DISABILITY LAW AND HUMAN RIGHTS

THEORY AND POLICY

JITIN BISWAS

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ISBN: 978-93-5496-992-8

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Models of Disability and Human Rights: Informing the Improvement of Built Environment Accessibility for People with Disability at Neighborhood Scale?

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Abstract: In the 21st century, even with the advent of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the existing built environment still fails the neighborhood accessibility needs of people with disability. People with disabilities' human right to the neighborhood is, at face value, enshrined in legislation and 'much' built environment accessibility legislation is in place. But, built environment accessibility practice has been, and continues to be, shaped by a hidden discourse based on theoretical underpinnings little understood by built environment practitioners. Similarly, built environment practitioners have little understanding of either the diversity of the human condition or the accessibility needs of people with disability. In Australia, the operationalization of built environment accessibility rights is, via opaque legislation, not necessarily reflective of the lived experience of people with disability, and weak in terms of built environment spatial coverage. Empirically, little is known about the extent of built environment inaccessibility, particularly neighborhood inaccessibility. Therefore, the question explored in this paper is: How might an understanding of models of disability and human rights inform the improvement of built environment accessibility, for people with disability, at a neighborhood scale? Literature related to disability and human rights theory, built environment accessibility legislation primarily using Australia as an example, and built environment accessibility assessment is drawn together. This paper argues that built environment practitioners must recognize the disabling potency of current built environment practice, that built environment practitioners need to engage directly with people with disability to improve understanding of accessibility needs, and that improved measure, at neighborhood scale, of the extent of existing built environment inaccessibility is required.

Keywords: models of disability; human rights; people with disability; built environment; accessibility; legislation; assessment; neighborhood

1. Introduction

Worldwide, a decade after the adoption of the United Nations Convention on the Rights of Persons with Disabilities (UN 2006), the existing built environment encompassing infrastructure, public buildings, commercial buildings and private dwellings still fails to meet the accessibility needs of people with disability. 'Neighborhood' is a location of participation notoriously hard to define, but one that has received attention as a key spatial and social construct and focus of policy and practice across a variety of fields including planning, community development, and health (Jenks and Demsey 2007; Bevan and Croucher 2011; Oliver et al. 2015). Many, if not most, neighborhood activities, ranging from the essential (residing somewhere, attending school) to the ordinary (grocery shopping) to the discretionary (recreation), still require the negotiation of discontinuous travel chains and/or are completely impeded by the presence of barriers (Deane and The National People with Disabilities and Carer Council 2009; Jackson and Green 2012; Pineda and Dard 2016; Stephens et al. 2017). Empirical evidence of the frequency and severity of impediments, the causes contributing to impediment, and clear insight into prioritizing rectification of impediments is still, however, sorely lacking (Green 2011). Furthermore, reflective of outmoded models of disability, the meaningful input of people with disability is still rarely sought (Oliver 1987, 1992; Imrie and Wells 1993; DRC 2004; Boys 2017). Why, at almost the end of the second decade of the 21st century, are the human rights of people with disability still being ignored?

Through more than 30 years of transdisciplinary built environment experience, I have come to the realization that built environment practice and academia around built environment practice does not have a history of understanding disability, or human rights legislation pertaining to built environment accessibility, or people with disabilities' lived experience of neighborhood accessibility. Furthermore, these three arenas appear to be rather siloed and the 'neighborhood', as a mediator between individual experience and community inclusion, is rarely considered. Imrie (2000) notes that '[w]ritings about disabled people are usually aspatial or lack geographical frames of reference' and believes that 'geographical and/or spatial terms of reference are important in understanding disabled people's lives.' (p. 5).In an attempt to draw together literature related to disability and human rights theory, built environment accessibility legislation primarily using Australia as an example, and built environment accessibility assessment, this paper is somewhat exploratory in nature. Focusing largely on literature from, and the built environment in the global north, the paper primarily seeks to illuminate the Australian context. Spanning across all sectors, the terms 'built environment practice' and 'built environment practitioner' are intentionally broader than conventional disciplinary descriptors of architecture/architect, planning/planner, and the like, and signify all those involved in legislating, shaping, funding, forming, making, and researching the built environment. 'People with disability' encompasses the diversity of experience of people with diverse impairments given all are users of the same/single built environment.

How might an understanding of models of disability and human rights inform improving built environment accessibility, for people with disability, at neighborhood scale? The following article sets out to probe this question. Firstly, salient Models of Disability, considered from a built environment perspective, are briefly presented. The topic of Human Rights in the context of the built environment, concentrating mainly on built environment accessibility legislation relevant to Australia, is then briefly covered. Common themes of inaccessibility, as experienced by people with disability, are tabled and various methods of assessing neighborhood accessibility are noted and/or outlined. Interactions between models of disability, built environment accessibility legislation, and current methods of neighborhood-scale accessibility assessment are then discussed. In conclusion, I propose a way forward to improving the accessibility of the existing built environment for people with disability at neighborhood scale.

2. Models of Disability: A Built Environment Perspective

Within and across the disability knowledge domain much research from many nuanced, and contested, perspectives has been, and continues to be, undertaken, much of it interdisciplinary. Built environment practitioners, however, have scant acquaintance with such endeavors (Imrie 2015; Boys 2017). Therefore this paper seeks to bring disability concepts, via the central notions of established disability models, into the view of mainstream, built environment practitioners; it does not purport to add to disability studies scholarship per se. Disability models considered to be the most salient to this paper are the well-established charity, medical, social, relational, and diversity models, and the currently developing human rights model of disability. Relationships between the selected models and the existing built environment are explored in greater detail in the following paragraphs.

2.1. Charity Model of Disability

Terminology such as moral model, charity model, and religious model, in relation to disability signposts an approach to disability characterized by notions of caretaking and protection, both in terms of the vulnerable 'other' needing protection and care and, later, the need to protect the economic and social order by controlling, via segregation, 'deviant members' of society (Braddock and Parish 2001, p. 31). Construction of institutions was a core response to this viewpoint. In Australia, UK, and USA, asylums for the 'mentally ill, retardates, degenerates, and defectives'[1] were a common landmark of the late 1800s and early 1900s; workhouses have a long history in the UK (Higginbotham 2018). Often large, imposing, containing cavernous dormitories, and sited within extensive grounds away from town centers, such structures are a clear-built manifestation of the institutional nature of the charity model of disability. Usually less architecturally imposing than workhouses and asylums but not necessarily better located in terms of nearby community services, segregated schools for 'the blind and the deaf' were also common. In Melbourne, Australia, full closure of 'Kew Asylum/Kew Cottages' only occurred in 2008, a decade ago, and Victoria's last disability institution with 76 remaining residents, Colanda House in Colac in western regional Victoria, was to be closed in 2014; the facility was constructed in 1976.Institutional care for elderly persons in facilities such as workhouses, infirmaries, almshouses, homes for the aged and infirm, and 'homes' was common in the UK and USA until the middle of the 20th century (Peace 2003; Fisher 1953). Similarly, within Australia, institutional care for elderly persons was provided by a combination of charitable benevolence and government intervention, within recognizably institutional physical environments until approximately post-WW2. Due to changes in government policy and subsidies, rapid growth in (institution-like)nursing homes occurred in the 1962–1972 period in Australia, with hostels for older persons subsequently also appearing (Le Guen 1993).

Historically therefore significant proportions of the population, being not only 'the disabled' but also 'the mentally disturbed', 'the elderly', and 'defective' children, have not been publicly visible and have been congregated into institutional care settings at a distance, both geographically and culturally, from wider society (Wolfensberger 1969; Barnes and Mercer 2003). It could be argued that a crucial consequence of the historically pervasive ideology of institutionalization is that much of the general built environment is inaccessible for people with disability. In the UK, USA, and Australia people with disability, particularly people with intellectual disability, are not now generally institutionalized as a first resort. However, a common consequence of de-institutionalization is the inability to access other built environments, at the neighborhood scale, particularly, due to the legacy of poor urban-scale design. Imrie (1998) observed that "western cities are characterized by a design apartheid where building form and design are inscribed with the values of an 'able-bodied' society" (p. 129)—a somewhat inevitable consequence of the charity model's invisible segregation of people with disability.

2.2. Medical Model of Disability

The medical model of disability is essentially a normative one, based on classifying levels of deviance or deficiency compared to a normative state (Nankervis 2006). Central tenets of the medical model of disability are that firstly, a person's 'impairment' can be diagnosed, cured, or at least rehabilitated, by modern medicine and/or medical technology, and secondly, such interventions will be provided by all-knowing professionals (Oliver 1998; Scotch 2000; Pfeiffer 2001). Espousing the view that medicine should treat and/or correct impairment for the social good, the thoughts and approaches of influential American sociologist Talcott Parsons (1951) contributed to the continued preeminence of

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[1] Indicative of the terminology used at the time (Wolfensberger 1969).

the medical model of disability (Pfeiffer 2001). Other, similar descriptors such as: personal tragedy model, individual model, and rehabilitation model, are often used interchangeably.

Inherently influenced by the medical model of disability, institutionalization reached its peak in the late 1960s in most western countries (Stainton [1998] 2017). Although imposing Victorian-era structures may have fallen out of favour at that time, resulting in less immediately identifiable built forms, sheltered workshops and dormitory-style living arrangements were still common. Much existing public transport infrastructure has also been built under the legacy of the charity and medical models of disability and is, therefore, inaccessible for many people with disability. In Australia, much of Melbourne's public transport infrastructure for trains and trams dates from the early 20th century, or before. Melbourne's above-ground train system went through major rebuilding in the 1950s and 1960s but, clearly, accessibility was not much considered. Melbourne's underground city loop train system was constructed in the 1970s with many accessibility shortcomings. Current tram stop upgrading work, in Melbourne, highlights the lack of thought originally given to people with disabilities' accessibility needs.

In 2015, people with disability comprized 18.3% of the Australian population (ABS 2017). Although the oft-repeated statistic of 'approximately 20%' is intended to communicate the substantial number of people with disability in the Australian population, it tends to imply a static 20% minority–majority 80% people without disability. In reality, membership of either statistical group is always in flux with all (100%) people likely to experience mobility and/or other built environment use difficulties at some stage during the course of life (Zola 1993). Compounding such problems is that reporting of disability demographics is often categorized under a 'primary' disability such as intellectual disability, autism, vision-impairment, hearing-impairment, wheelchair user, or user of another mobility aid such as walker, crutches, or walking stick, and as arrived at through precisely categorized medical diagnosis (Nankervis 2006). Therefore, medical model ideology tends to lead to the (unacknowledged) belief among built environment practitioners that built environment accessibility needs of people with disability will be resolved by individual provision of personalized, medical intervention and/or assistive technology. In reality, many people with disability have multiple impairments affecting built environment use in differing ways and significant swathes of the built environment are inaccessible at neighborhood scale.

Engendered by people with disabilities' low public profile, conformist societal attitudes, design precedents, weak legislation, and poor understanding of built environment accessibility needs of people with disability, a significant extent of the existing built environment, whether historical or 'modernist', has been designed within a paradigm of a charity-medical model of disability, albeit unconsciously.

2.3. Social Model of Disability

Significant social and rights movements of the 1960s around race, gender, sexuality, and disability led to profound questioning of the imbalances of power, knowledge, and rights of the status quo. This, however, tended to play out differently in different parts of the world. During this period in the UK of 'new ways of thinking', Finkelstein and Hunt (British researchers, disability activists, and major theorists) developed their social relational theory concluding that social exclusion of people with disability was an outcome 'of the materialist landscape of the industrial era' rendering them economically unviable (Hunt 1966; Finkelstein 1993; Finkelstein 2001; West 2012, p. 76). Viewed through such a lens, design of factories and workplaces, schools, public transport systems, and infrastructure was heavily influenced by the attitudes of the designers' clientele. It is likely, however, that built environment form-makers were not conscious of the effect on accessibility outcomes.

Moving beyond the previous, narrow, medical view of disability to a new, wider, societal view Oliver (1983, 1998, 2013), a British academic and disability activist, developed the social model of disability in the early 1980s. Essentially, in moving disablement from an internal, individual pathology location to a primarily, external, societal environment, the social model critiques and challenges the medical model approach (Oliver 1983; Scotch 2000; Pfeiffer 2001). The Social Model explains that disability arises from barriers within 'an oppressive and discriminating society' rather than impairment per se (Soder 2009). This shifts the onus of response away from the individual (to be cured) to society (to dismantle barriers that construct disability).

New ways of thinking also extended to built form. 'Post-modernist' architecture started to emerge in the 1960s.However the Australian version, popular in the 1980s, was rarely manifested in more than facade form and decoration, with little attention paid to post-modernism's underlying hallmark concerns of diversity and discrimination. Therefore, throughout this time in Australia in terms of accessibility for people with disability, urban layouts and building design remained largely untouched by the concerns of either post-modern social theorists or proponents of the social model of disability, thereby remaining as inaccessible as ever. The Social Model of Disability, in recognizing that the built environment is a disabling instrument in itself, is of great significance to built environment practice. Invariably, however, built environment practitioners in Australia are, still unaware of such concerns. This lack of understanding can be partly explained from a regulatory perspective. Although various state-based Building Regulations may have previously contained some provision for 'disabled access' the Australian *Disability Discrimination Act* (DDA, (Australian Government 1992)) was not enacted until 1992, the *Building Code of Australia* (BCA, (ABCB 2016)) was not fully adopted nation-wide until 1998, and the (Australian) *Disability (Access to Premises—Buildings) Standards 2010* (Premises Standards, (Australian Government 2010)) was not in force until 2011!

Oliver (2013) lamented thirty years on, that even though the social model had taken on a life of its own somewhat over-reaching his original intentions, 'still talking' rather than observable progress appeared to be the main outcome. Furthermore, in an environment of funding cuts to major services due to post-global financial crisis austerity measures and associated disability movement fragmentation, Oliver (2013) acknowledges that new disability models are warranted. The influence of broader social theories of: feminism, post-modernism, and post-structuralism, on the development of other disability models is, therefore, salient (West 2012).

2.4. Relational Model of Disability

In the late 1960s Nirje, a Swedish social theorist, formulated the principles of normalization emphasizing strong support of deinstitutionalization, recognition of the diversity of the human condition, and belief that people with disability and 'normal' (ordinary) life, including access to the built environment, are not mutually exclusive. This work represents part of an emerging grand idea of social inclusion for people with disability in the community and within the neighborhood (Nirje [1969] 1994). Following on in this continuum of Nordic interest in people–environment interaction, a new disability model developed around the end of 1990s–early2000s, and has subsequently been recognized as the (Nordic) Relational Model of Disability (Goodley 2011).

As identified by UK-based Critical Disability Studies scholar Goodley (2011), restated by Lid (2013) in Norway, and Carling-Jenkins (2014) in Australia, the Nordic Relational Model of Disability revolves around three main tenets being that disability is a person-environment mismatch, situational (contextual), and relative. In work underpinned by Relational Model of Disability theory Lid (2016) posits that accessibility for wheelchair users and people with vision impairment in urban areas requires a sound understanding of person-environment interaction.

The preceding discussion is of interest because it provides at least a partial explanation of why the Nordic-Scandinavian countries are considered, in many ways, to be at the vanguard of contemporary built environment accessibility policy. Norway, for instance, is to be 'universally designed by 2025' (Norwegian Ministry of Children, Equality and Social Inclusion (NMCEandSI 2016)). However, although those involved in disability studies in Australia, Carling-Jenkins for example, are somewhat cognizant of the relational model of disability, reference to this does not appear to exist in Australian built environment literature. In a further vindication of Imrie's concerns (Imrie 2015) of built environment practitioner indifference to disability, none of the people mentioned in this subsection are from a built environment disciplinary background.

2.5. Diversity Model of Disability

In the USA, Shriner and Scotch, professors specializing in social work, and sociology and political economy respectively, were also very concerned about the under-representation of people with disability in employment, reduced educational attainment, and the discriminatory nature of the existing built environment. Scotch and Shriner (1997) postulate that the *Americans with Disabilities Act* of 1990 (ADA, (USDoJ CRD 2017)) with its concomitant *Title II Regulations*, Title *III Regulations*, and *ADA Standards for Accessible Design*, has arisen out of the previously dominant minority group model of disability (a political strategy which relies on advocating for justice for a disadvantaged minority, (Bickenbach et al. 1999)) and as such is a deficient approach. Instead they proposed and explored, 'Disability as Human Variation', an alternative model intended to focus attention on how society's systems respond to variation introduced by disability (Scotch and Shriner 1997). Under this model, accessibility in the built environment, for example, is not solely achieved by antidiscrimination regulation requiring a 'universal' solution; the diversity of disability must be acknowledged (Scotch and Shriner 1997). Shriner and Scotch (2001) further question the socio-political definition of disability, in which (all) barriers faced by people with disability are (built-environment) imposed and therefore removable, feeling that this common underlying ideology of disability rights activists and independent living movements insufficiently recognizes that 'impairment' does have a bearing on accessibility outcomes.

Seeking to overcome the false dichotomy of ability/disability, Bickenbach et al. (1999) pursue the concept of universalism, proposing:

> While the 'social' model is now universally accepted, it is argued that universalism as a model for theory development, research and advocacy serves disabled persons more effectively than a civil rights or 'minority group' approach. (p. 1173)

Bickenbach et al. (1999) explain that universalism reflects the view that 'disablement is a universal human phenomenon' rather than a minority one (p. 1179). A universal approach to disability shifts the focus from 'special responses for special needs' (where such needs are competing with those of the general population, Zola 1989 in (Bickenbach et al. 1999) to an approach that 'accepts difference and widens the range of normal' along an ability–disability continuum that can be applied to all humanity (Bickenbach et al. 1999, p. 1182).

Spanish researchers Palacio and Romanach (2006) also sought to overcome the false dichotomy of ability/disability in the development, via the fields of bioethics and human rights, of the diversity model of disability. Palacio and Romanach (2006) intentionally use the all-encompassing term 'diversity', adding a somewhat postmodern outlook. The similarities and differences between the diversity model and universalism cannot be debated here, but both offer new ways of thinking to built environment practitioners. Nonetheless, Hamraie (2016) whose interdisciplinary scholarship bridges critical disability, race, feminist studies, architectural history, and science and technology studies argues that a 'normate template' notion continues to underpin present-day built environment theory and practice concluding that [built environment practitioners need to] 'foreground the political, cultural, and social value of [diverse] disability embodiments.' (p. 304).

2.6. Human Rights Model of Disability

As with previous disability models explored in this paper, the Human rights model of disability did not spontaneously appear, but rather, evolved within a continuum of rights-based approach thinking (Quinn et al. 2002; Degener 2016). In line with the USA's standing as a significant site for rights activism, social responses to impairment were heavily predisposed towards Human Rights discourses and resultant frameworks as proposed by the United Nations (Quinn et al. 2002). An early signpost towards the human rights model of disability is the UN Universal Declaration of Human Rights adopted, in 1948, shortly after the end of WW2 (Berghs et al. 2016). Declarations of rights often arise in response to established power imbalances constraining the ability of marginalized and/or minority groups to fully participate in all aspects of society and are hallmarked by written articulation, at high legislative level, of who does and doesn't have rights and what those rights are and are not. Content is usually informed by contemporaneous sociopolitical movements, such as civil rights, women's rights, children's rights, and, of course, disability rights (Berghs et al. 2016). In the built environment space, in response to the worldwide phenomenon of emphasis on rights and deinstitutionalization, disability research and activism work in the USA investigated 'needs based assessments' (characteristic of welfare policy) and (fairer) 'rights based assessments' in relation to independent living; building on such work the independent living movement emerged in Berkeley, California, in the early 1970s (Berghs et al. 2016).

The 1980s were pivotal in disability discourse and activism, globally. Along with the emergence of Oliver's social model of disability in the early 1980s, 1981 was the UN-decreed International Year of Disabled Persons, 1983–1992 was the UN Decade of Disabled Persons, Universal Design (UD) arrived in 1984, and the UN Convention of Rights of the Child encompassing children with disability was adopted in 1989. Continuing on into the 1990s saw an expanded commitment to disability antidiscrimination legislation, for example, the ADA (USA 1990), the Australian DDA (Australian Government 1992), and the UK *Disability Discrimination Act 1995* (now the Equality Act 2010, legislation.gov.uk). Notwithstanding such positive events, Hahn (2000), a pioneer in rights-based approaches, concluded a decade after the introduction of the ADA that it 'has not fulfilled many of the hopes of its proponents' (p. 192). Nonetheless, a (human) rights model of disability is evolving and continuing to gain traction, particularly in light of the UNCRPD, adopted by the UN in 2006. In discussing the development towards the UNCRPD, Bruce (2014) restates the views of prominent Disability Studies writers (e.g., Zola, Oliver, and Hahn) in explicitly problematizing inaccessible built environments for people with disability.

Increasingly, critiques of both the built environment and legislation regarding it, have been framed from discrimination and rights viewpoints. Schindler (2015) acknowledges that the ADA has achieved progress for people with disability but highlights the power of the built environment over people's lives and its discriminatory ability, through design and planning mechanisms, to segregate thereby reducing opportunity and autonomy. Theresia Degener (2016) characterizes the inaccessibility of the built environment as a human rights problem, suggesting that Disability Studies has moved beyond the debate of medical versus social models of disability and is now in a new era of human rights model of disability as epitomized by the UNCRPD.

It is perhaps the case that the human rights model of disability is in danger of becoming narrowly defined as being the UNCRPD. There is no doubt that in its various explicit and implicit references, the UNCRPD effectively requires all the built environment to be accessible for people with disability of all ages. Disability advocates believe that the UNCRPD's rights-based sociopolitical approach to barrier removal will engender both nondiscrimination and social inclusion (Berghs et al. 2016). On the other hand, weaknesses identified by various analyses include potential for no enforcement generally, toothlessness at nation-state level, ill-defined linkages with other legislative boundary-crossing bodies, and misinterpretation leading to ill-considered modified environments (Berghs et al. 2016). Perhaps the greatest danger, however, is that in advocating for individuals' rights its use will be restricted to personal protection and safeguard, rather than being the go-to tool to precipitate enabling environments (Berghs et al. 2016). This would mark an unwelcome return to disability being considered an individualized problem, suggesting that 'a continued role for the more established social model of disability' is defensible (Berghs et al. 2016).

2.7. Disability Models: A Conundrum for Built Environment Practice?

As highlighted in the preceding pages, built environment accessibility outcomes are critically affected by the way society positions and views disability. Built environment accessibility practice has been, and continues to be, shaped by a hidden discourse. Unless exposed, this will remain uncritiqued. It is a hope that the above analysis of disability models, provides some insights from a built environment perspective.

The various models are reflective of their different historical periods. The particular value of the social model to built environment practice is the emphasis on the way environment, including the built environment, constructs disability. Disability is not a preexisting, independent, condition; the nature and experience of disability is directly linked to the built environment, among other factors. More recent models emphasize diversity of human experience—this also has implications for built environment accessibility practice. The UNCRPD specifically draws attention to the wide-ranging extent of the built environment, for example, housing, public buildings, transport, and social/cultural/recreational locations. Notions of 'community' and 'inclusion' that focus attention on geographical areas, or neighborhoods, are embedded in the UNCRPD and the way people are supported to interact with their environment is considered crucial. Therefore, the human rights model of disability, via the UNCRPD, potentially offers very strong direction and breadth for built environment accessibility legislation and practice.

