitions of impairment and disability for DPI and the British Council of Disabled People, Barnes notes that original definitions were “later expanded to include all impairments – sensory and intellectual”.<sup>1036</sup> The new definitions recognise that “all physical conditions have psychological implications and that all intellectual impairments have physiological consequences [and] that these labels were imposed rather than chosen and that they were politically and socially divisive”.<sup>1037</sup> In 2000, Beresford asked, “what have psychiatric system survivors, madness and distress got to do with disability, the disabled people’s movement and, indeed, with disability studies?”.<sup>1038</sup> He notes that external forces have combined these two groups, which has had an impact on their development as collective identities:

“However we as disabled people or psychiatric system survivors may think of ourselves, we are still lumped together within the same externally imposed definitions, administrative categories and statistics. This has important ramifications for all of us, impacting both our individual and collective identities”.<sup>1039</sup>

These communities have become forcefully entwined by society. Said society has taken away specific choices regarding development and the future from these communities. Communities cease to have certain powers to dictate who they are and how to represent them in society and media. Despite the best efforts of some theorists and activists, society has bundled deviants from the normate in one umbrella category. It

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<sup>1036</sup> Colin Barnes, ‘Disability Studies: New or not so new directions?’ (1999) 14(4) *Disability and Society* 577, 578.

<sup>1037</sup> Ibid.

<sup>1038</sup> Peter Beresford, ‘What Have Madness and Psychiatric System Survivors Got to Do with Disability and Disability Studies?’ (2000) 15(1) *Disability and Society* 167, 167.

<sup>1039</sup> Ibid, 169.

is up to the disability community to determine if they share a collective identity or if separating into physical and mental categories would enable better rights activism.

Nevertheless, many theorists consider mental health functioning within a broader umbrella of disability. Morris includes mental health system survivors within her definition of disability.<sup>1040</sup> Beresford notes that “there are significant overlaps between the two populations” because “both [are] subject to discrimination and oppression”.<sup>1041</sup> He argues that “while the forms these [overlaps] take may vary and restriction of rights is an explicit commitment of policy for psychiatric system survivors, the denial of their human and civil rights is a shared experience of disabled people and survivors”.<sup>1042</sup> Though there are considerations and issues unique to psychiatric system survivors, the general principle of discrimination and ‘othering’ they experience is sufficiently similar to those experienced by persons with physical disabilities. Combining the groups makes sense to fight for human rights. McNamara similarly argues that “the disability movement must include survivors of the mental health system” because both categories of individuals experience barriers and disablement by society.<sup>1043</sup> Disability “is about removing people’s power, or denying access to power”.<sup>1044</sup> If a disability-focused human rights movement intends to provide agency to currently disenfranchised individuals, uniting under one identity and advocating together generates the loudest noise and most active rejection of current social norms.

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<sup>1040</sup> Morris (n962), x.

<sup>1041</sup> Beresford (n1038), 169.

<sup>1042</sup> Ibid, 169-70.

<sup>1043</sup> Julie McNamara, ‘Out of Order: Madness is a feminist and a disability issue’ in Jenny Morris (ed), *Encounters with Strangers: Feminism and Disability* (Women’s Press 1996), 198.

<sup>1044</sup> Ibid.

Unity also helps reduce any barriers evident within the collective, ensuring self-development and true inclusion:

“...the prejudice and discrimination which we must fight so hard to challenge and resist in society often also lies deep in our own hearts and minds. If we are to achieve full equality for ourselves and others, we must recognise and value both our differences and our similarities as survivors and disabled people”.<sup>1045</sup>

Further, the CRPD explicitly references psychiatry, demonstrating its inclusion in disability rights discussion. Not only does it argue that “disability is an evolving concept”,<sup>1046</sup> but that the PWD label “includes those who have long-term physical, mental, intellectual or sensory impairments”.<sup>1047</sup> The definition of disability is left purposely vague to allow interpretation but explicitly includes mental and physical impairments. The use of “intellectual” establishes that “mental” attempts to cover the “psychosocial dimension”.<sup>1048</sup> Moreover, the inclusion of the phrase “may hinder their full and effective participation in society” identifies the attitude the CRPD takes on social barriers and disablement. Echoing the theorists discussed above, the CRPD notes that all PWDs experience barriers to inclusion. These barriers may differ in their particulars, but the general theme covers all PWDs, so the collective should be considered one entity needing rights protections. Additionally, rights in the CRPD are

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<sup>1045</sup> Peter Beresford, Gloria Gifford, & Chris Harrison, ‘What Has Disability Got to do with Psychiatric Survivors?’ in Jim Read & Jill Reynolds (eds), *Speaking Our Minds: An Anthology* (Open University Press 1996), 213-14.

<sup>1046</sup> CRPD (n7), Preamble, para e.

<sup>1047</sup> Ibid, Art. 2.

<sup>1048</sup> Tina Minkowitz, ‘The United Nations Convention on the Rights of Persons with Disabilities and the Right to be Free from Nonconsensual Psychiatric Interventions’ (2007) 34 *Syracuse journal of International Law and Commerce* 405, 407.

drafted to uniquely cater to mental or physical conditions. Articles on the right to legal personhood<sup>1049</sup> and protection from degrading treatment<sup>1050</sup> demonstrate that the CRPD protects facets of life unique to psychiatric system survivors. The CRPD has been drafted to cater for both mental and physical, and the inclusion of both physical disabilities and survivors of psychiatry is not merely a tokenistic inclusion.

Regardless, some have provided reasons for keeping those with mental conditions separate from the general disability rights discussion. One of the hurdles preventing psychiatric system survivors from joining the collective disability identity is their unwillingness to identify themselves as disabled. Psychiatric system survivors associate disability with “the medicalisation of their distress and experience”, rejecting the “biological and genetic explanations of their distress imposed by medical experts.”<sup>1051</sup> They also may not consider themselves “emotionally or mentally distressed” but “celebrate their difference and their particular perceptions.”<sup>1052</sup> The label of disability carries considerable baggage, based on the lived experience of many psychiatric system survivors. In debating original definitions of disability generated by organisations such as the UPIAS, Plumb rejects their application to psychiatric system survivors as incorrectly labelling them as possessing hidden impairments. She argues that “far from furthering our struggles as system survivors, this definition reads to me as firmly placing us back into medical models of mental illness, chemical imbalance, and so on”.<sup>1053</sup> She posits that combining forces is akin to assimilation, concerned

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<sup>1049</sup> CRPD (n7), Art. 12.

<sup>1050</sup> Ibid, Art. 15.

<sup>1051</sup> Beresford, Gifford, & Harrison (n1045), 209.

<sup>1052</sup> Ibid.

<sup>1053</sup> Anne Plumb, ‘...Distress or Disability?: A Discussion Document’ in Jill Anderson, Bob Sapey, & Helen Spandler (eds), *Distress or Disability? Proceedings of a symposium held at Lancaster University, 15-16 November 2011* (Centre for Disability Research 2012), 3.

with the “lack of knowledge of OUR history of struggle, and the prospect of disabled people speaking on our behalf without this knowledge.”<sup>1054</sup> Using the ideas of distress and dissent, Plumb suggests that psychiatric system survivors have a relationship to society and culture similar to physical disability “except that we are not bound by any agreed definition of impairment, hidden or otherwise”.<sup>1055</sup> Therefore, including psychiatric system survivors within the PWD collective identity requires an appreciation for the different experiences each group has with society and their unique perspectives of the body.

Conditions of mental health reject existing notions of impairment, suggesting a more inclusive holistic collective understanding would apply more accurately. Following a queer/crip approach to disability, leaving disability open for interpretation allows people to define it for themselves. A truly queer approach would be to avoid labels entirely, as such terms are built on ableist history and stigma. Nevertheless, the crippling of queer and the application of the activist origins of these perspectives highlights the need to employ strategy. To queer the law, discussions must employ labels to enable the law to function, yet equally deconstruct those same labels to avoid the normative assumptions underpinning their formation.

Similarly, some people with physical disabilities “do not feel that psychiatric survivors are disabled because they do not have a physical impairment or their situation is not permanent”.<sup>1056</sup> There are social expectations of what disability looks like, with an inherent suspicion of those who do not “look” disabled within disability

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<sup>1054</sup> Ibid, 7.

<sup>1055</sup> Ibid, 5.

<sup>1056</sup> Beresford, Gifford, & Harrison (n1045), 209.

spaces.<sup>1057</sup> This mistrust of difference works both ways, with Plumb arguing that “the practicalities of change [they] are struggling for are in many ways very different”.<sup>1058</sup> In essence, psychiatric system survivors perceive PWDs as distinctly different based on their unique experiences interacting with society. In turn, one side distrusts the other on a certain level. This distrust manifests “fears and anxieties on both sides of being linked with the negatives often associated with the other”.<sup>1059</sup> Therefore, future development requires ameliorating language and understanding to describe and represent physical and mental conditions. There is a need for communication and unity, as collectives have internalised the social stigma, they experience for themselves and others. The issue lies within the structural inequalities in the attributes individuals cite in their performance as PWDs. More can be achieved if groups founded on physical and mental health worked together in identifying and deconstructing these inequities; there is camaraderie and concord in rejecting normalcy.

In summation, both the CRPD and theorists provide arguments for a united collective identity, hoping that the combined forces of persons with physical disabilities and psychiatric service survivors will result in a substantial change. On balance, a combination of physical and mental conditions in a disability definition provides more overall utility for these minority groups. Further, the broad interpretation of identity within the framework generates a general understanding of disability, enabling it to respect individuality and unique constructions of identity. By including varied identities within the broad disability collective, the framework allows for more profound debates on topics from myriad perspectives. In turn, the resulting policies

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<sup>1057</sup> Jessica Kellgren-Fozard, ‘Am I Disabled Enough? Ft. Hannah Witton’ (*YouTube*, 29 March 2019) <[https://www.youtube.com/watch?v=YorlAb3q\\_hs](https://www.youtube.com/watch?v=YorlAb3q_hs)> (accessed 21 November 2022).

<sup>1058</sup> Plumb (n1053), 12.

<sup>1059</sup> Beresford, Gifford, & Harrison (n1045), 209.



provide better coverage for a larger category of individuals with the agency to actively participate in the process.

### **6.3.2 The Right to Choose**

As another demonstration of the CRPD's commitment to individual agency, many of the rights found within either provide or enable the right to choose. In this regard, agency is given to the individual to use their rights as they see fit, rather than the power of the State to allow rights access in specific situations. There are several different means by which the CRPD affords the ability of individuals to dictate the application of rights. First, by establishing a need for free and informed consent, some rights ensure that decisions are made by PWDs rather than on their behalf. As such, PWDs are given the necessary information to decide their rights. Second, some provisions allow PWDs to choose how they access their rights so that the individual makes the final decision rather than the State or a third party. Third, the CRPD provides individuals with the ability to actively participate in the process of exercising their rights, shifting the narrative from the State permitting rights to individuals engaging with the system.

To begin, the CRPD demands the free and informed consent of PWDs in certain situations. Within Article 15 on torture, "no one shall be subjected without [their] free consent to medical or scientific experimentation".<sup>1060</sup> This right is absolute, with the International Criminal Tribunal precedent establishing that States cannot reserve against it.<sup>1061</sup> The human right is "particularly stringent and sweeping" as States are

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<sup>1060</sup> CRPD (n7), Art. 15(1).

<sup>1061</sup> *ICTY Prosecutor v Furundžija*, Trial Chamber Judgment (10 December 1998), paras 153-54.

“obliged not only to prohibit or punish torture but also forestall its occurrence”.<sup>1062</sup> It, therefore, places a positive duty on States to take adequate measures to protect PWDs, rather than merely a negative obligation to react to violations.<sup>1063</sup> Fennell argues that due to its entrenched nature, States may violate other articles of the CRPD through legislation potentially tantamount to torture, even if such policies do not explicitly violate Article 15.

Moreover, the CmRPD has further called upon States to introduce specific measures to prevent medical interventions without consent,<sup>1064</sup> doubling down on the use of pathology without individual engagement. This article is, therefore, clearly individually-focused, requiring the active participation of PWDs in any medical or social intervention. It marks a rejection of tutelary relationships – the “comparison of the insane person with the child”,<sup>1065</sup> the establishment of an imbalance of power between the rights holder and the duty holder. It ushers a new paradigm to “universally prohibit...interventions as manifestations of disability discrimination and social exclusion”.<sup>1066</sup> It demonstrates a shift towards a “without us, nothing” mentality, echoing sentiments in section 6.2 on rebalancing the rights relationship between individuals and States. By queering Article 15, it is not just a rejection of medicine without consent, but an acknowledgement that individual choice is of paramount importance. This provision does *not* echo the sentiments of the political activist

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<sup>1062</sup> Ibid, para 148.

<sup>1063</sup> Fennell (n990), 427.

<sup>1064</sup> See, for example, Committee on the Rights of Persons with Disabilities, ‘Concluding Observations: Morocco’ (25 September 2015) CRPD/C/MAR/CO/1, paras 32-33.

<sup>1065</sup> Robert Castel, *The Regulation of Madness: The Origins of Incarceration in France* (WD Halls tr, University of California Press 1988), 38.

<sup>1066</sup> Fennell (n990), 437.

movements discussed in section 4.4, who demonstrated vehement (albeit understandable) distrust of medicine.

In their report to the HRC, the UN Special Rapporteur on Health concluded that by emphasising informed consent, Article 15 establishes “the absolute prohibition of involuntary detention based on impairment and the elimination of forced treatment”.<sup>1067</sup> Further examples include “free and informed consent” concerning healthcare,<sup>1068</sup> which Weller argues, is “perhaps the most important element” of the right to health.<sup>1069</sup> Medical professionals must obtain consent before any treatment,<sup>1070</sup> and legislation must not permit “substitute decision-makers to provide consent” on behalf of PWDs.<sup>1071</sup> This principle echoes other international documents emphasising consent, such as the Declaration of Helsinki, which states the need to seek the “freely given informed consent” of the individual.<sup>1072</sup> However, it is a unique feature of the CRPD compared to other human rights documents.<sup>1073</sup> The result is a blending of approaches. Given the discussion of Weller and Oliver in previous sections, a removal of the final say from medical professionals could be seen as an acceptance of a social or individual model of disability. However, Kazou notes this is fundamentally

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<sup>1067</sup> Human Rights Commission, ‘Report of the Special Rapporteur on the Right to the Highest Attainable Standard of Physical and Mental Health’ (28 March 2017) A/HRC/35/21, para. 33.

<sup>1068</sup> CRPD (n7), Art. 25(d).

<sup>1069</sup> Penelope Weller, ‘Article 25: Health’ in Ilias Bantekas, Michael A Stein, & Dimitris Anastasiou (eds), *The Un Convention on the Rights of Persons with Disabilities* (OUP 2018), 724.

<sup>1070</sup> Committee on the Rights of Persons with Disabilities, ‘Guidelines on Article 14 of the Convention on the Rights of Persons with Disabilities, The Right to Liberty and Security of Persons with Disabilities’ (September 2015), para 11.

<sup>1071</sup> Committee on the Rights of Persons with Disabilities, ‘General Comment 1 (2014): Article 12: Equal recognition before the law’ (19 May 2014) CRPD/C/GC/1, para. 41.

<sup>1072</sup> World Medical Association, Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects (revised October 2013), para 26.

<sup>1073</sup> Weller (n1069), 726.

based on an ICF-adjacent understanding of disability.<sup>1074</sup> Further, Kerr and Shakespeare have been vocal about the need for healthcare whilst noting the concerns ‘innovation’ raises.<sup>1075</sup> Rather than attempting to indicate which singular model is correct, a queer/crip approach acknowledges the value of choice above all else.

Further, concerning the right to home and family, consent manifests in the right “to marry and to found a family based on free and full consent”.<sup>1076</sup> CRPD intervention has proved vital, as sixteen of the first forty-six concluding observations by the CmRPD found legislation explicitly restricting PWDs in the right to marry.<sup>1077</sup> The offending legislation includes, but is not limited to, explicitly blocking the right for PWDs to marry based on the deprivation of legal capacity,<sup>1078</sup> interdiction,<sup>1079</sup> a specific restriction on PWDs,<sup>1080</sup> or a State intervention through necessitating authorisation to marry.<sup>1081</sup> All of these violate Article 23, and States must repeal any legislation that functions to this effect.<sup>1082</sup> The CRPD emphasises individual autonomy in their family life and the agency to decide who and when to marry. As discussed above regarding relationships, an individual’s social connection to others significantly impacts their sense of self and

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<sup>1074</sup> Kazou (n993), 36.

<sup>1075</sup> Kerr & Shakespeare (n351).

<sup>1076</sup> CRPD (n7), Art. 23(1)(a).

<sup>1077</sup> János Fiala-Butora, ‘Article 23 Respect for Home and the Family’ in Ilias Bantekas, Michael A Stein, & Dimitris Anastasiou (eds), *The Un Convention on the Rights of Persons with Disabilities* (OUP 2018), 640.

<sup>1078</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations: Lithuania (11 May 2016) CRPD/C/LTU/CO/1, para 43.

<sup>1079</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations: Bolivia (4 November 2016) CRPD/C/BOL/CO/1, para 53.

<sup>1080</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations: Czech Republic (15 May 2015) CRPD/C/CZE/CO/1, para 45.

<sup>1081</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations: Uganda (12 May 2016) CRPD/C/UGA/CO/1, para 46.

<sup>1082</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations: Turkmenistan (13 May 2015) CRPD/C/TKM/CO/1, para 38.

identity. The fact that the CRPD includes consent in the right to family proves that it understands this importance.

The CRPD also provides explicit rights to choose the means of manifestation of disability-centric rights. First, through the liberty of movement and nationality, States must recognise the right of PWDs “to choose their residence”.<sup>1083</sup> This right also includes the right to “acquire and change a nationality”.<sup>1084</sup> Under the guise of objectivity and reasonableness, States have “continued to prohibit or restrict [PWDs] from moving within their borders or leaving or returning on spurious grounds”.<sup>1085</sup> Nationality can be an essential characteristic of an individual’s identity, forming a sense of pride and belonging. By focusing on the individual and respecting this facet of identity, the CRPD affords them agency to associate with a collective and develop themselves.

Second, the CRPD gives PWDs the right to make decisions about their everyday life. Article 19 affords the right “to live in the community, with choices equal to others”,<sup>1086</sup> including the “opportunity to choose their place of residence”.<sup>1087</sup> Shifting from institutional to community-based housing, PWDs can “reclaim control over their lives and make personal choices”.<sup>1088</sup> It is argued that this links “the notion of

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<sup>1083</sup> CRPD (n7), Art. 18(1).

<sup>1084</sup> Ibid, Art. 18(1)(a)

<sup>1085</sup> Lawrence Mute, ‘Article 18: Liberty of Movement and Nationality’ in Ilias Bantekas, Michael A Stein, & Dimitris Anastasiou (eds), *The Un Convention on the Rights of Persons with Disabilities* (OUP 2018), 514.