From a built environment perspective, the preceding discussion raises somewhat of a conundrum, particularly in relation to built environment practice in Australia. Worldwide, including Australia, enforcement of existing built environment accessibility legislation is widely cited as a problem (NZHRC 2012; USDoJ CRD 2017; AFDO 2015; DARU 2016; NMCEandSI 2016; Sawadrsi 2011; Ariffin 2016; ACPF 2014; IDRM 2004). Nonetheless, in my experience there is a perception within critical/disability studies that a human rights model of disability, with associated UNCRPD-derived 'prescriptive' built environment accessibility legislation, would achieve more tangible results more quickly. Unfortunately, my experience indicates that built environment accessibility is already being treated, thoughtlessly, as a regulatory exercise by most built environment practitioners. As highlighted in the following Section 3 of this paper, much of the Australian built environment is not directly subject to built environment regulatory controls. Therefore, I believe there is real danger that a solely rights-based, prescriptive, approach, even if comprehensive, would merely further entrench the current tick-box mentality, with unimproved outcomes at the neighborhood scale.

3. Human Rights Legislation and the Built Environment: An Australian Viewpoint

At face value, people with disabilities' right to inclusion in the neighborhood is enshrined in 'disability' legislation. However, we know from disabled peoples organizations (DPOs), disability advocates, human rights commissions' complaints lists, media reports, and people with disability themselves, that significant difficulty in exercising such rights is still being experienced. Is this due to inadequacies in legislation? Built environment accessibility legislation is indeed somewhat opaque, as illustrated by the following paragraphs.

3.1. Accessibility Legislation

3.1.1. At International Level: UNCRPD

Within disability policy and legislation in Australia, and elsewhere, it is acknowledged that the UNCRPD is the umbrella human rights instrument addressing disability (Commonwealth of Australia 2018). Beyond the specific directives contained in Article 9 Accessibility various other Articles, (such as Article 19 Living independently and being included in the community, Article 20 Personal mobility, Article 24 Education, Article 27 Work and employment, Article 28 Adequate standard of living and social protection, Article 29 Participation in political and public life, and Article 30Participation in cultural life, recreation, leisure and sport) effectively require all the built environment to be accessible for people with disability (UN 2006). The UNCRPD also mandates the inclusion of people with disability, in communicating views about built environment experience (UN 2006). Therefore, from an 'Accessibility in the Built Environment' perspective, the content of the UNCRPD, is ground breaking.

However, there are several layers of procedure between a UN member state signing the convention and the convention being directly enforceable through domestic legislation within that country.

Although only a miniscule number of UN member states have no involvement in the convention, there are significant differences in official commitment levels. Only approximately half of the world's countries have fully committed in signing and ratifying both the convention and its accompanying optional protocol. Amongst other potential benefits for people with disability, only full commitment, that is, signing and ratifying both the convention and the optional protocol, allows (individual) claimants to take a case directly to the UN. Notably, the USA's commitment had not (mid-2017) extended beyond signing (UN 2017). A contributing factor to USA's non-UNCRPD ratification is a governmental view that the USA's ADA, with its attendant standards, is sufficiently *prescriptive* to achieve an accessible built environment (Hamraie 2012). This governmental view is, however, contested as evidenced by numerous media reports and advocacy organizations' electronic communication platforms. [2]

Australia has signed and ratified both the Convention and the Optional Protocol. Australia's ratification expresses acceptance of the inherent obligations (ALRC 2014). However, unless Australia passes appropriate domestic law the UNCRPD is not directly enforceable within the Australian judicial system (McSherry 2014). Effectively, in the Australian built environment context, it is *policy,* not enacted legislation. Furthermore, most built environment practitioners within Australia are neither familiar with UNCRPD content nor aware of its significance in relation to built environment accessibility practice.

3.1.2. Built Environment Accessibility Legislation: At National Level

In response to difficulties experienced by returned servicemen, laws specifically referencing the welfare, and rights, of people with disability started gaining momentum after WW2, particularly in the USA (The Guardian 2017). As previously highlighted, the 1960s–1990s period saw significantly strengthened legal provisions concerning rights throughout the world. Nonetheless, prior to the adoption of the UNCRPD, '[a]ccording to the Inter-Parliamentary Union, only one third of countries have antidiscrimination and other disability-specific laws.'(UN 2008). Over a decade later however, most countries have various laws and multiple official government policies in place proscribing discrimination, upholding rights, and enhancing wellbeing of people with disability; the content of same is, however, somewhat variable (DREDF 2017). The USA legislative package of ADA, ADA Regulations, and integral *ADA Standards for Accessible Design* (the latter running to hundreds of pages), is rights-based. *ADA Standards for Accessible Design* are also 'prescriptive', that is, there is much detailed information about what *must* be done within the built environment to satisfy the stipulated accessibility requirements.

Australia's DDA is a complaints-based document. In a sense, it is also 'performance-based' in that detailed prescriptive requirements are not contained within the act, rather, it is necessary to satisfy the 'objects' of the act. These are contained in one paragraph consisting of three brief, explanatory parts. Only part of the first part appears to be of direct relevance to the built environment:

(a) to eliminate, as far as possible, discrimination against persons on the ground of disability in the areas of:

  (i) work, accommodation, education, access to premises, clubs and sport; and

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[2] For example: http://usicd.org/index.cfm/crpd, https://www.hrw.org/news/2013/07/26/us-ratify-disability-rights-treaty, http://www.catholicethics.com/forum-submissions/the-us-fails-to-ratify-the-un-convention-on-the-rights-of-persons-with-disabilities, https://www.ahead.org/CRPD/Myths%20and%20Facts, https://www.huffingtonpost.com/2013/10/08/ada-violations_n_4064270.html, https://dredf.org/2017/10/04/ada-under-attack-tell-house-representatives-oppose-h-r-620/, https://dredf.org/web-log/2017/06/23/no-roll-backs-civil-rights-past-plaintiff-opposing-h-r-620-ada-notification-act/.

(ii) the provision of goods, facilities, services and land; and... (Australian Government 1992, p. 1)

However, notwithstanding its central 'do not discriminate' intention, implementation detail is somewhat lacking. Therefore, built environment practitioners do not understand the significance of DDA requirements which are thus commonly ignored.

To address perceived gaps and to further Australia's DDA implementation outcomes, subordinate *legislation* via a suite of 'Disability Standards', being the: *Disability Standards for Accessible Public Transport 2002* ((Australian Government 2002), Transport Standards), *Disability Standards for Education 2005* ((Commonwealth of Australia 2006), Education Standards), and the Premises Standards (2010), has subsequently been enacted. Each of these standards has limitations in terms of directing built environment practice effectively. The first half, approximately, of the Premises Standards covers 'legalities', for example: Preliminaries, Scope of Standards, Commission Exemptions, and Review, before moving on to (technical) Deemed-to-satisfy provisions. Premises Standards technical content generally aligns with that of the BCA in numbering, presentation and detail. However all three Disability Standards, and the BCA, have complex inclusions and exclusions.

In terms of built environment accessibility, oversight of transport *premises* has now been transferred to the Premises Standards. Potential shortcomings of this legislative move include: nullifying compliance target date timetabling, the relationship between compliance-timetabled rolling stock and compliance un-timetabled built infrastructure impacting people with disabilities' built environment accessibility, and the restricting of public sector scrutiny by effectively putting transport premises into the (individual) buildings regulatory system. In addition, the Premises Standards do not apply to most private dwelling stock nor to public realm-pedestrian environment infrastructure. Each of the Disability Standards features largely inaccessible language. The Education Standards are written in 'policy-speak' and hence ignored by built environment practitioners whereas the Transport Standards and Premises Standards are written in built environment regulatory code language incomprehensible to those without sufficient background technical knowledge and access to all referenced documents; the latter are not freely available.

The Premises Standards and the BCA, in the context of built environment accessibility, are commonly referred to as being harmonized. The BCA is a national-level, *performance-based,* document and has been since 1996 (ABCB 2017). Nonetheless, the on-going inclusion of technical-looking deemed-to-satisfy provisions has contributed to a continued perception of prescription. It is a common misconception that the technical detail presented in the deemed-to-satisfy provisions, in both the premises standards and the BCA, is prescriptive. This is not the case. Ultimately, the legislated requirement is to satisfy the performance requirements, compliance with Deemed-to-satisfy provisions is merely an undemanding way to acceptably demonstrate so-called satisfaction. However, if one looks closely one will discover that significant portions of buildings, for example, fit-out, fixtures, and fittings are not directly covered in deemed-to-satisfy provisions which mainly focus on wheelchair-accessible paths of travel and toilets.

Although the Premises Standards and BCA are commonly referred to as being harmonized, some BCA Performance Requirements are omitted from the Premises Standards and the 'legalities' part of the Premises Standards is not included in the BCA at all. What has been 'harmonized' is, predominantly, the replication of deemed-to-satisfy provisions. However, Deemed-to-satisfy provisions Parts D4 Braille and tactile signs and D5 Accessible water entry/exit for swimming pools in the Premises Standards are appended to Part D3 in the BCA, confoundingly called Specifications (deemed-to-satisfy), and numbered differently. The BCA's: Part D3 Access for people with a disability, Part E3 Lift installations, and Part F2.4 Accessible sanitary facilities, all being deemed-to-satisfy provisions, do not make any direct, or inferred reference, to either the *Disability Discrimination Act*, or the Disability Standards.

Bourne out by my extensive consulting and provision of professional education experience, architects and building designers tend to rely on the BCA as their only built environment accessibility regulatory source. This is rather problematic on three counts. Firstly, referenced documents such as Australian Standards[3] are published by private sector entity SAI Global and are not freely available. Secondly, effectively, the BCA does not cover the accessibility of either public realm infrastructure, including the pedestrian environment, or most private dwellings. This is particularly concerning as, in terms of spatial coverage, those categories of built form comprise most of the built environment. The 'public realm', being, roads and other transport infrastructure, the pedestrian environment, parks and the like, *not buildings*, is thus not subject to building permit regulation. Building accessibility legislation requirements are also therefore not directly triggered. Current built environment accessibility legislation in Australia being not directly applicable to private dwellings is reflective of conventional content which can be traced back to the USA's ANSI (1961) *A117.1 Accessible and Usable Buildings and Facilities* first issued in 1961. Detached and semi-detached housing comprise approximately 87% of Australia's private dwellings (Heath 2017). Thirdly, if the fine print is closely read, it can be discerned that the deemed-to-satisfy provisions of the BCA (and the Premises Standards) allow plenty of opportunity for suboptimal outcomes and/or 'avoidance'. Such avoidance does not obviate the DDA complaint process but complainants' capacity to complain is often limited by meagre resources.

4. Assessing Neighborhood Accessibility

An essential component of this tripartite paper is the lived experience of people with disability, at the neighborhood scale. Illustrated in Table 1: Accessing the neighborhood? an extensive survey, undertaken as part of my current PhD studies, has established that across 'anglophone' countries, Europe, Asia-Pacific, Africa, and Latin America, many people with disability find their everyday environments a daily, overwhelming struggle. Within the literature common themes are very obvious: social inclusion stymied by inability to navigate broken travel chains; built environment areas of greatest concern being housing, public realm pedestrian environment (at the community/neighborhood scale), and public transport; lack of enforcement of existing legislation identified as a very significant problem; and inconsistent and/or misinterpretation of existing legislation also identified as problematic.

Table 1. Accessing the neighborhood?

Themes	Social exclusion • Community/neighborhood inclusion stymied by broken travel chains Inequitable built environment • Unsuitable housing • Deficient public realm pedestrian environment • Unusable public transport infrastructure Legislation inadequacies • Legislation not enforced • Legislation misinterpreted
Regions	'Anglophone' countries, Europe, Asia Pacific, Africa, Latin America
Countries	UK, New Zealand, Canada, USA, Australia; France, Turkey, Slovenia, Poland, Germany, Kosovo, Sweden, Norway; Malaysia, Thailand, Japan, China, India, Singapore, Pacific Islands; Ethiopia, Sierra Leone, Uganda, Zambia, Egypt, Ghana; Mexico, Belize, Honduras, Suriname, Brazil, Chile
References	(HoC WEC 2017; NZHRC 2012; Stephens et al. 2017; USDoJ CRD 2017; AFDO 2015; Rains and Butland 2012; DARU 2016; Sander et al. 2005; Baris and Uslu 2009; Zajac 2013; Basha 2015; NMCEandSI 2016; Sawadrsi 2011; Sarma 2016; Ariffin 2016; Wee et al. 2015; ACPF 2014; Tudzi et al. 2017; IDRM 2004; Pereira Martins et al. 2016; Rotarou and Sakellariou 2017)

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[3] There is much confusion around the difference between Australian Standards and Disability Standards. In the built environment accessibility context, the former are, effectively, merely guidelines and the latter are indeed legislation.

Given the breadth of the existing built environment inaccessibility problem as articulated above, what processes are in place for improving same? As a starting point, what tools are available to empirically assess the accessibility for people with disability, at neighborhood scale, of the existing built environment?

Generally positioned within the 'expert' domain, access auditing refers to assessment by experts for compliance against accessibility legislation. In the prescriptive USA system this involves working through the very lengthy ADA and associated detailed standards. Although still available, the *ADA Best Practices Tool Kit for State and Local Governments* does not appear to have been updated since 2008 (USDoJ CRD 2008). In 2016, the (USA) Institute for Human Centered Design, through its New England ADA Center, produced *ADA Checklist for Existing Facilities* (Existing Facilities) along with various other recreational facilities checklists including, for example, amusement rides, various water-based recreational activities, and shooting facilities. The publicly available Existing Facilities checklist, based on the USA *2010 ADA Standards for Accessible Design*, is technical-compliance based requiring equipment, expert knowledge, many Yes/No boxes checked, accumulated photographic record dealt with, and possible solutions noted, after which it is expected that the possible solutions will be costed, a plan developed, changes made, and progress annually monitored (IHCD 2016). Typologically, more and more of the USA's built environment is being covered by ADA checklists. Nonetheless, although ongoing development of publicly available Access Auditing tools is occurring via new, and updated, ADA checklists for example, such assessment tools are invariably compliance-based without input from people with disability. Data collected remains as discrete, islands of information. Although checklist content may include cost estimates, compliance-achieving rectification recommendations are the intended main output. Neither interrogating the legislation itself nor identifying user preference prioritization is contemplated. The process, therefore, is invariably reduced to a financial transaction, not an upholding of rights.

In Australia's performance-based system 'compliance' is interpreted, by experts, against various deemed-to-satisfy provisions often referencing Australian Standards but not covering off all aspects of building structure, form, or fit out. Also in Australia, similarly to the USA, esoterically comprehensive spreadsheets of information are produced and input from people with lived experience of disability is generally not sought. Prioritization of rectifications is arrived at through combinations of expert opinion and costing differentials. In both the USA and Australian legislative systems, public and commercial building accessibility is the customary target. Lack of specific accessibility legislation directly applicable to private housing, public space, and pedestrian environments makes 'compliance' auditing of such areas, in Australia, a flawed undertaking. In Australia the Access Institute, a private sector registered training organization, runs various 'accessibility in the built environment' programs at diploma, certificate iv, and short course level. Short courses offered vary in duration from two–three hours to one–two days and access audit templates for attendees' future use are issued (Access Institute 2017). Nonetheless, courses are applicable to discrete parts of the built environment in isolation only and offered on a commercial transaction basis. There is no expectation that data obtained from subsequent assessments will be used for any wider, community oriented, benefit. No publicly available, peer-reviewed, standardized checklists are in widespread use amongst the Australian Access Consulting community. The lack of attention paid to developing, and maintaining, publicly available access auditing tools is, perhaps in Australia at least, a reflection of the now privatized nature of built environment 'compliance' consulting services, resulting in private-practice-developed methods being treated as commercial-in-confidence. Operationalization of (expert) Access Auditing invariably involves tick-boxing a list of pre-determined items corresponding to defined regulations. Underpinning theoretical concepts, for example adherence to any particular disability model or acknowledgement of human rights requirements, are not communicated–the list is the list.

Beyond the type of access auditing described above, there are a range of other measurement approaches. In relation to fitness and recreation environments an assessment tool, *Accessibility Instruments Measuring Fitness and Recreation Environments* (AIMFREE), was first used in assessing

35 health clubs and fitness facilities in a US national field trial (Rimmer et al. 2005). A major driver of AIMFREE development was the identification of highly inaccessible, neighborhood-scale, public realm pedestrian environments for people with disability, and in this context, 'health clubs may present a viable alternative for participating in physical activity' (Rimmer et al. 2005, p. 2022). Several further studies, in either full or modified form, have been undertaken in Canada, USA, Kuwait, and Singapore (Arbour-Nicitopoulos and Ginis 2011; Calder and Mulligan 2014; Rimmer et al. 2017). Albeit with limitations, principally being length of 422 questions and some problematic psychometric properties, AIMFREE methodology is considered satisfactory, particularly regarding content validity and development of appropriate scoring calculations (Calder and Mulligan 2014). Various AIMFREE Manuals in both professional and consumer versions can be ordered from National Center on Health, Physical Activity and Disability (NCHPAD); purchase price and content unknown (NCHPAD 2017). AIMFREE is specifically applicable to sport/fitness and recreation centers, a rather esoteric component of the built environment, typologically, locationally, and spatially.

Lau et al. (2015) proposed the *Building Inclusiveness Assessment Score* (BIAS) for assessing the disability inclusiveness of university buildings. Originally intended to be conveyed as one final score, the development and testing process conducted in Hong Kong indicated that making the Physical Disability Inclusion Subscore (PDIS) and the Visual Impairment Inclusion Subscore (VIIS) explicit was warranted (Lau et al. 2015). Assessment items included in BIAS are intentionally derived from international accessible design guidelines, built environment accessibility legislation and standards, and universal design principles; 'subjective' input from people with disability is not sought (Lau et al. 2015). Such attitudes are indicative of, firstly, the tension between compliance-based built environment assessment and sidelined disability studies lived experience and, secondly, the naive belief that standards and guidelines are 'right', and properly reflective of people with disability accessibility needs. Several built environment accessibility assessment methodologies developed in other parts of the world, including BIAS, are referenced in literature back grounding development of the *Composite Disability Design Inclusiveness Score* (CDDIS), a method of assessing the inclusivity of university buildings in Ghana specifically (Tudzi et al. 2017). Further development of the methodologies mentioned is not apparent.

A range of other nonconventional accessibility investigation tools, designed to determine public realm accessibility for people with disability, do not appear to be in use or undergoing further development.[4] Elsewhere and across a range of, mainly, public realm environments, several research projects investigating built environment accessibility for people with disability have developed measurement methods and generated data (Kadir and Jamaludin 2012; Zajac 2013; Wee et al. 2015; Pereira Martins et al. 2016; Buhler et al. 2015; Stephens et al. 2017). Production of replicable built environment accessibility assessment tools was not, however, a defined intention. Findings arrived at using conventional accessibility/walkability tools in the interdisciplinary *Street Mobility and Network Accessibility* project indicated high accessibility/walkability potential (Mindell et al. 2017). Fine grain analysis, however, found that people with disability were disproportionately affected by poor quality pedestrian environments, particularly deficient pedestrian crossings and footpaths (Mindell et al. 2017).

In Australia, Green (2011) devised a new tool, the *Universal Mobility Index* (UMI), purporting to quantitatively measure, comparatively rate, and longitudinally track equity of access across all parts of the built environment using a participatory approach. The UMI is explicitly founded on the social model of disability and methodologically intended to function as a rights-based indicator (Green 2011). The UMI tool consists of two main components—built environment component and

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[4] See, for example: *Access Audit Tool*, Lewis, McQuade, and Thomas, early 2000s; the oft-referenced 2009 Ankara work of Baris and Uslu; *International Transportation Accessibility Survey* (ITAS), 2010 International Conference on Mobility and Transport for Elderly and Disabled Persons; *A Methodology for Enhancing Life by Increasing Accessibility* (AMELIA-AUNT-SUE), (Evans 2010; AUNT-SUE 2010; Mackett et al. 2012); and *Rating of Accessibility and Safety* (ValeAS), (Biocca 2014).

policy environment component—the latter considers whether the opinions of people with disabilities on the built environment are meaningfully acknowledged and included (Green 2011). The built environment component requires neighborhood accessibility assessment being undertaken by people with disability themselves. Therefore, its characteristics, in underpinning theory, components, and measurement methods, are markedly different to conventional access auditing. The first pilot of the UMI was undertaken for my Masters research project in the Kensington (Victoria, Australia) neighborhood in 2011 with results published in 2012 (Jackson and Green 2012).

Therefore, although various work is being done in various specialized directions it appears there is not any overall neighborhood scale built environment accessibility assessment tool in widespread use. Other than the UMI, current and past built environment accessibility assessment tools and methods commonly lack explicit theoretical regard to disability models and/or human rights requirements. Furthermore, excluding the concept of access auditing, tools and/or assessment methods presented above are virtually unknown in built environment practice. Many have been developed from a non-built environment disciplinary perspective. Given the general spatial scale of assessment this is somewhat understandable; the nuances of built environment production are, however, difficult to comprehend from a non-built environment perspective. On the other hand, reflective of the lack of understanding within the built environment knowledge domain of the lived experience of people with disability, accessibility assessment tools developed from a built environment perspective, BIAS for example, tend to be building typology specific, expert-driven, and compliance-based with, at first impression, complicated calculating processes.

5. Putting it All Together

5.1. Disability Models: Application in the Built Environment Context

Deeply entrenched ways of thinking exemplified by the charity and medical models of disability have had a profound influence on the shaping, forming, and making, of our existing built environment. While it is doubtful that most built environment practitioners in the past sat at drawing boards dreaming up ways to deliberately design-out ‘the disabled’, the net result of their exclusionary ‘othering’ actions is the same: a built environment that continues to fail the accessibility needs of many people with disability. This has occurred not just at the individual building scale but is also evident in enduring urban layouts, for example, poor pedestrian environments, deficient public transport provision, and unsatisfactory location of residential and other services. Deinstitutionalization, now considered a societal norm has, doubtless, resulted in reduced incidence of full-time institutional care. However many residents of group homes are routinely unable to access local pedestrian environments, services, and public transport; children with disability and their carers community access needs are not addressed; and the laudable ideal of ageing in place is an accessibility nightmare in many cases, both at home and within the neighborhood. Although some current urban planning and design practices such as tactical urbanism and biophilic design may be post-modernist in their participatory-ness and natural-world focus, outcomes are still informed by entrenched design-school attitudes, the result being that the accessibility needs of people with disability are still ignored.

The medical model of disability is generally accepted to lack social focus and typical disability reporting, of ‘primary’ impairment or medical diagnosis of ‘greatest severity’, does not convey the multifactorial lived, person + environment, experience of many people with disability. Therefore, in the quest to improve built environment accessibility, the social model of disability serves as a powerful wake-up call. Firstly, it shifts the focus away from the individual, but perhaps more importantly, at least in the context of built environment practice, it recognizes that the built environment is a disabling instrument in itself. The relational model of disability, being tied in with the Nordic way of life, legislation, policy, and professional proficiency also provides some pointers, particularly given Nordic/Scandinavian standing at the vanguard of built environment accessibility practice. In figuring out how to improve the accessibility of the existing built environment, at neighborhood scale, we surely need to consider all users. But who is ALL? The false dichotomy of ability/disability is a pitfall to be avoided; the post-modernist diversity model of disability aids understanding in this regard. The human rights model of disability is a forceful reminder of the rights of people with disability.

Built environment practitioner ignorance of people with disabilities' accessibility needs is compounded by slow rates, overall, of built environment renewal. Pinnegar et al. (2008) concluded that the Australian built environment changes at a rate of only around 1.25% per year. Therefore much of the existing built environment has indeed been informed by the charity and medical models of disability. The social model of disability has now been in existence for approximately four decades, the relational, diversity, and human rights, disability models are more recent. Unfortunately though, the concept of models of disability is virtually unknown in Australian built environment circles.

5.2. Built Environment Accessibility Rights Instruments: Implementation Issues

Neighborhood inclusion for all is apparently enshrined in law via various rights declarations and national-level regulatory mechanisms, and the groundbreaking advent of the UNCRPD. However in many ways, albeit unconsciously, the ways of thinking derived from the charity and medical models of disability are still underpinning current building regulations at the within-country level. Entrenched and poorly built environment accessibility outcomes at the neighborhood scale thereby continue.

Human rights instruments vary markedly in content, format, and prescription versus performance orientation, profoundly influencing interpretation. However, those that call for more certainty, via more prescription along the lines of the standards integral to the USA's ADA, perhaps do not understand the nuances of built environment design, the wide variation in built environment existing conditions, and the particularities of project-specific challenges. It is physically impossible to write detailed prescriptive requirements covering every possible situation, and attempting to do so risks reduction to tick-box compliance devoid of understanding of the diversity of the human condition. Additionally, reducing design outcomes to a set of pre-determined, potentially outmoded, solutions risks stifling innovation, an essential component in the quest to obviate disability-related inequality of existing built environment access. On the other hand Australia's performance-based system, theoretically encouraging endless innovation, is not necessarily superior in all respects, if one's aim is to improve the existing built environment sooner rather than later.

Evidently, there are also resources imbalances at the nation-state level throughout the world. Nonetheless, living in a developed country does not automatically translate to all its citizens enjoying full access to the built environment. In Australia, if we are not mindful, our charity-medical model inaccessible built environment legacy is likely to be further entrenched. Replacement and/or renewal of the overall existing built environment and particularly of the public realm is, historically, slow. Increasing appreciation of the value of retaining existing structure, which in the context of sustainability concepts such as embodied energy and carbon and virtual water is to be encouraged, is likely to decelerate, rather than increase, 'natural' renewal.

Due to the various factors discussed in the preceding paragraphs it is likely that built environment (in)accessibility, in Australia at least and particularly within the public realm and housing, will continue to be problematic if reliance on the current legislative framework is continued in isolation. Perhaps there are other processes that can also be utilized to improve the accessibility of the built environment, at neighborhood scale, for people with disability?

5.3. Improving Neighborhood Accessibility: Measure

There is still not any overall neighborhood scale built environment accessibility assessment tool, in widespread use. In Australia, as elsewhere, within either the academy or professional practice, concerted research and development of neighborhood-scale accessibility assessment tools aimed at evaluating the lived experience of diverse people with disability has not, to date, occurred. Without such information and given the extent of the problem, it is difficult to see how a well thought-out, rather than reactionary, program of improvement can be determined. As a first step, measurement of existing conditions is essential, particularly in the face of scarce resources (Green 2011).

6. Conclusions

The fact that the built environment is still inaccessible in the 21st century is staggering. Self-evidently, built environment practitioners are unfamiliar with contemporary accessibility expectations and fail to realize that historically entrenched ways of practice continue to construct disability. The social model of disability, compelling practitioners to confront the disabling nature of built environment practice, is fundamental to improving built environment accessibility outcomes.

Improving built environment accessibility outcomes also requires built environment practitioners to understand the accessibility needs of people with disability. People with disability are not a homogenous group. People with disability are diverse, as are all of the members of a society. There is, however, only one built environment. To ensure that our built environment is as accessible as possible for all people, built environment shapers, formers, and makers, must engage directly with people with disability—an uncommon activity, historically. Furthermore, to ensure that people with disabilities' built environment accessibility needs are not inadvertently overlooked, *a la* charity and medical models of disability, a human rights model of disability is warranted.

Globally, significant built environment accessibility rights legislation and policy frameworks already exist, for example, the groundbreaking UNCRPD, national disability discrimination acts, 'disability standards', building code accessibility requirements, and other guidelines within-country. However, in attempting to achieve built environment accessibility, existing legislation does not, nor can it, provide all the answers. Nonetheless, built environment practitioners take for granted that it does, due to lack of understanding, encountering, or interacting, with disability. Furthermore most built environment practitioners are not aware of the full content or significance of built environment accessibility legislation. People with disability experiencing major difficulties accessing the existing built environment within the neighborhood therefore continues. Areas of greatest concern are housing, the public realm's pedestrian environment, and public transport. These areas comprise the greatest spatial content of neighborhoods, and in Australia these areas are, coincidentally, the areas of the built environment with the weakest, least direct, accessibility legislation. Current codifying of built environment accessibility (human) rights via legislation within-country is opaque, risking stymieing positive outcomes flowing from the UNCRPD.

Also coincidentally, empirical data regarding the extent of the existing built environment inaccessibility problem, particularly at the neighborhood scale, is not readily available. Cogent processes of improvement are unlikely without such information. Various ways of measuring neighborhood accessibility have shown promise in the past but have not progressed. Subject to further piloting—perhaps the UMI, originally devised by Green and consciously underpinned by social model of disability and rights-based approach—might fill this gap.

Understanding disability models and acknowledging human rights can beneficially inform improvement of accessibility of built environment for people with disability at neighborhood scale. However, built environment practitioners must firstly recognize that, exemplified by the charity and medical models of disability and best explained by the social model of disability, built environment practice is a potent disabling instrument in itself. Secondly, it is essential for built environment practitioners to always engage with people with disability directly, rather than assuming tick-box compliance of codified human rights is sufficient. Thirdly, if existing built environment conditions are not well-understood, accessibility improvement progress is likely to be impeded.

Acknowledgments: Publishing cost fully funded by Deakin University through the Knowledge Unlatched initiative. No other funding has been received.

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2

The Inclusion of the Lived Experience of Disability in Policymaking

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Abstract: This paper examines the process under way in Iceland to align national law with the UN Convention on the Rights of Persons with Disabilities, focusing on the Convention's call for the active involvement of disabled people and their representative organizations in policy and decision making on matters that affect them. The paper draws on comments submitted by Icelandic DPOs on draft legislation intended to replace the existing law on services for disabled people, focusing on comments relating to their ability to participate in and affect the policymaking process. Furthermore, it draws on interviews with leaders of representative organizations of disabled people that solicited their views on the issue. The findings indicate that there is a reluctance on behalf of Icelandic authorities to make changes to the established process, which limits the active participation of disabled people and their representative organizations. The draft legislation has neither been revised to include provisions for expanding the participation of DPOs in policy and decision making, nor to ensure that disabled people themselves participate in the process.

Keywords: disability; CRPD; inclusion; policymaking

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1. Introduction

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) reflects the fundamental principle that those most affected have the right to participate in decisions that impact them, a contribution that has been called "one of the most progressive developments in human rights law provided by the CRPD" (Stein and Lord 2010, p. 698). There is an emphasis on participation that runs throughout the Convention that embeds within it an advocacy role for civil society organizations representing disabled people, which also extends to disabled people themselves (Meyers 2016; Stein and Lord 2010; Sabatello 2014). The preamble sets the stage by proclaiming that "Persons with disabilities should have the opportunity to be actively involved in decision making processes about policies and programs, including those directly concerning them" (United Nations 2007). Further emphasizing this stand in Article 4(3), the Convention demands that State parties "closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations when developing and implementing policies and legislation concerning persons with disabilities." The Convention maintains a focus on the importance of participation in the monitoring processes where it states that civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully (Article 33(3)), requiring states parties to recognize the obligation set out in Article 4(3). Finally, Article 34(3) encourages states parties to give "due consideration" to representation by persons with disabilities on the monitoring body (Stein and Lord 2010).

The CRPD sets out to create a new politics of disability and calls for changes to the process norms with regard to how disability policy is made. Bearing in mind how the Committee on the Rights of Persons with Disabilities (CRPD Committee), the body of independent experts that monitors implementation of the Convention by the States Parties, defines representative organizations of disabled people, this paper asks the question whether the new draft legislation on disability services currently before the Icelandic parliament, intended to bring national legislation into compliance with the CRPD, sufficiently embodies the Convention's call for changes to the process norms, particularly the principle that those most affected have to right to participate in decisions that most impact them. This is a question that may have wider relevance to other States Parties in the process of aligning national legislation with the CRPD. To shed light on this, the paper draws attention to the important role of DPOs in the drafting of the Convention and highlights those articles that lay the foundation for the argument that disabled people should be recognized as decision makers in their own affairs. Furthermore, it draws on theories that focus on the active involvement of marginalized groups, including disabled people, as a necessary component of changing their position of oppression. The paper then goes on to address the process underway in Iceland and examines comments submitted by Icelandic DPOs on the draft legislation pertaining to their views on the policymaking process. Furthermore, it draws on interviews with leaders of DPOs about their perceptions of their ability to affect decision making.

The prominent role afforded to civil society, particularly disabled people and their representative organizations, in the implementation and monitoring of the CRPD can be attributed to the unprecedented involvement of non-governmental organizations (NGOs), and in particular disabled persons' organizations (DPOs), in the drafting process of the Convention (Brennan et al. 2016; Degener 2016; Kanter 2014). Over 400 NGOs were accredited by the Ad Hoc Committee, the body responsible for the drafting of the treaty, which was at the time a historically high number for a UN process (Degener 2016; Kanter 2014). The involvement of civil society extended to a Working Group established by the Ad Hoc Committee to produce the first draft of the Convention. An unusual feature of the Working Group, which met in January 2004, was that it was equally composed of States, NGOs/DPOs and National Human Rights Institutions (NHRIs).[1] The DPOs were mostly led by and composed of disabled people themselves and much of the language of the Convention, when it was finally adopted, reflected their inputs during the Working Group. Further, many State delegations included disabled people who also helped shape the dialogue. This unique way of working—affording equal status to civil society in a treaty drafting process—gave the Convention an edge it would otherwise have lacked. It built relationships of trust with States and demonstrated how the lived experience of disabled people could enrich the process of developing norms and international standards.

An emphasis on the lived experience of disability was high on the agendas of many of the DPOs. The International Disability Caucus (IDC), a coalition of over 70 world-wide, regional and national DPOs that worked together to coordinate their efforts during the Ad Hoc Committee, put forth a suggestion that the Monitoring Committee be composed entirely or of a majority of disabled people (Stein and Lord 2010; Kumpuvuori and Virtanen 2017). The suggestion was rejected by the Ad Hoc Committee, as was the proposal that the Chair of the CRPD Committee be a disabled person

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[1] Membership of the Working Group included 27 States from every region of the world and six global NGOs/DPOs who had equal standing with the States in the Working Group's deliberations. NHRIs were represented by one person nominated by the International Coordination Committee (ICC) of NHRIs; there were three in all throughout the entirety of the process (Anuradha Mohit from the Indian National Human Rights Commission, Charlotte McLain-Nhlapo of the South African Human Rights Commission and, in the latter stages, Gerard Quinn of the Irish Human Rights Commission). The NGOs/DPOs included the World Blind Union, the World Federation of the Deaf, Inclusion International, and Rehabilitation International. They were mostly led by and composed of disabled people themselves.

(Stein and Lord 2010). However, it is worth noting that the call for disabled people themselves to have significant representation and a leading role in the Convention's monitoring body has materialized. As Degener (2016) points out, in 2016 the CRPD Committee consisted of 18 independent experts who were all disabled people except for one.

As a human rights convention, the CRPD aims not only to ensure disabled people their full human rights; it also recognizes that a part of having full human rights is the right to participate in decision making with regard to one's own affairs. In fact, as Gerard Quinn (Quinn 2009) points out, one of the key changes that the CRPD brings with it is that it treats disabled people as subjects capable of making decisions regarding their own lives and not as objects to be managed or cared for. The recognition of the right to be in charge of one's own life and affairs draws on Articles 12 and 19 of the CRPD, which lay the foundation for actualizing the right to make decisions regarding one's own life and to effective inclusion in society. Article 12 emphasizes the right to legal capacity for people with disabilities "on an equal basis with others and in all areas of life." As Quinn (2010) argues, legal capacity is instrumental to the recognition of a person as a human being and of full personhood. Having legal capacity provides recognition of the right to make decisions for oneself and to enter into contracts (O'Donnell and O'Mahony 2017; Quinn 2010). Article 19 provides further support for the right to personal autonomy by recognizing the right to independent living and community inclusion as a human rights issue (Brennan et al. 2016). While the Article does not include a definition of the term "independent" (O'Donnell and O'Mahony 2017), it reflects the principles of autonomy and choice, which align with the key principles outlined in Article 3 of the Convention. These include "independence of persons", "freedom of choice", and "full and effective participation in society". In addition, the two Articles, 12 and 19, are interdependent (Committee on the Rights of Persons with Disabilities 2014a; Keys 2017; O'Donnell and O'Mahony 2017). In order to live independently, it is necessary to have the legal capacity to make decisions and enter into agreements. In turn, the right to live independently and in accordance with one's own choices provides a platform to exercise the right to legal capacity and individual autonomy. Furthermore, the rights stated in Articles 12 and 19 are fundamental for the active participation of disabled people in policy and decision making that affects them, as stated in Article 4(3). As Mary Keys points out, it is necessary to have the right to choose to be able to actualize the right to participate actively in political life at all levels, including in policymaking (Keys 2017).

The importance of full and active participation by marginalized groups in the policymaking process has been recognized by many, including Young (1990), Oliver (1990), Charlton (2000), Guldvik et al. (2013), Keys (2017) and Priestley et al. (2016). Young argues that society's structures and norms are a reflection of existing power relations, created and defined by dominant groups to maintain the status quo (Young 1990). To change their position of oppression, marginalized groups must be a part of the political structure, engage in setting the agenda and defining the issues, and redefining the concepts that relate to their lives. Without their active involvement, their position of marginalization and oppression will be maintained (Young 1990). Keys adopts a similar focus and points out that to be able to leave behind the paternalistic approach that has created and maintained the historic disadvantages that disabled people have experienced, it is necessary that they themselves participate in policymaking to change laws and policies that do not reflect their experiences (Keys 2017). This focus draws attention to Dorothy Smith's argument that recognizing lived experience as knowledge is pivotal to the ability of marginalized groups to assert themselves. Smith maintains that all knowledge is socially constructed and that people's understanding of the world is derived from how they are differently socially located (Smith 1990). However, "privileged forms of discourse [are] claimed by master narratives", meaning that the knowledge produced by some people and groups are given greater acceptance (Mann and Kelley 1997, p. 395). Smith points out that, traditionally, everyday life experiences have been undervalued as the basis for knowledge, weakening the position of marginalized groups. Recognizing knowledge that emerges from lived actualities will strengthen the knowledge claims of marginalized and oppressed people (Smith 1990). Smith's focus on the need to value the knowledge provided by everyday lived experiences reflects the emphasis of the DPOs during the drafting of the CRPD, as well as the subsequent focus of the Convention on ensuring the full participation of both disabled people and their representative organizations in policy and lawmaking in all matters affecting them.

It is important that the participatory focus is maintained as states parties assume the task of aligning national laws with the CRPD, particularly as it pertains to the lived experience of disability. A state commits to develop and reform national laws and bring them in line with the CRPD when ratifying the Convention (Stein and Lord 2009). As of 30 September 2017, 175 countries have ratified the CRPD and are in various stages of fulfilling this obligation. This includes Iceland, which ratified the CRPD in 2016 and is in the process of finalizing draft legislation that has as its stated goal to bring Icelandic law into alignment with the Convention. This draft legislation, entitled “Laws pertaining to services for disabled people with significant support needs” (Althingi 2016–2017), is the central legislation concerned with disability issues in Iceland. In combination with other draft legislation on social services provided by local authorities in general (i.e., not specific to disabled people), it is intended to replace the existing Icelandic law on services for disabled people from 1992, the Act on the Affairs of Disabled People (No. 59/1992) (Althingi 1992). (Amendment 1055/2010 was passed in 2010, reiterating the obligation to uphold the aims of the CRPD.) The draft legislation states that the authorities shall ensure that disabled people and their representative organizations have the ability to influence policy and decision making in matters that pertain to their affairs (Article 1 of the draft legislation). This point is further reiterated in Article 4 of the draft legislation, which states that disabled people shall have the opportunity for active participation in policymaking in matters that concern them.

It is important to recognize, as Quinn points out, that adopting a legal text will not automatically translate into changes on the ground. “There is no guarantee that the new values that are embedded in the text of the Convention will be internalized and then operationalized” (Quinn 2009, p. 216). There are indeed hurdles to be cleared. As Arstein-Kerslake points out with regard to legal capacity and Article 12, not only does it require states parties to make changes to their existing legal systems; it also tests people’s ability and willingness to change their often ingrained perceptions of disabled people as lacking in decision making skills (Arstein-Kerslake 2017). Furthermore, it is important to recognize that the full and active participation of disabled people does not mean that their opinions, suggestions and comments will translate directly into law and policy outcomes. The final decision making remains in the hands of democratically elected representatives.

2. Methods

This paper draws on qualitative data from two sources: transcripts of interviews with leaders of Icelandic disabled people’s representative organizations; and comments submitted by representative organizations on the draft legislation “Laws pertaining to services for disabled people with significant support needs” (Althingi 2016–2017).

2.1. The Interviews

Eleven semi-structured in-depth interviews were conducted with leaders of nine disability groups and organizations in Iceland in 2016 and 2017. The focus of the interviews was to obtain the leaders’ perceptions and experiences of their ability to affect the changes underway aimed at implementing the CRPD in Iceland. This focus is derived from the belief that disabled people themselves are best positioned to judge whether policies aimed at delivering equality have been successful or not, a perspective adopted by Sherlaw and Hudebine (2015), as well as Disability Rights Promotion International (Samson 2015). To this end, semi-structured interviews were chosen as a method of inquiry to gain knowledge of the subjective understanding, perspectives and meaning that participants attach to the issues. They enable the interviewees to direct the discussion to what they find to be of importance and to express the meaning they attach to concepts, while at the same time allowing the discussion to be directed toward predetermined topics in keeping with the theme of the research (Esterberg 2002; Taylor et al. 2016).

Purposeful sampling was used to identify and recruit participants as it allows researchers to select participants who have experience or particular insight and knowledge into the concepts being explored (Creswell and Plano Clark 2017). The leaders selected were of both genders. Six of the 11 leaders were women and five were men. Their ages and educational background varied. While the participants differed as to how long they had served as leaders of their organizations, they all had considerable experience in promoting disabled people's rights in various capacities, and all had spoken in public on the issue.

An effort was made to provide a balanced representation of leaders of both established disability organizations and grassroots and activist groups. The five established organizations that were a part of this study, including three large umbrella organizations, are comprised of both disabled people and non-disabled people. Their rules vary with regard to whether or not non-disabled members can serve in leadership positions or on their boards. Some of these organizations own and operate services for disabled people and are thus in some cases employers of staff and specialists, as well as being interest organizations. Six interviews were conducted with leaders of established organizations. Of these six leaders, three were disabled and three non-disabled. In addition, five interviews were conducted with leaders of activist groups; in the case of a horizontally organized group, a representative was interviewed. The activist groups referred to in this paper are all comprised of, run and directed by disabled people. All five leaders interviewed were disabled. The groups and organizations represented varied considerably with regard to how long they had been operational, ranging from less than five years to more than fifty. Membership also varied greatly, with one of the three established umbrella organizations claiming approximately 30 thousand members, with some of the activist groups having fewer than 50. This fact was not considered to be of concern as the focus of the study was predominantly on their views and experiences with regard to the ability of disability groups and organizations to participate in policy and decision making on matters of concern to disabled people.

All the interviews were conducted in Icelandic and direct quotations were translated by the first author of this paper. In addition, keeping in mind the small size of the Icelandic population, both names and identifying details have been omitted to the extent possible to ensure confidentiality. All participants gave informed consent and agreed to have the interviews recorded. In one instance, a list of topics to be discussed was provided in advance to give room for preparations.

2.2. Comments on the Draft Legislation

Following the initial discussion by Althingi (the Icelandic Parliament) during its 146th session (2016–2017) of the draft legislation on "Laws pertaining to services for disabled people with significant support needs", it was sent to the Althingi's Welfare Committee, which opened it for public comment. A total of 36 comments on the draft legislation were submitted by public, private and academic institutions, as well as groups, organizations, associations, local authorities and individuals. Of these, 12 were submitted by 10 different disability groups and organizations (Althingi 2017a). (Two organizations submitted two comments).

The comments submitted by disability groups and organizations differed in scope. A number of the organizations submitted comments that were primarily focused on areas specific to the interests and needs of their membership. This includes the Communication Center for the Deaf and Hearing-Impaired (Samskiptamidstöd heyrnarlausra og heyrnarskertra), which primarily focused on the draft's omission of reference to disabled deaf citizens, as Icelandic sign language is now recognized as an official language in Iceland (Althingi 2011). In the same manner, the Center for User-led Personal Assistance (CUPA) (NPA Midstödin) focused predominantly on the need to secure the right to personal assistance, as did the Icelandic Federation of Physically Disabled People (Sjálfsbjörg) and the Association of Rehabilitated People with Spinal Cord Injuries (Samtök endurhæfdra mænuskaddadra), for the most part. These and other comments that do not relate to the focus of the paper are not addressed in the findings.

Four of the 10 disability organizations that submitted comments on the draft legislation addressed the issue that is the focus of this paper—the active participation of disabled people and their representative organizations in policy and decision making processes on issues that concern them—but to varying degrees. The paper examines predominantly the comments of two of the organizations, the umbrella organization the Organisation of Disabled in Iceland (ODI) (Öryrkjabandalag Íslands) and the activist feminist disability group Tabu, as these two organizations made the most extensive comments relating directly to the subject of the paper. The two other organizations that touch on the issue, the umbrella organization the National Association of Intellectual Disabilities (NAID) (Landssamtökin Throskahjálp) and CUPA, did so without making it a focus area of their comments in the same manner that ODI and Tabu did.

The analysis of the data, as it pertains to the interviews and the comments submitted by the representative organizations was based on an inductive process (Creswell 2009). To analyze the data, the grounded theory method was employed. This method reflects the premise that theory can be developed from rigorous analysis of empirical data (Charmaz 2014). In keeping with this approach, the collection and analysis of data was directed by the constant comparative method of grounded theory. This method calls for data gathering to be continued while data is simultaneously coded and analyzed, and analytical memos developed, with the goal of identifying central themes to help direct further data collection and theory building (Charmaz 2014). The goal of this approach is to identify central themes while the process is ongoing to help direct further data collection and theory building (Charmaz 2014). To this end, interviews were conducted in three intervals, in December 2016, April 2017 and July 2017, until it was concluded that new information obtained had ceased to provide further insight. Initially, broad questions were posed to leaders of the representative organizations about their approaches to advancing the rights of disabled people. As the research progressed and themes began to emerge from the analysis of the interviews, the questions were narrowed. The interviews were recorded, transcribed and coded. Coding consisted of detailed reading of the transcripts followed by sorting and organization of the codes, revealing patterns in the data that helped develop a deeper understanding of the issues at hand (Creswell 2009). Based on the findings, the information relating to the theme of this study was selected and further analyzed.

3. Findings

On 17 February 2014, the Icelandic Minister of Social and Housing Affairs established a working group tasked with drafting the new legislation on services for disabled people; it completed its work in October 2016. The draft legislation (Althingi 2016–2017) opened for comments toward the end of Althingi's 146th session in the spring of 2017, was based on the group's proposal. The working group was initially comprised of 12 persons, who included the appointed representatives of Althingi, government ministries, local authorities, and several interest groups and NGOs, including two umbrella organizations representing disabled people, ODI and NAID.[2] Representatives of organizations representing disabled people thus made up only one-sixth of the working group, or 17%. In addition, only one of the two representatives designated by these organizations was a disabled person. This person resigned in March 2015 and was replaced by a non-disabled person. As a result, for 19 months no disabled person served on the working group.