<sup>1086</sup> CRPD (n7), Art. 19.

<sup>1087</sup> Ibid, Art. 19(a).

<sup>1088</sup> János Fiala-Butora, Arie Rimmerman, & Ayelet Gur, ‘Article 19: Living Independently and Being Included in the Community’ in Ilias Bantekas, Michael A Stein, & Dimitris Anastasiou (eds), *The Un Convention on the Rights of Persons with Disabilities* (OUP 2018), 549.

independence to choice and control over daily living arrangements, rather than to unaided functional ability”<sup>1089</sup> and that PWDs can more effectively control essential aspects of their lives and take power away from those who would seek to choose on their behalf. The CmRPD has rendered institutional care,<sup>1090</sup> forced institutionalisation,<sup>1091</sup> and conditional institutionalisation<sup>1092</sup> can all violate Article 19. Therefore, the CRPD sets the standard for functional, meaningful choice – a high threshold that provides PWDs with an increased agency to decide the location and manner of their residency. These are important not only given the history of isolationism, but also to ensure that ‘identity’ forms organically outside of characteristic boundaries.

Further, this is a positive obligation on States, who must actively counter the challenges of outdated legislation rather than allowing them to persist.<sup>1093</sup> States cannot continue to fund violating institutional practices but divert funds into a community-based supported residence. Moreover, States must provide several meaningful options to ensure that PWDs have a functional choice.<sup>1094</sup> Coercing an individual into institutionalisation as the only feasible option is a violation.<sup>1095</sup> These options include “all aspects of a person’s living arrangements, such as daily schedule,

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<sup>1089</sup> Ibid, 536.

<sup>1090</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations: Belgium (28 October 2014) CRPD/C/BEL/CO/1, para 32.

<sup>1091</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations: Denmark (30 October 2014) CRPD/C/DNK/CO/1, para 42.

<sup>1092</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations: Australia (21 October 2013) CRPD/C/SRB/CO/1, para 41.

<sup>1093</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations: New Zealand (31 October 2014) CRPD/C/SRB/CO/1, paras. 39.

<sup>1094</sup> Committee on the Rights of Persons with Disabilities, ‘General Comment 5 (2017) on Living Independently and Being Included in the Community’ (27 October 2017) CPRD/C/GC/5, para 25.

<sup>1095</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations: Serbia (23 May 2016) CRPD/C/SRB/CO/1, paras. 39-40.

routine, and lifestyle”.<sup>1096</sup> The CRPD provides autonomy to PWDs over a broad array of topics relating to independent living, enabling them to make choices important to their sense of self.

In planning a family, PWDs have the right to “decide freely and responsibly on the number and spacing of their children”.<sup>1097</sup> Paragraph 1(b) is clearly “concerned with the chronological first step in the parent-child relationship, with the act of becoming a parent”.<sup>1098</sup> States undermine the right to find a family through various financial, physical, or attitudinal barriers.<sup>1099</sup> The CRPD, therefore, seeks to provide PWDs with the power to establish a family unit on their terms. Echoing the discussion on relationships in the previous section, forming social connections significantly impacts the development of individual and collective identity. Founding a family can create a helpful support unit for individuals, especially when PWDs experience discrimination and prejudice throughout other parts of society. The identity framework assists in placing the importance of family in the spotlight, emphasising the utility and agency this right affords PWDs.

PWDs also maintain the right to work, which manifests in the CRPD as the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible”.<sup>1100</sup> The insistence on work “freely chosen” is an apparent attempt to “address situations where people with

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<sup>1096</sup> Fiala-Butora, Rimmerman, & Gur (n1088), 548.

<sup>1097</sup> CRPD (n7), Art. 23(1)(b).

<sup>1098</sup> Fiala-Butora (n1077), 642.

<sup>1099</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations: Hungary (22 October 2012) CRPD/C/HUN/CO/1, para 36.

<sup>1100</sup> CRPD (n7), Art. 27(1).

specific types of impairments are strongly encouraged to take up jobs that have been prejudicially considered appropriate” for PWDs.<sup>1101</sup> As an example, the CmRPD demonstrated chagrin at China for steering PWDs into the “blind massage” profession.<sup>1102</sup> It is clear that the CRPD values accessibility and inclusion in the workplace, promoting individual choice to work in a preferred career. Linking to Section 6.2 on relationships, individuals can dictate various aspects of their employment. Employment demonstrates the importance of an identity framework analysis, placing immense agency within the individual and usurping it from both employers. The State ensures that the clear intention of the AHC and CmRPD concerning the right to work is manifest.

Lastly, the CRPD ensures the active participation of PWDs in activities relating to disability-centric rights. Regarding liberty of movement, PWDs are “free to leave any country, including their own”,<sup>1103</sup> allowing PWDs to travel between countries. Individuals have the right to travel without necessitating a reason, meaning that “neither legal nor administrative hurdles should be placed in the way of [PWDs] to stop them from travelling abroad”.<sup>1104</sup> Such hurdles have included the denial of documents for both travel and proof of nationality, which also extends to anyone fleeing persecution or poverty who has the right to seek refugee status.<sup>1105</sup> Therefore, PWDs have the right to access other parts of the world through travel and participating in a

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<sup>1101</sup> Ilias Bantekas, Facundo Pennilas, & Stefan Trömel, ‘Article 27: Work and Employment’ in Ilias Bantekas, Michael A Stein, & Dimitris Anastasiou (eds), *The Un Convention on the Rights of Persons with Disabilities* (OUP 2018), 771.

<sup>1102</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations: China (15 October 2012) CRPD/C/CHN/CO/1, paras. 41-2.

<sup>1103</sup> CRPD (n7), Art. 18(1)(c)

<sup>1104</sup> Mute (n1085), 527.

<sup>1105</sup> Council of Europe Commissioner for Human Rights, *The Right to Leave a Country* (Council of Europe 2013).



global community. To support PWDs accessing the community, the CRPD gives them the right to participate in cultural life, recreation, leisure, and sport. This right manifests on an equal basis with others.<sup>1106</sup> It includes “access to cultural materials in accessible formats”,<sup>1107</sup> cultural activities such as television, film, and theatre,<sup>1108</sup> and “planned cultural performances or services, such as theatres, museums, cinemas, libraries and tourism”.<sup>1109</sup> By enabling PWDs to access culture on their terms, the CRPD ensures that they can develop and thrive, helping contribute to an inclusive and multicultural community. Individuals can learn from each other and progress in their search for identity, empowering them to interact with the community further.

PWDs also have human rights to access information. The right to the freedom of expression, opinion, and information access includes the “freedom to seek, receive and impart information and ideas...through all forms of communication of their choice”.<sup>1110</sup> PWD must have access to information they readily wish to seek in a format that is accessible to them. Accessibility is key to “respect, protect, and fulfil equality rights”<sup>1111</sup> by providing States with positive obligations to act proactively in enabling access to information. Self-expression is a crucial aspect of forming and performing identity, with access to information aiding in developing identity further. Individuals can also utilise their right to expression and knowledge to help facilitate access to other rights within the Convention. To further improve access to information, PWDs have the right to “an inclusive, quality and free primary and secondary education”.<sup>1112</sup>

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<sup>1106</sup> CRPD (n7), Art. 30(1).

<sup>1107</sup> Ibid, Art. 30(1)(a).

<sup>1108</sup> Ibid, Art. 30(1)(b).

<sup>1109</sup> Ibid, Art. 30(1)(c).

<sup>1110</sup> Ibid, Art. 21.

<sup>1111</sup> CRPD GC2 (n1015), para 14.

<sup>1112</sup> CRPD (n7), Art. 24(2)(b).

In summary, reading these provisions through the lens of queer/crip identity, the importance of individual growth and development becomes clear. Discussion in Chapter Seven will consider specific characteristic boundaries such as geographic location and type of disability. However, by interpreting these rights from a position of post-structuralism, it becomes clear that personal choice takes priority. At section 2.4, Butler discusses performance and citations, noting that highlighting the inequalities does not guarantee that change will occur. Therefore, it is important that conceptualising disability within the CRPD reflects the need to deconstruct restrictive boundaries. By providing considerable choice within the aforementioned provisions, the CRPD leaves development to the individuals, facilitating the change Butler speaks of.

### **6.3.3 Power to the People**

There are also ways in which the CRPD requires States to aid PWDs in accessing their rights actively. The CRPD requires States to facilitate certain activities by implementing processes and systems to help guarantee rights access. The CRPD also requires States to take positive steps to support PWD engagement. States have obligations to aid PWDs in accessing their rights keenly. To help facilitate rights principles in the CRPD, States must “take appropriate measures to provide access by [PWDs] to the support they may require in exercising their legal capacity”.<sup>1113</sup> These measures do not indicate an endorsement of supported decision-making. Instead, State support in ensuring PWDs can make decisions themselves. PWDs have the right

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<sup>1113</sup> Ibid, Art. 12(3).

not to use support.<sup>1114</sup> The CmRPD emphasises that support is “a broad term that encompasses both informal and formal support arrangements, of varying types and intensity”.<sup>1115</sup> States must provide various means to aid PWDs in accessing support systems.

Facilitating PWD access to such systems whilst rejecting supported decision-making “forms the foundation of the ‘support paradigm’ underpinning universal legal capacity”.<sup>1116</sup> Series and Nilsson argue that this new paradigm is “based on a radical reimagining of legal personality”.<sup>1117</sup> Support moves away from the “classic contractor”<sup>1118</sup> or “the myth of the masterless man”<sup>1119</sup> mentality of PWD capacity towards a new conceptualisation of “an interconnected and interdependent vision of humanity”.<sup>1120</sup> PWDs are no longer treated as unable to decide for themselves but instead as individuals capable of actively making and articulating choices. Moreover, States do not merely have a negative obligation to avoid forcing incapacity on PWDs, but a positive commitment to facilitate PWDs in making decisions.

Individuals can self-determine their right to habilitation and rehabilitation. Chapter Seven will discuss rehabilitation later when examining creativity; however, a cursory glance here aids in developing an analysis of agency. States must pass

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<sup>1114</sup> CRPD GC1 (n1071), paras 19 & 29(g).

<sup>1115</sup> Ibid, para 17.

<sup>1116</sup> Series & Nilsson (n8), 363.

<sup>1117</sup> Ibid.

<sup>1118</sup> Ngaire Naffine, ‘Who Are Law’s Persons? From Cheshire Cats to Responsible Subjects’ (2003) 66(3) *Modern Law Review* 346, 362.

<sup>1119</sup> Gerard Quinn & Anna Arstein-Kerslake, ‘Restoring the “Human” in “Human Rights” – Personhood and Doctrinal Innovation in the UN Disability Convention’ in Conor Gearty & Costas Douzinas (eds), *Cambridge Companion to Human Rights Law* (CUP 2012), 37.

<sup>1120</sup> Series & Nilsson (n8), 363.

legislation to ensure PWDs can “attain and maintain maximum independence, full physical, mental, social and vocational ability and full inclusion and participation in all aspects of life”.<sup>1121</sup> Individuals need access to rehabilitation services and must also be included in developing said services. Rehabilitation needs to be explicitly designed for the participation of PWDs, understanding their needs and requirements because this right explicitly aids PWDs in developing their human rights for independent living, personal assistance, and access to assistive technologies.<sup>1122</sup> Unfortunately, this article has received little CmRPD comment. However, “on some issues, there is enough to get a clear idea of the Committee’s views”.<sup>1123</sup> Bickenbach and Skempes argue that the CmRPD’s understanding of Article 26 is “not to require countries to create special, parallel rehabilitation services for [PWDs], but rather to create these services informed by their needs and requirements”.<sup>1124</sup> For example, the need for early intervention of rehabilitation services to help include children in society from a young age.<sup>1125</sup> The explicit inclusion of PWDs in the development process of these services highlights the control the CRPD places in individuals to both access and affect the advancement of State policies.

States must also facilitate the right to PWD participation in political and public life. States must ensure that PWDs can “effectively and fully participate in political and public life on an equal basis with others...including the right and opportunity for [PWDs]

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<sup>1121</sup> CRPD (n7), Art. 26(1).

<sup>1122</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations: Italy (6 October 2016) CRPD/C/ITA/CO/1, para 67.

<sup>1123</sup> Jerome Bickenbach & Dimitros Skempes, ‘Article 26: Habilitation and Rehabilitation’ in Ilias Bantekas, Michael A Stein, & Dimitris Anastasiou (eds), *The Un Convention on the Rights of Persons with Disabilities* (OUP 2018), 745.

<sup>1124</sup> *Ibid*, 746.

<sup>1125</sup> CmRPD: Bolivia (n1079), para 60.

to vote and be elected”.<sup>1126</sup> Du Plessis and Njau acknowledge that participation “is a theme that runs throughout the entire Convention”.<sup>1127</sup> Further, participation is a prerequisite to accessing other CRPD rights effectively.<sup>1128</sup> States must take positive measures to facilitate individual participation in the political process, either by electing a representative to an elected position or by running for such a position themselves. The ability to effectively and fully participate in political and public life ensures that PWDs can “assert individual autonomy, including the freedom to make choices and to be recognised as persons before the law”.<sup>1129</sup> Choice and personhood are essential features of the CRPD, and focusing on individuality by requiring States to facilitate individual access to rights highlights the PWD agency.

State support in facilitating individual control of rights is equally important. To begin, regarding personal mobility, States need to take “effective measures to ensure personal mobility with the greatest possible independence” for PWDs.<sup>1130</sup> The CRPD obligates States to support PWDs in accessing this right “in the manner and at the time of their choice”<sup>1131</sup> and to provide them with “quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries”.<sup>1132</sup> This

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<sup>1126</sup> CRPD (n7), Art. 29(a).

<sup>1127</sup> Ilze Grobelaar du Plessis & Jehoshaphat Njau, ‘Article 29: Participation in Political and Public Life’ in Ilias Bantekas, Michael A. Stein, & Dimitris Anastasiou (eds), *The UN Convention on the Rights of Persons with Disabilities* (OUP 2018), 849.

<sup>1128</sup> Rachele Cera, ‘Article 29: Participation in Political and Public Life’ in Valentina Della Rina, Rachele Cera, & Guisepe Palmisano (eds), *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer 2017), 527.

<sup>1129</sup> Plessis & Njau (n1127), 849.

<sup>1130</sup> CRPD (n7), Art. 20.

<sup>1131</sup> *Ibid.*, Art. 20(a).

<sup>1132</sup> *Ibid.*, Art. 20(b)

obligation applies to all PWDs irrespective of the kind or severity of impairment.<sup>1133</sup> Examples of effective measures include using sign language during driving instruction and examination<sup>1134</sup> and providing mobility aids for individuals with complex physical disabilities.<sup>1135</sup> As such, State efforts should have broad coverage, and States should consider geographic equality when developing mobility support systems.<sup>1136</sup> A queer approach to these responsibilities further proves that States need to assume positive obligations to undo the discriminatory barriers faced by PWDs.

States also must support PWDs in their freedom of expression and opinion, and access to information. To achieve this, States must accept and facilitate “the use of sign language, Braille, augmentative and alternative communication, and all other accessible means, modes, and formats of communication of their choice”.<sup>1137</sup> The right to expression is a right to “both understand and be understood”.<sup>1138</sup> PWDs need the ability to communicate to participate in society effectively. States must provide PWDs with information to aid in making their own choices, respect their communication method, and support its usage. Scheinwald notes that Article 21 provides specific examples of support measures, making “avoidance of implementation on the grounds of vagueness difficult to justify”.<sup>1139</sup> Moreover, Varney posits that the list is non-exhaustive to ensure that “provisions remain relevant as technology progresses,”

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<sup>1133</sup> Lalin Kovudhikulrungsri & Aart Hendriks, ‘Article 20: Personal Mobility’ in Ilias Bantekas, Michael A. Stein, & Dimitris Anastasiou (eds), *The UN Convention on the Rights of Persons with Disabilities* (OUP 2018), 568.

<sup>1134</sup> CmRPD: Serbia (1095), para. 41.

<sup>1135</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations: Slovakia (17 May 2016), CRPD/C/SVK/CO/1, para. 59.

<sup>1136</sup> Kovudhikulrungsri & Hendriks (n1133), 568-9.

<sup>1137</sup> CRPD (n7), Art. 21(b).

<sup>1138</sup> Disabled Peoples’ International (n221).

<sup>1139</sup> Aaron Scheinwald, ‘Who Could Possibly Be against a Treaty for the Blind?’ (2012) 22 *Fordham Intellectual Property, Media, and Entertainment Law Journal* 445, 462.

resulting in new communication formats.<sup>1140</sup> Communities based on disability often form their means of communication based on shared understanding and accessibility. Leaving options for new forms of communication promotes individual and collective agency to spearhead the development of the right to expression and access to information.

Moreover, producing complex communication formats, such as Braille, can be a “laborious and expensive process”.<sup>1141</sup> Therefore, States should “not only accept the use of alternative forms of communication by ensuring their availability and by investing in the training of interpreters and transcribers”.<sup>1142</sup> Viewed in totality, these provisions understand the importance of communication to PWDs, but also the necessary positive steps States must take to actually realise them. McRuer argues that society experiences compulsory able-bodiedness, and these provisions make attempts to address those imbalances.

Concerning the right to home and family life, “the right to marry involves support to [PWDs] to marry and found a family”.<sup>1143</sup> There is an implied violation of article 23 when States introduce barriers that, in practical terms, make it difficult for PWDs to marry,<sup>1144</sup> if States prevent PWDs from gaining financial incentives to marry,<sup>1145</sup> or if

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<sup>1140</sup> Eliza Varney, ‘Article 21: Freedom of Expression and Opinion, and Access to Information’ in Ilias Bantekas, Michael A Stein, & Dimitris Anastasiou (eds), *The Un Convention on the Rights of Persons with Disabilities* (OUP 2018), 595.

<sup>1141</sup> Katie Ellis & Gerard Goggin, *Disability and the Media* (Palgrave Macmillan 2015), 41.

<sup>1142</sup> Varney (n1140), 595.

<sup>1143</sup> Fiala-Butora (n1077), 641.

<sup>1144</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations: Chile (13 April 2016) CRPD/C/CHL/CO/1, para 47(b).

<sup>1145</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations: United Arab Emirates (3 October 2016) CRPD/C/UAE/CO/1, para 41.

States allow or perpetuate social and attitudinal barriers against PWDs concerning marriage.<sup>1146</sup> The CmRPD sees the States' role as a supporter of the right to marry, establishing responsibilities on the State to reduce barriers and provide aid where needed. Acknowledging the intersectional aspect of human rights and its impact on individual agency, Fiala-Butora highlights the gender gap in the right to found a family. For PWDs to overcome multiple disabling barriers based on gender and disability, States must take "special measures".<sup>1147</sup> The CmRPD emphasises the need to "repeal discriminatory provisions of family and other laws to ensure equal rights of all women and men".<sup>1148</sup> The individual's identity is fundamental to understanding the unique barriers they may face in exercising their rights. Referencing identity characteristics as critical facets of State policy to support the right to marry demonstrates the impact a queer/crip perspective can have on rights interpretation.