The two umbrella organizations representing disabled people on the working group are also the two representative organizations of disabled people that have the right, according to Icelandic law, to be consulted on policy and decision making on issues affecting disabled people. It is important to note here that neither fulfills the criteria established by the CRPD Committee in its Guidelines on the

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[2] An additional representative of the Ministry of Welfare was added at a later date.

Participation of Disabled Persons' Organizations (DPOs) and Civil Society Organizations in the work of the Committee (Committee on the Rights of Persons with Disabilities 2014b). DPOs, according to the Guidelines, are organizations that are "comprised by a majority of persons with disabilities—at least half of its membership—governed, led and directed by persons with disabilities (Committee on the Rights of Persons with Disabilities 2014b). Following the example of Sturm et al. (2017), this paper will henceforth use "disability organizations" (DO) as a general term when both organizations that do and do not fulfill the criteria are concerned.

The comments submitted by ODI and Tabu on the draft legislation stand out as both the most comprehensive and critical in nature. They are also the most relevant to this discussion as they make the issue that is the subject of this paper—ensuring the active involvement of disabled people and their representative organizations in policy and decision making processes on matters that concern them—a special focus of attention. Their comments provide valuable insight into how they perceive their ability to be heard by the authorities and to affect the policymaking process.

The two other representative organizations that address to some extent the issue of active involvement are NAID and CUPA. In the case of NAID, which like ODI, was part of the working group tasked with drafting the new legislation, it expresses frustration in one instance about not being heard on its objection to the omission of a requirement for a minimum number of residents living in a service area. In addition, NAID emphasizes the importance of ensuring active consultation with disabled people and their representative organizations with regard to future regulations to be set by the Ministry on the basis of the draft legislation. In a second comment, NAID stresses the need to ratify the Optional Protocol to the Convention to strengthen the ability of disabled people to pursue their rights in their interactions with the authorities. As for CUPA, it had been granted observer status in a project group established in 2011 by the Ministry of Social and Housing Affairs to lay the groundwork for the introduction of personal assistance as a legally mandated service option in the draft legislation. In its comments on the draft legislation, CUPA states that comments received from DPOs had been taken into account in the proposal submitted by the project group to the working group, which then incorporated them into the draft legislation. In other regards, the comments submitted by NAID and CUPA do not focus on the subject of this paper.

Pointing to the obligations stated in the CRPD, both ODI and Tabu strongly criticize the very limited amount of time granted to civil society for the submission of comments on the draft legislation (Althingi 2017a). "It is important to note that this way of working is very inaccessible and unprofessional, and contradicts the objectives and principles of the CRPD," states ODI. When the legislation was initially opened for comments, only 10 days were allocated to the process. The perceived rush led the DOs to comment that the lack of time devoted to the process was in contravention of the CRPD, which places an obligation on states to ensure the active participation of disabled people and their representative organizations. The Welfare Committee of Althingi, which was responsible for reviewing the draft legislation before submission for further parliamentary action, responded to the criticism at its meeting of 29 May 2017 (Althingi 2017b). It recognized its obligation pursuant to Article 4(3) of the CRPD and suggested that further parliamentary action on the draft legislation be postponed so that additional time could be given, until 7 September 2017, for comments to be submitted.

3.1. Organisation of Disabled in Iceland (ODI)—The Ability to Affect Outcomes

One of the concerns expressed by ODI is that the draft legislation does not sufficiently reflect the need to ensure the full participation of disabled people through their representative organizations in policymaking in matters pertaining to them, as stated in Article 4(3) of the CRPD. "The authorities have failed greatly in its compliance with this Article," ODI states in its comment (Althingi 2017a). Furthermore, ODI emphasizes the need to clarify that wherever the draft refers to "participation", the wording "active participation" should be used, and suggests that the law specify in certain articles collaboration with umbrella organizations. ODI cites Kumpuvuori and Virtanen's (2017) analysis of what constitutes full DPO participation, according to which two conditions must be met, the first being that the participation of DPOs extend from the very beginning of the policy formulation process to the very end, and, secondly, that the opinions, perspectives and suggestions presented by DPOs are taken into account and not ignored. Keeping in mind that ODI is one of two DOs appointed to the working group that drafted the legislation and that it participated from when it was first convened until the conclusion of its work, ODI's criticism seems to be directed more toward the second point, that is a lack of meaningful participation, where the perspectives and suggestions made by the DOs are not taken into account in the policy outcome. ODI's comments on the draft legislation, which are both extensive and critical, seem to bear this out.

Among the issues raised by ODI are the need to review and rewrite a number of articles of the draft legislation to sufficiently reflect the intent of the CRPD. Furthermore, it points to the need to redefine the definition of disability contained in the draft legislation's first Article on Objectives to sufficiently reflect the CRPD's understanding of the interplay between society and impairment. "ODI respectfully suggests that a real collaboration with disabled people, their representative organizations and academic institutions take place in order to avoid inconsistency" in how disability is defined (Althingi 2017a). ODI points out that the draft neglects to sufficiently state the right of disabled parents to assistance, as stipulated in the CRPD, Article 23(2), and to a lack of understanding of the independent living ideology behind personal assistance. All in all, ODI proposes changes in one form or another to about half of the 42 articles of the draft legislation, suggesting that despite having participated in the work of the committee, its perception is that it was not sufficiently able to affect the policy outcome. ODI's overall position is summed up with the comment that if the proposed legislation becomes law, it is clear that the Icelandic state still has a considerable distance to go to achieve compliance with the CRPD (Althingi 2017a).

3.2. Tabu—Giving a Voice to Disabled People Themselves

In its comments, Tabu also criticizes what it maintains is a lack of meaningful involvement by disabled people and their representative organizations in the drafting of the proposed legislation. Unlike ODI's criticism, which seems to be predominantly concerned with not being able to affect policy outcomes, Tabu focuses on disabled people themselves being given a proper voice and recognized as having valuable expertise to offer.

Tabu's criticism is two-pronged. First, it criticizes the inadequate representation of disabled people and their representative organizations in the working group preparing the draft legislation, which amounted to 17% of the membership (Althingi 2017a). To rectify the problem, Tabu suggests increasing the number of representatives of disabled people. Secondly, Tabu criticizes the fact that the participation of disabled people themselves is not ensured and points out: "According to the current law on the affairs of disabled people, ODI and NAID are the only ones with the legal right to be consulted on matters pertaining to disabled people. It's clear that times have changed and it is appropriate to increase the number of seats for disabled people at the table where decisions are made," Tabu further states in its comments on the draft legislation. "ODI and NAID have made important contributions in the past decades in the fight for disabled people's rights but it is clear that it is very problematic that more often than not they send non-disabled people to the table. This is in contradiction with the CRPD." (Althingi 2017a). Tabu draws attention to the need to make a clear distinction between the two types of disabled people's organizations, those that are led by disabled people and those that are led by non-disabled people representing disabled people's interests. Or, put another way, organizations of disabled people and organizations for disabled people. This echoes the importance that the CRPD Committee attaches to this distinction, as evidenced by its Guidelines on the Participation of DPOs (Committee on the Rights of Persons with Disabilities 2014b).

In its comments, Tabu emphasizes that the expertise of disabled people when it comes to their needs and lives, based on their own lived experience, must be effectively harnessed in policy and decision making. To this end, Tabu offers its expertise, in addition to identifying two other activist groups comprised of and led by disabled people themselves, CUPA and the Self-Advocacy Group of People with Intellectual Disabilities (Átak—Félag fólks med throskahömlun), and calls for all three to be given consultative status on issues pertaining to disabled people's affairs on an equal footing with the two umbrella organizations stating that, "All these groups are led by disabled people and our contribution, knowledge and experience are a necessary addition to working groups, committees and other policymaking that concerns disabled people." (Althingi 2017a). In addition, Tabu emphasizes the CRPD's call to also include the participation of disabled children and youth. The increase in representation suggested by Tabu would have raised the percentage of disabled people and their representatives to about 30% of the working group's membership, which, for the purposes of comparison, is closer to what Sherlaw and Hudebine (2015) report being the case in France, for example. Furthermore, it would have ensured the inclusion of at least three disabled people. Tabu maintains that such a change would not only lead to a better work product, drawing on the expertise and lived reality of disabled people themselves, but also serve to empower disabled people by giving them an opportunity to serve in such a capacity. Tabu points out how challenging it is for a single disabled person to be put in a position of having to face a committee comprised almost exclusively of non-disabled people, many of whom represent the interests of the authorities.

3.3. Interviews with Leaders—Pro Forma Consultations

The experience of not being "heard" by the authorities and not being able to affect policy outcomes, is supported by the findings of the in-depth interviews that this paper draws on. While the leaders of the established organizations focus primarily on advancing the rights of disabled people through collaboration with authorities, they shared with the activist groups interviewed the experience of having difficulty at times being heard by the authorities in the sense that their comments and suggestions were either not taken into account in the formulation of policy or in other ways acted upon. A lack of funds was frequently cited as a reason for inaction. "You experience an incredible reluctance," said a leader of an established organization. Another commented: "And of course, we always get the same answer. It doesn't matter what issue category you ask about, it's always just money." Reflecting on the collaboration with the authorities, one of the leaders stated "sometimes it feels to me as if it's pro forma. They have to include us. And then it's like decisions have already been made at some kind of pre-meeting, where you have the feeling that all the decisions have been made in advance." A leader also mentioned having to remain vigilant about ensuring that the comments made by DO representatives were included in minutes of the meetings. A leader of an activist group recounted similar experiences and reported feeling that other meeting participants were sometimes either not interested in what he had to say or just ignored his comments.

The issues highlighted by Tabu also find support in the in-depth interviews with leaders of other activist groups. They reveal feelings of frustration over not being given due access to decision making bodies. "We are the ones who have experienced disability on our own skin. Without this experience, it is really impossible for people to fully understand," stated a leader of an activist group. Another leader expressed a similar sentiment, "If you're not disabled, you don't have the experience to draw from. You can't imagine what being disabled is like, no matter how hard you try." A third said "Nobody can properly see things with our eyes." All the leaders expressed the importance of ensuring that disabled people themselves have a leading voice in matters that concern them. Similar to Tabu's comment on the draft legislation, the activist leaders also pointed to the need for the authorities to make more of a distinction between DPOs for disabled people and DPOs of disabled people. "These old organizations have been around for so long," said one leader. "Sometimes you get the feeling that they're protecting the rights of their staff or the interests of some system. Maybe it's a bit difficult to sit on both sides of the negotiating table," said one leader referring to the fact that some of the established organizations own and operate services for disabled people.

The activist leaders also reported a lack of responsiveness on the part of the authorities and a feeling of being ignored at times when trying to speak up for disabled people's interests. "Sometimes we feel that because we are critical of the system, we are not popular with the authorities and they want to minimize their engagement with us," stated a leader of an activist group. The leaders described how they sought to counter this apathy and to gain recognition of disabled people as experts in their own affairs and as leaders in the fight to secure full rights, a role that has traditionally been occupied exclusively by others. The means they employed were intended to establish disabled people themselves as the ones on the front lines, speaking up, taking to the streets in demonstration, delivering declarations to the authorities, taking the initiative of drafting proposed legislation for submission to the authorities, and writing and publishing first-person accounts of the lived realities of disabled people (Löve et al. 2017).

3.4. The Active Participation of Disabled People

The data gathered indicates that there is less focus on ensuring the participation of disabled people, and thereby the lived experience of disability, among both the established DOs and the authorities, compared to activist groups made up of and run by disabled people themselves.

The draft legislation under consideration in Iceland does not include a reference to the criteria contained in the guidelines issued by the CRPD Committee on what constitutes a DPO, and therefore seems to lack the emphasis embodied in the CRPD on ensuring the inclusion of the lived experience of disability in decision making. While the draft legislation stipulates, in Chapter 1 on Objectives and Definitions (Article 1) and Chapter 2 on Governance and Organization (Article 4), that disabled people shall have the opportunity to actively participate in policy and decision making that relate to their affairs, other articles refer to consultations with representative organizations without specifying how such organizations should be defined (Althingi 2016–2017). In Althingi's first discussion (and only one to date) of the draft legislation, on 2 May 2017, one member of Althingi raised the need to clarify how disabled people and service users would be able to convey their views on matters that affect them. "This whole regulatory framework is rather confusing," she noted, "and points to a lack of a coordinated strategy as to how consultations with users, representative organizations and others will be managed". Changes to the decision making process were otherwise not mentioned and there was no discussion of the need to increase DPO representation, as defined by the CRPD Committee. Nor did the Minister address the issue in his response to questions.

While being critical of the process, ODI does not raise the need to increase the number of DOs with the right to participation on matters pertaining to disability issues, nor does it mention the need to ensure the inclusion of disabled representatives. ODI does suggest the addition of a sentence to a number of articles of the draft legislation stating the obligation to engage in active collaboration with umbrella organizations, thereby excluding the grassroots and activist groups. There is only one reference to the need to include disabled people themselves, in ODI's comments on Article 9 on housing where it suggests adding a reference to active collaboration with disabled people and their umbrella organizations, while again excluding reference to other types of organizations (Althingi 2017a).

Finally, as stated earlier, the Welfare Committee of Althingi, in its meeting of 29 May 2017, responded to the comments it had received at that time. While suggesting an extension of the time provided for submission of comments and that consideration of the draft legislation be delayed until Althingi's fall session of 2017, the Committee did not suggest accommodating changes that would either increase DOs representation in general or ensure the participation of disabled people themselves. Furthermore, nor did it in general respond to other comments and criticism concerning the need to ensure the active participation of disabled people and their representative organizations.

4. Discussion

The drafting process initiated by the Icelandic authorities, intended to align Icelandic disability law with the CRPD, was criticized by both ODI and Tabu as inadequate in terms of ensuring the full participation of disabled people and their representative organizations in setting laws and policies pertaining to their rights and matters that concern them. Referring to Article 4(3), ODI stated that "[t]he authorities have failed greatly in its compliance with this article" (Althingi 2017a). However, the two

DOs criticize the process from different perspectives. ODI, which was involved in the drafting process from start to finish, is critical of the policy outcome and submits extensive and critical comments on the draft legislation. In its comments, ODI calls attention to the fact that having representation doesn't ensure a DO's ability to impact outcomes if its suggestions and opinions are ignored. The experience of not being able to affect decision making, even when participating in the decision making process, is not unique to ODI or the leaders of the Icelandic DOs interviewed. A study carried out in nine European countries on the ability of organizations representing disabled persons to affect the implementation of the CRPD on a national level found mixed results, with some organizations reporting having difficulty affecting policy outcomes despite being represented in the process (Waldschmidt et al. 2017). Other international research—including in Italy (Biggeri et al. 2011); Bulgaria (Mladenov 2009); Canada, the U.S. and the U.K. (Levesque and Langford 2016); and Africa (Lang et al. 2011)—has also pointed to mixed results with regard to the ability of DOs to affect policy and have concluded that both structural and attitude changes are needed, as well as ensuring sufficient resources and capacity building among disabled people and DOs, to effectively participate in policymaking processes. There is, however, as stated earlier, a need to differentiate between, on the one hand, the right to full and active participation in the policymaking process on equal footing with others, and, on the other, the demand that one's opinions, perceptions and suggestions be included in the policy outcome. Such a demand, which this paper does not make, can be seen as running counter to the principles of representative democracy, which allocate the ultimate policymaking power to elected representatives.

While ODI focuses on its impact on the policy outcome, Tabu and the other activist groups focus predominantly on the lack of recognition of the need for disabled people themselves to be a part of the policymaking process. As the composition of the working group bears out, DOs had very limited representation during the drafting of the legislation. In addition, for more than a year-and-a-half (19 months), the working group did not have any disabled persons among its members. Moreover, no representative organizations made up of, run and directed by disabled people—the criteria established by the CRPD Committee—were represented in the working group. This lack of significant participation is in stark contrast to the prominent focus on the participation of DPOs and disabled people themselves during the drafting of the CRPD, an emphasis that became embedded into the Convention, and is reflected in its recognition of the lived experience of disability and that the persons most affected have the right to participate in decisions that impact them (Stein and Lord 2010).

The two other DOs that comment on participation in decision making, NAID and CUPA, are less critical in their comments, with CUPA expressing a positive experience in the project group that worked on articles of the draft legislation pertaining to personal assistance. Like ODI, NAID has a seat at the table in the established policymaking process and may, therefore, have less of a reason than those not included to suggest changes to it. Moreover, as the interviews reveal, the leaders of the established organizations express a commitment to working within the established process. This may also apply to the other established organizations that did not address the issue of participation in their comments on the draft legislation. CUPA, for its part, has succeeded in gaining partial access to the process on the one issue that dominates its agenda, personal assistance, and that may explain why—when it comes to this matter—it does not specifically address the need for change. As for the activist groups, which do not have access to the process as it is currently constructed, one can speculate that they may feel that the process is so closed and the barriers to entry so high that they do not feel sufficiently empowered to demand access. As Sherlaw and Hudebine point out, all participatory processes involve tension. "Participation of the vulnerable and needy often involves institutions and persons giving up a degree of power, which is no easy option, and is often unwelcome and strenuously resisted" (Sherlaw and Hudebine 2015, p. 15). Changing the status quo requires a radical approach. Tabu has challenged the status quo by demanding entrance, possibly leading the way for others.

The importance of the participation of disabled people in policy and decision making is emphasized by Young and Keys, who point out that without disabled people's active contribution and involvement in setting the political agenda, defining the issues that relate to their lives from their own perspectives and needs, their marginalization will be maintained, leaving in place laws that have created and maintain their historical disadvantage (Keys 2017; Young 1990). The work of the Icelandic activist groups, and Tabu's comments on the draft legislation, reflect Young's and Keys's positions. Furthermore, they embrace Smith's position on the validation of everyday lived experience as knowledge. This understanding is also echoed in the responses by the leaders of the activist groups interviewed; they assert that only with the lived experience of disability can one fully comprehend "what it is really like", underlining the importance of disabled people themselves having a leading voice in matters that concern them.

The Icelandic activist groups have set out to change the perception of disabled people as lacking the capacity to be in charge of their own affairs, and to introduce and gain recognition of this position in the political arena. However, as the draft legislation and the response of the Welfare Committee to the comments received show, their efforts seem to have made limited inroads with the authorities and the established disability organizations.

The draft legislation makes no reference to establishing the participation of DPOs as defined by the CRPD Committee in its guideline for DPOs, which would ensure recognition of the lived experience of disability and pave the way for changes to the process norms with regard to how disability policy is made. This is of particular concern as ODI and NAID, the two representative organizations that have the right to consultative status on disability issues according to Icelandic law, and which therefore represent the interests of disabled people in shaping policy and legislation, fail to meet the CRPD Committee's criteria for DPOs (Committee on the Rights of Persons with Disabilities 2014b).

Furthermore, it is of interest that while ODI, for its part, emphasizes the need to ensure full and effective participation, it does not suggest increasing the number of representative organizations that have consultative status in order to strengthen and embolden the voice of the disability community, nor does it suggest that disabled people themselves be ensured representation. Further, ODI appears to actively distance itself from organizations by disabled people by stating in its comments on the draft legislation that "consultation with umbrella organizations for disabled people", to the exclusion of other types of disability organizations, should be specified in three articles of the draft legislation (Althingi 2017a).

The Welfare Committee, which makes suggestions on changes to draft legislation during the legislative process, before Althingi votes on it, did not in its meeting of 29 May 2017 address Tabu's request to increase the overall representation of DOs on matters pertaining to disability, or the request to ensure the participation of disabled representatives. To date, the Committee appears to have paid little attention to calls for increased and effective participation by disabled people and their representative organizations, apart from its decision to extend the time for submitting comments from the initial ten days to over three months. In that instance, the Committee stated that its decision to do so was in recognition of its obligations under Article 4(3) of the CRPD (Althingi 2017b).

As far as the process of aligning Icelandic disability law with the CRPD is concerned, there seems to be a reluctance to fully embrace the fundamental principle reflected in the CRPD, that the persons most affected have the right to participate in decisions that impact them (Stein and Lord 2010). The CRPD's call for new process norms with regard to how disability policy is made seems to require more changes to the current consultation process than the Icelandic authorities are prepared to initiate. This is particularly the case with regard to making a distinction between the two types of representative organizations, ensuring the participation of disabled people themselves, and recognizing the value of their contribution and their expertise based on their everyday lived experience of disability.

This draws attention to Quinn's point that there is no guarantee that by setting laws, new values will be internalized (Quinn 2009, p. 216). The lack of confidence in the ability of disabled people to be in charge of their own affairs is deeply rooted. Throughout history, disabled people have been identified as different, kept at the margins of society and perceived as having little to contribute (Braddock and Parish 2001). Their status as non-producers and dependents led, in great part, to their segregation and marginalization, and robbed them of the opportunity to participate as citizens and exercise full civic and political rights (Snyder and Mitchell 2006).

Article 4(3) sets out to create a new politics of disability. It calls for changes to the process norms with regard to how disability policy is made. In the past, disabled people were commonly excluded from the process of policymaking on matters that pertained to them, reflecting the position of the medical model on disability, which views disabled people as having to be taken care of and managed by others. The result has been laws that have mostly fallen short by curbing the rights of disabled people and their quality of life. By expanding the policymaking process as Article 4(3) of the CRPD does, to include disabled people through their representative organizations, it enables a new politics of disability to emerge. The laws and policies produced as a result are likely to better serve and reflect the needs and perspectives of disabled people themselves. However, in order to live fully up to the intent of the CRPD and its emphasis on incorporating the lived experience of disability, it is important that States Parties adopt the CRPD Committee's criteria as to what constitutes a disabled people's representative organization, namely that they are governed, led and directed by persons with disabilities.

It is important to recall that the full and active participation of disabled people should not be taken to mean that their opinions, suggestions and comments will automatically translate into law and policy outcomes. Rather, the new politics of disability bring disabled people and their representative organizations into the democratic process as contributing participants in the development of solutions to policy issues that take into account different perspectives and needs, in addition to their own. Thus, Article 4(3) should be seen to describe a process whereby social policy is co-produced.

5. Conclusions

The findings indicate that the new draft legislation on disability services in Iceland does not sufficiently embody the Convention's call for changes to the process norms with regard to how disability policy is made. The new process calls for the active involvement of disabled people through their representative organizations, as defined by the CRPD Committee in its guidelines on DPOs, that are led and directed by disabled people. The criteria established by the Committee are aimed at ensuring that the lived experience of disability is incorporated into the policymaking process. It seems that this priority is not given due attention in the draft legislation, which makes no reference to the need for changes to the current process to ensure that the lived experience of disability is brought to bear in policy and decision making. The limited representation of DOs, and the fact that those represented do not meet the CRPD Committee's criteria for what constitutes a DPO, is a cause for concern. It seems to contradict the fundamental principle embodied in the CRPD that those most affected have the right to participate in decisions that impact them. Accepting disabled people as full participants with valuable knowledge and expertise means letting go of ingrained perceptions of disabled people as lacking in capacity for decision making and management of their own affairs. With this in mind, it is important to recognize that the call for a new politics of disability embodied in Article 4(3) of the CRPD provides a path forward toward the co-production of social policy with the active and effective contribution of civil society. The need to fully take into consideration the CRPD Committee's criteria for how to define DPOs in the context of the CRPD may be of relevance to other States Parties as they align their national legislation with the Convention as part of the ratification process. Furthermore, the co-production of social policy described above may have a wider application, not exclusive to the case of disability policy but to social policy making in general.

Author Contributions: Laufey Löve and Rannveig Traustadóttir conceived and designed the study; Laufey Löve carried out the research and had the lead role in analyzing the data; Laufey Löve, Gerard Quinn and Rannveig Traustadóttir contributed to defining the analytical direction and legal context; James Rice contributed to the theoretical context of the study; Laufey Löve wrote the paper; Rannveig Traustadóttir, Gerard Quinn and James Rice contributed to editing.

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3

Reconsidering Sheltered Workshops in Light of the United Nations Convention on the Rights of Persons with Disabilities (2006)

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Abstract: Sheltered work and related practices remain a prevalent service for people with intellectual disabilities. However, as a result of being placed in these, participants overwhelmingly remain segregated and excluded from their wider communities. This paper explores whether, with the advent of the United Nations Convention on the Rights of Persons with Disabilities, we can at least begin to assess the equality implications of such placements and argue that the experience of segregation itself represents numerous rights violations and discrimination. Having considered traditional equality mechanisms and their bearing on people with intellectual disabilities, this discussion explores how far the Convention's re-envisioning of the basic principles of equality can perhaps provide a more promising outlook and ideological stance. Indeed, during the Convention's inception, the negotiations circled around the conflicting opinions as to the purpose, usefulness, and future of sheltered work, revealing the existing tensions between protection and autonomy, shrouding all disability policy discussions. As a result, the question of sheltered work is not explicitly addressed in the treaty and the Committee on the Rights of Persons with Disabilities have been unable to definitively declare that the practice of sheltered work constitutes an act of discrimination. However, the Committee does as times demand that sheltered workshops be phased out where it is obvious that the practice of sheltered work is directly linked to the exploitation of workers. Moreover, certain provisions in the Convention might help in determining wrongful discrimination in some, if limited, instances.

Keywords: intellectual disability; sheltered workshops; United Nations Convention on the Rights of Persons with Disabilities; equality; dignity; discrimination

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1. Introduction

People with intellectual disabilities face considerable barriers in accessing employment in mainstream settings. These are largely attitudinal as well as systematic. Often a robust system of disability services and disability benefit payments, operate to deter people from becoming emancipated and independent from the rigid structures of traditional, all encompassing institutions. As a result, people with intellectual disabilities remain segregated from mainstream society. This paper aims to question this segregation and consider how the practice of placing people with intellectual disabilities in sheltered work settings contributes to their segregation and exclusion.

Specifically, this discussion will address how the widespread segregation of people with intellectual disabilities has persisted in light of evolved conceptions of equality. Arguably this segregation is founded in inequality as the result of unequal treatment. Despite the evolving nature of equality then, its development has not seen an equal regard of all members of society. This failure to encompass some groups of society can perhaps be rectified when we revisit the core purpose of existing human rights frameworks. This involves identifying the main purpose of equality which lies in bestowing upon each individual an equal concern for their inherent dignity. A renewed global commitment to equality as presented by the latest international human rights convention adopted in 2006, the United Nations Convention on the Rights of Persons with Disabilities (CRPD; Convention), will be assessed according to its potential to strengthen arguments against segregated policies such as sheltered work.

As the latest human rights treaty and the first to deal with disability specifically, the CRPD was eagerly awaited. The global disability community anticipated that it would bring about a sea change for all persons with disabilities based on its innovative approach to disability equality. Indeed, the treaty did deliver on this front and has prompted a widespread process of disability reform (Quinn 2009). However, some argue that it does not positively impact the lives of all persons with disabilities evenly (Dimopoulos 2010). Others consider that, even though they are equally entitled to benefit from the provisions of the Convention, people with intellectual disabilities have faced marginalization to such an extent that they are often not well placed to gain from its changes (ILO 2011). This paper therefore attempts to test how the Convention will fare in light of the on-going controversy over sheltered workshops and explore how far the treaty may instigate policy changes for people with intellectual disabilities.

The Problem with Sheltered Work

Before we begin our discussion we should perhaps explore the concept of sheltered work and adopt a working definition of practices included thereunder. This will not only highlight the existing concerns related to the practices but simultaneously also clarify why sheltered work is a suitable example to use in contemplating the reach and strength of the Convention. The act of placing persons in sheltered workshops was predominantly chosen because of its tangible effects experienced overwhelmingly only by persons labeled as having an intellectual disability. Thus, they provide a unique angle from which to address the debate over segregation and its justification. Moreover, the example of sheltered work was chosen based on the prevalence of segregated work and employment policies across the globe. Besides quota systems, sheltered employment, in its varied formats is one of the most widely used employment measures for people with disabilities across Europe (Mallender et al. 2015). Germany and Spain even reported a growth in sheltered workshop placements (Shima et al. 2008; Flores et al. 2011) and Dague (2012) finds that 75% of adults with intellectual disabilities in the US remained in sheltered work settings despite claims of exploitation (Kennedy 2007; Diament 2011; Cohen 2014). Even international bodies such as the Organization for Economic Co-operation and Development report of the on-going significance and widespread use of segregated employment settings in the wake of controversy (OECD 2003).

Despite their global popularity, there are perhaps as many common markers that denote a similar practice, as there are national, regional and context specific characteristics of the sheltered workshop. Based on the divergent and context-specific approaches, arriving at a distinct definition of sheltered work is therefore almost impossible. In light of these considerable difficulties, the International Labour Organization consider that, for the purposes of general discussions of these, sheltered workshops might best be understood as a conceptual idea rather than a definite employment policy (2003). It is therefore important to note that the term sheltered work, as it is used herein, denotes that act of placing predominantly people with intellectual disabilities in sheltered employment or work facilities where they are subject to atypical working conditions, for an extended period of time.

These defining markers are chosen based on their prevalence across welfare and employment systems globally, but other common indicators exist. For example, as is evident from their name, sheltered workshops are facilities that are ‘sheltered’ from general or regular work settings, often even geographically located in insulated and isolated places. These work settings are usually run by non-governmental organizations, for-profit or charitable organizations, either privately or on behalf of the State (Samoy and Waterplas 1992). Commonly, these protected environments almost exclusively provide work for people with disabilities, alongside other disabled people (Mallender et al. 2015). The tasks are usually carried out under the instruction of supervisors or trainers, involving the employment of persons without disabilities to support production and regulate the working environment. Comparative studies have discerned that with a few exceptions, sheltered work implies a manufacturing industry, often on a sub-contract basis (OECD 1992, 2003). The simple work activities undertaken can range from clerical activities to, assembling, packing, woodwork, manufacturing, servicing, sewing, or sheet metal work (Miglioire 2010). Other reports however point to the meaningless nature of the work conducted in the sheltered workshop (Holmqvist 2009).

The differences in approaches, on the other hand, prove to be perhaps one of the most discernable problems when discussing the phenomenon of sheltered work. These are also significant and arise from the varied approaches and opposing views as to the purposes and objectives of the sheltered workshop. Tracing the history of these institutions reveals that largely sheltered work settings have evolved from religious or medical institutions and were therefore run according to an ethos of charity and medical treatment. As a result, sheltered workshops, besides their employment and work objectives, can often continue to be regarded as therapeutic, rehabilitative, or specialist training provisions and are intertwined with States' health and social policy measures. This hybrid of treatment, training, and work interventions gives sheltered work settings a broad mandate and makes comparisons difficult and at times confusing.

Accordingly, such settings can also operate according to varied ideologies and headings, which can range from 'Work Centre' in the US to 'Occupational Activity Centre' in Portugal. Such irregularity can lead to unclear or confusing legal statuses, rendering participants in these systems as eternal clients or patients, as opposed to fully fledged workers (Visier 1998; Mallender et al. 2015). Particularly in Eastern European States, this has had alarming effects, where people remain isolated and exploited in sheltered workshops that are run as large institutions (Franičević 2008). Elsewhere, these uncertainties concerning sheltered workshop attendees has resulted in court cases taken by individuals challenging their non-worker status in Germany, Austria, and France with varied success (Court of Justice of the European Union 2013).

These cases and claims of exploitation are also often linked to debates over pay and wages in sheltered workshops. Despite national minimum wage regulations, these are often exempt from such regulations, as they are usually not regarded to be a typical work environments. This is the direct consequence of denying workers in sheltered workshops the formal recognition of their employment status (OECD 1992). Advocacy organizations, however, arguing for equal rights contend that some participants in sheltered workshops are entitled to receive a minimum wage because their working conditions are comparable to that of an employee (Inclusion Ireland 2007). The issue of pay is therefore a particularly controversial one, which has been fuelled by recent media reports revealing that the CEOs of sheltered industries and charities receive six-figure salaries, yet continue to exploit their workers in the US and in Ireland by paying sub-minimum wages (Holland 2007; Schecter 2013; Deegan 2015).

A review of the quantitative data available showed that across 24 American states on average sheltered workers earned $101 per month for approximately 74 h of work per month (Migliore et al. 2007). Low wages are a characteristic of sheltered workshops beyond the U.S. and a persistent feature of sheltered workshops on a global scale. In fact, most comparative research studies on sheltered work address the issue of low remuneration received by participants (Samoy and Waterplas 1992; Visier 1998; Mallender et al. 2015). The issue of payment has also been bought to the attention of international bodies such as the International Labour Organization, which heard a complaint against Japans 'welfare factories' alleging that their workers' low wages violated the relevant ILO Conventions (ILO 2009).

There are, however, opponents to the idea of paying sheltered workshop workers a minimum wage, as well as staunch advocates of the segregated system in general (Price 2016; Moore 2017). These represent more protectionist views of disability policy generally. This camp argues that, without such facilities, people would be left stranded with nothing to do. Moreover, without legislative exemptions, these would not be sustainable as a business, as sheltered workshops are generally not profit-making businesses. In fact, some run at a loss and are heavily reliant on state subsidies and grants. Others argue that the discussions over low wages in sheltered workshops are moot, as the payments received are not comparable to a wage, rather they are top up payments, received in addition to benefit payments (O'Reilly 2007). Others contend that sheltered workshops must continue as some individuals with disabilities will never receive a proper wage due to their inability to be economically productive and perform work of economic value (Corley 2014). Sheltered workshops then at least offer protection from the open labour market and a place for people with disabilities to meet.

Disability scholars have, however, pushed back on these views, arguing that they merely support archaic assumptions that people with intellectual disabilities are unable to work and therefore contribute meaningfully to their societies. This has led Visier (1998) and Taylor (2003) to denounce the sheltered workshop system because it fails to serve people with disabilities but rather contributes to their stigmatization as unproductive, worthless citizens. Even where the sheltered workshop is primarily intended to rehabilitate and treat its participants, disability is largely perceived as an 'incapacity', a label which, as Bach (2016) notes, the sheltered workshop only serves to foster, rather than remedy. Additionally, contrary to the aims of reducing obstacles to employment, the result of sheltered work placements and the effect of segregation often lowers expectations and enhances negative public attitudes making it more difficult for individuals to transition into meaningful employment (Kregel and Dean 2002). As a result of these low transition rates (in Germany, the rate is lower than 1%), persons with disabilities remain in sheltered employment, isolated from their communities (Gottlieb et al. 2010).

Bach (2016) remarks that workplace research shows that intellectually disabled individuals are often more loyal, reliable, and have lower rates of absenteeism compared to other workers. It is then not only the inappropriate wages or low transition rates that are a major factor in the sheltered workshop controversy, but the very reasoning behind the concept of sheltered and segregated workspaces. Unsurprisingly disability activists identify that it is often the negative perceptions and the persistent, underlying perception that people with intellectual disabilities are best segregated, as the toughest barriers to overcome (National Center for Learning Disabilities 2014). This is because, to many, a sheltered workshop placement represents an act of being 'sorted out' and separated from mainstream settings and communities. Instead, a system of 'specialized', disability-specific interventions and 'care' applies, which denies many the opportunities and experiences available to non-disabled peers. This can then be the root of ensuing, consequential symptoms that lead to poverty and an overall inferior legal status. The sheltered workshop system on a whole has thus come to represent a practice that fails to respect people with intellectual disabilities and moreover one that is premised on the denial of rights and opportunities.

As a discrete and insular minority within society, people with intellectual disabilities have been subject to purposeful unequal treatment, institutionalized and segregated to a disproportionally greater extent than individuals without intellectual disabilities. Disability rights campaigners argue that the long-standing practice of placing people in separate, specialist facilities has caused their exclusion, which has been broad in its scope and purposeful (Campbell and Oliver 1996). Often this is a result of systematic policy approaches which are, arguably, fundamentally discriminatory. First, because the very act of placing only persons with disabilities in segregated institutions amounts to unequal treatment compared to those without disabilities who are not placed in these. Second, referring to the common markers and negative outcomes of the placements noted above, in effect those placed in sheltered work settings are often materially poorer and are often denied the same rights as other workers. Overall, attaining substantively equal outcomes for workers in sheltered workshops compared to workers in open and competitive employment is almost impossible. A factor which is aggravated by the length of the placement.

This paper will proceed to argue that this experience of exclusion is largely based on the unchallenged notion that segregation is an inevitable consequence of living with a disability. This exclusion, however, interferes with the equal enjoyment of human rights generally and constitutes a violation of people's dignity. In this way, traditional equality models that consider how to achieve equality for other minority groups have been unable to include the characteristic of intellectual disability in their scope. In response to this shortcoming, this paper argues that we need to revert to the basic promises of equality and human rights law in our attempt to conceptualize an approach to equality that includes people with intellectual disabilities, using the Convention as a framework. This approach will rely on determining that every individual possesses an equal right to have their inherent dignity respected and to lead a dignified life. Using this as the litmus test of equality, this paper will attempt to question whether, considering that the experience of segregation that is so endemic to the practice, sheltered work infringes upon individuals right to lead a dignified life and otherwise interfere with the enjoyment and protection of their rights.

2. Equality

Indeed the practice of sheltered work throws up important debates. This includes considering whether or not such practices are inherently discriminatory, considering the endemic concerns and negative consequences of such placements that largely result from segregation, an integral part of the sheltered work experience. However, discussing whether it is fair or not requires a more contextual debate that reflects on disability equality generally, as well as one that considers the case of intellectual disability specifically. This is undoubtedly necessary considering that, throughout the evolution of equality, the conceptual shifts between formal, procedural, and substantive equality approaches have often failed to reflect on the intricacies of intellectual disability. This is largely due to the limited platforms on which people with intellectual disabilities have been able to advocate for their equal rights and thrash out the meaning of equality from their perspectives. As a result, people with 'severe' disabilities have been excluded from seminal discussions of justice and traditional equality. The field of disability discrimination has thus remained under-theorized and left wanting (Clifford 2014).

Perhaps this is because, in considering the application and limits of existing equality theories in terms of their sensitivity to the case of intellectual disability, we realize that it is still largely expected and accepted that this group will inhabit segregated spaces. Not only does the blanket segregation of this entire group go largely unchallenged, but it is often widely justified based on the group's (perceived) innate inability to attain the merit-worthy attributes to be considered as an 'equal' in the first place (Rioux 1994). These operational (mis-)conceptions as to their ability and therefore their eligibility are perhaps the biggest challenge to equality claims that people with intellectual disabilities face. Undeniably then, any discussion over whether segregation is still an acceptable form of discrimination must build upon practicable, if differentiated notions of equality and its overarching purpose. This will help us in our debate intended to reconsider the practice of sheltered work.

2.1. Is Segregation a Form of Discrimination?

Where academic attention has been paid to discussing how equality and disability intersect, Colker (2009) notes that 'separate' has often been considered as 'unequal' by disability campaigners. Increasingly this has also led to claims that to segregate persons with disabilities from their communities is a violation of their human dignity. Undeniably, these claims have supported arguments to close large, residential institutions and end the horrific practices therein (Brignell 2010). This has particularly gained footing in the US with the help of the landmark *Olmstead* (United States Supreme Court 1999) decision, which determined that people had the (human) right to receive services in the most integrated setting available (Flores 2017). This case was argued on the basis that the unnecessary segregation of persons with disabilities was a violation of their dignity and constituted a form of discrimination contrary to the Americans with Disability Act [1990]. While such a definitive statement of discrimination may not be as easily made in other jurisdictions lacking a similarly powerful civil rights bill, what we can learn from this American example is how central the idea of dignity to disability rights considerations is (Wohl 2016). The concept of dignity and its necessity for a good life featured heavily in finding that the unnecessary segregation wrongly denied individuals their right to access the community and their right to receive services in the least restricted setting (Caley 2010).

Disability scholar Degener (2016b), like Bach, notes that there are some underlying notions intrinsic to the sheltered workshops system that reveal a particularly harmful misconception about 'disability' that consequentially interfere with the respect for an individual's inherent dignity. These create a significant prejudice and serve to continuously justify the segregation of people with disabilities. Degener traces the use of segregated facilities such as sheltered workshops and their legitimacy back to a reliance on particularly two assumptions associated with the notoriously problematic medical model view of disability. This model describes an approach to disability that still determines the disability policy landscape today and continues to have a detrimental impact on the human rights claims of persons with intellectual disabilities under the cloak of protectionism. The first is that disabled persons, above all else, require medical interventions, shelter, and welfare services; a need that can override any consideration for the inherent dignity and autonomy of individuals; and the second is that impairment can preclude legal capacity and interfere with the eligibility for rights claims. In combination, these assumptions distract from the idea that people with intellectual disabilities can make rights claims and that their segregation is inherently discriminatory.

Unsurprisingly then, not everyone is convinced that segregating people into sheltered workshops is the result of discrimination that is harmful and therefore objectionable. Colker (2009) and Brennan-Krohn (2016) for example believe in the need to retain a reliance on disability-specific institutions regardless of whether these interfere with a person's right to choose, lead a dignified life, or effectively segregate certain groups from the rest of society. These equality theorists identify a need for practical approaches to disability policy that acknowledge and reflect upon the 'real differences that sometimes accompany disability' (Brennan-Krohn 2016). Similarly, bioethicists Asch, Blustein, and Wasserman contend (Asch et al. 2008) that the way in which Western society is currently organized, it is inevitable that some people will continue to have their needs singularly met by institutional arrangements.

Explaining why this will particularly continue to apply to people with intellectual disabilities, Brennan-Krohn (2016) elaborates that, while a fully accessible world in which all persons are included and where the difference of disability is fully nullified might be 'relatively easy to imagine for a person who uses a wheelchair', for a person with profound impairments, affecting their ability to interact and communicate, this will be much more difficult to achieve. According to this reasoning, it is then unlikely that the differential treatment of persons with complex disabilities will ever be challenged holistically. In other words, their segregation in a sheltered workshop is not regarded as discriminatory, primarily because they will never be able to take up any other form of employment and therefore be eligible for any other legal status than that of a passive participant, regardless of the substantial disadvantages of the sheltered work placement. The difference of their disability is simply deemed to be too profound to ever warrant any other form of service provision or full entitlement to the range of rights claims that others enjoy. Segregation is then not regarded as a form of discrimination but and inevitable consequence of disability and goes largely unchallenged.

2.2. Equality and Intellectual Disability—An Unhappy Liaison

The pursuit of equality through time has largely focused on ensuring equal rights to all citizens. As a result of this pursuit an interdependent relationship between two modes of rights has developed. This sees an intermingling and interdependence of equality of treatment, i.e., negative, legal rights, and positive, social rights to pursue substantive equality which may indeed require special treatment on a discriminatory basis. Disability scholars agree however that beyond the remit of the formal-substantive dimensions of equality, making rights tangible for people with intellectual disabilities requires additional attention (Silvers 1995; Reicher 2011). In fact, the traditional framework of rights has been notoriously weak in enforcing or protecting the rights of persons with intellectual disabilities. Undoubtedly, this is in part influenced by the preoccupation with solutions and remedies that comprise measurable entities that quantify what an equal outcome entails. These are premised on somewhat subjective opinions of justice and injustice and of what is fair and unfair. As noted above, 'intellectual disability' has then simply not been able to satisfactorily adhere to these binary understandings.

Young and Quibell (2000) consider that this difficultly largely stems from the fact that equality law in the Western, liberal tradition has focused too much on its subjects as autonomous individuals and on the protection of this autonomy from state interference. The individualistic nature of rights according to the liberal design presupposes that all rights holders are self-determining, independent agents. To the detriment of those who may require supports to act and make decisions, this requirement has systematically excluded some persons from the benefits of rights enjoyment and protection. As a result, certain groups who are deemed incapable of rational thought or autonomous agents quickly become ineligible; persons with intellectual disabilities especially have therefore been cast off as non-rights holders.

Although for some groups this illegitimate status may have been rectified over time (Winter 2003), persons with intellectual disabilities are still categorically deemed unqualified to be respected legal actors and rights holders because they are considered to lack autonomy or the ability for independent thought (Goodley and Katherine 2016). This is largely because, as Silvers (2005) acknowledges, these concepts are built on normative ideals and ideologies of normalcy that foster an apparition of a 'species typicality' upon which an eligibility standard is determined. Carlson (2001) similarly identifies that this standard is the product of 'cognitive ableism', a term coined by Carlson to describe the prejudice and the oppression of people with intellectual disabilities resulting from the bias towards individuals that seemingly demonstrate a normative cognitive ability.

The experience of exclusion then largely manifests itself owing to the perception that the intellectual disability characteristic entails an inherent, insurmountable difference—insurmountable in so far that no existing equality mechanism has been able to account and negate the challenges posed by the difference it represents. These are also considered too great to be accommodated by any legal or regulatory mechanism. Minow (1990) considers how in law the difference posed by intellectual disability is treated as intrinsic and solely regarded in terms of its bearing on the individual in question. All too readily then the exclusion experienced is regarded as an inevitable and natural consequence of living with impairment. The differential treatment in the form of segregation based on intellectual disability thus features as a part of legitimate employment and rehabilitation policies (Sheppard 2017).

The unchallenged nature of these dominant and rigid legal frameworks and policies compounds the unequal and unfair treatment of people with intellectual disabilities, harboring their stigmatization and the notion that their exclusion is inevitable. The effects of such systemic inequality can quickly become cumulative with particularly negative consequences for those most marginalized and silenced. Segregation and exclusion therefore pose a deeper challenge to equality than perhaps conventional acts of discrimination. This is particularly the case if we consider that institutional placements so impedes the exercise of rights afforded to everyone else outside the institution, that the placement therein alone, as opposed to a community-based setting or in the 'least restrictive settings possible', has been considered an act of discrimination, as in the *Olmstead* case (Bliss and Wells 2012). In the absence of such strong case law outside of the U.S., it will be useful to consider how the Convention will bear upon the arguments of how sheltered work intersects with the rights of persons with intellectual disabilities.

2.3. Equality and Dignity in the CRPD

The principle of equality is firmly rooted in international human rights law and is also central in the Convention.[1] As the leading norm therein, the principle of equality pursued in the treaty bestows

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[1] Article 1 of the CRPD establishes that the purpose of the Convention is to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity'.

upon all persons an equal recognition and protection, securing all human rights to all persons on an equal basis. This follows the dogma of human rights law generally which understands that all rights are owed equally to all human beings by virtue of their common humanity. Theoretically then, there was perhaps no need for a new Convention, as existing treaty law incorporated people with disabilities in its protection. In their practical implementation, however, existing instruments were so broad and generic that certain 'grey areas' left particular groups effectively unprotected (MacKay 2006). In fact, similar to national equality frameworks, the 'universal' human rights regime had not proved to be all that effective in the context of disability, primarily because the conception of equality applied was not 'disability sensitive' enough to incorporate all individuals, and significant violations of individuals' dignity remained commonplace (Arnardóttir 2009). The Convention's main purpose was then to rectify this shortcoming by firmly placing a more substantive conception of equality at the centre of its provisions and clearly articulating a legal right to equality on behalf of persons with disabilities. Undeniably, it has been successful in achieving this and demonstrates a thorough re-interpretation of equality, based on the express adaptation of universal human rights to the unique situation of disability.