Through the right to education, States must create legislation that enables PWDs to "learn life and social development skills to facilitate their full and equal participation in education and as members of the community".<sup>1149</sup> An example of accessibility in education posits that to provide students with access to schools, "they should also have access to the entire physical and built environment before coming to school, and on the way between home and school".<sup>1150</sup> Without providing access to societal features external to education, such as the physical environment and information, PWDs "would not have equal opportunities for participation in their

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<sup>1146</sup> CmRPD: Hungary (n1099), para 36.

<sup>1147</sup> Fiala-Butora (n1077), 641.

<sup>1148</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations: Qatar (2 October 2015) CRPD/C/QAT/CO/1, para 42.

<sup>1149</sup> CRPD (n7), Art. 24(3).

<sup>1150</sup> Dimitris Anastasiou, Michael Gregory, & James M Kauffman, 'Article 24: Education' in Ilias Bantekas, Michael A Stein, & Dimitris Anastasiou (eds), *The Un Convention on the Rights of Persons with Disabilities* (OUP 2018), 696.



respective societies”.<sup>1151</sup> Therefore, States must support individuals in every aspect necessary to secure access to inclusive education. The characteristics of the individual help understand the accessibility considerations needed, which echoes the principles of support referenced in the right to habilitation and rehabilitation. PWDs are also afforded agency with State support to “attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life”.<sup>1152</sup> This will be considered in greater detail in Chapter Seven on inclusion.

Finally, States must support individuals in exercising their right to work and employment. States must take positive steps to ensure that PWDs can “exercise their labour and trade union rights”.<sup>1153</sup> Further, States must provide “effective access to general technical and vocational guidance programmes, placement services, and vocational and continuing training”.<sup>1154</sup> The focus of States often continues to be “to provide specialised or segregated services targeting only [PWDs] instead of ensuring that mainstream series are prepared to include” them.<sup>1155</sup> The CRPD, therefore, requires that States reduce barriers and support PWD access to work and training. For example, if PWDs cannot access training due to failing entry requirements, the CRPD tasks States with reassessing said entry requirements to ensure that restrictions are not discriminatory.<sup>1156</sup> Such amendments to policy rely on an intersectional understanding of the impact of identity on disability inclusion and access.

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<sup>1151</sup> CRPD GC2 (n1015), para 1.

<sup>1152</sup> CRPD (n7), Art. 26(1).

<sup>1153</sup> *Ibid*, Art. 27(1)(c).

<sup>1154</sup> *Ibid*, Art. 27(1)(d).

<sup>1155</sup> Bantekas, Pennilas, & Trömel (n1101), 784.

<sup>1156</sup> *Ibid*, 785.

## 6.4 Conclusion

This chapter is part one of a double feature on the impact of the identity approach on the interpretation of the CRPD. It demonstrates how focusing on identity gives PWDs the right to speak and be heard. It drastically alters the dynamic between individuals and States, imbuing PWDs with the agency to negotiate for themselves. By acknowledging a Foucauldian perspective of power, a queer interpretation of the provisions within the CRPD highlights the fluid nature of power within the rights relationship. A queering of the CRPD also understands the dynamic qualities of stigma as posited by Goffman. The provisions noted in section 6.3 all work together to reduce the need for PWDs to mask or correct aspects of themselves, prioritising inclusion and diversity. The problems lie with the State's response to disability, not with individuals themselves.

As such, a queer/crip reading of the CRPD understands the provisions that require prioritisation to undo existing barriers. For instance, reading rights as a fluid relationship highlights the unique considerations required when third parties share responsibility with the State to facilitate rights, ensuring that PWDs are not ignored or forgotten. Further, identity places the agency in the rights-holder, providing a myriad of situations where PWDs have more negotiation power in rights application. These fit on a sliding scale from the entitlement to informed consent on one end to the requirement of States to facilitate and endorse PWD rights on the other end. In each of these situations, a queer/crip perspective demonstrates a rejection of the rescuer complex endemic of the social model. PWDs are not merely disabled by society, incapable of participating. Instead, PWDs are capable individuals who can take an active role in their lives.

## Seven: Inclusive Rights for All

“The adoption of this Convention is a great opportunity to celebrate the emergence of comprehensive guidelines the world so urgently needs. It is an opportunity to reaffirm our universal commitment to the rights and dignity of all people without discrimination. The Convention can also provide the much-needed impetus for wider cultural changes in the way that the world perceives disabled people”.<sup>1157</sup>

### 7.1 Introduction

This chapter works in tandem with Chapter Six to demonstrate practical applications of an identity approach to the rights within the CRPD. This chapter focuses on inclusivity, reasonableness, and creativity. Inclusivity is the premier goal of the CRPD, to include PWDs in society. States must repeal examples of exclusion and segregation, instead focusing on actively involving PWDs by removing societal barriers. However, there is a clear distinction between true inclusion and mere integration, meaning States must be careful in creating genuinely inclusive legislation. One such method of ensuring inclusivity has been adhering to ideals of reasonableness. The CRPD uses reasonable accommodation to include PWDs, as an immediate anti-discrimination policy and a stepping-stone towards inclusion. However, reasonableness is temporary and causes more segregation issues, merely shifting the point of discrimination from

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<sup>1157</sup> UN President of the General Assembly, ‘Statement of HE Ms. Sheikha Haya Rashed Al Khalifa, President of the 61<sup>st</sup> Session of the General Assembly, at the Adoption of the Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities’ (*United Nations*, 13 December 2006) <<https://www.un.org/en/ga/president/61/pdf/statements/20061213-personswdisabilities.pdf>> (accessed 20 August 2021).

one locale to another. Constructing an access ramp solves the immediate concern of getting wheelchair users into the building, but creating a separate mode of ingress separates and isolates visitors of the building into two groups: the abled and the disabled. Certainly, the obvious short-term problems have been remedied, but to achieve greater inclusion of PWDs and the erosion of discriminatory social barriers, rights implementation must follow principles of queer/crip inclusion.

Therefore, through an identity approach, the CRPD necessitates an alternative means of implementing inclusivity through the application of creativity. Through a recontextualisation of human rights through a creative queer lens, the CRPD promotes rights with unique disability-centric aspects. After all, to be queer is to be creative, to dismantle problematic structures and promote inclusivity in society. The point here being that a queering of disability as a positionality between various sources changes our understanding of disability, and this aids us in interpreting rights under the CRPD differently. As an example, many argue that the CRPD does not introduce new disability-focused rights. However, several provisions within the CRPD provide unique interpretations of existing rights. Further, there is arguably one provision within the CRPD, namely the right to habilitation and rehabilitation, which has no non-disabled mirror and is not based on an existing human right within past international human rights conventions. It is a prime example of how, through a queer/crip lens, the CRPD is creative in addressing the barriers faced by PWDs and promoting the full and effective participation of PWDs in society. Therefore, this chapter demonstrates how identity aids in realising truly inclusive and creative application of human rights for PWDs.

## 7.2 Inclusive: True Disability Inclusion

Identity enables the true inclusivity of individuals in the human rights system. It also ensures the universal application of rights provisions, ensuring no one is left behind. As emphasised by the CmRPD, PWDs should have access to rights "without discrimination and based on equal opportunities".<sup>1158</sup> They are no longer merely welfare recipients, instead maintaining individual autonomy and liberty to access rights. As demonstrated in Chapter Four, other disability models often ignore inclusive policies in favour of advocating a particular position on the location of disability. In turn, this perspective ensures that the individual plays no part in the discussion and that their perspective maintains no bearing on the conversation or outcome. Using a queer approach to disability avoids inconsistent policies and arbitrary distinctions between different statuses of disability identity.

The following section will argue that an identity framework and utilising inclusivity could provide answers to the questions left unanswered by other models. Concerning biology, it can reduce reliance on medical assessments of the body, understanding that disability manifests in a myriad of ways, and it does not rely on diagnosis or adhering to a particular set of rules. It could also afford PWDs the option to seek medical intervention if they choose, but not requiring it as part of the life course. Regarding governance, it redistributes the power dynamic between medical professionals, lawmakers, and individuals with lived experience. It also removes the structures that force PWDs to conform to a particular way of life or standard of living. Finally, concerning rescue, identity understands that disability experience should not immediately lend itself to the infantilisation of PWDs, removing their ability to self-

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<sup>1158</sup> Committee on the Rights of Persons with Disabilities, 'General Comment 4 (2016) on the Right to Inclusive Education' (25 November 2016) CPRD/C/GC/4, para 1.

determine and live as they see fit. By including varied disability identities and treating them with universally-applied levels of respect, a queer/crip approach affords the individual agency in how they are treated and where their disability factors into interactions. As noted in Chapter Six, a queering of Shakespeare's interaction approach marks a shift away from "nothing about us, without us" to "without us, nothing". There can be no erosion of barriers without active engagement; real change can only happen if lived experience is at the helm.

### **7.2.1 What is Inclusion?**

Article 3 provides the general principles central to the CRPD, with inclusion and "full and effective participation" at its core.<sup>1159</sup> Additionally, it references the respect for inherent dignity, autonomy, and independence,<sup>1160</sup> a need for States to promote non-discrimination measures,<sup>1161</sup> and the importance of society's acceptance of PWDs "as part of human diversity and humanity".<sup>1162</sup> The CRPD intends for PWDs to participate fully in society on equal terms based on respect and dignity. However, the current rights methodology only facilitates the integration of PWDs into society, assimilating them into a pre-existing society with as few barriers as possible. There is a clear distinction between inclusion and mere integration. Society imbues within PWDs the belief that they need to fit in.

As such, it is important to begin with a caveat: 'inclusive' policies potentially reinforce existing binaries of outside/inside. As noted in Chapter Two, society is based

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<sup>1159</sup> CRPD (n7), Art. 3(c).

<sup>1160</sup> Ibid, Art. 3(a).

<sup>1161</sup> Ibid, Art. 3(b).

<sup>1162</sup> Ibid, Art. 3(d).

on normative values; arguably, inclusion can only be understood within the context of the normative structure to fit in. Within the context of sexuality, Duggan coins the term 'homonormativity' to explain the triangulation of neoliberal politics and centrality.<sup>1163</sup> Building on Warner's 'heteronormativity' and Rubin's sexual hierarchy,<sup>1164</sup> Duggan argues that normative systems allow certain categories of individuals that appear palatable. It is a politics of liberal equality that upholds and sustains desexualised and depoliticised perspectives of same-sex couples. Importantly, it does not contest the "dominant heteronormative assumptions and institutions but upholds and sustains them while promising the possibility of a demobilised gay constituency and a privatised, depoliticised gay culture anchored in domesticity and consumption".<sup>1165</sup> It is the tacit agreement of specific 'lifestyles' through assimilation, moving the chosen ones from suppression to inclusion within a privileged, powerful normate. The discussion of sexual liberation movements, from privacy and autonomy to public visibility, echoes the movements of the disability rights movement; see the discussion of the history of queer at Section 2.3 and the development of crip theory at Section 3.2. As such, an argument can be made that references to inclusion in the CRPD demonstrate the normative principles of charity and pathology activists warned about, and critiqued in Chapter Four.

Inclusion founded upon the entrenchment of ableist values is not true inclusion. Duggan argues normativity "invokes a political mainstream described as reasonable,

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<sup>1163</sup> Lisa Duggan, 'The New Homonormativity: The Sexual Politics of Neoliberalism' in Dana Nelson & Russ Castronovo (eds), *Materialising Democracy: Toward a Revitalised Cultural Politics* (Duke UP 2002).

<sup>1164</sup> See Michael Warner, *Fear Of A Queer Planet: Queer Politics and Social Theory* (University of Minnesota Press 1993); Gayle Rubin, 'Thinking Sex: Notes for a Radical Theory of Politics of Sexuality' in Carole Vance (ed), *Pleasure and Danger: Exploring Female Sexuality* (Routledge 1984).

<sup>1165</sup> Duggan (n1163), 179.

centrist, and pragmatic”.<sup>1166</sup> Therein lies the solution: the history of queer and crip is devoid of any considerations of reasonableness and pragmatism. In Section 2.4, Butler outlines the ways queer deconstructs the normative. However, they also note the potential futility of queer, suggesting “there is no promise that subversion will follow from the reiteration of constitutive norms; there is no guarantee that exposing the naturalised status of heterosexuality will lead to its subversion”.<sup>1167</sup> Further, McRuer acknowledges the limitations to crippling the queer, suggesting “this crisis and the anxieties that accompany it can be invoked in a wide range of cultural texts precisely to be (temporarily) resolved or alleviated”.<sup>1168</sup> Section 3.3 notes the intrinsic masculine and heterosexual biases within the law, and it is these very biases that draw academics such as Zanghellini and Gonzalez-Salzberg to queer the law. A queer/crip approach to rights retains these values and attempts to reject normativity, regardless of presumed futility. Therefore, references to inclusion in this chapter will utilise a queer interpretation, where ableist expectations of centring disability within a compulsory able-bodied society are rejected. Sections will make the distinction between inclusion and integration, the latter pertaining to instances of assimilation within an ableist social structure.

Two other important considerations arise regarding inclusion. The first question asks what its interaction with “participation” is. As Arduin notes, inclusion and participation maintain a tenuous and ambiguous relationship.<sup>1169</sup> It is unclear how these concepts interact, with provisions in the CRPD seemingly conflicting in the

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<sup>1166</sup> Ibid, 176.

<sup>1167</sup> Butler (n501), 23.

<sup>1168</sup> McRuer (n409), 493.

<sup>1169</sup> Sarah Arduin, ‘Article 3: General Principles’ in Ilias Bantekas, Michael A Stein, & Dimitris Anastasiou (eds), *The Un Convention on the Rights of Persons with Disabilities* (OUP 2018), 98.



application of both inclusion and participation of PWDs. Provisions regarding independent and community living,<sup>1170</sup> as well as habilitation and rehabilitation,<sup>1171</sup> place inclusion ahead of participation, arguing for treating them in unison. As an alternative, the right to education treats inclusion as an utterly separate principle to participation, understanding that true inclusion exists beyond social involvement.<sup>1172</sup> Finally, the preamble,<sup>1173</sup> purpose,<sup>1174</sup> and right to accessibility<sup>1175</sup> all reference participation without mention of inclusion. Arduin indicates that the CRPD needs to clarify further “the extent to which the concept of inclusion functions as an instrument for guaranteeing full and effective participation” of PWDs.<sup>1176</sup> As demonstrated in Chapters Two and Three, both participation and inclusivity feature as principles of a queer disability logic, highlighted in applications of Crip Theory. As such, they ultimately appear as tenets of the identity approach. Therefore, this section maintains that inclusion is relevant to but independent from, participation. It will use the right to education as a practical demonstration of this distinction, aided by the fact that the CmRPD has also done so at length.<sup>1177</sup>

The second question is how disability inclusion has historically functioned. In Chapters One and Four, there are examples of different approaches taken to responding to disability. Using a queer/crip lens, it becomes clear that there are four different modes society has utilised - exclusion, segregation, integration, and inclusion. As expected, the exclusion is antithetical to inclusion. To exclude PWDs is

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<sup>1170</sup> CRPD (n7), Art. 19.

<sup>1171</sup> Ibid, Art. 26(1).

<sup>1172</sup> Ibid, Art. 24(1).

<sup>1173</sup> Ibid, Preamble, paras. (e), (k), (m), & (y).

<sup>1174</sup> Ibid, Art. 1.

<sup>1175</sup> Ibid, Art. 9.

<sup>1176</sup> Arduin (n1169), 99.

<sup>1177</sup> CRPD GC4 (n1158).

not to include them, to “directly or indirectly prevent from or deny access to [rights] in any form”.<sup>1178</sup> As demonstrated in Chapters One and Four, the exclusion is a feeling PWDs are all too familiar with, having experienced rejection from society for centuries. In exclusionary settings, PWDs lack any access or comparative setting. In contrast, segregated systems provide rights to PWDs “in separate environments designed or used to respond to a particular impairment or...various impairments, in isolation from non-disabled people.”<sup>1179</sup> Typically these environments manifest in States creating separate systems for PWDs, isolating them from the rest of society. The former omits any form of opportunity for education and development of the individual, whilst the latter provides education crafted specifically for PWDs. Segregation can occur in situations without malicious intent from the State, as in cases where institutions specialise in educating persons with specific disabilities to enable proper education in individualised environments.<sup>1180</sup> These two concepts demonstrate the typical understanding of social separation and physical geographic barriers experienced by PWDs, roughly matching a pathologised view of disability concerning separation and treatment for their best interests.

On the other hand, integration is “the process of placing [PWDs] in existing mainstream...institutions with the understanding that they can adjust to the standardised requirements of such institutions”.<sup>1181</sup> For example, within integrated education, PWDs attend the same schools as their non-disabled peers in the same community setting. Integration removes some of the physical barriers of segregated

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<sup>1178</sup> Ibid, para 11.

<sup>1179</sup> Ibid.

<sup>1180</sup> See, for example, the specialised education institutions discussed in Committee on the Rights of Persons with Disabilities, ‘Inquiry concerning Spain’ (4 June 2018) CRPD/C/20/3.

<sup>1181</sup> CRPD GC4 (n1158), para 11.

schools but generates additional physical and social barriers. Typically, integration “focuses solely on enhancing the ability of the student to comply with the established standards”.<sup>1182</sup> The CmRPD provides “conditioning inclusion on the extent of their potential of the individual” as an example of prohibited behaviour of States to “evade the obligation to provide reasonable accommodation”.<sup>1183</sup> Integration often ignores the issues which benevolent segregation attempts to rectify by forcing PWDs to interact in a system that does not consider their accessibility needs.<sup>1184</sup> Creating integrated systems establishes a special quality to barriers, where outsiders believe that they have solved existing discriminatory practices, when in reality they have created new, markedly invisible, social barriers.

Inclusion is the attainment target for the CRPD. Disability inclusion means “understanding the relationship between the way people function and how they participate in society and ensuring everybody has the same opportunities to participate in every aspect of life to the best of their abilities and desires”.<sup>1185</sup> Inclusion is the means, method, and result; an inclusive system establishes the framework for participation, aids in facilitating access, and is the experience felt by PWDs on successful full participation. The British Council note that “taking deliberate steps to involve more disabled people in work” promotes inclusion and makes “cultural relations interventions more relevant, credible and impactful. It extends our learning

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<sup>1182</sup> United Nations Human Rights Council, ‘Thematic Study on the Right of Persons with Disabilities to Education’ (18 December 2013) A/HRC/25/29 & Corr. 1, para 4.

<sup>1183</sup> CRPD GC4 (n1158), para 18.