The Convention primarily re-envisions equality by emphasizing the basic principles of human rights law generally. In doing so, it reiterates the principles of equal concern and respect for each human being based on their shared and common humanity. This recognition is extended to decisively include all persons with disabilities, identifying that human rights are rights inherent to each human being and that all individual must be equally recognized as rights bearers and agents under the law. Moreover, the overall tenor and the rationale of the CRPD draws heavily on the core principles of integrity, dignity and the respect for difference which acknowledges that 'disability' is an integral part of humanity and contributes to human diversity (Bickenbach 1999).

Closer consideration of the Convention's general principles, as laid out in Article 3, thus reveals how the Convention embraces perhaps the most novel and dynamic conception of equality available at treaty level.[2] This article is pivotal as it is intended to guide the interpretation of the Convention as a whole, but also clarify how its individual articles are to be transposed into national legislation. The Convention anticipates that this will require multiple equality tools, demonstrating a thorough understanding of existing approaches and incorporating broad, philosophical notions of autonomy, independence, and respect for difference. Further evidence of how the Convention embraces its equality mandate is found in nearly every article that reiterates the importance of inclusion and the requirement that the rights therein can be enjoyed on an equal basis with others, focusing on accessibility and participation as supporting mechanisms. Moreover, the Convention presupposes procedural equality, expressly refers to equality of opportunity, and at times anticipates equality of results. The Convention also explicitly refers to practical policy tools to assist in achieving equality such as reasonable accommodation, affirmative action, 'specific measures', and its prescriptive Article 5 on equality and non-discrimination. Overall, the Convention embodies a multi-layered approach devoted to the ideal of universal equality for all, whilst simultaneously aware that equality is a dynamic concept that must be 'tailored to the specific realities and experiences of those whom it is supposed to serve' (Arnardóttir 2009).

Besides its unique application of equality concepts and tools, the Convention signifies an awareness of the social construction of disability. Essentially, the treaty effectively highlights particularly the structural disadvantages that contribute to the experience of disability which it aims to dismantle. This central objective is outlined in the Convention's preamble (y), where it declares that it 'will make a significant contribution to redressing the profound social disadvantage of persons

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[2] The concepts addressed in Article 3 signify that all rights, duties and freedoms are to be granted and implemented according to the principles of: '(a) the respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; (b) non-discrimination; (c) full and effective participation and inclusion in society; (d) respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; (e) Equality of opportunity; (f) Accessibility' (. . .).

with disabilities'. This is reflective of the social model of disability in which, as is widely known, the CRPD is rooted (Degener 2016a).

Perhaps the most transformative effect of this recognition of the need to challenge existing approaches and the resulting social disadvantages is, as Arstein-Kerslake (2014) aptly describes, that individuals with disabilities are no longer seen as passive recipients of 'special', 'protectionist', and largely segregated care. Central to the success of this Convention is the recognition that people with disabilities are rights holders in their own right, regardless of ability. Instead, the acknowledgement and protection of rights is unconditional and based on the sole premise of our shared humanity; eligibility is thus inconversant with merit. The Convention thus embodies a new conception that views individuals with disabilities not as ineligible and unqualified but 'as an equal who has been systematically marginalized and excluded from society and for whom State Parties must work for and with to achieve substantive equality' (Arstein-Kerslake 2014).

The Convention has then not only promoted global reform in disability policy towards the creation of more equal societies, but it also indicates how the concept of equality itself has evolved. Quite decidedly, it presents an approach to disability equality that bears upon the fundamental construct of human rights, requiring a restoration of the principles of equal respect for dignity and the identification of our collective, societal responsibility in achieving purposeful and meaningful lives. The Convention thus finally makes the 'dignity paradigm' a fundament of equality (Kalb 2011) by making a purposeful theoretical distinction between treating people equally (or decidedly unequally) in the distribution of resources and treating them *as equals*. It simultaneously also reiterates the universality, indivisibility, and inter-relatedness of all human rights according to the principle of universal, inherent dignity. Grant (2007) understands that the fundament of new human rights law owes to a reinterpretation of the 'equality of dignity paradigm', which acknowledges that equal respect and equal worth are the foundation for equal rights. Inevitably, considering sheltered work in a post-Convention era then requires discussing whether sheltered work and segregating practices are compatible with this focus now placed on the equal respect for inherent dignity, before anything else.

3. The CRPD and Its Take on Sheltered Workshops

Sheltered workshops and related practices were discussed during the drafting stages of the Convention. In fact, provided how frequently these were referred to in the contributions by each delegation, it is surprising then that sheltered work, often referred to as 'alternative work settings', were not mentioned in the final text. Besides the frequency, the transcripts of the discussions also reveal the discrepancies in approaches and attitudes towards disability held by delegations. These reflected the diverging approaches to disability policy that also manifest themselves in sheltered work practices with different, context-specific consequences for persons with intellectual disabilities. Accordingly, depending on the welfare and employment systems of the relevant delegations represented, these approaches ranged from paternalistic to inclusionist, from protectionist to rights-based interventions.

It is then particularly the discussions on sheltered work that reveal how these diverging attitudes and approaches came to head. In fact, the opinions differed to such an extent that the issue of sheltered workshops, and how, if at all, to deal with these in the treaty, were divided up until the very last minute of the drafting process. This reveals not only the political tightrope the Committee Chair, tasked with amending the draft text, had to walk, but also how widespread sheltered work practices are, as well as the views as to their purpose.

Overall, the transcripts reveal a general understanding amongst the negotiating community that people with intellectual disabilities experienced significantly higher levels of harmful discrimination and an extent of exclusion that remained largely unchallenged (United Nations Enable 2004a). However, only few delegations identified that the segregation resulting from placements in sheltered work settings where to be labeled as a wrongful from of discrimination and should thus be considered unacceptable. These opinions, largely voiced by (Disabled Persons Organizations (DPOs)), argued that sheltered work represented a form of unnecessary segregation, effectively leading to the exclusion of persons with disabilities. The practice was therefore an act of discrimination and was inconsistent with the very purpose of the Convention. Advocates regarded the drafting of an international disability rights convention as an ideal opportunity to categorically denounce these.

Many DPOs spoke out in opposition of sheltered workshops generally, arguing that these keep people excluded and foster notions that people with intellectual disabilities cannot be meaningfully employed. These argued that sheltered workshops were an outdated concept that signified a form of institutionalization, representing an ongoing barrier to inclusion as evidenced by the low transition rates from these to open employment. The International Disability Caucus, a coalition of DPOs set up for the purposes of negotiating the Convention, called for the elimination of all forms of institutionalization even those intended to fulfill the right to work. Challenging the notion that sheltered work created work opportunities, they contended that such measures represent limitations and fail to protect the right to work and to gain a living by work which is freely chosen (International Disability Caucus 2004). People with Disability Australia (PWDA) clarified that the Convention must not be construed as creating rights to segregated employment because this merely contributed to the permanent 'warehousing' of persons with disabilities. Rather, the Convention must affirm the right to full participation in the mainstream labour market.

Dignity also featured as a crucial concept during the discussions on the right to work. Broadly referring to work and training in sheltered workshops or in other confined environments, Palestine noted that the CRPD must protect the right to work and must include a reference to work that is freely chosen or accepted and 'preserves dignity'(United Nations Enable 2004b). The World Network of Users and Survivors of Psychiatry also commented that the issue of free choice was integral to the right to work (United Nations Enable 2004a). Cameroon emphasized the importance of strengthening the promotion of paid employment and suggested changes that emphasized independent, as well as remunerative work. Canada suggested including stronger wording that ensured career opportunities for all people with disabilities on the open labour market (United Nations Enable 2004b).

Despite these State interventions commenting on the right to choice of work and access to work on the open labour market, New Zealand was one of the only State delegations that specifically called for the closure of alternative work settings. It held that the Convention must clearly signal that sheltered work and other forms of segregation were no longer acceptable. Referring to the historic segregation of persons with disabilities, New Zealand emphasized that protecting people from unnecessary segregation was a pivotal issue (United Nations Enable 2005). The Convention needed to be unambiguous in its position on sheltered work so as to avoid presenting State Parties with a choice between providing either inclusive *or* segregated services. DPOs agreed that anything that can be construed as justifying and institutions and arguments that maintained sheltered workshops only served to reduce the responsibility of State Parties to support people with disabilities into open employment (United Nations Enable 2006).

Other delegations held opposing views. Accordingly, sheltered workshops should continue to exist, as these were a means employed by States to fulfill the right to work. A coalition of National Human Rights Institutions spoke out in support of sheltered work. The coalition argued that, from a legal perspective, the concept of sheltered work could be viewed as fulfilling the requirement on both State Parties and employers to reasonably accommodate workers with disabilities in the labour market. The practice of sheltered work should be revered as a form of reasonable accommodation and endorsed as a valid equality tool. Others agreed that because sheltered workshops would continue to exist based on the continued demand, the priority of the present Convention should then be on regulating rather than denouncing these (United Nations Enable 2004b). As the standard setting body in the area of work and employment, the ILO heavily weighed in on these debates. It explained that the Convention must reflect the 'reality' that some people are unable to work on the open labour market and that many people with disabilities worked in 'protected workshops'. Provisions for these alternative forms of work must be made (United Nations Enable 2004a). A failure to mention alternative workplaces would only harm those most marginalized and run the risk of aggravating the precariousness of the work situations that persons with disabilities were engaged in. Namibia agreed that the Convention should urge States to regulate the sector effectively by standardizing the rules and governance of these, harmonizing them with those of typical work.

Seemingly aware of the arguments both for and against sheltered work, as well as the Convention's overall purpose, the World Network of Users and Survivors of Psychiatry issued some pragmatic solutions. It considered that, based on their prevalence, sheltered work is likely to continue; however, the economic exploitation that is rampant and endemic in the sector must be curbed through regulation. The group recommended that the role of health care and rehabilitation services in sheltered work must not be overlooked. It urged the Committee to take note that, all too often then, what is called 'rehabilitation' is often 'busy-work' imposed on people instead of real opportunities promoting full social participation (United Nations Enable 2005).

Evidently, there were mixed opinions on the role of sheltered workshops and what these represented. These ranged from seeing these as genuine places of work, which required the application of rights-based employment regulations, to regarding such places as the embodiment of historical disadvantages, the harmful segregation and exploitation faced by people with disabilities using protectionist interventions. These divergent opinions culminated in a disagreement on whether the Convention should generally support or denounce these.

The Chair of the drafting committee ultimately chose not to include any reference to sheltered work practices in the final text of the Convention. This decision was based on the concerns raised by the disability community that these ultimately constituted unnecessary segregation and required careful review. Given how feverishly this issue was debated, it is nevertheless surprising that any reference to sheltered work was entirely omitted. Weller (2011) notes that this is a rare occasion that exemplifies the use of a purposeful silence in the Convention. As a tool for negotiation, silence was occasionally used in this manner for political reasons. This helped avoid an impasse over certain, contentious issues that could jeopardize the success of the whole Convention. If a specific aspect or decision was hotly debated and no agreement could be reached, silence over the matter was then a means to circumvent the problem and maintain a consensus securing the success of the negotiations.

As a result, the Convention is silent on sheltered workshops, which does little to help us in our attempt to consider sheltered work through the Convention's new equality prism and question its discriminatory implications. In fact, this has indeed, quite detrimentally, even had the opposite effect. Its silence has left a wide margin for potential misinterpretations or misuse thereof. The failure to reach an agreement on sheltered work has meant that State Parties have enacted the Convention inconsistently. Exploiting its silence on the matter, some have interpreted the Convention as justifying the continuation of sheltered work practices or used to argue for more segregated work provisions. The right to work as one that is fulfilled by sheltered settings or as a form of reasonable accommodation then effectively overrides the Convention's overall objective of inclusion. The Convention's overall stance on sheltered work has thus been subject to conflicting interpretations. For example, Mallender et al. (2015; IGOS 2011), taking a similar view to the Coalition of National Human Rights Institutions during the negotiations, consider that sheltered workshops are a form of reasonable accommodation. Reporting to the European Parliament then, these researchers suggest that the Convention even sets a legal obligation on States to provide sheltered workshops. A look to the how the Convention's treaty body, the Committee on the Rights of Persons with Disabilities, has embraced this silence and what it has interpreted it to mean for sheltered work practices may be more useful.

3.1. Concluding Observations, Sheltered Work Since the Adoption of the Convention

The Convention's silence on the topic of sheltered work has also impacted the interpretations thereof by the treaty body itself. This has become evident over the years through the accumulation of international jurisprudence and growing high-level commentary based on the Convention. The CRPD publishes their opinions on State implementation reports in the form of Concluding Observations.

These provide a suite of information on the state of disability reform since the adoption of the Convention in a given State and provide a unique insight into how the treaty has been interpreted both nationally and internationally, assessing its impact. On a broader scale, an analysis of the existing collection of Concluding Observations gives us perhaps the widest and most current impression of the sheltered work debate available. A review of these Committee reports clearly signals that sheltered work continues to dominate the field of employment services for specific groups and, as a result, their continued segregation and exclusion.

Commenting on the situation in Canada, the Committee noted that particularly women and young persons with disabilities remained in sheltered workshops (CRPD/C/CAN/CO/1) (Committee on the Rights of Persons with Disabilities 2017a). The prevalence of sheltered workshops in Slovakia and Serbia, including a significant rise in numbers of these in Bosnia Herzegovina, also caught the Committee's attention ((CRPD/C/SVK/CO/1) (Committee on the Rights of Persons with Disabilities 2016c); (CRPD/C/SRB/CO/1) (Committee on the Rights of Persons with Disabilities 2016d); (CRPD/C/BIH/CO/1) (Committee on the Rights of Persons Disabilities 2017b). It also remarked upon the increasing manifestation of a segregated labour market in Austria and Germany (CRPD/C/AUT/CO/1) (Committee on the Rights of Persons with Disabilities 2013) and that many other States used sheltered workshops and similar 'specialized' and segregated employment models to employ persons with disabilities (CRPD/C/BOL/CO/1) (Committee on the Rights of Persons with Disabilities 2016b).

Besides expressing concern over States' continued reliance on segregated systems to employ persons with disabilities, the Committee has also regularly expressed concern over the practices within such States. It often cited that minimal wages or other forms of payment received by workers were problematic (CRPD/C/AUT/CO/1) (Committee on the Rights of Persons with Disabilities 2013). The Committee, based on its observations, even considered that Hong Kong's sheltered workshops operated in a manner that violated Article 16 of the Convention that enumerated the right to freedom from exploitation, violence, and abuse. The Committee reached this conclusion based on the 'daily allowance' received by persons with disabilities working in sheltered workshops, which it found to be 'too low' and 'bordering exploitation' (CRPD/C/CHN/CO/1) (Committee on the Rights of Persons with Disabilities 2012). The Committee also expressed concern in relation to the practices in Occupational Activity Centres in Portugal, noting in particular the working conditions and the average wage received by workers with disabilities (CRPD/C/PRT/CO/1) (Committee on the Rights of Persons with Disabilities 2016a). The Committee also urged Korea and Germany to eliminate its sheltered workshops through 'immediately enforceable exit strategies'. (CRPD/C/DEU/CO/1) (Committee on the Rights of Persons with Disabilities 2015); (CRPD/C/KOR/CO/1) (Committee on the Rights of Persons with Disabilities 2014).

The collection of Concluding Observations reveal that the Committee has provided substantial and definitive commentary on sheltered or segregated employment structures. The Committee has overwhelmingly found that sheltered work and conditions thereof to be inconsistent with the Convention and contrary to human rights provisions therein. As a result, the Committee has consistently encouraged State Parties, many of which still heavily rely on sheltered work structures, to review such practices and related legislation and bring them in line with the Convention. At times, the Committee was even explicitly referred to the rights violations occurring in sheltered workshops. In light of its observations of Serbia, for example, the Committee required that the State dismantle its sheltered workshop system and ensure the respect of all rights at work, of all workers, 'in accordance with the Convention' (CRPD/C/SRB/CO/1) (Committee on the Rights of Persons with Disabilities 2016d). Similarly, the Committee encourages Portugal to review its practices and legislation concerning the operation of its Occupational Activity Centres, 'from a human rights perspective to bring them into line with the Convention' (CRPD/C/PRT/CO/1) (Committee on the Rights of Persons with Disabilities 2016a).

Despite the fact that, on these occasions, the Committee has expressed clear criticisms addressing the fact that some sheltered work practices were contrary to the provisions within the CRPD, it has not identified that the resulting experience of segregation itself was problematic. The Committee has therefore failed to address the experience of exclusion from an equality perspective. In relation to such a finding, in fact, the CRPD Committee has to date been quite conservative in its interpretations of the Convention. This is evident in its failure to explicitly call out the segregation experienced as part of the sheltered workshops placements as a form of discrimination itself. Arguably, this is a missed opportunity on behalf of the Committee to categorically denounce sheltered work practices and addressing how the ideologies therefore conflict with the aims of the Convention. While the Committee does refer to some problematic practices that may be the result of a sheltered work placement, such as differentiated wage payments and reduced working standards, it does not refer to the practice, nor the resulting segregation, as a form of discrimination itself.

3.2. Exclusion as a Form of Discrimination in the CRPD

While the Convention, and by implication the Committee, leave the vital question of sheltered work susceptible to (mis-)interpretations; the treaty elsewhere does specify that exclusion is an equality issue and potentially represents a form of discrimination. Under the Convention, State Parties are bound to ban discrimination on the basis of disability and must guarantee 'equal and effective legal protection against discrimination on all grounds' (Article 5(2), CRPD). Helpfully, Article 2 of the Convention clarifies that, specifically, some types of exclusion on the basis of disability shall be considered as a form of discrimination, specifically where it interferes with or has the 'effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field' (Article 2, CRPD).

While Article 2 does not consider that *all* forms of exclusion are to be considered as discriminatory, it does suggest that it be tested for its implications. If these are so great as to impact upon the enjoyment of equal rights of persons with disabilities, then a finding of discrimination is present. Article 2 does not necessarily encourage an exploration of exclusion, which is rooted in any attention to dignity, or lend itself to a blanket statement that renders all segregation experienced in sheltered workshops as discrimination. Instead, it requires an assessment of the nuances and effect of each individual experience of segregation, in accordance with the Convention's overall commitment to a more substantive, tailored approach to equality. Representing a form of conditionality then, this has the potential of stifling the Convention's lofty aims of achieving greater, (unconditional) inclusion and increasing the social participation of all person with disabilities. Although the Convention employs an exciting combination of equality tools, it is ultimately still confined to their traditional functioning. This sees processes of equality subject to tried and tested mechanisms and existing anti-discrimination frameworks that are subject to the reservations thereof. Determining the equality implications of sheltered work is therefore not straightforward. Instead, a decision of whether the segregation experienced constitutes a form of discrimination will require an individual assessment of each claim and only elicit individual redress. The definition of discrimination as provided in Article 2 of the Convention is therefore only of limited significance in considering the practice of sheltered work as a whole.

4. Conclusions

This discussion takes the example of sheltered workshops to test the effectiveness of the Convention in challenging the segregation of people with intellectual disabilities. Sheltered workshops are chosen based on their notoriety as places of exploitation. Their controversial nature is long documented and has flared up debates addressing all aspects of equality. Linking the experience of segregation with the exclusion and social disadvantages experienced by people with intellectual disabilities, this paper questions the legitimacy of sheltered work in light of the Convention on the Rights of Persons with Disabilities. This required a discussion over how to better define equality for people with intellectual disabilities. It was argued that, because of the segregation experienced as a result of the placement in confined services with limited opportunities, sheltered work impedes upon participants' right to lead a life of equal worth and importance and their right to dignity.

The Convention then is committed to protecting the inherent dignity of all persons and employs innovative approaches to achieving disability equality. The Convention, however, does not grant us the satisfaction of a sweeping and explicit denouncing of sheltered work practices. As a result of complex negotiations, the CRPD has remained silent on the sheltered workshop debate. Without a clear position expressed therein, different interpretations of the Convention's bearing on these have been effected. As a result, the CRPD Committee are still addressing the same, known concerns of exploitation in regard to sheltered work that were identified during the negotiations. The Committee has at least used the Concluding Observations to point out, in certain instances, that sheltered workshops should be closed in favour of more open options.

Primarily, the difficulty in declaring that sheltered workshop placements are discriminatory lies in the varied and divergent definitions and purposes of these, which is in turn determined by dichotomous policy dimensions which can lie somewhere between rights-based and protectionist. As a result, the often conflicting interests representing protectionism on the one hand and autonomy on the other, which dominated the drafting of the Convention, continues to define the disability policy landscape today.

The Article 2 definition that includes exclusion as a potential form of discrimination is indeed a unique and exciting innovation of the Convention. However, as an interpretive provision, it is one that still exists within the confinement of traditional legal systems and requires individual tests for a finding of discrimination through the experience of exclusion. Each incident of segregation would then be tested for the harmful effect of that placement and its impact upon an individual's right to dignity and to lead a dignified life. This innovative definition cannot be used to challenge whole policies or argue for the closure of entire segregated systems.

Overall, the most prevalent employment services for persons with intellectual disabilities are still principally offered in segregated, institutional settings. Despite its novel and broad equality perspectives, the Convention has only had a limited bearing on the dichotomous power dynamics of the disability policy landscape. The non-discrimination and equality paradigms of the treaty, however noble and dignity-focused, has not effectively carried over to holistically address and the widespread exclusion of persons with intellectual disabilities who still largely inhibit separate spaces and lead segregated lives. One redeeming aspect originating from the Convention's framework is perhaps its potential in determining that exclusion and segregation in some circumstances is to be considered as discriminatory albeit only in individual cases. Therefore, while it cannot provide us with arguments for the blanket protection from segregation, the Convention may be used to provide individual rights protections and remedies.

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4

"More Honoured in the Breach than in the Observance"—Self-Advocacy and Human Rights

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Abstract: Background: Since the adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD), human rights have become central for disability advocacy. The CRPD requires that disabled people and their representative organisations (DPOs) have a prominent role in the implementation and monitoring of the Convention. However, the representation of people with intellectual disabilities or autistic people is still often indirect, carried out by parents or professionals. Methods: This is a qualitative research which looks at how self-advocates (SAs) with intellectual disabilities or autism participate in DPOs and how they see the role of human rights and laws such as the CRPD in their advocacy. Data was collected in the UK and in Hungary between October 2016 and May 2017. A total of 43 advocates (SAs and other advocates) were interviewed. For the analysis, thematic analysis was used. Results: findings indicate that most participants have limited knowledge of the CRPD and human rights. Human rights are usually seen as vague and distant ideas, less relevant to everyday lives. SAs may not feel competent to talk about the CRPD. The inclusion of SAs in DPOs is mostly tokenistic, lacking real participation. Conclusions: The CRPD can only bring meaningful change to SAs if they get full membership in DPOs.

Keywords: self-advocacy; intellectual disabilities; autism; learning disability; disabled people's organisations; DPOs; disability movement; Hungary; United Kingdom; human rights; UN CRPD

1. Introduction

Much has been written about disability rights and particularly about the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UN General Assembly 2007): numerous academic and civil society accounts have been produced both nationally and internationally (García-Iriarte et al. 2015; Sabatello and Schulze 2014). This trend is not specific to disability rights—human rights legislation and human rights mechanisms have never been as elaborate and strong as today (Bantekas and Oette 2013). The amount of knowledge produced under the 'human rights model' (Degener 2014) is sharply growing including civil society accounts, monitoring reports, state bodies' official statements and various indicators and statistics, which provide a wealth of information about how human rights of disabled people are respected or breached around the globe. Ten years after the ratification of the CRPD, such reports became central to understanding the lives of disabled people and it seems the progress in implementation is palpable everywhere. Our knowledge about the human rights of disabled people has never been so comprehensive and so detailed.