<sup>1184</sup> See, generally, UNICEF, *The Right of Children with Disabilities to Education: a Rights-based Approach to Inclusive Education* (UNICEF 2012).

<sup>1185</sup> Centre for Disease Control and Prevention, ‘Disability and Health Promotion: Disability Inclusion’ (CDC, 16 September 2020) <<https://www.cdc.gov/ncbddd/disabilityandhealth/disability-inclusion.html#:~:text=Disability%20inclusion%20means%20understanding%20the,of%20their%20abilities%20and%20desires.>> (accessed 22 February 2022).

and seeks to ensure different skills and experiences are used, which benefits everyone”.<sup>1186</sup> Arduin notes that “the principle of participation in society is a novel principle in international human rights treaty law”<sup>1187</sup> Both participation and inclusion are relatively unique to the CRPD. Article 23 of the CRC refers to “the child's active participation in the community”,<sup>1188</sup> however there is a difference in the intensity of usage of participatory rights between the CRC and the CRPD. The CRC is not tokenistic, but the CRPD places greater significance on PWD participation. Just as the AHC utilised participation and inclusion in its unique convention drafting process, the CRPD also uses these principles to expand and develop disability rights further than previously established.

Nevertheless, there has been inconsistency in applying inclusion through substitution with integration. This conflict between the two principles demonstrates a deeply rooted problem with current disability rights logic. On the one hand, State implementations of human rights attempt to integrate PWDs into society. On the other hand, said human rights implementation attempts to protect communities of disability to maintain a sense of collective identity and culture. These appear to function at odds with each other. To respect the unique aspects of disability identity and culture stemming from a community, it cannot conform to a rigid social structure. Most minority collective identities form in opposition or isolation to the normate; Deaf Culture exists independent of the speaking/hearing world, and Crip/Disability Pride is a political activism movement for a marginalised group. To integrate PWDs into

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<sup>1186</sup> British Council, ‘Promoting Inclusion A British Council Guide to Disability Equality’ <<https://www.britishcouncil.org/sites/default/files/guide-disability-equality.pdf> > (accessed 22 February 2022).

<sup>1187</sup> Arduin (n1169), 96.

<sup>1188</sup> CRC (n69), Art. 23(1).

society, States make changes to existing systems constructed for the normate to accommodate individuals of varying abilities. Nevertheless, society has evolved over centuries with a specific category of the individual at its core. PWDs are forced into a social structure ill-equipped to fully embrace them and their unique qualities. Education provides a prime example of this conflict. On the one hand, integrating and assimilating individuals into society, and on the other hand, genuinely including individuals in an open society. Individuals must be able to self-determine and live without State intervention unless individuals expressly request it.

### **7.2.2 Inclusive Education**

The CmRPD purports that “education is integral to the full and effective realisation of other rights”.<sup>1189</sup> It is foundational and “a means of realising other human rights”.<sup>1190</sup> It “epitomises the indivisibility and interdependence of all human rights” as it is a civil, political, economic, social, and cultural right.<sup>1191</sup> It manifests at a vital juncture of the development process of individuals, and quality education enables PWDs to “obtain the means to participate fully in their communities and be safeguarded from exploitation”.<sup>1192</sup> As a feature of several human rights conventions, it demonstrates the progressive realisation of education as a core tenant of the human rights framework. Beginning as one of the original rights in the UDHR,<sup>1193</sup> and expanding under the ICESCR,<sup>1194</sup> the right to education has developed to feature in specialist rights

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<sup>1189</sup> CRPD GC4 (n1158), para 44.

<sup>1190</sup> Ibid, para 10(c).

<sup>1191</sup> Committee on Economic, Social, and Cultural Rights, ‘General Comment No. 11 (1999): Plans of Action for Primary Education’ (10 May 1999) E/C.12/1999/4, para 2.

<sup>1192</sup> CRPD GC4 (n1158), para 10(c)

<sup>1193</sup> Universal Declaration of Human Rights (adopted 10 December 1948) UNGA Res 217 A(III) (UDHR), Art. 26.

<sup>1194</sup> UDHR (n32), Art. 13.

conventions to respect the needs of specific minority characteristic demographics.<sup>1195</sup> The CRPD makes advances in PWD-specific education rights. Article 5 ensures “equal protection and equal benefit of the law” to all PWDs.<sup>1196</sup> To address the systemic and structural discrimination faced by PWDs, State parties “must take affirmative action measures, such as removing architectural and communicative or other barriers, to mainstream education”.<sup>1197</sup> Article 24 provides for “an inclusive education system at all levels and life-long learning” for all PWDs “without discrimination and [based on] equal opportunity”.<sup>1198</sup> Article 24 also mentions reasonable accommodation directly in discussing the inclusion of the individual's requirements into rights realisation.<sup>1199</sup> Inclusion is incorporated into the right to education, functioning as a “fundamental human right of all learners”.<sup>1200</sup>

Inclusivity, therefore, features heavily in the discourse on education, becoming the focus of the CmRPD’s General Comment 4. The CmRPD emphasises the relationship between truly realised inclusive education and the need for reasonable accommodation. The CmRPD defines true inclusion as:

“a process of systemic reform embodying changes and modifications in content, teaching methods, approaches, structures, and strategies in education to overcome barriers with a vision serving to provide all students of the relevant age range with an equitable and participatory

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<sup>1195</sup> See, for example, CRC (n69), Arts. 23, 28 and 29.

<sup>1196</sup> CRPD (n7) Art. 5(1).

<sup>1197</sup> CRPD GC4 (n1158), para 45.

<sup>1198</sup> CRPD (n7), Art. 24(1).

<sup>1199</sup> *Ibid*, Art. 24(2)(c).

<sup>1200</sup> CRPD GC4 (n1158), para 10(a).

learning experience and the environment that best corresponds to their requirements and preferences".<sup>1201</sup>

Inclusive education is “central to achieving high-quality education for all learners, including those with disabilities” and developing “inclusive, peaceful and fair societies”.<sup>1202</sup> Further, inclusive education “can provide both quality education and social development” for PWDs.<sup>1203</sup> It can “guarantee universality and non-discrimination in the right to education”.<sup>1204</sup> In summation, “the right to education is a right to inclusive education”.<sup>1205</sup> Therefore, States must ensure their national education systems, both public and private, are fully inclusive for all PWDs.

Paragraph 12 of GC4 lists the core features of inclusive education. First, education must take a “whole systems approach” and invest resources “in advancing inclusive education and...introducing and embedding the necessary changes in institutional culture, policies and practices”.<sup>1206</sup> Second, States must promote “a whole educational environment” with “committed leadership of educational institutions [to change] the culture, policies and practices needed”.<sup>1207</sup> Third, change requires “a whole-person approach”, recognising “the capacity of every person to learn, and high expectations...for all learners, including learners with disabilities”.<sup>1208</sup> Such an approach offers flexible learning “adapted to different strengths, requirements and learning styles”.<sup>1209</sup> Fourth, States must employ “supported teachers” who receive “the

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<sup>1201</sup> Ibid, para 11.

<sup>1202</sup> Ibid, para 2.

<sup>1203</sup> UNHRC (n1182), para 68.

<sup>1204</sup> CRPD GC4 (n1158), para 2

<sup>1205</sup> UNHRC (n1182), para 3.

<sup>1206</sup> CRPD GC4 (n1158), para 12(a).

<sup>1207</sup> Ibid, para 12(b).

<sup>1208</sup> Ibid, para 12(c).

<sup>1209</sup> Ibid.

education and training they need to give them the core values and competencies to accommodate inclusive learning environments".<sup>1210</sup> Fifth, the resulting education system must afford "respect and value for diversity".<sup>1211</sup> States must ensure that all learning community members are "equally welcome and [receive] respect for diversity" irrespective of identity characteristics.<sup>1212</sup> Finally, the system must generate "a learning-friendly environment", as truly inclusive learning environments manifest "where everyone feels safe, supported, stimulated and able to express themselves".<sup>1213</sup> These features function in tandem to create a singular education system that is fully accessible to PWDs, promotes their educational development, and ensures future inclusion with the rest of society.

Additionally, CESCR<sup>1214</sup> and the CmRPD<sup>1215</sup> provide four tenets that education systems must follow to ensure inclusion. These features are "interrelated and essential",<sup>1216</sup> requiring they function together and take "the best interests of the student...[as] a primary consideration".<sup>1217</sup> First, education must be available to PWDs, as outlined in previous sections. Both "public and private education institutions and programmes must be available in sufficient quantity and quality", emphasising access "throughout the community".<sup>1218</sup> The obligation of the State does not relate to public schooling alone but also to provide legislation and regulation for private education. What education institutions require to function "depends upon numerous factors,

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<sup>1210</sup> Ibid, para 12(d).

<sup>1211</sup> Ibid, para 12(e).

<sup>1212</sup> Ibid.

<sup>1213</sup> Ibid, para 12(f).

<sup>1214</sup> Committee on Economic, Social, and Cultural Rights, 'General Comment No. 13 (1999): The Right to Education' (8 December 1999) E/C.12/1999/10, paras 6(a)-(d).

<sup>1215</sup> CRPD GC4 (n1158), paras 21-24.

<sup>1216</sup> CESCR GC13 (n1214), para 6.

<sup>1217</sup> Ibid, para 7.

<sup>1218</sup> CRPD GC4 (n1158), para 21.



including the developmental context within which they operate”.<sup>1219</sup> Second, all facets of education “must be accessible to everyone, without discrimination”.<sup>1220</sup> Accessibility relies on the right to non-discrimination, “especially to the most vulnerable groups”.<sup>1221</sup> Here, the CESCR defers to the UNESCO Convention against Discrimination in Education, which considers discrimination in education as “any distinction, exclusion, limitation or preference which...has the purpose or effect or nullifying or impairing equality of treatment in education”.<sup>1222</sup> Discrimination manifests in several forms, such as depriving groups of education at any level,<sup>1223</sup> limiting an education level to an inferior standard,<sup>1224</sup> establishing segregated systems or institutions,<sup>1225</sup> or “inflicting on any person or groups of persons conditions incompatible with the dignity of man”.<sup>1226</sup> Importantly, non-discrimination is “subject to neither progressive realisation nor the availability of resources”;<sup>1227</sup> the obligations on the State apply “fully and immediately to all aspects of education and encompasses all internationally prohibited grounds of discrimination”.<sup>1228</sup>

Accessibility also maintains an element of physicality, realised either by “attendance at some reasonably convenient geographic location...or via modern technology”.<sup>1229</sup> Using technologies allows for enhanced learning opportunities and

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<sup>1219</sup> CESCR GC13 (n1214), para 6(a).

<sup>1220</sup> CRPD GC4 (n1158), para 22.

<sup>1221</sup> CESCR GC13 (n1214), para 6(b).

<sup>1222</sup> UNESCO Convention against Discrimination in Education (adopted 14 December 1960, entered into force 22 May 1962), UNTS 429, Art. 1(1).

<sup>1223</sup> *Ibid*, Art. 1(1)(a).

<sup>1224</sup> *Ibid*, Art. 1(1)(b).

<sup>1225</sup> *Ibid*, Art. 1(1)(c).

<sup>1226</sup> *Ibid*, Art. 1(1)(d).

<sup>1227</sup> CESCR GC13 (n1214), para 31.

<sup>1228</sup> *Ibid*.

<sup>1229</sup> *Ibid*, para 6(b)

quality and increased access. The CmRPD goes further and includes “buildings, information and communication tools...the curriculum, educational materials, teaching methods, assessments and languages and support services” into its understanding of physical accessibility.<sup>1230</sup> Various factors feed into a PWD’s ability to access education; for example, sending PWDs to specialist schools on the other side of the State is not reasonable.<sup>1231</sup> Moreover, States must consider economic accessibility, ensuring that “education [is] affordable to all”.<sup>1232</sup> Regarding disability, schooling needs to be free, and PWDs cannot shoulder the financial burden of measures to reduce barriers and increase inclusion. Education must be affordable at all levels, and reasonable accommodation of PWDs “should not entail additional costs” to access.<sup>1233</sup> Section 7.4 will discuss creativity; ultimately, accessibility is “a dynamic concept, and its application requires periodic regulatory and technical adjustments”,<sup>1234</sup> often requiring creative approaches.

The CmRPD inquiry into Spanish education highlights the problems with segregation and separate education standards. Spain relies on special schools dedicated to teaching a particular type of disability, established to provide coverage to large geographic areas in a single location. This system generates exclusion on two separate fronts: it keeps children from “the mainstream education system and separated from their immediate community”.<sup>1235</sup> Teaching PWDs separately from other children generates “parallel tracks of school life, employment and later residence,

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<sup>1230</sup> CRPD GC4 (n1158), para 22.

<sup>1231</sup> CmRPD (n1180), para. 26.

<sup>1232</sup> CESCR GC13 (n1214), para 6(b).

<sup>1233</sup> CRPD GC4 (n1158), para 24.

<sup>1234</sup> Ibid.

<sup>1235</sup> CmRPD (n1180), para. 28.

leading to very different life outcomes”.<sup>1236</sup> The general domestic legislation in Spain provides for non-discriminatory education yet still uses archaic language for disability and allows for segregation based on disability in certain situations dictated by the State. Therefore, though Spain’s newer legislation tries to be inclusive, it leaves the door open for segregation and discrimination. Such discrimination causes States to leave behind pupils, establishing barriers to entry into society before adulthood. The CmRPD conclude that “two separate modalities of education cannot coexist in an inclusive education system...the system must consist of one modality for all students and must be based on the quality of the education”.<sup>1237</sup>

This ongoing commentary from the Committee on Spain’s inadequate education system demonstrates the effect of a queer approach to the realisation of human rights. The Committee’s perspective on realising an inclusive education system has shifted over time, showing a willingness to move the needle and plot a new course to better achieve the intended goal. Rather than entrenching itself in a rigid understanding of inclusion, the Committee utilises the flexibility afforded by the Convention to target the root causes of inequalities. Further, the right to an inclusive education highlights a rejection of able-bodied normativity, rejecting the ‘compulsory able-bodiedness’ McRuer speaks of within society. The Spanish education system, founded upon medical diagnosis of intellectual and psychosocial disability and segregation of children into different systems based on perceived ability, bleeds ableist normativity. Despite the legislative changes enacted by Spain (complemented

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<sup>1236</sup> OHRCH, ‘Spain must ensure inclusive education for persons with disabilities, UN human rights experts say’ (OHCHR, 29 May 2018) <<https://www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=23135&LangID=E>> (accessed 24 February 2022).

<sup>1237</sup> Ibid.

by the Committee in their concluding observations), a culture of ableism and exclusion perpetuates the education system at a regional level. The Committee understands that legal change necessitates social change, and the CRPD enables this by addressing systemic and mechanical preconceptions. Maintaining a queer heart that can attack these prejudicial biases, targeting the rotting core of discrimination, promotes the full and effective incorporation of rights into truly inclusive legal systems.

Third, the CmRPD places value in acceptability, the “obligation to design and implement all education-related facilities, goods and services taking fully into account and respecting the requirements, cultures, views and languages” of PWDs.<sup>1238</sup> In particular, States should focus on “the form and substance of education, including curricula and teaching methods”.<sup>1239</sup> Such developments must focus on “personality, talents, and creativity” and the “mental, physical and communicational abilities” of PWDs to ensure their fullest potential.<sup>1240</sup> The CmRPD correctly notes that the education of PWDs “too often focuses on a deficit approach, on their actual or perceived impairment”.<sup>1241</sup> The disability experience is understood as pathology and integration, therefore “limiting opportunities to pre-defined and negative assumptions of their potential”.<sup>1242</sup> Referencing the Spanish inquiry again, in practice, such a system “focuses on the pupil’s failings and deficiencies, resulting in their being stigmatised as unfit for mainstream education”.<sup>1243</sup> Rather than “exploring all possible ways of including the pupil, the diagnosis prevents mainstream schools from providing support

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<sup>1238</sup> CRPD GC4 (n1158), para 25.

<sup>1239</sup> CESCRC GC13 (n1214), para 6(c).

<sup>1240</sup> CRPD GC4 (n1158), para 16.

<sup>1241</sup> *Ibid*, para 16.

<sup>1242</sup> *Ibid*.

<sup>1243</sup> CmRPD (n1180), para. 38.

measures and reasonable accommodation”.<sup>1244</sup> This system identifies children with disabilities as problematic, ostracising them from society. Within their conclusions in *Calleja Loma & Calleja Lucas v Spain*, the CmRPD emphasise the need to fix the education system to include disabilities, not separate students based on perceived ability.<sup>1245</sup> The chosen education system does not utilise a medicalised analysis of children with disabilities.

Moreover, the curriculum “has to be acceptable”, meaning PWDs should get a say in the content and manner of their education.<sup>1246</sup> They should be able to contribute to the composition of the curriculum in ways that are “relevant, culturally appropriate and of good quality”.<sup>1247</sup> If they are omitted, pupils with disabilities “can find themselves left by teachers and the administration in a setting that offers very poor or very few prospects for the pupil and for [their] performance”.<sup>1248</sup> Genuinely inclusive education systems consider the needs and wishes of PWDs, incorporating them into educational plans and policies. Focusing on core tenets of disability identity respects the interests of PWDs, helping reduce future barriers to entry into society. These requirements are notably subjective but important to PWDs to ensure that various aspects of the disability identity are respected and transferred down through generations. To this end, parent groups and organisations of PWDs “should be involved in the education process at all levels”,<sup>1249</sup> involving critical figures in the PWD experience to help shape the education system. The phrase “at all levels” indicates an active participation in critical aspects of teaching rather than merely impacting policy

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<sup>1244</sup> Ibid.

<sup>1245</sup> *Calleja Loma & Calleja Lucas v Spain* (41/2017) CRPD/C/23/D/41/2017.

<sup>1246</sup> CESCR GC13 (n1214), para 6(c).

<sup>1247</sup> Ibid.

<sup>1248</sup> CmRPD (n1180), para. 28.

<sup>1249</sup> UNGA Res 48/96 (n156), Annex, Rule 6.3.

and content. However, education is “the right of the individual learner and not, in the case of children, the right of a parent or caregiver”,<sup>1250</sup> especially given the history of segregation and detention suffered by PWDs. Segregation functions more in the best interests of the carer, not the PWD. The CRPD seeks to undo this power imbalance. As such, inclusivity “values the well-being of all students, respects their inherent dignity and autonomy and acknowledges individuals' requirements” and their ability to be included in and contribute to society effectively.<sup>1251</sup> Guidance on content and manner of education from parents and other third parties is essential, yet the individual right holder holds the final word on their education. Identity ensures that the individual remains at the centre of discourse; any rights implementation methods which ignore PWDs or fail to include them at all stages is at odds with the identity approach. This perspective has practical implications for tangible avenues for PWDs in exercising their rights. The CRPD is notably silent on implementation, leaving power with States. In theory, identity solves these issues. However, practical application extends beyond the scope of this thesis.

Finally, education must be adaptable. If States adopt an approach utilising the various tools within the CRPD, such as universal design, the resulting education system will follow a “set of principles providing teachers and other staff with a structure for creating adaptable learning environments and developing instruction to meet the diverse needs of all learners”.<sup>1252</sup> Educational institutions and the curriculum must be flexible to “adapt to the needs of changing societies and communities”,<sup>1253</sup> promoting the idea of one singular education system, not segregated parallel systems. Moreover,

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<sup>1250</sup> CRPD GC4 (n1158), para 10(a).

<sup>1251</sup> Ibid, para 10(b).

<sup>1252</sup> Ibid, para 26

<sup>1253</sup> CESCRC GC13 (n1214), para 6(d).

the system must respond to students' needs "within their diverse social and cultural settings".<sup>1254</sup> It has to teach PWDs in their community to understand the varied meanings of the term both geographically and socially.<sup>1255</sup> Notably, "each student learns in a unique manner", which involves the following several factors: "developing flexible ways to learn; creating an engaging classroom environment; maintaining high expectations for all students while allowing for multiple ways to meet expectations; empowering teachers to think differently about their teaching, and focussing on educational outcomes for all".<sup>1256</sup>

### **7.2.3 Who Is Included?**

The previous sections demonstrate a theoretical understanding of inclusive rights, highlighting through an application to education the possible issues States face in navigating the distinction between integration and inclusion. Promoting truly inclusive education structurally changes the aims and processes followed in education systems. A consequence of this is the ambiguity of the application of inclusion policies, where it becomes uncertain to establish the recipient of inclusive rights. As such, are disability-centric rights applicable only to PWDs, or do their parameters overlap with rights associated with their non-disabled peers? Does a non-disabled child have the right to engage in play and leisure activities, especially in education settings, with children with disabilities so they can experience and learn about a wider variety of individuals and statuses of ability? Inclusivity promotes community – not merely one based on disability, but also one of a wider geolocated social group. This is a very queer question, utilising the post-structural foundations to test the CRPD.

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<sup>1254</sup> Ibid, para 6(d).

<sup>1255</sup> CRPD GC4 (n1158), para 27.

<sup>1256</sup> Ibid, para 26.

Younger generations have become more aware of disabilities, and barriers preventing individuals from interacting with PWDs have started to recede. According to Article 8 on awareness-raising, States must ensure that non-disabled children have as great an opportunity as possible, and over as long a period as possible, to develop respect for children with disabilities and their rights. One of the best ways to ensure this is to include children with and without disabilities in the same inclusive education settings, so they can learn from each other and develop community bonds. This sentiment echoes the language of Article 10 of the CRPD, which “expressly forbids [PWDs] to live in a particular living arrangement and obliges States to provide the necessary services that allow all [PWDs] to live in the community in a meaningful and integrated way”.<sup>1257</sup> These two function in tandem to establish an additional arrow in the quiver of children with disabilities seeking an education in their geographic community.

Several provisions in the CRPD promote the inclusion of PWDs in their community from the perspective of best interests. Legislation should ensure that “the best interests of the child [is] a primary consideration”.<sup>1258</sup> Though the CRPD expressly aims to consider children with disabilities, it implies the importance of the best interests of all children. Further, education should foster “at all levels of the education system...an attitude of respect for the rights of persons with disabilities”.<sup>1259</sup> To establish this level of respect, States must provide access to “an inclusive, quality and free...education on an equal basis with others in the communities in which they

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<sup>1257</sup> Ibid, 532-3.

<sup>1258</sup> CRPD (n7), Art. 7(2).

<sup>1259</sup> Ibid, Art. 8(2)(b).



live".<sup>1260</sup> Section 7.2.2 demonstrates that children with disabilities have the right to education within their community. The reverse must be true, that non-disabled children have the right and benefit to grow up around children with disabilities. Education confers a collective community identity, generating an experience and focal point around which children can identify. Not only does this enable children with disabilities to feel connected with their local community, a role often alien to them by social and structural ostracisation. It also builds a sense of community spirit in others, with a diverse foundation and a rejection of homogeneity. Inclusive education is not, as noted above, the integration of children with disabilities into an existing educational structure but the crafting of a rich and unique system that considers various backgrounds, needs, abilities, and experiences.

Regarding the right to play, States must "ensure that children with disabilities have equal access with other children to participation in play, recreation, and leisure and sporting activities, including those activities in the school system".<sup>1261</sup> The right to play is critical for a child's development. Bantekas et al. argue that Article 30(5)(d) is "at the very least highly unfortunate" as it "rejects the notion of a right to sport and simply urges States to accommodate disabled participation in sports, as well as provide a sufficient degree of accessibility".<sup>1262</sup> This argument is flawed. Paragraph 5 identifies the overarching aim of including PWDs in recreation and sporting activities equally with others. Moreover, 5(a) includes PWDs in mainstream sporting activities, and 5(b) develops disability-specific sporting activities. Therefore, unless 5(d) seeks

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<sup>1260</sup> Ibid, Art. 24(2)(b).

<sup>1261</sup> Ibid, Art. 30(5)(d).

<sup>1262</sup> Ilias Bantekas et al, 'Article 30: Participation in Cultural Life, Recreation, Leisure, and Sport' in Ilias Bantekas, Michael A. Stein, & Dimitris Anastasiou (eds), *The UN Convention on the Rights of Persons with Disabilities* (OUP 2018), 919.

to undo these two passages, it cannot reduce the right to disability-focused sports and inclusion in mainstream sports, converting it to a mere accommodation. Instead, 5(d) identifies the right that children with disabilities have to sports and recreation activities with other children of their age, especially at school. Additionally, Bantekas et al.'s perspective focussed on the explicit right to disability-specific sports. However, shifting to a holistic and inclusive perspective of sport and play amongst children, irrespective of the status of ability, provides a different standpoint. It is clear from this lens that 5(d) conveys the ability of children with disabilities to engage in play with their non-disabled peers. Likewise, the passage provides the same ability and benefit to non-disabled children, who should be able to engage in play with other children.

Finally, the case of *Bellini v Italy* is an example of the Committee pushing definitional boundaries.<sup>1263</sup> In *Bellini*, the author is the caregiver to her daughter, who has several disabilities and requires constant and consistent care. This includes attending specialised care centres almost daily, and providing care throughout the night to prevent or limit her daughter's self-sustained injuries. The author is also a carer to her husband, who requires continuous assistance after a brain haemorrhage. She does all of this by herself, acting as liaison for her husband and daughter in communicating with external institutions. Simultaneously, she was employed and worked remotely, as her caring responsibilities were not conducive with office-based employment. However, her telecommuting rights were revoked in 2017, preventing her from continuing employment. The author claimed that Italy's lack of legal recognition of and support for family caregivers violated the rights of her, her daughter's and her partner under the CRPD.

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<sup>1263</sup> *Bellini* (n429).

The interesting claim for the purpose of this discussion was that the author brought claims on her own behalf in her capacity as the family caregiver. Bellini argued that she had rights protection as someone who did not claim to have a disability, for three reasons: “(a) that a fundamental connection exists between the carer and the person with disabilities; (b) that caring activities without any legal recognition is a form of discrimination; and (c) that caring is a substantive right”.<sup>1264</sup> The Committee noted that there are instances in which the rights of persons with disabilities cannot be realised without the protection of family caregivers.<sup>1265</sup> Within their consideration of admissibility, the Committee appears to have been persuaded strongly by reason (a) and, to a much lesser extent, by reason (b). They do not discuss the notion of ‘caring’ as an independent right under the Convention.

Family members are mentioned within the Convention, though in limited capacities. The preamble notes that both “persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities”.<sup>1266</sup> Further, Article 28 ensures “access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses”.<sup>1267</sup> Within Article 5, though family are not mentioned explicitly, the Committee used their sixth general comment to expand protections from

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<sup>1264</sup> Ibid, para 6.6.

<sup>1265</sup> Ibid, para 6.7.

<sup>1266</sup> CRPD (n7), preamble para (x).

<sup>1267</sup> Ibid, Art. 28(2)(c).

discrimination to those who are associated with persons with a disability.<sup>1268</sup> Article 5 maintains such a wide scope to “eradicate and combat all discriminatory situations”.<sup>1269</sup>

Reading these in unison, the Committee found that the Convention confers rights on family members to assistance from the State, but only within the context of Article 28(2)(c).<sup>1270</sup> The Committee emphasises the narrow margin they have afforded Bellini. The rights of family members must be ‘indivisibly linked’ to the protection of a family member with disabilities, and only if affording the caregiver a right is a “necessary prerequisite” to realising the rights of the family member with disabilities.<sup>1271</sup> The Convention does not provide sweeping rights to people without disabilities, and decisions on who can receive protections under the Convention must be made on a case-by-case basis.

Ultimately, the Committee found that Italy had violated Bellini’s right to support services in providing her family with an adequate standard of living, under Article 28(2)(c) in conjunction with Article 5; Italy was under an obligation to offer Bellini and her family access to adequate individualised support services.<sup>1272</sup> However, in their conclusions and recommendations for Italy’s general obligations, the Committee only mention family caregivers within the context of support services for persons with disabilities where applicable.<sup>1273</sup> Again, this falls short of applying broad obligations

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<sup>1268</sup> Committee on the Rights of Persons with Disabilities, ‘General Comment No. 6 (2018) on Equality and Non-Discrimination’ (26 April 2018) CRPD/C/GC/6 at para 20.

<sup>1269</sup> *Bellini* (n429), para 7.9.

<sup>1270</sup> *Ibid*, para 6.8.

<sup>1271</sup> *Ibid*.

<sup>1272</sup> *Ibid*, para 8(a)(ii).

<sup>1273</sup> *Ibid*, para 8(b)(iii).

on States to provide protections to people without disabilities, framing their rights within the context of the rights of family members with disabilities.

Nevertheless, this is clear evidence of the CRPD taking an inclusive view of disability and a holistic understanding of the access needs of persons with disabilities in realising their rights. Given that some rights under the Convention will need the support of persons without disabilities to realise, those persons can experience rights protections under the CRPD. Regardless of how pragmatic the Committee appears to be in their decision in *Bellini*, the result is that a person who made no claims of having a disability was afforded rights protections under a Convention specifically written to protect persons with disabilities. The fact that the wording of the CRPD not only allows this reading, but renders it a logical and necessary conclusion, demonstrates a queer understanding of social categories.

Finally, *Bellini* goes further than the provisions discussed at Section 6.2 on the inclusion of third parties. When considering the rights relationship, it is clear how third parties are necessary to help facilitate individual rights. The argument in Section 6.2.1 is that existing principles give rights to third parties either as proxy to or instead of the individual; the right is owned by the individual but exercised by the third party. However, a queer reading of *Bellini* highlights something very different: her rights under the CRPD were *in addition to* the rights of her daughter and husband. This is an example of someone who does not have a disability having somewhat-independent, exercisable rights under the CRPD.

### **7.3 Reasonable: The Failures of Accommodation**

The previous section discusses what true inclusion looks like. However, it is essential to consider how the law implements inclusion in practice. Inclusion is not favourable differential treatment. Instead, inclusion is the reimagining of structures to better facilitate the abilities and accessibilities of the wider populace. Therefore, when looking for inclusive legal provisions from States, one must consider the practical steps taken to restructure systems with non-normate groups in mind. Using education as an example, such research into inclusion would seek policy decisions to alter the general structure of education within a State to ensure that PWDs can fully realise their right to tangibly access and engage with education. However, the discussion within this section highlights that some education systems rely on reasonable accommodation when considering PWD access to education, creating several issues and not successfully including PWDs in the education system. Ultimately, this thesis suggests that a queer/crip inclusion is the only accurate perspective when tackling these issues. This section will outline the failings of reasonableness and reasonable accommodation to undo the harms experienced by PWDs, to help establish the need for a queer perspective on inclusion.

#### ***7.3.1 Developing Disability Education***

The CRC predates the CRPD by almost two decades, with State parties signing the CRC on 20<sup>th</sup> November 1989 and the CRC entering into force on 2nd September 1990. The CRC is also the most successful international convention for ratification, sporting 140 signatories and 196 State parties. General provisions in the CRC aid in the discussion of inclusion. The CRC also provides standards of education for children at various levels. Analysis of these provisions helps track the international community's perspective of inclusion within social structures over the last three decades. Further,

the CRC focuses on age as an individual characteristic, highlighting children as a vulnerable class due to differential societal treatment of those in pre-maturity. Naturally, there is an overlap between the CRC and the CRPD concerning children with disabilities, with both conventions dedicating articles to children with disabilities.

LeBlanc notes that “over the history of the negotiations on the convention, the notion that positive measures should be taken to ensure that disabled children are integrated into the community, and thus made to feel as though they are full members, always enjoyed broad-based support”.<sup>1274</sup> Modern rights discourse indicates that ‘integration’ and ‘full membership’ are not as interconnected as States believed in the late 1980s and early 1990s. The CRC is not nearly as progressive and inclusionary for disability rights as previously imagined, thus demonstrating the necessity for the CRPD to fill in the gaps. Comparing the right to education within both helps document the shift from integration to inclusion and provides insights into the practical realisation of inclusive education.

Article 12 of the CRC requires State parties to “assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child”.<sup>1275</sup> This provision is part of a package of participation rights,<sup>1276</sup> establishing that children are capable of independent thought and self-reflection equally to adults and should therefore receive equal respect for

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<sup>1274</sup> Lawrence J LeBlanc, *The Convention on the Rights of the Child: United Nations Lawmaking on Human Rights* (University of Nebraska Press 1995), 102.

<sup>1275</sup> CRC (n69), Art. 12(1).

<sup>1276</sup> Laura Lundy, John Tobin, & Aisling Parkes, ‘Article 12: The Right to Respect for the Views of Children’ in John Tobin (ed), *The UN Convention on the Rights of the Child: A Commentary* (OUP 2019), 401.

participation. Additionally, participation is essential for children to feel involved in the rights process and to actively engage in society on an equal basis to others. To this end, commentators note that “the implementation of Article 12 can play a critical role in the development of children and enable them to take an active part in the construction of their own identity and sense of personal autonomy”.<sup>1277</sup> As discussed in Chapter Four, individuals participate in social interactions, using their identity to develop a deeper understanding of themselves and their identity. The cyclical nature of identity formation demonstrates the benefits of participatory rights. Further, the CmRC promotes the participation rights of children with disabilities in all rights,<sup>1278</sup> which reflects the CRPD’s promotion of the “full and effective participation [of PWDs] in society on an equal basis with others”.<sup>1279</sup>

Critically, respecting children’s views “recognises their right to membership of a community” and can also “help them develop the skills necessary to exercise this entitlement meaningfully”.<sup>1280</sup> Community is an important aspect of identity formation and development. Individuals use subscriptions to collectives to establish their locale within societal identity structures. Collective identity memberships also help reinforce internally established ideas of self. Participation rights ensure that individuals have access to communities. Moreover, CRC GC12 ensures that children have presumed capacity to make decisions, avoiding a conditional rights paradigm for legal capacity and personhood.<sup>1281</sup> This deviates from the disability rights discussions in Chapter Four, especially capacity-based mental health laws. Capacity-based safeguards often

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<sup>1277</sup> Ibid, 399.

<sup>1278</sup> CRPD GC6 (n1268), para. 5.

<sup>1279</sup> CRPD (n7), Art. 1.

<sup>1280</sup> Lundy, Tobin, & Parkes (n1276), 401.

<sup>1281</sup> Committee on the Rights of the Child, ‘General Comment 12: The Right to Be Heard’ (2009) CRC/C/GC/12, para 20.



rely on a subjective assessment by a third party as part of rights access. Such policies gatekeep individuals from meaningful societal development of identity through restricting participation. Imbuing a third party with the determining power over an individual's ability to participate negates the purpose of participation rights. This further exemplifies the importance of the agency discussion in Section 6.3 and the reasons why queer and crip advocate for or emphasise the importance of individual agency.

The CRC's Article 23 tackles the intersection of childhood and disability. Detrick argued in 1999 that Article 23 is "an innovative universal human rights provision" as "neither the UDHR nor the ICCPR and the ICESCR contain special provisions relating to disabled persons".<sup>1282</sup> As a participatory right, it maintains that "a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community".<sup>1283</sup> It echoes the sentiment established in Article 12, which emphasises participation as integral to community engagement. It also acknowledges that PWDs benefit from being included in the community, a matter of great importance to the CRPD. Inclusion and participation are general principles in Article 3(c) of the CRPD.<sup>1284</sup>

However, other passages within Article 23 create ambiguity and concern. Paragraph 2 allocates assistance to "special care" of the child with disabilities appropriate "to the circumstances of the parents or others caring for the child".<sup>1285</sup>

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<sup>1282</sup> Sharon Detrick, *A Commentary on the United Nations Convention on the Rights of Children* (Martinus Nijhoff 1999), 381.

<sup>1283</sup> CRC (n69), Art. 23(1).

<sup>1284</sup> CRPD (n7), Art. 3(c).

<sup>1285</sup> CRC (n69), Art. 23(2).

This provision appears to aid participation and inclusion, understanding the barriers faced by PWDs and the need for measures to overcome said barriers. However, the use of archaic language in “special care” and the extension of the right to assistance to those caring for the child exudes levels of segregation. It allows for third parties to dictate the best course of action for caring for (or ‘treating’) the child, providing the option of separate care on an alternative path from non-disabled peers. It also risks infantilising the child further, removing individual power and choice instead of bestowing it on parents, guardians, carers, and medical professionals.

Further, paragraph 3 requires States to provide “special needs” to PWDs, which are “designed to ensure that the disabled child has effect access to and receives education”, among other provisions.<sup>1286</sup> This human right targets “the child’s achieving the fullest possible social integration and individual development”.<sup>1287</sup> Again, the use of archaic language regarding both accessibility and access demonstrates at least a tacit agreement with integratory thought, as demonstrated in the *travaux préparatoires* for the CRC. In developing Article 23, several States demonstrated an interest in inclusive education in some form. Australia proposed that the final article provide aids and appliances to ensure equal opportunity and access to educational institutions.<sup>1288</sup> Canada argued that States must accommodate children with disabilities “within the same educational institutions attended by other children”.<sup>1289</sup> Both of these highlight an inclusionary mindset similar to provisions found in the CRPD,<sup>1290</sup> understanding the benefits of a singular educational system for all and the

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<sup>1286</sup> Ibid, Art. 23(3).

<sup>1287</sup> Ibid, Art. 23(3).

<sup>1288</sup> Economic and Social Council, ‘Report of the Informal Open-Ended Working Group on the Rights of the Child’ (15 March 1982) E/1982/12/Add.1, C, para. 107.

<sup>1289</sup> Ibid, para. 109.