The voices of disabled people in the production of this knowledge are central within the disability rights movement (Degener 2016). However, not all disabled people have an equally strong voice. Little attention is being given to people with intellectual disabilities or autism within human rights literature and it is virtually unknown how they see the last ten years' progress. For example, while implementation reports are usually developed by disabled people's organisations (DPOs) or human rights groups or state bodies, people with intellectual disabilities and autistic people almost never take a leading role in drafting such reports, let alone participate in drafting them. Organisations representing autistic people or people with intellectual disabilities are still led (with few exceptions) by parents or professional advocates while self-advocates with intellectual disabilities or autism remain weightless within 'their own' organisations.

It is rarely asked how much self-advocates know about the CRPD or other relevant international or domestic human rights instruments. It is unexplored what they think about the impact of the CRPD and other relevant laws, or if they think the human rights approach is useful for them at all. We also do not know how meaningful is their participation within the disability rights movement or how they are involved in implementing or monitoring the CRPD.

Based on empirical data from the United Kingdom and Hungary, the present article will focus on people with intellectual disabilities and autistic people who engage in disability advocacy (self-advocates). It will be appraised how self-advocates participate in the movement of disabled people, and how they think about human rights in general or the CRPD (and other laws) in particular.

DPOs often call on governments to involve them more in the implementation and monitoring of the CRPD; it is time to take a look at how meaningfully DPOs themselves can involve people with intellectual disabilities or autistic people within their own human rights advocacy.

2. Background

Self-advocacy is not only individual resistance to oppression or a group activity, but is part of the broader social movement of disabled people's organisations. Although the term 'disability movement' is widely used in academia and in civil society (Goodley 2011; Shakespeare 2013), it must be stated that there is no common agreement on what the disability movement actually means (Beckett 2006), where its boundaries lie and what it means to members of the movement. When the 'disability movement' is mentioned, it usually means the looser or stronger alliance of those organisations that are controlled or managed by disabled people. Depending on national or international contexts, such organisations may represent one or more of the following groups: people with physical impairments, people with visual impairments, deaf people, people with hearing impairments, people with intellectual disabilities, autistic people, etc. Importantly, while acknowledging that self-advocacy is part of the broader disability movement (Aspis 1997; Mccoll and Boyce 2003), there are also salient differences and even tensions between groups of disabled people which must be explored in order to understand where self-advocacy stands today.

2.1. Self-Advocates in the Disabled People's Movement

Despite the developments of disability advocacy in the global West and internationally, the marginalisation of people with learning disabilities within the movement has been observed by several authors (Aspis 2002; Campbell and Oliver 1996; Chappell 1998; Chappell et al. 2001; Dowse 2001; Garcia-Iriarte 2016; Goodley 2004; Stalker 2012). Critical voices demanding equal recognition of people with intellectual disabilities or autism in the broader disability movement have been heard since the 1990s.

For example, Chappell (1998) asserted that the voice of people with intellectual disabilities is largely missing both from the movement and from the academic discipline called disability studies, a view shared by others (Boxall 2002; Stalker 2012). Most researchers in disability studies have ignored the problems of people with intellectual disabilities (Ryan 2016), because there was too much focus on bodily impairments and intellectual disabilities are '*located in the backwater of disability studies*' (Chappell 1998). When self-advocates get into leadership roles, their involvement may still be tokenistic (Beckwith et al. 2016).

An autistic self-advocate's opinion exposes systemic fractions and power relations in the disability movement:

> 'Any attempt by a group of disempowered people to challenge the status quo—to dispute the presumption of their incompetence, to redefine themselves as equals of the empowered class, to assert independence and self-determination—has been met by remarkably similar efforts to discredit them. (. . .) [they try] to deny that the persons mounting the challenge are really members of the group to which they claim membership. This tactic has been used against disability activists with learning disabilities and psychiatric disabilities as well as against autistic people.' (Sinclair 2005)

Of course, the marginalisation of self-advocates is rooted in multiple factors and not only in the contesting interests of different groups. There are several reasons why joining the disability movement for people with intellectual disabilities is difficult. For instance, debates and arguments are difficult for them to follow, and the social model itself is too abstract for many self-advocates to understand and interpret it. Information about general knowledge available for the rest of society is limited, or inaccessible (Aspis 1997; Stalker 2012). Also, although progressive frameworks are becoming available (Arstein-Kerslake and Flynn 2016), people who are assessed to have 'limited mental capacity' are still systematically deprived of their legal capacity (Fundamental Rights Agency 2013; Simplican 2015) or voting rights (Priestley et al. 2016; Schriner et al. 1997) which makes it extremely difficult to exercise citizenship, agency or political activism. Furthermore, many self-advocacy groups work in relation to and rely on social services which makes it almost impossible for them to criticise systemic practices or more structural oppression (Aspis 1997; Buchanan and Walmsley 2006; Chappell et al. 2001; Dowse 2001; Goodley 2000). The relationship between collective and individual advocacy actions may also be controversial: self-advocates willing to act are expected to wait for meetings organised and decisions taken which many of them find difficult (Aspis 2002), and perhaps new, unorthodox ways of advocacy actions should be explored that suit people with intellectual disabilities or autistic people better (Dowse 2001).

There may be a 'hierarchy of impairments' in the movement where people with intellectual disabilities fight to be recognised as other than '*stupid*' (Stalker 2012), exercising resilience not only in relation to the society of non-disabled people but also to their peers with physical or other impairments, because according to self-advocate Simone Aspis, people with other disabilities '*are using the medical model with us*' (Campbell and Oliver 1996). It was also revealed that in the history of the disability movement such internal hierarchy has been present from the beginning.

> ' . . . I hate to say but there was a pecking order within the disability community, and people with a cognitive disability were on the bottom of that order. And so nobody wanted to associate with us.' (Pelka 2012)

There are also distinctive features and needs that may differentiate people with intellectual disabilities from other disability groups. For example, personal experiences (as opposed to abstract concepts) are more important to them, because life experiences or concrete examples make things easier to understand (Boxall 2002; Stalker 2012). Also, while most disabled people identify with their label ('blind' or 'deaf'), similar identification is often problematic for people with intellectual disabilities (Beart 2005; Chappell et al. 2001) which impacts their participation in the movement that expects them to accept a collective identity.

It also matters *who controls* DPOs. Parent-led organisations have always played an important role in intellectual disabilities (Goodley and Ramcharan 2010; Goodley 2000; Gray and Jackson 2002; Simplican 2015; Wehmeyer et al. 2000). Until today, it is still advocacy organisations founded and controlled by parents or professionals who often act as representatives of the 'field' of intellectual disabilities or autism. Tensions between autistic self-advocacy organisations and powerful charities led by professionals have been present in the US (McGuire 2012; Ne'eman 2010). In Britain, with the presence of 'people first' groups or other self-advocacy organisations, this substitute representation is perhaps more balanced and self-advocacy enjoys a certain level of visibility. However, the dominance of parents is still unchallenged internationally: it is parents or professionals who represent people with intellectual disabilities in several 'national disability councils' across Europe, for example in Greece, Germany, Hungary, Italy, Latvia, the Netherlands, Norway, Poland, and Spain (European Disability Forum 2016). It is also parents and professionals who control international advocacy organisations such as Autism Europe or Inclusion Europe, although international self-advocacy networks are gaining more importance (Epsa 2017; Nagase 2016).

In the first decades of autism advocacy, it was also parents and families that established advocacy organisations (Bagatell 2010; Balázs and Petri 2010; Chamak and Bonniau 2013; Kemény et al. 2014; Sinclair 2005; Waltz 2013; Ward and Meyer 1999). Autistic self-advocates only became visible from the late 1990s onwards (Waltz 2013). The problem with representation by parents in advocacy is summarised by autistic self-advocate Jim Sinclair (Ward and Meyer 1999):

> 'Parents and professionals acting on behalf of us is not the same as us, speaking of ourselves. Parents and professionals are more concerned about taking care of disabled people, than with freedom and rights for disabled people.'

Canadian autistic self-advocate Michelle Dawson even argued that the national organisation:

> 'Autism Society Canada should change its name to reflect its real objectives, membership, and governance. The new name should indicate that this organization is by and for parents, e.g., Parents of Autistic Children Canada'. (Dawson 2003)

2.2. Self-Advocacy and the Human Rights Approach

Since the adoption of the CRPD in 2007, and other human rights legislation such as national anti-discrimination laws, much of disability advocacy uses the language and concept of human rights. Very few targeted studies have investigated the participation of self-advocates in human rights advocacy (Birtha 2014a, 2014b). It can be assumed that self-advocacy may have a rather complicated relationship with the human rights approach, especially because the above-discussed disability movement, since its start in the 1970s, has been concerned with and shaped human rights (Harpur 2012; Hurst 2003; Pelka 2012; Shakespeare 2013). In fact, the human rights approach itself has grown out of the social model and disability studies (Degener 2016; Kayess and French 2008), and as such it may have carried on with the heavy heritage of marginalising or excluding self-advocates.

The gradual development of rights-based legislation has long been an aim and tool for disability advocacy (Degener 2000; García-Iriarte et al. 2015; Hurst 1999; Vanhala 2010), but not until the adoption of the Americans with Disabilities Act (ADA) (Americans with Disabilities Act 1990) did the human-rights-based language started to become dominant among disability advocates (Quinn and Flynn 2012). According to Theresia Degener, '*with the paradigm shift from the medical to the social model of disability, disability has been reclassified as a human rights issue*', where the ADA was a '*major milestone*' on the road toward equality (Degener 2000). From the 1990s on, similarly important national laws were adopted in almost all countries in Europe (Vanhala 2015), including Britain (Disability Discrimination Act 1995) and Hungary (Hungarian Parliament 1998).

The prominence of the human rights approach to disability advocacy was further strengthened by the CRPD. Ever since its ratification, the CRPD has been described by using enthusiastic and sometimes metaphoric language in academic literature: '*out of darkness, into light*' (Kayess and French 2008); '*new era or false dawn*?' (Lawson 2006); a '*moral compass for change*' (Quinn 2009); and '*a conscience for the global community on disability issues*' (García-Iriarte et al. 2015). The CRPD is most commonly mentioned among legal scholars as a '*new paradigm*' or '*paradigm shift*' (Bartlett 2012; Harpur 2010, 2012; Kayess and French 2008; Mittler 2016; Sabatello and Schulze 2014) which brings about the 'human rights model' to disability (Degener 2014, 2016).

Such enthusiasm about human rights, however, is not shared by everyone. Prominent founders of the social model and disability studies (Oliver and Barnes 2012) have repeatedly asserted that contemporary human rights mechanisms are partial and ideological, and they fail disabled people because human rights laws are unable to challenge existing structures of power, leaving fundamental socio-economic systems unchallenged. For example, British anti-discrimination laws will never be effective alone, without trying to achieve more profound politico-economic changes (Barnes and Oliver 1995). For others, for example feminist disability scholar Kristjana Kristiansen, the impact of disability human rights approaches is limited because '*the rhetoric is lovely (. . .) but there is no teeth in it*' (Kristiansen 2012). Others warn that cross-national DPOs and donor organisations using the human rights framework may ignore local DPOs' needs, their organisational knowledge and specific circumstances, and potentially co-opt them by providing funds for narrowly-understood human rights advocacy instead of acknowledging other issues such as local material needs in the Global South (Meyers 2016). Furthermore, critical disability scholars have raised concerns about global human rights as a potential form of colonisation that may maintain power imbalances between Western and non-Western interpretations of what disability rights actually mean for disabled people living in the Global South (Meekosha and Soldatic 2011). Notably, critics of the human rights approach rarely make reference to the specific needs and perspectives of self-advocates with intellectual disabilities or autism.

Although these concerns are still debated by scholars and advocates, nonetheless the CRPD—paraphrasing Hasler's observation about the role of the social model in the disability movement (Hasler 1993)—has become the new '*big idea*' of the international disability movement. Unfortunately, in the absence of focussed research it is unclear whether self-advocates are similarly enthusiastic and how they see the role of the CRPD and human rights laws in their own everyday advocacy. Although the CRPD itself makes it mandatory in Article 4 and Article 33 to include disabled people in the monitoring and implementation of the CRPD, it remains unknown how self-advocates with an intellectual disability or autistic self-advocates perceive their own involvement in the work of DPOs representing them. This paper explores these questions, through reporting the analysis of an empirical study on self-advocacy.

3. Methodology

The findings to be presented are part of a broader research project focussing on the participation of self-advocates within the disability movement. The project is a doctoral study that is based on empirical data from two countries, the United Kingdom (UK) and Hungary. Both countries have ratified not only the CRPD (Hungary in 2007, the UK in 2009), and other major UN Conventions such as the Convention on the Rights of the Child (both in 1991) or the Convention on the Elimination of All Forms of Discrimination against Women (Hungary in 1980, the UK in 1986), but both countries have several domestic human rights laws covering disability rights as well (Vanhala 2015). Furthermore, both Hungary and the United Kingdom have seen a number of national and local DPOs working for disabled people and using the human rights model—including dozens of civil society organisations in both countries that represent people with intellectual disabilities or autistic people.

The main objective of the doctoral study is to explore how people with intellectual disabilities or autism participate in the broader disability movement; in particular, how autistic self-advocates or self-advocates with an intellectual disability perceive their own advocacy work against the backdrop of contemporary disability advocacy. The main research question of the doctoral study is '*to what extent do self-advocates with intellectual disabilities and autism currently shape the policies and actions of the disability movement?*'

Although data comes from two different countries, the study is not a comparative one. Instead, empirical data is collected and analysed together from the two countries—it is expected that similarities between the two countries will suggest an increased level of validity of findings that may imply broader, international trends or tendencies. However, any differences between the two countries will be highlighted and explored.

The present study employs a qualitative methodology and forms the first phase of the doctoral research project. The main aim of this first phase was to conceptualise self-advocacy based on the perception of members of the advocacy movement of people with intellectual disabilities and autistic people. Focus groups and semi-structured interviews were conducted in both countries. Themes for the data collection emerged from a comprehensive literature review. (The full list of themes discussed at interviews and focus groups is in Annex 1.) Recruitment started through major DPOs and the researcher's professional network, and later several participants were included through 'snowballing' sampling.

Understanding the present strengths and difficulties of self-advocacy would be difficult without appraising the overall situation of the autistic or intellectual disability movement, which includes not only strictly-understood self-advocates and their groups, but also previously mentioned forms of advocacy bodies such as parents' organisations, professional advocacy organisations or bodies, human rights watchdogs, or organisations of mixed profile (e.g., led jointly by disabled people and others). Therefore, the study takes an open approach to assessing the place of self-advocacy in the disability movement: both self-advocates and their non-disabled colleagues, supporters, allies and other advocates working in the field were asked to participate, thereby establishing an assemblage of various individual views on contemporary self-advocacy. The main inclusion criteria was that participants had significant experience in advocacy or self-advocacy.

Altogether 43 people participated in four focus groups and 25 interviews. Both individual interviews and focus groups (four in each country) were planned, but only in the (much smaller) Hungary were they organised where participants could more easily travel to focus groups. In United Kingdom, in order to provide wider geographical coverage, interviews were preferred because participants lived at various locations often several hundred kilometres apart from each other. In other cases, participants who lived close to each other preferred individual interviews for confidentiality or other reasons (e.g., limited time to attend focus groups or feeling anxious about talking in front of others). This limitation of the data collection, however, has minimal impact on how findings can be analysed and interpreted. Participants (Table 1.) were recruited from four sometimes overlapping types of disability advocates:

- autistic self-advocates (n = 11);
- self-advocates with intellectual disabilities (n = 8);
- family members and professionals with significant experience in advocating for/with autistic people: 'advocates in autism' (n = 10);
- family members and professionals with significant experience in advocating for/with people with intellectual disabilities: 'advocates in intellectual disabilities' (n = 14).

Table 1. Participants.

Participants	United Kingdom	Hungary	Total
Self-advocates with intellectual disability	4 interviews (including 1 group interview, n = 2)	1 focus group (n = 3) + 1 interview = 4 participants	8
Autistic self-advocates	5 interviews	1 focus group (n = 4) + 2 interviews = 6 participants	11
Advocates working in intellectual disability	5 interviews	1 focus group (n = 5) + 4 interviews = 9 participants	14
Advocates for autistic people	5 interviews	1 focus group (n = 4) + 1 interview = 5 participants	10
Total	Total in the UK: n = 19 participants	Total in Hungary: n = 24 participants	**n = 43 participants**

This open approach to recruiting participants was further expanded by not restricting participation to those who worked within formally established DPOs, because the disability movement consists of not only self-defined DPOs but also of other formal or informal groups of people and even individuals who speak up against injustice or human rights offenses. Therefore, people belonging to grassroots groups and individual self-advocates/advocates were also invited to participate. This resulted in the inclusion of participants, who—for example—used to be involved in DPOs but at the time of data collection did much of their advocacy as part of informal or ad-hoc groups. Others, such as some self-advocates, had official membership in DPOs but they considered themselves 'individual self-advocates' and indeed did the bulk of their advocacy as private individuals. Others had extensive, sometimes decades-long experience in doing or supporting self-advocacy, but they also worked as 'solo' advocates, for example by running their own website, blog, publishing articles in local papers or books, giving trainings on several issues, etc. Some participants used arts as part of their self-advocacy work, working away from formal advocacy organisations. Attention was also given to other factors such as the size of the advocacy organisation or geographic coverage. In both countries, participants who are actively involved with the best-known umbrella DPOs participated as well as others who belong to local, grassroots groups, often working in remote, rural areas.

It was hoped that this open and inclusive approach to recruitment would provide richer data that demonstrates the opinions of many layers and groups of the social movement of disabled people.

The four categories of participants also overlapped, because some self-advocates ($n = 2$) had both intellectual disability and autism; while some parent-advocates or professionals were active both in intellectual disability and autistic advocacy ($n = 7$). There were parent-advocates and self-advocates who disclosed having other types of disabilities such as visual or physical impairments. Finally, it appeared during data collection that many so-called 'professional advocates' (such as trained advocates or support workers, DPO officials or human rights lawyers) had family backgrounds that included siblings or other family members with a disability. This implies that a significant part of the movement of intellectual disabilities or autism have a stronger, even lifetime commitment to advocacy that should be seen more than just a job they are holding.

The data collection was conducted in Hungary in late 2016 and in the United Kingdom in the first half of 2017. Interviews and focus groups were conducted in Hungary and in the United Kingdom. Participation was voluntary and anonymous. There were limitations to anonymity and confidentiality for focus groups where participants could mutually identify each other and hear each other's opinions—consent forms highlighted this limitation and explicitly asked for consent from all participants. Similarly, consent was asked from all participant self-advocates when one support worker was present at a focus group with self-advocates. Reasonable adjustments were given to participants, for example focus groups and interviews were organised at venues with low sensory stimuli. Some participants asked to be interviewed on Skype to reduce anxiety arising from personal meeting. In other cases, the researcher consulted support workers to understand the communicational needs of self-advocates with intellectual disabilities. All information sheets, consent forms and complaint forms were produced both in Hungarian and in English, and also in easy-read Hungarian and easy-read English. Transcription of recorded interviews and focus groups was done by the researcher. All translations during data collection and data analysis were done by the researcher himself. The data collection was approved by the University of Kent Tizard Ethics Committee in June 2016.

For the analysis of data, thematic analysis was employed, using the NVIVO software. Interviews and focus group transcriptions were read several times by the researcher, which was followed by coding and identifying emerging themes. Questions or statements around human rights and the human rights advocacy of DPOs were included in the present analysis. All interviews and focus groups included the following themes/questions:

- How much do you know about the CRPD or human rights? How much do others know about them?
- What do you think about human rights and the CRPD in the context of your advocacy work or in general? Are they useful or effective tools?

- Please evaluate the involvement of self-advocates within DPOs or the broader movement of people with intellectual disabilities/autism by using the 'ladder of participation' by Arnstein (Arnstein 1969).

In the present article only those findings will be presented that closely relate to the topic of discussion: human rights and self-advocacy, and the participation of self-advocates in the work of DPOs and the disability movement.

4. Results

Findings are organised under three themes that are central not only for self-advocates but for the whole of disability advocacy: *knowledge (of human rights laws)*, *usefulness (of human rights tools)* and *participation (in DPOs)*. These three descriptive themes derive from the interview/focus group guides where separate questions addressed participants' knowledge of human rights, the perceived usefulness of human rights and self-advocates' involvement in DPOs. All three themes have also been seen as essential parts of advocacy. Knowledge has been the focus of disability studies from its beginnings (Thomas 2002). Human rights tools should be an integral part of disability advocacy and their increased use is suggested by several authors (Flynn 2013; García-Iriarte et al. 2015). Participation has long been a core demand of disabled people since the early days of disability advocacy, when a British DPO laid down the foundations of the social model (UPIAS 1975).

Although it is acknowledged that international human rights treaties of the United Nations like the CRPD, and national legislation (including laws prior to or after the countries' ratification of the CRPD) are distinct categories, and should be separated when discussing human rights, during data collection a simplified approach was taken. During interviews and focus group, both the CRPD and domestic laws such as the Equality Act in the UK (2010) and the Equal Opportunities Act in Hungary country (1998) were referred to as 'human rights laws' or 'human rights legislation', because most participants were assumed to have limited legal knowledge and to not necessarily be familiar with terms like 'treaty' or 'convention'. This approach ensured that participants could not only understand questions or prompts about legal issues but that they also felt competent enough to speak confidently. Therefore, while acknowledging the vagueness of the wording, in the discussion of findings both the CRPD and national legislation will often be referred to by participants as 'laws'.

4.1. 'I Am Only Aware in a Very Vague Way'—Knowledge of Human Rights

It has been widely acknowledged since the early days of the disability movement that knowledge is necessary for the empowerment of disabled people (Goodley 2011; Hasler 1993; Oliver 1990; Shakespeare 2013). '*Knowledge is power*' the saying goes and indeed, understanding human rights in general or actual laws such as the CRPD seems to be a necessary element of human rights based advocacy.

All participants were asked questions about both their knowledge about human rights in general and more specifically, about their knowledge about the CRPD or domestic human rights laws. Usually in one single prompt was given such as '*How much do you know about human rights? Or actual human rights laws like the UN CRPD? Have you heard of these*?' but when needed, further questions were asked or clarification was given, for example when people could not recall what the CRPD was. All participants agreed that knowing about and understanding rights was fundamental in order to seek justice or to do advocacy. Even those acknowledged the importance of laws who claimed they were not familiar with legal matters, for example because their advocacy work rarely covered legal issues. The overall approval of the salience of the law and rights is demonstrated by the statements of two British self-advocates with intellectual disabilities who make a clear connection between laws and their everyday lives.

> Researcher: Do you think it helps if people with a learning disability learn about the law or rights?

> Self-advocate 1 & 2: Yes!
>
> Self-advocate 1: Yes, 'cause how they're gonna now what they are entitled to? Like all this disability living allowance! This is what's changing, isn't it?

At the same time, recognising the importance of law did not mean participants claimed actual knowledge about human rights. When asked about their familiarity with the CRPD or other human rights laws, an overwhelming majority of participants stated to have limited or superficial knowledge. A group of experienced parent-advocates, leaders of local and national DPOs in Hungary said:

> Researcher: Are you familiar with human rights laws like the CRPD?
>
> Advocate 1: I couldn't list up what it says, but I know about the CRPD.
>
> Advocate 2: I wouldn't know either.
>
> Advocate 3: I wouldn't know the whole thing but the parts about democracy I am familiar with, of course.
>
> Advocate 1: I am not, for sure.