<sup>1290</sup> For example, references to “inclusive education”: CRPD (n7), Art. 24(1).

need for accessibility considerations to realise an inclusive system fully. However, there was no consensus amongst the Committee, and the final passages mention “the fullest possible social integration and individual development”.<sup>1291</sup> This closely echoes the submissions from Poland, which suggested children with disabilities should receive education “in conditions most similar to those provided to all other children, aiming at the social integration of such a child”.<sup>1292</sup> There is a clear distinction between inclusion and integration, as social integration ensures PWDs can fit into society as best they can, rather than changing how society treats PWDs. As such, it authorises segregated education if it ensures social integration, as evidenced in the Spanish education system as an example.<sup>1293</sup>

Finally, Article 28 accounts for the right to education, including vocational training and guidance. States must “recognize the right of the child to education and with a view to achieving this right progressively and [based on] equal opportunity”.<sup>1294</sup> Further, Article 29 outlines the aims of the right to education.<sup>1295</sup> To achieve these aims, States must “encourage the development of different forms of secondary education, including general and vocational education, and make them available and accessible to every child”.<sup>1296</sup> The CRC does not explain its foundational understanding of equality and accessibility but defers to the UNESCO Convention against Discrimination in Education.<sup>1297</sup> Article 1 defines discrimination as “any distinction, exclusion, limitation, or preference which, being based on the child’s or [their]

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<sup>1291</sup> CRC (n69), Art. 23(3).

<sup>1292</sup> UNESC (n1288), para. 106.

<sup>1293</sup> CmRPD (n1180).

<sup>1294</sup> CRC (n69), Art. 28(1).

<sup>1295</sup> Ibid, Art. 29.

<sup>1296</sup> Ibid, Art. 28(1)(b).

<sup>1297</sup> Detrick (n1282), 485.

parent's...disability, birth, or other status...has the purpose or effect of nullifying or impairing equality in the enjoyment or exercise of the right...to education".<sup>1298</sup> In particular, this may include depriving or limiting a child's access to education,<sup>1299</sup> establishing segregated education systems,<sup>1300</sup> or inflicting undignified treatment on the child.<sup>1301</sup>

For a more modern example, the cases of *DH*<sup>1302</sup> and *Horváth*<sup>1303</sup> demonstrate the international community's intention on inclusive education regarding minorities. In both cases, there was a disproportionately high representation of Roma children in segregated schools, educated in different institutions from other children. These schools offered worse education than ordinary schools and compromised individual development. The State claimed a "need to adapt the education system to the capacity of children with special needs" and that they would divert children into a separate system because "their low intellectual capacity measured with the aid of psychological tests in educational psychology centres".<sup>1304</sup> The applicants brought actions under ECHR Article 14 (non-discrimination) in conjunction with Article 2 of Protocol 1 (right to education).

The ECtHR acknowledged that Article 14 "does not prohibit a member State from treating groups differently...to correct factual inequalities between them".<sup>1305</sup> In

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<sup>1298</sup> UNESCO Convention (n1222), Art. 1.

<sup>1299</sup> *Ibid*, Art. 1(1)(a-b).

<sup>1300</sup> *Ibid*, Art. 1(1)(c).

<sup>1301</sup> *Ibid*, Art. 1(1)(d).

<sup>1302</sup> *DH and Others v Czech Republic*, App no. 57325/00 (13 November 2007).

<sup>1303</sup> *Horváth and Kiss v Hungary*, App. No. 11146/11 (20 January 2013).

<sup>1304</sup> *DH* (n1302), para. 197.

<sup>1305</sup> *Horváth* (n1303), para. 101.

certain circumstances, “a failure to attempt to correct inequality through different treatment may...give rise to a breach”.<sup>1306</sup> The court acknowledged the Roma people as a specific vulnerable minority.<sup>1307</sup> Further, they recognised the “special needs of minorities and an obligation to protect their security, identity and lifestyle, not only [to safeguard] the interests of the minorities themselves but to preserve a cultural diversity of value to the whole community”.<sup>1308</sup> However, the Court noted an important distinction for different treatment. Different treatment of minorities is discriminatory if “it has no objective and reasonable justification”,<sup>1309</sup> if “it does not pursue a legitimate aim”,<sup>1310</sup> or if there is not a reasonable relationship of proportionality between the means employed and the aim sought to be realised”.<sup>1311</sup> In *Timishev*, the ECtHR found that “no difference in treatment which is based exclusively or to a decisive extent on a person’s ethnic origin is capable of being objectively justified in a contemporary democratic society built on the principles of pluralism and respect for different cultures”.<sup>1312</sup> Therefore, different treatment to undo structural discrimination is justifiable, whereas different treatment based on a specific protected characteristic violates human rights.

In both cases, the ECtHR accepted that the State’s motivation for keeping segregated systems was “to find a solution for children with special educational needs”.<sup>1313</sup> However, it also emphasised “concerns about the more basic curriculum

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<sup>1306</sup> *Stec and Others v United Kingdom*, App no. 65731/01 (12 April 2006), para. 51.

<sup>1307</sup> *Horváth* (n1303), para. 102.

<sup>1308</sup> *Oršuš and Others v. Croatia* [2010] ECHR 337, para. 148.

<sup>1309</sup> *DH* (n1302), para. 196.

<sup>1310</sup> *Larkos v Cyprus*, App no. 29515/95 (18 February 1999), para. 29.

<sup>1311</sup> *Ibid.*

<sup>1312</sup> *Timishev v Russia*, [2005] ECHR 858, para. 58.

<sup>1313</sup> *DH* (n1302), para. 198.

followed in these schools and...the segregation the system causes".<sup>1314</sup> In *DH*, the tests used to establish the psychological aptitude of children were subject to debate and contained potentially discriminatory aspects. Therefore, the test could not constitute objective and reasonable justification, and the State's law violated the ECHR.<sup>1315</sup> Equally, in *Horváth*, the ECtHR found that aptitude tests were in danger of cultural biases and lacked safeguards to prevent discrimination.<sup>1316</sup> In both instances, the Court suggested that keeping separate school systems is not reasonable, even if attempting to pursue a legitimate goal of protecting a vulnerable minority, yet fell short of actively forbidding the use of segregated education.

There is also an interesting comparison between these cases and the report on Education in Spain by the CmRPD noted previously. Though *DH* and the CmRPD inquiry are a decade apart, they both still demonstrate the impact of segregated education on minority groups. Educating children in segregated systems maintains both physical and experiential separation and difference. Teaching PWDs separately from non-PWDs means that the content and quality of education can be different, which further compounds the social othering caused by physical segregation. Further, the ECtHR cases and the CmRPD inquiry show that continued use and support of segregated education fails in protecting vulnerable groups. It perpetuates and teaches inequality by manifesting different systems and teaching PWDs that they are different. PWDs internalise segregation, causing further divides. Therefore, genuinely inclusive education avoids segregation based on a protected characteristic and requires the

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<sup>1314</sup> *Ibid.*

<sup>1315</sup> *Ibid.*, para. 199.

<sup>1316</sup> *Horváth* (n1303), paras. 121-123.

active participation of vulnerable people in the development and function of the education system.

### **7.3.2 Accommodation or Participation?**

Participation is the facilitator for individuals to engage with human rights actively. Rather than being a passive receiver and beneficiary of rights, a participatory individual engages in various human rights stages, including formation, interpretation, and application. As such, participation is multi-dimensional. Sinclair outlines the level of participation, the focus of the decision-making, the nature of the participation activity, and the individuals or groups involved as all important factors in realising participation.<sup>1317</sup> Engaging in each dimension in detail is not necessary for this thesis; acknowledging the breadth of the matter is sufficient to establish the principle. Therefore, participation creates a valuable opportunity for human rights. Sandland demonstrates how focusing on participation within rights applications can provide a net benefit to the rights holder. He notes that participation offers “present and future benefits to the [individual or group] concerned, including enhanced life experiences, the development of a sense of self-worth, and capacities, confidence, and so on”.<sup>1318</sup>

Within the context of child rights and the CRC, a human rights discourse through the lens of participation “embraced and amplified these new constructions of the child as subject”,<sup>1319</sup> affording them greater agency and access to rights. Sandland notes that participation rights “emphasise the present and future autonomy and agency” of

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<sup>1317</sup> Ruth Sinclair, ‘Participation in Practice: Making it Meaningful, Effective and Sustainable’ (2004) 18(2) *Children & Society* 106, 108.

<sup>1318</sup> Sandland (n629), 95.

<sup>1319</sup> *Ibid.*

people.<sup>1320</sup> Participation rights in the CRPD enable PWDs to – at least in theory - practically live the life established by protection rights in theory. Both individuals and collectives can access participatory rights equally. Furthermore, they apply to both the public and private spheres. As such, participatory rights apply “equally to parental or other domestic decision-makers...as to public actors and institutions in their dealings with children”.<sup>1321</sup> Sandland details the introduction and impact of participation rights to unrepresented groups through international conventions. Though his focus rests on child rights, substituting children for PWDs within his discussions still accurately reflects the intentions of the CRPD in seeking inclusion for PWDs.

However, participation must be functional and active. Early iterations of participation rights lay in theory, considering how marginalised voices could be lifted and heard. Nevertheless, Tisdall argues that “the honeymoon of such theoretical advocacy of children and young people’s participation has also passed”,<sup>1322</sup> with a shift of focus to practical considerations, ensuring that groups get a foot in the door rather than just a slightly larger soapbox to stand on. Percy-Smith asserts that “relatively little attention has been paid to the wider social, organisational, and systemic contexts within which young people participate”.<sup>1323</sup> Sinclair acknowledges that “participation is often used simply to mean being listened to or consulted. In this sense, the term takes on a very passive connotation”.<sup>1324</sup> To this end, participation should be active, which implies “some presumption of empowerment of those involved” for the “very

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<sup>1320</sup> Ibid, 94.

<sup>1321</sup> Ibid.

<sup>1322</sup> Kay M Tisdall, ‘Is the Honeymoon Over? Children and Young People’s Participation in Public Decision-Making’ (2008) 16(3) *International Journal of Children’s Rights* 419, 420.

<sup>1323</sup> Barry Percy-Smith, ‘From Consultation to Social Learning in Community Participation with Young People’ (2006) 16(2) *Children, Youth and Environments* 153, 172.

<sup>1324</sup> Sinclair (n1317), 110.



specific purpose of enabling [individuals] to influence decision-making and bring about change”.<sup>1325</sup> As Cairns uncovered through a large participation project, “being involved in a dialogue is a much more satisfying experience, and the potential rewards for everyone concerned are much greater”.<sup>1326</sup> Therefore, “more attention needs to be placed on the effectiveness of participation in conveying the reality of young people’s experiences and values, how young people’s voices are responded to and what happens when different voices collide”.<sup>1327</sup> This echoes the shift in disability discourse referred to by Bartlett, the ‘dreary hangover’ of transitioning from theoretical conceptualisation to actual application and policy, as children and PWDs are autonomous and require meaningful participation.

The starting point for participation rests in communication rather than capacity. The CmRC, citing Lansdown,<sup>1328</sup> notes that “the child is able to form views from the youngest age, even when she or he may be unable to express them verbally”.<sup>1329</sup> Therefore, the “full implementation of [the right to be heard] requires recognition of, and respect for, non-verbal forms of communication”.<sup>1330</sup> The ability to have views transcends the ability to articulate those views to others. The individual has the innate capacity to form views and beliefs regardless of the ability to articulate them to others. The law should therefore begin with this established understanding, acknowledging that vulnerable individuals have views, so the law must respect and facilitate these views as much as possible.

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<sup>1325</sup> Ibid, 111.

<sup>1326</sup> Liam Cairns, ‘Investing in Children: Learning How to Promote the Rights of All Children’ (2001) 15(5) *Children & Society* 347, 357.

<sup>1327</sup> Percy-Smith (n1323), 172.

<sup>1328</sup> Gerison Lansdown, *The Evolving Capacities of the Child* (UNICEF 2005).

<sup>1329</sup> CRC GC12 (n1281), para. 21.

<sup>1330</sup> Ibid.

Additionally, participation “should not only be a momentary act, but the starting point for an intense exchange...on the development of policies, programmes, and measures in all relevant contexts”.<sup>1331</sup> Participation is an exchange and interaction which develops over time, a relationship between individuals, groups, and broader society. Inclusion takes time and so necessitates regular and consistent opportunities for active participation. As such, the overlap between inclusivity and participation is clear. As discussed in the previous section, true inclusion through a queer/crip lens rests at the intersection of physical and social inclusion, which fits nicely with the concept of active participation. As far as ‘social’ participation in contexts such as education, leisure or sport is concerned, there is a positive correlation between the efficacy of participation rights and the notion of well-being for individuals.<sup>1332</sup> Participation, therefore, leads to better outcomes for both individuals and organisations.<sup>1333</sup>

Nevertheless, the CRPD refers to State obligations to ‘accommodate’ PWDs, which is distinctly different from inclusion and participation. As established above, the substantive content of participation “respects the autonomy of the child, with participation requiring something more than mere involvement or consultation”.<sup>1334</sup> Linguistically, there is a clear distinction between accommodation and inclusion, alluded to in Section 7.2.1. Whilst the act of inclusion requires one to “invite, welcome,

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<sup>1331</sup> Ibid, para 13.

<sup>1332</sup> Katrina Lloyd & Lesley Emerson, ‘(Re)examining the Relationship Between Children’s Subjective Wellbeing and Their Perceptions of Participation Rights’ (2017) 10 *Child Indicators Research* 591.

<sup>1333</sup> See Perpetua Kirby et al, *Building a Culture of Participation: Involving Children and Young People in Policy, Service Planning, Delivery and Evaluation* (Department for Education and Skills 2003).

<sup>1334</sup> Sandland (n629), 95.

or encourage the involvement of [a person] in an activity, conversation, etc.”<sup>1335</sup> to accommodate an individual or group is to “adapt oneself to another” through application, attribution, or ascription.<sup>1336</sup> To accommodate within a pre-established social structure, States would merely adjust and adapt the structure to the needs of those outside the normate. To include within the same social structure, States would reassess the foundations of said structures to redevelop them into something which works for all.

There is a distinction between the autonomy the State intends for individuals to have and the level of involvement and participation that individuals want. One of the reasons for the “emerging chasm between process and outcome is adult policy makers’ and professionals’ lack of attention to power in participation”.<sup>1337</sup> Previous iterations of individual empowerment manifested through “tokenism rather than genuine partnership”.<sup>1338</sup> The issue rests in “the balance between autonomy and benevolence” as “participation implies agency and...constitutes the displacement of benevolence—as well as of adult power and authority”.<sup>1339</sup> As noted in Section 4.4, society does not have the best track record of toeing the line between autonomy and benevolence, as charitable interactions can restrict recipients' ability to speak for themselves. Further, the CmRC notes that “many longstanding practices and attitudes” and “political and economic barriers” prevent the inclusion of children in the

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<sup>1335</sup> Oxford English Dictionary, ‘Include, v.’ (*OED Online*, September 2016), <<https://www-oed-com.nottingham.idm.oclc.org/view/Entry/93571#eid795205>> (accessed 15 July 2022).

<sup>1336</sup> Oxford English Dictionary, ‘Accommodate, v.’ (*OED Online*, December 2011), <<https://www-oed-com.nottingham.idm.oclc.org/view/Entry/1127?rskey=lAm4NU&result=2&isAdvanced=false#eid>> (accessed 15 July 2022).

<sup>1337</sup> Bill Badham, ‘Participation – for a Change: Disabled Young People Lead the Way’ (2004) 18(2) *Children & Society* 143, 145.

<sup>1338</sup> Sandland (n629), 95.

<sup>1339</sup> *Ibid.*

participatory rights conversation.<sup>1340</sup> Therefore, human rights policy must provide individuals with the tangible participatory capability to ensure that they have the greatest level of autonomy. If the status quo has not succeeded, then there should be a new approach to ensure that States sufficiently apply rights principles and that international bodies tasked with commenting on State application can effectively advocate for the rights holders.

Finally, focussing on the dynamic relationship between individuals, society, and State is important, as the involvement of children is “dependent on the cooperation of adults”.<sup>1341</sup> Likewise, without active participatory ability, the capacity to make changes rests in the State and not with PWDs. A system reliant on accommodation over inclusion results in PWDs seeking permission from those in power rather than having the autonomy to involve themselves. Therefore, using an identity lens, PWDs maintain greater autonomy within the duty holder and rights holder dynamic because they have the agency and autonomy to voice their problems with the current system and highlight where the State has failed in providing policies and resources for the realisation of human rights.

#### **7.4 Creative Interpretations of Rights**

The previous sections demonstrate that the identity approach of disability maintains inclusivity as a core tenet of functional rights application. The failings of reasonableness to provide meaningful, lasting change highlight the importance of

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<sup>1340</sup> CRC GC12 (n1281), para 4.

<sup>1341</sup> Laura Lundy, ‘Voice is Not Enough: Conceptualising Article 12 of the United Nations Convention on the Rights of the Child (2007) 33(6) *British Educational Research Journal* 927, 929.

creativity in cementing inclusive rights. To provide genuinely inclusive rights, States must enable access to the PWD collective in as expansive a manner as is feasible, so that said rights are as easy to exercise as possible. Queering CRPD rights provides creative outcomes and unique interpretations of existing rights, in turn avoiding the reliance on reasonableness as the band-aid, the tourniquet to stem the bleeding of societally established discrimination.

This section will consider three CRPD rights and assess them concerning the principle of creativity. These rights sit at different points of a sliding scale, from the trite to the novel, from demonstrations of pre-existing legal principles to developing unique rights and ideas. First is the right to equal recognition before the law, as capacity-based decision-making places undue burdens on PWDs to prove that they can make decisions for themselves, a problem that non-disabled individuals do not experience. This right demonstrates taking an existing human rights principle and converting it into a disability-centric right to counteract a discriminatory practice specific to PWDs. Second is the right to live independently and be included in the community, as society often ostracises PWDs due to structural and cultural barriers. States, therefore, must reduce these barriers and include PWDs in their community through the continuation and rearticulation of pre-existing rights to an adequate standard of living, liberty and freedom of movement, and right to the community. The third is the right to habilitation and rehabilitation, which arguably does not exist for people without disabilities for lack of a situation to (re)habilitate to/from. The CRPD, therefore, takes the opportunity to manifest a new right to function in a unique PWD experience.

### **7.4.1 Equal Recognition**

Article 12 ensures that PWDs have the right to the recognition of their legal personhood everywhere.<sup>1342</sup> This extends to ensuring States respect their legal capacity “in all aspects of life”<sup>1343</sup> by placing positive obligations to promote access to support structures to facilitate legal capacity.<sup>1344</sup> States must ensure that said support structures respect “the will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstance, apply for the shortest time possible, and are subject to regular review by a competent, independent and impartial authority”.<sup>1345</sup> Finally, Article 12 provides examples of important situations in which PWDs must exercise their legal capacity, such as owning or inheriting property and managing their finances.<sup>1346</sup> Article 12 demonstrates that society tends to restrict PWDs when non-disabled individuals live and decide freely; the assumption that everyone has capacity unless proven otherwise does not apply to PWDs. Capacity is automatic for those without disabilities but is conditional for PWDs. It is also insufficient to merely rearticulate the same general right available to all. Instead, the CRPD demonstrates parameters for national legislation to ensure effective application. Nevertheless, there is a disagreement between commentators on Article 12. Quinn argues that it is “not so much a huge leap forward as it is a mirror that enables us to see more clearly what went wrong, why it is wrong, and how to put it back together”.<sup>1347</sup> He posits that it merely recontextualises

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<sup>1342</sup> CRPD (n7), Art. 12(1).

<sup>1343</sup> Ibid, Art. 12(2).

<sup>1344</sup> Ibid, Art. 12(3).

<sup>1345</sup> Ibid, Art. 12(4).

<sup>1346</sup> Ibid, Art. 12(5).

<sup>1347</sup> Gerard Quinn, ‘Liberation, Cloaking Devices, and the Law: A Personal Reflection on the Law and Theology of Article 12 of the UN CRPD’, (*Rights & Enforcement – The Next Steps, BCNL Conference, Sofia, 16 October 2013*) <<https://studylib.net/doc/14435705/liberation--cloaking-devices-and-the-law>> (accessed 10 January 2022).

the core human right to legal capacity, ensuring it applies equally to all. Conversely, Minkowitz defines Article 12 as “revolutionary”,<sup>1348</sup> suggesting that “the right to free and informed consent is...an exercise of legal capacity”, and without a guarantee of equal legal capacity, PWDs would have little recourse to fight against forced interventions.<sup>1349</sup> Nevertheless, identity helps develop this application of creativity, acknowledging the impact that the clarifications on implementation provide.

Article 12 finds its origins in Article 6 of the UDHR and Article 16 of the ICCPR, which states that "everyone has the right to recognition everywhere as a person before the law".<sup>1350</sup> As Kanter explains through the provision of example, "any law or practice by which a [PWD] is not registered at birth, refused a document of identity or disqualified from inheriting property or otherwise recognised under law, would be a violation of Article 12(1)".<sup>1351</sup> However, its unique feature is the emphasis on the legal capacity and personality of PWDs.<sup>1352</sup> This highlights the unique ways PWDs can experience a lack of personhood compared to their non-disabled peers; as Plumb posits, “it is the nature of [the] intervention and its consequences” that compounds the discrimination faced by PWDs.<sup>1353</sup> Those without disabilities rarely risk infantilisation and loss of autonomy to self-govern their lives purely through existing.

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<sup>1348</sup> Minkowitz (n1048), 408.

<sup>1349</sup> Ibid.

<sup>1350</sup> UDHR (n32), Art. 6.

<sup>1351</sup> Arlene S Kanter, *The Development of Disability Rights Under International Law: From Charity to Human Rights* (Routledge 2015), 237.

<sup>1352</sup> Series & Nilsson (n8), 349.

<sup>1353</sup> Anne Plumb, ‘UN Convention on the Rights of Persons with Disabilities: out of the frying pan into the fire? Mental health service users and survivors aligning with the disability movement’ in Helen Spandler, Jill Anderson, & Bob Sapey (eds), *Madness, Distress, and the Politics of Disablement* (Polity Press 2015), 191.

Therefore, it is important that States truly respect PWD autonomy and personhood and provide support where needed.

During AHC negotiations, the International Disability Caucus advocated for support over substitution at various opportunities. During the fourth session, they argued that the Article 12 proposal lacked a solid description of a procedure for restricting capacity, advocating for the passage to “respect the will and preferences of the individual concerned”.<sup>1354</sup> They also spoke out specifically against the Canadian proposal that referred to equality and support yet permitted a “competent, independent, and impartial authority” to “find a person unable to exercise their legal capacity with support” and appoint someone to make decisions on the individual’s behalf.<sup>1355</sup> By leaving the backdoor open for paternalistic assessments of capacity, the Canadian proposal undermined the principle of equality and support within their proposal. Equality should be a principle with universal access and application. As such, to suggest that there are situations where a third party can render an individual incapable of knowing or articulating their will and preferences demonstrates that the drafter of the proposal does not consider PWDs equal to non-PWDs. This is true regardless of the competency or impartiality of the purportedly “impartial” third party, adjectives which the discussion in Chapter Four highlights are contentious and refutable. These examples demonstrate how different the final version CRPD is to earlier negotiated versions, and how inclusivity remained a bargaining chip on the table.

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<sup>1354</sup> Ad Hoc Committee established by UNGA Res 56/168, ‘Comments, proposals and amendments submitted electronically’ <<https://www.un.org/esa/socdev/enable/rights/ahcstata12fscomments.htm>> (accessed 21 November 2022).

<sup>1355</sup> Ibid.



Support became a significant discussion point within the drafting of Article 12. During the seventh session, the International Disability Caucus emphasised the distinction between supported and substituted decision-making. In their eyes, “in a supported situation, the [PWD] is at the centre of the discourse. The premise of supported decision-making is that it ranges from zero to 100 per cent and is a dynamic concept”.<sup>1356</sup> The International Disability Caucus’ definition of support “applied even to circumstances where a person could not express a choice so long as they were at the centre of the discourse”.<sup>1357</sup> The key point here is that the individual is at the centre of discourse, that they are the essential factor when discussing the application of human rights principles. Extrinsic factors such as social perspectives, opinions of medical professionals, or the allocation of resources should not trump the will and preferences of the individual. Further, given a lack of parity in the rights discussion, for example, an inability to communicate the perspectives between the duty holder and rights holder, the State must do all it can to champion the individual's voice and avoid capacity-based decision-making. They must exhaust all methods of supporting the individual in receiving and understanding information, as well as formulating and articulating a response. A truly inclusive system must achieve all four to ensure PWDs can exercise their legal personhood.

Nevertheless, the language of Article 12 stops short of expressly mentioning supported versus substituted decision-making, instead relying on references to promote access to support. The final version reads closer to the Canadian proposal

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<sup>1356</sup> Rehabilitation International, 'UN Convention on the Human Rights of People with Disabilities: Ad Hoc Committee Seventh Session - Daily Summary' (*United Nations*, 18 January 2006) <<https://www.un.org/esa/socdev/enable/rights/ahc7sum18jan.htm>> (accessed 21 November 2022).

<sup>1357</sup> Series & Nilsson (n8), 347.

from AHC session four than any of the submissions from the International Disability Caucus. Dhanda identifies that this refers to colonial-era policies rendering certain peoples as sub-human for control.<sup>1358</sup> As such, Article 12 “does not prohibit substituted decision-making, and there is language which could even be used to justify substitution. Under the circumstances, it could well be argued that the article would be a stranglehold of the past on the Convention. However, such a contention can be made only if the universal reach of the capacity formulation is diluted or ignored and the article is read divorced from the process of advocacy and negotiation”.<sup>1359</sup> Further, Series and Nilsson note that “the possibility that Article 12 does not prohibit substitute decision-making and guardianship has created a powerful platform for difficult conversations about the nature and effects of restrictions on legal capacity experienced by [PWDs] worldwide”.<sup>1360</sup> Quinn notes that ‘least restrictive alternatives’ is a phrase “that in a roundabout way reinforces the deprivation of capacity if sanitised by a consolation prize”.<sup>1361</sup> The language in Article 12 ensures that the door remains open in some capacity for potential backtracking or States exploiting loopholes to defend failure to develop. This was a concern of Oliver and Shakespeare in their articulations of disability models. Therefore, a queer approach may be needed to alleviate these concerns and avoid unwanted pathologisation.

The subsequent discussion demonstrates that Article 12 was meant to trigger a shift toward supported-judgment decision-making through a departure from substituted-judgment decision-making. In their first General Comment, the CmRPD

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<sup>1358</sup> Amita Dhanda, 'Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future' (2006-07) 34 *Syracuse Journal of International Law and Commerce* 429.

<sup>1359</sup> *Ibid*, 460-1.

<sup>1360</sup> Series & Nilsson (n8), 340.

<sup>1361</sup> Quinn (n1347).

recognises that “all persons, regardless of disability or decision-making skills, inherently possess legal capacity”.<sup>1362</sup> To emphasise the inherent capacity of PWDs, and to alleviate the barriers created by society in exercising said capacity, the CmRPD requires the abolition of all forms of substitute decision-making.<sup>1363</sup> Further commentary notes that legislation cannot limit decision-making ability “on grounds of disability and mental incapacity”.<sup>1364</sup> For many, “ending guardianship and other forms of substitute decision-making is central to wider advocacy goals of ending institutionalisation [and] forced treatment.”<sup>1365</sup> Shifting towards supported decision-making also combats the “loss of fundamental citizenship rights such as the ability to vote, marry, and own property”.<sup>1366</sup> Equal recognition before the law is imperative for PWDs, given that it impacts a vast swathe of other rights within the CRPD. In other words, progressively changing the system ensures that the global community is “chipping away at the edifice of civil death”.<sup>1367</sup>

A queer reading of Article 12 acknowledges the two separate concepts of legal personality and capacity. Identity follows the same logical analysis of other models with the former, acknowledging that all human beings have the right to legal personality and the ability to access human rights. However, to queer capacity requires dismantling substituted judgment decision-making. In its wake, a reformed system would enable PWDs to make decisions for themselves and access their rights to the greatest extent possible. The individual should access their legal personhood regardless of capacity. Astrachan, Ruck Keene, and Kim argue that the system of

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<sup>1362</sup> CRPD GC1 (n1071), para 25.

<sup>1363</sup> *Ibid*, para 26.

<sup>1364</sup> Series & Nilsson (n8), 340.

<sup>1365</sup> *Ibid*.

<sup>1366</sup> *Ibid*.

<sup>1367</sup> Quinn (n1347).

capacity is fundamentally flawed as presumes a binary of capacity/incapacity, where both cannot exist concurrently.<sup>1368</sup> It also relies on establishing a standard of capacity, a benchmark from which to compare. A queer approach would agree with their assessment, viewing capacity as a normative structure perpetuating ableist narratives. It is regrettable that Article 12 mentions capacity, even if it attempts to side-step the issue.

Therefore, a queer interpretation of Article 12 advocates for legal personhood separate to capacity, in terms of functionality and intentionality. Functionality is self-explanatory, as States must consider what physical accommodations, they need for people to access facets of society. Regarding intentionality, States must consider what the person intends to do and what matters to them. Individuals will place greater importance on something dependent on their predisposition and experiences. This reflects Plumb's position on how an intervention is used, that not everyone will inherently seek or reject medical intervention. Individuals' choices, beliefs, and pathways are unique and valid. It is the job of the State to facilitate these rather than fight them, to include PWDs rather than merely integrate them into society.

#### **7.4.2 Independent Living**

Article 19 provides PWDs with the equal right to “live in the community, with choices equal to others”.<sup>1369</sup> It obliges States to “take effective and appropriate measures to

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<sup>1368</sup> Isabel Marie Astrachan, Alexander Ruck Keene, & Scott YH Kim, ‘Questioning Our Presumptions about the Presumption of Capacity’ (2023) 0 *Journal of Medical Ethics* 1.

<sup>1369</sup> CRPD (n7), Art. 19.

facilitate full enjoyment by [PWDs] of this right and their full inclusion and participation in the community”.<sup>1370</sup> It further provides examples of how States can ensure full access to independent community living. First, PWDs have “the opportunity to choose their place of residence and where and with whom they live” and “are not obliged to live in a particular living arrangement”.<sup>1371</sup> Second, PWDs have “access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”.<sup>1372</sup> Third, States provide “community services and facilities for the general population” to PWDs on an equal basis to others which “are responsive to their needs”.<sup>1373</sup> Commentators argue that this is not a new right but a reconstruction of existing rights through adapting old rights to benefit PWDs<sup>1374</sup> and shifting the viewpoint of PWDs from objects to rights holders.<sup>1375</sup> Regardless, a queer interpretation of Article 19 highlights how this right moves the needle towards the partial novelty and endorses a paradigm shift of care through community-based treatment.

While the CRPD directly copies the UDHR and ICCPR for Article 12, the same cannot be said for Article 19. In other conventions, the right to independent living does not have an exact non-disability-specific provision. Instead, the CRPD references multiple rights to create an article focussed on essential features of inclusive living for PWDs. Commentators cite Article 29 of the UDHR, Article 12 of the ICCPR, and Article

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<sup>1370</sup> Ibid.

<sup>1371</sup> Ibid, Art. 19(a).

<sup>1372</sup> Ibid, Art. 19(b).

<sup>1373</sup> Ibid, Art. 19(c).

<sup>1374</sup> Fiala-Butora, Rimmerman, & Gur (n1088), 531.

<sup>1375</sup> Don McKay, 'Symposium: The United Nations Convention on the Rights of Persons with Disabilities' (2007) 34 *Syracuse Journal of International Law & Commerce* 323.

11 of the ICESCR as sources for Article 19 of the CRPD. However, these provisions do not account for the entirety of Article 19. Within the CRPD, PWDs have the right to choose their residence and avoid obligations to live in a particular living arrangement. They have access to “a range of in-home, residential, and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”.<sup>1376</sup> These services and facilities should be available to all, irrespective of their ability. On its face, these provisions are unique to PWDs.

The CmRPD has defined key aspects of Article 19 in General Comment 5. Regarding independent living, they state that PWDs must have “all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives”.<sup>1377</sup> They argue that “personal autonomy and self-determination are fundamental to independent living”<sup>1378</sup> and that independent living is linked to “the development of a person’s identity and personality”.<sup>1379</sup> However, they emphasise that States must not interpret ‘independence’ literally. Although “independent living is an essential part of the individual’s autonomy and freedom”, it “does not necessarily mean living alone”.<sup>1380</sup> It also does not mean “the ability to carry out daily activities by oneself”.<sup>1381</sup> Instead, PWDs are not “deprived” of the opportunity of choice and control regarding personal lifestyle and daily activities”.<sup>1382</sup> By rejecting normative values of

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<sup>1376</sup> CRPD (n7), Art. 19(b)

<sup>1377</sup> CRPD GC5 (n1015), para 16(a).

<sup>1378</sup> Ibid.

<sup>1379</sup> Ibid.

<sup>1380</sup> Ibid.

<sup>1381</sup> Ibid.

<sup>1382</sup> Ibid.

independence as isolation, a queering of Article 19 highlights the fluidity of community and independence, affording the individual the ability to choose.

Another important facet of Article 19 is a PWD's inclusion in the community. The CmRPD emphasises that full and effective inclusion and participation in society, as enshrined in Article 3(c) of the CRPD, applies to Article 19.<sup>1383</sup> As such, States must enable PWDS to live “a full social life [with] access to all services offered to the public and to support services offered to [PWDs] to enable them to be fully included and participate in all spheres of all social life”.<sup>1384</sup> This right to inclusion also affords PWDs “access to all measures and events of political and cultural life in the community”.<sup>1385</sup> Again, this provision deconstructs normative systems by establishing access to communal support and engagement as a metric of success. There is hope for a more transparent system, where care and living are home-based, communal, and personal. Individuals can develop their own identity with disability in whatever manner they wish, yet State obligations remain the same.

General Comment 5 also tackles independent living arrangements. The CmRPD begins with a reminder that States' focus must be on “life settings outside residential institutions of all kinds”.<sup>1386</sup> Article 19 does not merely focus on “living in a particular building or setting”.<sup>1387</sup> Instead, it is “about not losing personal choice and autonomy [due to] all imposition of certain life and living arrangements”.<sup>1388</sup> They acknowledge

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<sup>1383</sup> Ibid, para 16(b).

<sup>1384</sup> Ibid.

<sup>1385</sup> Ibid.

<sup>1386</sup> Ibid, para 16(c).

<sup>1387</sup> Ibid.

<sup>1388</sup> Ibid.

that historically, PWDs experience the systemic reduction of autonomy in the home through State intervention and welfare. As such, an individual's home cannot be an independent living arrangement "if they have other defining elements of institutions or institutionalisation".<sup>1389</sup> This mirrors sentiments from the Supreme Court on liberty in care; a gilded cage is still a cage, as it does not matter if States make it as comfortable or individual as possible.<sup>1390</sup> Finally, States must engage in discussions regarding "isolation and segregation from independent life within the community" as well as "lack of choice over whom to live with" and "rigidity of routine irrespective of personal will and preferences"<sup>1391</sup> Though institutions may offer PWDs some choice and control, these choices "are limited to specific areas of life and do not change the segregating character of institutions".<sup>1392</sup> Throughout, the CmRPD emphasises the importance of individual autonomy, respect for individual capacity, and the ultimate goal of active participation and full inclusion of PWDs in society.

In light of the discussion at Section 4.4, living independently and being included in the community has been considered "one of the most important rights" in the CRPD "since choice, freedom, and inclusion are considered prerequisites for exercising all other rights".<sup>1393</sup> Many associate the creation of Article 19 with debates stemming from the independent living movements in the US and UK during the 1970s. These movements were championed by the Centre for Independent Living at the University of California at Berkeley<sup>1394</sup> in the United States of America and the UPIAS

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<sup>1389</sup> Ibid.

<sup>1390</sup> *P (by his litigation friend the Official Solicitor) v Cheshire West and Chester Council* [2014] UKSC 19, per Lady Hale, para 46.

<sup>1391</sup> CRPD GC5 (n1015), Para 16(c).

<sup>1392</sup> Ibid, Para 16(c).

<sup>1393</sup> Fiala-Butora, Rimmerman, & Gur (n1088), 530.

<sup>1394</sup> See, for example, Joseph P Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (Times Books 1993).



and the creation of the social model of disability in the United Kingdom. The push for independent living as a recognised right for PWDs represented the “struggle of persons with mobility impairment to exercise their right to make personal decisions and to remove medical and professional control”.<sup>1395</sup> It is also associated with “the call to remove enforced institutionalisation of people with intellectual and psychiatric disabilities and to fight against restrictive guardianship laws”.<sup>1396</sup> As such, Article 19 maintains at its core the valuable nature of independence and autonomy for PWDs, given that many experience restrictions on their liberty and agency by the State and by medical professionals. By queering Article 19, it is clear how the relationship dynamic changes in a way that addresses society’s ability trouble. By altering the position of disability in relation to care, a queer approach rejects the compulsory able-bodied nature of healthcare, establishing it instead as a discourse between States and individuals.

Finally, within the context of the rest of the CRPD, Article 19 interacts with the principles of “individual autonomy and independence” outlined in the preamble, which includes the freedom for PWDs to “make their own choices”.<sup>1397</sup> It also reflects the “respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of person” outlined in Article 3.<sup>1398</sup> Together, these principles help establish perspectives of equality and agency for PWDs in the community. Moreover, they give PWDs the ability to choose their community rather than have it forced upon them through the external application of labels or restrictions of geographic location. Using an identity lens, PWDs can use Article 19 to establish

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<sup>1395</sup> Fiala-Butora, Rimmerman, & Gur (n1088), 532.

<sup>1396</sup> *Ibid.*

<sup>1397</sup> CRPD (n7), Preamble, para. n.

<sup>1398</sup> *Ibid.*, Art. 3(a).

their social and community foundations on their terms, on an equal basis to non-PWDs. Commentators are partially correct that Article 19 is not a novel right, as it ensures that PWDs can achieve the same principles of community life and independent living as their non-PWD peers. However, articulating this right through the lens of a queer/crip identity demonstrates creativity, as the notion of living independently in the community is not an accessible right to non-PWDs. The very nature of highlighting this unique restriction on PWDs demonstrates that it is a particular circumstance requiring unique intervention by the CRPD. Using identity as the lens through which to understand disability as it relates to the person's membership in a community, the CRPD can better articulate the need to respect individuality and autonomy in affording PWDs the ability to exercise their Article 19 rights to the place and grow roots within the community of their choice.

#### **7.4.3 *Habilitation and Rehabilitation***

The final example of how a queer/crip interpretation of rights within the CRPD promotes creativity is the right to habilitation and rehabilitation within Article 26. On the sliding scale referred to at the start of Section 7.4, if equal recognition is on the trite end of the scale, and independent living is in the middle of the scale, habilitation is at the novel end. This provision confers a right which does not exist for elsewhere, going beyond mere recontextualisation of existing rights to establish a brand-new human right devoid of modernist and structural norms. Though habilitation and rehabilitation are different, for ease, this section will refer to Article 26 as a right to rehabilitation.

Article 26 requires States to “take effective and appropriate measures, including through peer support, to enable [PWDs] to attain and maintain maximum

independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life".<sup>1399</sup> Further, to realise this right, States shall "organise, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services".<sup>1400</sup> There is an overlap with Article 9 due to the openness of the term 'rehabilitation'. Bickenbach and Skempes argue that it would be inappropriate for environmental modifications such as accessibility ramps on public buildings to fall under Article 26 rather than Article 9.<sup>1401</sup> Nevertheless, rehabilitation and accessibility share ideals of fully realised PWD inclusion in society. To ensure true inclusion, Article 26 reflects the "full enjoyment of the right to the highest attainable standard of physical and mental health, the right to employment, the right to education, and the right to independent living of [PWDs] and to highlight its significance for the promotion of social participation in all aspects of community life".<sup>1402</sup>

Article 26 was one of the most contentious rights at the AHC sessions.<sup>1403</sup> Many service-user-led organisations voiced concerns about expressly including provisions on access to medicine, given the paternalistic view of PWDs by existing rehabilitation systems. As noted in Sections 4.2 and 4.4, there is a "presumption that people with impairments could and should be fixed to fit into the normal world lies at the heart of the view that disability was entirely a personal misfortune, a tragedy that should elicit pity and motivate attempts, however futile, to cure the person".<sup>1404</sup> However, there was a consensus at the AHC sessions on the value of rehabilitation in promoting PWD

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<sup>1399</sup> Ibid, Art. 26(1).

<sup>1400</sup> Ibid, Art. 26(1).

<sup>1401</sup> Bickenbach & Skempes (n823), 736.

<sup>1402</sup> Ibid, 734.

<sup>1403</sup> Ibid, 735.

<sup>1404</sup> Ibid, 735.

inclusion. Therefore, they proceeded with debates on the content of a rehabilitation right. Originally, rehabilitation featured as a part of the right to health and would have therefore been a part of Article 25. Nevertheless, from the third session onward, there was broad agreement on separating health and rehabilitation into different articles due to the possibilities afforded by social rehabilitation settings independent of medicine.<sup>1405</sup>

Rehabilitation has many features and covers a variety of services. There is a distinction between services and supports that “return an individual to a situation of independence, ability, inclusion, and participation – such as would be experienced prior to an injury or the onset of a health condition” and those that “bring the individual to maximal independence – in the case of children born with congenital impairments”.<sup>1406</sup> Rehabilitation is a far-reaching concept. It “targets improvements in individual functioning”, for example, by “improving a person’s ability to eat and drink independently”.<sup>1407</sup> It also includes “making changes to the individual’s environment”, for example, by installing a handrail.<sup>1408</sup> As such, rehabilitation generates a wealth of possibilities for improving the quality of life and inclusion of PWDs in society.

Nevertheless, paragraph 1(b) explicitly states the need for services to be voluntary, reflecting caution about the over-medicalisation of PWD experiences, treatment, and care. Further, the CmRPD notes the over-reliance on State policies on

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<sup>1405</sup> Landmine Survivors Network, 'Daily Summary of Discussions related to Article 21: Right to Health and Rehabilitation' (*United Nations*, 1 June 2004), <<https://www.un.org/esa/socdev/enable/rights/ahc3sum21.htm>> (accessed 29 November 2022).

<sup>1406</sup> Bickenbach & Skempes (n823), 735.

<sup>1407</sup> World Health Organisation & The World Bank, *World Report on Disability* (WHO 2011), 96.

<sup>1408</sup> *Ibid.*

health-related analysis when implementing rehabilitation measures.<sup>1409</sup> Policies should promote housing, social and vocational development, and mental and physical health.<sup>1410</sup> Therefore, Article 26 explicitly targets inclusion through a multitude of individual characteristics. It is insufficient to focus on one particular feature of an individual's disability. Instead, States must take a holistic approach to the individual and offer them various rehabilitative services and support systems.<sup>1411</sup> Further, identity helps highlight the various essential characteristics of the individual, affording them the tools to introspectively analyse their needs and articulate those to the State when seeking support.

Again, this highlights the importance of the individual within this conversation, as a queering of Article 26 ensures that they set the pace and parameters of treatment. There is an inherent risk of perpetuating normative ideals of ability by establishing concepts of habilitation: the questions arise of *what* they are being treated for and *why*. A system whereby States dictate the location and timing of treatment has the trappings of McRuer's ability trouble – States cannot adequately control or support PWDs, so the best approach is to change them, to make them easier to integrate into society. If Article 26 was written from this perspective, then Kazou would be correct in her interpretation of the CRPD retaining medical perspectives on disability. However, given the focus of voluntary participation in paragraph 1(b), this right clearly rejects normative ableist values and pushes for queer inclusion.

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<sup>1409</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations: Ukraine (2 October 2015) CRPD/C/UKR/CO/1, para 48.

<sup>1410</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations: Paraguay (15 May 2013) CRPD/C/PRY/CO/1, para 61.

<sup>1411</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations: Thailand (12 May 2016) CRPD/C/THA/CO/1, para 41.

Bickenbach and Skempes suggest that the right to rehabilitation is not new.<sup>1412</sup> They cite rule 3 of the UNSR, part of the preconditions for equal participation, as the provision most closely related lexically to Article 26. The UNSR define rehabilitation as:

“a process aimed at enabling [PWDs] to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/or social functional levels, thus providing them with the tools to change their lives towards a higher level of independence. Rehabilitation may include measures to provide and/or restore functions or compensate for the loss or absence of a function or for a functional limitation”.<sup>1413</sup>

In Chapter One, this thesis acknowledges the value the UNSR provided in guiding the conversation of PWD rights away from paternalistic medicalisation towards an inclusive framework under the CRPD. For example, the UNSR explicitly states that the rehabilitation process “does not involve initial medical care”.<sup>1414</sup> However, the UNSR is not a document which confers human rights that PWDs could rely upon, nor does it provide any binding obligations upon States to engage in policy changes. Instead, Bickenbach and Skempes cite the UN Co-ordinated International Program for the Rehabilitation of the Physically Handicapped as the first *right* to rehabilitation.<sup>1415</sup> Subsequent documents reiterate the right, with CESCR acknowledging the “right to physical and mental health also implies the right to have access to and to benefit from, those medical and social services...which enable [PWDs] to become independent,

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<sup>1412</sup> Bickenbach & Skempes (n823), 737.

<sup>1413</sup> UNGA Res 48/96 (n156), para 23.

<sup>1414</sup> *Ibid.*

<sup>1415</sup> Economic and Social Council, ‘Report to the Economic and Social Council on the eighth session of the Social Commission’ (2 June 1952) E/2247 E/CN 5/287.

prevent further disabilities, and support their social integration”.<sup>1416</sup> Article 23 of the CRC reiterates this point.<sup>1417</sup> Together, these documents demonstrate that PWDs have a right to rehabilitation in the same vein as a right to health services within the discussion of PWD-centric rights.

The above discussion demonstrates that rehabilitation has been a part of the PWD rights discourse for decades. However, it does not highlight the location of related non-PWD rights in other documents. Articles 12 and 19, discussed in the previous two sections, clearly have “mirrors” concerning non-PWD rights provisions, which the CRPD sources and rearticulates to apply expressly to PWDs. In this regard, they take existing rights and ensure that the CRPD highlights important provisions for PWDs. However, Article 26 lacks such a mirror. The reasoning for this lack should be clear. As noted in earlier parts of this section, the right to rehabilitation stems from principles of health to optimise the individual's functioning and promote independence, ability, and participation.<sup>1418</sup> This is a process of moving an individual from point A, a lack or loss of function, towards point B. Non-PWDs do not have a point A or point B in this scenario, as there is nothing to rehabilitate them from and nothing to fix or restore. Chapters One and Four demonstrate that society has structured itself around the normate as a gold standard and highlight the problems this has caused for PWDs. Therefore, to suggest that Article 26 is not a new right would be erroneous. Looking through a queer/crip lens highlights that the CRPD has been creative in forming a new human right for PWDs to help dismantle social barriers and promote their inclusion in society.

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<sup>1416</sup> CESCR GC5 (n11), para 34.

<sup>1417</sup> CRC (n69), Art. 23.

<sup>1418</sup> Thorsten Meyer et al, 'ISPRM Discussion Paper: Proposing a Conceptual Description of Health-related Rehabilitation Services' (2014) 46 *Journal of Rehabilitation Medicine* 1.

There are two final considerations to make, and the first is whether the above discussion should matter. The debate of whether Article 26 is truly novel, or if Bickenbach and Skempes are correct in sourcing it elsewhere, seems meaninglessly academic. However, by demonstrating that a queer/crip interpretation of Article 26 reveals it to be unique for PWDs, this section shows the power of queer. Articles 12 and 19 prove that Zanghellini and Gonzalez-Salzberg are correct to assert that queer can reinterpret existing legal principles. However, Article 26 proves that queer can do something radically new. The second consideration is the impact this discourse has on the blurring of disability boundaries. Given the discussion in Chapter Four, Shildrick would argue that reading Article 26 as unique to disability would itself perpetuate an us/them binary, an unhelpful segregation. However, the point here is that Article 26 is a unique right by virtue of a fluid articulation of disability. If the above discussion is read in conjunction with the conversations on inclusion and the boundaries of rights access at Section 7.2.3, it is further proof of the success of a queering of the CRPD. A queer/crip identity lens provides the necessary foundations to understanding disability to ensure that rights under the CRPD are available to all.

## **7.5 Conclusion**

The subject matter of this chapter is true inclusion for PWDs in accessing human rights. It demonstrates how an identity approach facilitates inclusivity in interpreting the CRPD. The passage at the start of the chapter highlights the need for change in the interpretation and application of human rights and broader social changes towards PWDs. As such, this chapter provides a three-part narrative of nurturing inclusivity within the CRPD and the benefits an identity approach provides to expedite this process.



Section 6.2 begins with the topic of inclusion. It is an overarching aim of the CRPD and a focus of the identity approach. Section 6.2 defines inclusion as the actual realisation of agency and participation of individuals on an equal basis with others. It demonstrates how inclusion functions differently from exclusion, segregation, and integration, which are policy methods used by States at various points in history to regulate PWD interaction with society. Whilst these three methods cater to the unique needs of PWDs in different ways, they all fail to protect PWDs adequately and inflict various harms upon them. Instead, States should seek true inclusion when structuring national laws and policies. The chapter uses education as a facilitative example of how an identity perspective changes how States can look at rights within the CRPD to promote inclusivity. It also suggests that a post-structural approach pushes beyond restrictive social categories and applies rights to all, with examples of non-PWDs gaining rights under the CRPD.

Section 6.3 tackles reasonableness, the preferred method of realising CRPD rights. Due to various social, economic, and political factors, it may take States longer to implement fully inclusive policies, and reasonable accommodations can temporarily address immediate problems during this slower development process. However, the aspirations of reasonableness and true inclusion do not sufficiently align, leading to further discordance. Only by using a queer/crip approach can we interpret the provisions within the CRPD in a way that affords tangible realisation and rejects ableist normativities.

Section 6.4 subsequently considers creativity. If a queer approach changes our understanding of disability, it follows that it would also alter how we can interpret the

provisions within the CRPD. It highlights how three CRPD rights provisions function differently if viewed through the lens of a queered inclusion. Using identity shows how the rights to equal recognition, independent living, and rehabilitation can go beyond current boundaries and afford PWDs greater inclusion within society. It also shows how an inclusive identity perspective can change our perspective of the purpose of the CRPD. The three example provisions used all sit on a sliding scale from trite to novel, from existing human rights provisions to new PWD-exclusive human rights. Using identity, it becomes clear that the CRPD has untapped potential and that a change in theoretical approach results in a swing of the needle and a more developed narrative.

## Conclusion

This thesis establishes a new approach to disability through the lens of a queer/crip identity. The CRPD entered into force on the third of May 2008, making it the first international convention passed in the twenty-first century. It marked a turning point for disability rights in the international sphere, boasting a unique drafting process featuring involvement from service users and activist groups. It allowed the international community to alter the narrative and change the discussion. Nevertheless, over a decade has passed, and many of the problems facing PWDs prior to the CRPD remain. Therefore, this thesis proposes that the international community has not exhausted all avenues for conceptualising disability. The community stands within a room looking at multiple doors; behind each door is a different method of understanding disability. Identity is a new door to open and explore behind.

To achieve this goal, the introduction provided four research questions. First, what are the key components of existing models of disability? Chapters One and Four address this topic. Chapter One analyses the history of disability rights within international human rights law. It sets the scene and establishes the legal foundations of the disability model discussion. It demonstrates that the CRPD is a culmination of work over numerous decades to change the narrative of PWDs. International conventions did not refer to PWDs explicitly, instead theorising that their inclusion was implied. This exclusion matches the alienation and exclusion faced by PWDs by society, casting them as background material never to consider important.

Once human rights documents mentioned PWDs, the language used was overtly medical. This shift reflected changes in social attitudes towards PWDs, now considering disability as an abnormality requiring treatment. Through the last few

348

decades in the twentieth century, there was a noticeable change in language from paternalism to integration to inclusion. The CRPD marked the endpoint in this transitional period, identifying PWDs as a group with equal access to rights based on humanity and dignity. The CRPD used markedly different language, and Chapter One highlights several significant instances where the CRPD references issues important to the disability rights discussion.

Chapter Four outlines many of the existing models of disability as part of its critical analysis of the flaws each model experiences. It overviewed the essential characteristics attributed to moral, medical, and social models. It demonstrates the flaws of these models through the format of biology, governance, and rescue. Chapter Four followed this format to highlight each model's key components and highlight some important general topics that unite them.

The second research question asked how existing models of disability hold up to analysis from queer theory and crip theory. Chapter Two considered the research of Shakespeare, as he uses a critical realist approach to articulate disability as a relational interaction. Viewing disability as an interaction is correct, though the foundation of critical realism has several flaws. Chapter Two highlighted these issues and offers queer theory as an alternative. It outlines the history of queer, before assessing Butler's work in developing the theory. In Chapter Three then provides crip theory and queer legal theory, both of which are relevant modifiers to queer when assessing human rights law and disabilities. In Chapter Four, existing models of disability are critiqued through the lens of queer.

The third question posed was what a model of disability would look like if it articulated disability as a facet of identity. Chapter Five takes some sociological theory on identity, and the discussion of queer and crip in Chapters Two and Three, to formulate this new identity approach. It uses existing disability models as foundations to build upon, crafting a uniquely queer commentary device. There is also consideration to how the approach differs from existing models, and highlights responses to concerns raised by utilising a postmodern and post-structural approach to critique an area historically rife with normative structural values.

The final question asked how this resulting identity approach of disability would interact with the CRPD. Chapters Six and Seven demonstrate how a new approach to disability changes the way we view disability within the CRPD; in turn, this changes the potential interpretations of rights provisions within the CRPD. In Chapter Six, identity highlights interesting relational dynamics and issues of individual agency. Current models of disability do not sufficiently consider the interactions between the rights-holder and the duty-holder. However, the identity approach uncovers significant power imbalances in the rights relationships stemming from policy applications of CRPD rights.

Further, identity helps understand various methods of promoting individual agency. The CRPD openly includes mental, psychosocial, and physical states of being within the disability category. Equally, identity welcomes the variety of lived experiences within the disability umbrella. Nevertheless, Chapter Five provides perspectives of commentators and activists who reject the term disability. A queer/crip approach to disability assesses the positionality of disability within the dynamic between individual and society, avoiding the need for structural labels. Additionally, taking this approach

to the CRPD demonstrates the different levels of agency available, ranging from the right to choose to the power to participate.

Chapter Seven considers inclusion, reasonableness, and creativity. In assessing inclusion, a queer approach recognises both the physical and social elements needed to understand inclusion without perpetuating normative values of assimilation. Regarding reasonableness, queer acknowledges the short-term power of accommodations yet highlights the structural inequalities that remain when retaining ableist normative systems. Finally, the discussion on creativity highlights how a queer/crip approach to disability identifies unique aspects of existing rights, demonstrating the power of queer. Considering Articles 12 and 19, it is clear how queer can address current issues within existing rights, offering new interpretations of trite principles. However, queering Article 26 identifies it as a right unique to disability. Novel interpretations help modernise the CRPD and ensure it can keep pace with current-generation thinking.

As the content of this thesis is predominantly theory-based, relying on a doctrinal and socio-legal analysis of disability rights discourse, there is further potential for this research. This research could take the form of a queer analysis of specific rights within the CRPD, using the identity approach to critique a specific right in greater detail. Empirical research could also use the identity approach by conducting qualitative research within different points of interaction between society and an individual or collective who identifies with disability. This research would provide a chance to test the identity approach in practice, and the results could further shape the approach. There are numerous possibilities for this research going forward, which is cause for optimism.

In summation, a queer/crip approach provides a new angle to provide commentary on the CRPD and other disability-centric rights instruments. It embodies postmodern and post-structural mentality to commentary, whilst also respecting lived experience. It places the individual at the centre of the conversation. The key point from this thesis is that the conversation around defining and conceptualising PWDs within a human rights context needs to progress and develop. Further, that identity aligns better with the ethos of the CRPD than other models of disability. It provides solutions to many common problems that befall existing models of disability. To return to the words of Eleanor Roosevelt within the introduction, in the pursuit of “equal justice, equal opportunity, equal dignity without discrimination” for all, identity provides another arrow in the quiver of human rights advocates.

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