According to the leader of another advocacy organisation representing people with severe intellectual disabilities in Hungary: '*The families in our organisation don't have a clue about these, the Convention and all . . .* ', and another professional advocate who has worked many years at a Hungarian national learning disability organisation adds '*I assume most people are not really familiar [with human rights]. And I am saying this because there haven't been studies or surveys to show how much people know about these things. Studies should be done!*'

Participants from the United Kingdom have similar claims, most of them reporting very little knowledge about human rights laws and some of them seeing very little awareness across the field of intellectual disabilities or autism.

> I am only aware in a very vague way. I do know a little bit about the Disability Discrimination Act in this country which actually doesn't have many teeth when it comes to education. But I am not, I would not say I am very knowledgeable about these, not more than anyone else. (UK advocate in intellectual disabilities)
>
> Yes, I have heard of it [the CRPD]. I can't say I'll tell you details of it off the top of my head right now. (laughs nervously) (UK advocate for autistic people and their families)
>
> I have read things about it but can't remember the details. (UK advocate for autistic people)

Others recognise that knowledge about human rights or the CRPD itself is growing, but they see limited effects in the broader society or even among disabled people—and human rights may be associated with international DPOs like Autism Europe.

> [The knowledge] is growing but that's just a very... (. . .) You know, we live in a little bubble where we know these things and we talk about these things and get excited about these things but people next door to me never heard of them. And the majority of people with disabilities never heard of them. (UK advocate in intellectual disabilities)
>
> I just don't [know much about them]... There was this Autism Europe thing, a written document about something... And then there's a European Convention on disability rights I think. And another one, it's again I think it's a worldwide one, that is part of English law. (UK advocate for autistic people)

The tension between the recognition of the importance of rights and the lack of familiarity with them was explained by several participants. Training may be helpful but it has limited effect in practice—for others membership in formal advocacy organisations, especially 'big DPOs' seems a decisive factor. The translation of rights on paper into actual advocacy actions may also be challenging.

> Our organisation just got a bit of funding to start trainings on it [the CRPD]. It's complicated. (. . .) You go to a training session where you hear you have the right to this and this and this, and what society and the state should be doing, and they don't tell you what to do when it doesn't happen. And I think that's the big gap that people don't know what to do when it isn't happening.' (UK advocate in intellectual disabilities)
>
> Within our movement the problem is that even if we look at self-advocates, they are OK at the central organisation, and we have few groups here and there, if we include local self-advocacy groups . . . But even if we take local groups into account, they only cover very few people in a local town, if they even exist! Where are the others, what about them? (Hungarian advocate in intellectual disabilities)
>
> The only people who are in touch with organisations would tend to know about it. (UK advocate in intellectual disabilities)
>
> I don't think they do [know about human rights]. They are thinking about their personal, one issue at the moment, or what they need. I think when what they need links directly that time with what's in the news and then they link it altogether. But until that point I don't think they really do unless they have someone or that's their obsession. And then they would know about that, the processes. (UK advocate supporting autistic people)

Self-advocates themselves, similarly to their non-disabled colleagues, admitted often limited or even '*sketchy*' knowledge about the CRPD and other human rights laws. For example, three Hungarian autistic self-advocates say:

> Self-advocate 1: (whispering) I still have not read it!
>
> Self-advocate 2: I have read it but I wouldn't say I feel competent. Or in other words, I just don't see where this Convention reaches my life or the lives of people I know, because I have never had to use it, to make a reference to it. Interestingly, whenever I have had to stand up for something it has never escalated that far, I never had to use them [human rights].
>
> Self-advocate 3: I know it [the CRPD] superficially, and I come across it every now and then in my work. Last time about 2–3 weeks ago, I think.

Another Hungarian autistic self-advocate adds '*only those who are part of advocacy organisations would know about these things, and even then, this is a knowledge that takes years to be learned. And this applies not only to self-advocates, but parent advocates and professionals as well.*' For two Britain-based self-advocates with intellectual disabilities the CRPD was completely unknown, even though they have been actively involved in empowering other self-advocates for years—on the other hand they claimed to have better knowledge of British human rights laws.

> Researcher: Have you heard about the UNCRPD?
>
> Both: No.
>
> Researcher: And other human rights laws? The Equality Act? The Disability Discrimination Act?
>
> Self-advocate 1: Yeah, we heard about all of these, 'cause we used to go through all of them during the trainings.

Another participant reported having better knowledge of some domestic human rights laws.

> Our kind of domain is so much about the UK and England specifically that it [the CRPD] just doesn't come up on the radar. (UK advocate for people with intellectual disabilities)

Some others see gradual improvements in the knowledge about the CRPD and other human rights instruments. An autistic self-advocate from Hungary stated *'Fortunately, more and more people hear about the Convention. The 'nothing about us without us' slogan could even be the best PR for it because it just puts it so clearly what it's all about!'*

Good examples were also mentioned. Self-advocates with intellectual disabilities who worked for umbrella DPOs in both countries were reporting having a deeper understanding of the CRPD and they themselves participate in producing materials about it: one of them gave an interview to a website run by self-advocates, another one wrote an article for their newsletter about provisions of the CRPD. However, this was a minority among participants.

Knowledge about human rights and their actual use in advocacy may be gained because people recognise their relevance. One participant from an advocacy organisation in Hungary fighting for people with severe intellectual disabilities stated: *'I would not know about them either if I didn't know that communication is a basic right which should be implemented across the education system so they should provide tools to support'*.

It is also important that several participants claimed to have no competence on human rights because rights and the law are seen as requiring special expertise or technical language. According to one self-advocate with intellectual disability in Hungary who is actively involved in CRPD-based advocacy: *'it is lawyers who know best. The CRPD is up to the lawyers, they are the ones who can comment on it!'* Such statements may expose fundamental problems in the empowerment of self-advocates in the human rights movement; if special expertise or highly educated 'experts' are needed to even talk about human rights then emancipatory knowledge may remain inaccessible to those who most need it.

4.2. 'More Honoured in the Breach Than in the Observance'—Usefulness of Human Rights

Participants were also asked how useful they thought human rights laws such as the CRPD or national human rights legislation were. Since the disability movement has long engaged with legislative changes and all participants had substantial experience in advocating for themselves or others, it was assumed that participants would have enough knowledge to assess the effectiveness or usefulness of human rights in their own advocacy (or in the advocacy of others).

Many participants expressed that they do not use human rights law in their everyday advocacy, for example, because other laws are more relevant to their work. In this context, little acknowledgement was given to the fact that international or national human rights legislation itself can influence other laws. For example, some participants see the CRPD as too general to be used for specific cases.

> To be honest we don't use the CRPD because when we go to meet a school principal we use the Education Act, so we prefer laws that are more concrete!!! And not ones that are more... general. So all in all I don't think we use it. (Hungarian advocate for autistic people)

> I am sure we stored it [the CRPD] somewhere in our minds and we even use it somehow, but if we used it every day then I would probably be able to tell you what for ... So obviously we don't use it. (Hungarian advocate for autistic people)

Another advocate said although they do not use the CRPD in their everyday actions, it still formed the basis when establishing their advocacy organisation—and the CRPD is still very relevant for changing national laws.

> The CRPD was seen as a basis when we started this whole thing, how to build up our organisation ... We did think about human rights. But we don't refer to them in our everyday work. But I also think that for a national level advocacy, when the national DPO

> fights for us, then it is crucial that they refer to the CRPD, because when they negotiate with the Government then the CRPD is important. It is another issue how seriously the Government take it. (Hungarian advocate for autistic people)

Other participants, like an advocate for autistic people from Hungary stated the CRPD was a useful basis for a monitoring they asked to be carried out to assess a social service's compliance with human rights. In some cases, the CRPD is seen to be the main point of reference during the advocacy of a DPO.

> They use the CRPD all the time in ÉFOÉSZ [the Hungarian national DPO in intellectual disabilities], and they can tell you about anything they do how it relates to provisions of the Convention. So they can tell anyone why it is important what they are doing. (Hungarian advocate for people with intellectual disabilities)

For an autistic self-advocate in Hungary the question about the usefulness of the CRPD prompts an emotional reaction.

> 'I just pulled an ugly face, I am saying this for the sake of the voice recording, because it is such a deep and instinctive reaction I am giving. No! I don't see it working. They are trying, trying to take human rights seriously at many places but it does not work! (. . .) the Convention has made an effect, yes a minimal one.'

Similarly, an autistic self-advocate from the United Kingdom sees laws ineffective in practice: *'The National Autistic Society (. . .) has been effective in the political sphere in getting the Autism Act approved. But this is, quite like in Hamlet . . . "more honoured in the breach than in the observance". It's just ignored! So ineffective laws! I think this is very interesting.'*

For another Hungarian autistic self-advocate, it is not the Convention to be blamed for its limited effect:

> The Convention has made an impact already, not a big impact but some things have happened, for example people started to discuss what it means and the whole concept has reached a lot of people. But I also think we should not have too high expectations from the Convention itself—it is a good enough concept, but it is ultimately up to us what is implemented of it.

There was a wide consensus among participants that human rights laws make too little impact on practical aspects of people's lives, which makes it difficult to see progress in human rights implementation both in the UK and in Hungary.

> In my role I am not seeing the Convention as helping individuals it's a very . . . ehm . . . it's a pretty thing to have but whether it has made a difference in people's lives, lived experiences, I don't think very much. (UK advocate for people with intellectual disabilities)

> I think human rights feel like big, vague ideas at a distance that doesn't feel very applicable. (UK autistic self-advocate)

For self-advocates with intellectual disabilities in Hungary, the CRPD has potential, although its implementation remains wanting.

> Self-advocate 1: The trouble is that in my experience the UN CRPD only exists on paper, implementation is still lacking. The whole society will need to come together to make it real what is written in it.

> Self-advocate 2: The UN Convention is good because it is written down what countries need to do after ratification. I think Hungary will go to the UN in October 2017 to tell them what happened. I think things are in progress, it is a bit slow but it is going.

> Self-advocate 3: It is happening with hiccups. If you use rights you can achieve more.

Another participant, a human rights defender of people with intellectual disabilities in Hungary puts the emphasis on both practical and conceptual uses of the CRPD: '*The point is that it [the CRPD] applies general human rights specifically for disabled people, so rights cover them like everyone else. (. . .) and this is crucial not only on the theoretical but on the practical level, because the more people will use it the more significance it gets*.'

Several participants said that the lack of progress is due to extra-legal factors, for example the reluctance of government bodies or the lack of translation of rights into actual actions or good practices.

> I think the rights are already there but the institutions and bodies are reluctant to apply them. The implementation of laws is very meek and there are no sanctions if rights are breached. (Hungarian advocate for people with intellectual disabilities)

> I often see in my practice that although legislative changes are made by the government, but in many cases the practice don't follow. For example in supported decision-making, there are no support networks, no practical experience, there are no trainings for parents, no trainings for judges and so on. So it is not only legal progress that needs to be done, because we already have better laws than before but they are not implemented! (. . .) A lot of changes have been made following international examples and I don't know whom to blame for this, but there are hardly any existing practices based on the Convention. What could be better against the medical model than the human rights model, yes—but we need methodology to do it! (Hungarian advocate for people with intellectual disabilities)

One autistic self-advocate in the UK noted that existing human rights discourses may exclude overall systemic problems such as economic power imbalances between the Global North and the rest of the world.

> How can someone from like a poorer country receive services up to the same level as someone from a rich country, if we are not looking at economic power and debt repayment and these kind of conversations outside the bill of human rights? (UK autistic self-advocate)

Some participants would like to see profound changes in how we see disabled people in society and they emphasise that the success of the human rights approach relies on a number of other factors, outside the remit of the CRPD—and even disability as an inclusive category is contested by the autistic community, leaving the rights-based language problematic in this context.

> I think all of these [human rights] approaches are valid and necessary, but it is not going far enough. We still not have the conversation to restructuring normative society and the principles within the law and how our system works and equally in the academic establishment. (UK autistic self-advocate)

> I think it [human rights] is filtering down in the wider disability movement, but I think autism is different and has its own agenda compared to wider... I mean there is still quite an issue about whether we want to call an autistic person disabled at all and there are many opinions about that among autistic people. It is nowhere near as clear-cut as with other disabilities and if I have sensory issues (. . .) People talk about minorities and the rights of women and things and then they have the disabled as a broad category but what they mean by disabled is someone in a wheelchair, that is their idea of what disability is. (UK autistic self-advocate)

In both countries, national contexts are seen to be responsible for the lack of progress in the implementation of the CRPD.

> Rights can only work if the rule of law is respected by the state. You need the separation of powers, mechanisms independent from the government etc. We don't really have those anymore in Hungary. This is a new political system we have now. (. . .) Human rights are totally alien here, they are very uncertain, the state is only disturbed by them. (Hungarian advocate for people with intellectual disabilities)

> I think some countries are better than others and the UK has chosen to mostly ignore it so there are very little investment in raising awareness of the Convention or any of the [UN] Conventions ... the children's lobby have done better but look how, the CRC has been in existence... it's been more than 30 years now. So I think children's rights are better known, disabled people's rights are not. In the UK, I mean. (UK advocate in intellectual disabilities)

On the other hand, not only negative statements were made. Several participants assessed the CRPD and the human rights approach as useful in that it is already driving some changes—including changes on the legal or discursive level.

> Basically everything from nothing is . . . should be around the Convention. (. . .) I think thanks to people who have lobbied the government, and also people with learning disabilities we've made improvements. But I feel it's just . . . . What needs to be more practical is getting all governments to do it (. . .), but I think things are getting better. (UK self-advocate with intellectual disabilities)

> The Convention is certainly there in the work of our organisation, it is a basis. A compass. (Hungarian advocate for people with intellectual disabilities)

> To some extent yes, there are cases when it [the Equality Act] helps. The principles are good. I mean there are people who are willing ... I think there are... When people know what reasonable adaptations to make. (UK advocate for autistic people)

> Now that you ask, yes, we do use the Convention, like last week I think we sent a letter to a head teacher and we mentioned it in it. (Hungarian advocate for autistic children)

The CRPD as a framework appeared to be powerful for some participants, inducting new ways of thinking about progressive changes not only nationally but also internationally.

> The CRPD has given us a framework for having conversations about what people should expect. And because it is a common framework, it can be used across countries and it explains what it is reasonable to expect of your life and of your country. And I think that's a very useful tool for advocacy. (UK advocate for people with intellectual disabilities)

The careful enthusiasm and scepticism among participants about the usefulness of the human rights approach is largely based on their own experiences, both as advocates and as disabled people (or their relatives). One statement by a Hungarian advocate seems to be emblematic when he likened the slow progress in human rights implementation to another emancipatory movement: '*I agree with others. But I am an optimist, because the suffragette movement started in the 1920s and Switzerland only gave voting rights to women in 1972. This is 52 years. I still hope it will take shorter time for us.*'

4.3. Self-Advocacy within Disabled People's Organisations

Finally, participants were asked to assess the participation of self-advocates within the DPOs representing them or within the intellectual disability/autistic advocacy movement. This aspect of the study is based on the pivotal provision made in Article 4 and Article 33 of the CRPD which makes it mandatory for state parties to ensure the involvement of disabled people in the monitoring and implementation of the convention. Arguably, such provision should be available to all disabled people, therefore it is important to see whether self-advocates with an intellectual disability or autistic people participate in DPO decisions meaningfully or not.

To assess the participation in DPOs, a well-known visualisation was used; Arnstein's ladder of participation (Arnstein 1969) is a widely referenced conceptualisation of citizen involvement in decision making. (See Annex X.) Using the ladder of participation in the disability context is not unknown, for example it has been used when looking at the involvement of autistic people in research (Pellicano et al. 2014) and was referenced when DPO involvement in the monitoring of the CRPD was studied (Birtha 2014b). The ladder of participation offered itself as a particularly useful tool in the study because of its accessibility and relative simplicity. Nonetheless, for participants with an intellectual disability, a more simplified version was used with only five steps on the ladder (as opposed to eight steps in the original concept).

All participants were asked to assess where self-advocates stand on the ladder within DPOs representing them or within the autistic movement or the movement of learning disability organisations. (Prompts depended on participants' backgrounds, for example their personal experiences in DPOs.) Many participants found it hard to generalise but with the exception of two participants all of them agreed to locate self-advocacy on the ladder. Several participants were unable to point at one actual step on the ladder, instead preferred to provide approximate locations, for example 'somewhere down here' or 'somewhere in tokenism'.

Findings were consistent across all subgroups and the two countries, and not different between intellectual disabilities and autism: self-advocates have a low to moderate level of participation in organisations representing them, away from 'citizen participation', mostly standing around informing, consultation and placation. The overwhelming majority of participants saw self-advocates being on levels of tokenism within organisations claiming to represent them.

> Below placation . . . (. . .) I think generally we would be in the level of tokenism. We tend to be listening but we actually don't give enough options for them and the support to be truly the way it should. (UK advocate for autistic people)

> Participation is always individual, how you actually involve them, it is a process, but I'd say the average person with a learning disability in advocacy is there in the middle, in tokenism at best. (Hungarian advocate for people with intellectual disabilities)

> Autistics are down there in therapy in general population, and in advocacy organisations maybe on the level of being informed. (Hungarian autistic self-advocate)

One autistic self-advocate in Hungary pointed out that the disabled people's movement itself is yet to comply with the CRPD: '*. . . actually, there is the saying "nothing about us without us", which I think is in the Convention itself, and this means they [DPOs] have to involve us, so that we are there in the decisions taken about us. But this is not happening at all.*'

Some participants see possible explanations for the tokenistic involvement of self-advocates in charities.

> I still think this would be within the degrees of tokenism but slightly up, in the middle of this (consultation). And it's interesting you mention charities, because I do think sometimes there's a hidden agenda to speak for these people rather than allow them to have a voice themselves. There are some great charities out there, but there's also a lot of . . . careerist out there, people who made a quite comfortable career with a relatively good income from speaking on behalf of them. (UK advocate for people with intellectual disabilities)

Several participants stated that the level of participation is variable over time. According to a Hungarian advocate for people with intellectual disabilities '*we are trying to bring it up to partnership level in our organisation, but it is just not working yet*'. In some cases, improvements may happen, but sometimes there is a setback in progress within organisations.

> Mencap moved toward citizen control and pulled back to placation and I think has slipped now to consultation in how it works. In terms of the broader disability movement insofar as there's one, the problem is that intellectual disability just hasn't managed to get any purchase at all. (UK advocate for people with intellectual disabilities)

For some autistic self-advocates in both countries, the progress in participation is happening—although only sporadically and slowly.

> We are only starting to reach the level if informing, if they listen to us at all. Although we see there are already some organisations where they take us seriously and don't just tell us 'you little stupid thing, what do you want?' (Hungarian autistic self-advocate)

> I think in advocacy, for the most part they would be in the middle. At the level of informing. What we are aiming toward is partnership, (. . .) so there are isolated pockets where there are good practices where it is moving away from tokenism. (UK autistic self-advocate)

There were few participants who saw the participation of self-advocates in DPOs largely at the lowest level, around manipulation, with 'no power'. For instance, a British autistic self-advocate stated '*As I said I don't feel part of the community, and I struggle with the language of intervention but the main trope is still around, the behaviour analysis and . . . equally there's . . . At large the establishment still has its power, so we are there, down (no power).*'

A notable exception to the majority opinion is that—consistently between the two countries—there were several self-advocates with intellectual disabilities who saw themselves being on the level of citizen control. For example, two British self-advocates with intellectual disabilities stated:

> Self-advocate 1: Now? Definitely now in the top! When I was in the [care] home, back then, more down here, halfway through, therapy and manipulation. I felt I weren't in control. And I was pushing them limits to get my control. Because I knew what I wanted and I KNEW what I wanted to do but it's like how do I say it unless I'm doing something wrong.

> Self-advocate 2: I was down there in the past, NO POWER but now up to partnership and control. Jumped from manipulation and now I am in the green.

Similarly, a Hungarian self-advocate with intellectual disabilities claimed '*I think I am up here on citizen control, because I get the information I need and I have worked a lot to achieve this so I can also help others to achieve it.*' This finding reasserts previous studies: self-advocacy groups for people with intellectual disabilities can provide meaningful control for people over certain aspects of their lives, including in their advocacy work. This must be recognised along with the broader observation made by most participants about tokenism in the movement, especially because although profound changes in the involvement of self-advocates are yet to be seen, self-advocacy itself has the potential to change people's lives which is a potential strength to build on when pursuing progressive changes in DPOs.

5. Conclusions

Findings were consistent across the two countries and they indicate that a significant part of the advocacy movement working for autistic people or people with intellectual disabilities have little actual knowledge about the CRPD and other human rights laws. Although there are some self-advocates and other advocates who are more familiar with human rights, they are likely to be found around 'big DPOs' such as national umbrella organisations that work closer to international organisations. This is consistent with the findings of Meyers (2014), who found that human rights frameworks are mostly pursued by national or international DPOs and local or grassroots organisations often follow different agendas. People involved in advocacy or in self-advocacy often see little relevance of human rights laws in their everyday advocacy and it is difficult for them to translate human rights into practical things. Significantly, some advocates and self-advocates feel they are 'not competent' to talk about human rights because of the level of expertise it requires, which implies that they feel disempowered when they are expected to use human rights as an advocacy tool.

Self-advocates and advocates in intellectual disabilities or autism usually saw very little progress in the implementation of the CRPD and thought human rights are vague concepts that are yet to become relevant to their lives. Participants who saw progress observed legal changes that are yet to make real impact and progress was seen to be very slow. Both the reluctance of state bodies and broader societal or political factors, outside the powers of the CRPD were blamed for the lack of progress. On the other hand, other participants appraised the important change the CRPD has brought about in the discursive level, allowing for new dialogue about what is needed for real change.

Both self-advocates and non-disabled advocates agree that the involvement of self-advocates in organisations, including major DPOs is tokenistic and stuck on the level of informing, formal consultation or placation. The low level of meaningful participation runs the risk that the disability movement, even when using the 'human rights model', pursues advocacy targets that are set by others such as parents and professionals and not by self-advocates themselves. Existing power relations within the movement are not seen to be changing, leaving professionals and parents in control. Some participants also see 'pockets of' good practices but few of them see real improvements in the meaningful participation of self-advocates within the movement.

Although the findings of the study do not represent the views of all self-advocates (and all their non-disabled allies) in the two countries, the consistency of findings between the two countries indicates a strong relevance to other countries and the international movement of disabled people. The disabled people's movement has been using the human rights model to challenge the continuing social exclusion of disabled people, but such change cannot happen until people with intellectual disabilities and autistic people get full membership within the movement.

The disability rights movement has a duty to address and openly discuss the continuously limited participation of self-advocates in the movement and start planning and implementing progressive changes accordingly. Therefore, the findings of the present article will be shared with DPOs and self-advocates in both countries and internationally.

Author Contributions: Gabor Petri is a doctoral candidate at the Tizard Centre, University of Kent, under the supervision of Julie Beadle-Brown and Jill Bradshaw. The present article forms a first analysis of data collected through his doctoral research. Gabor Petri co-designed the study, collected, transcribed, translated and analysed the data, and wrote up the article. Julie Beadle-Brown and Jill Bradshaw took active part in advising and guiding the research from its early phase, including its co-design and ethics, and they also provided input for the analysis of data. The doctoral research is supported by a Tizard Centre Scholarship.

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5

Freedom of Opinion and Expression: From the Perspective of Psychosocial Disability and Madness

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Abstract: This article argues that civil mental health laws operate to constrict how people think, understand, and speak about psychosocial disability, madness, and mental distress. It does so with reference to views and experiences of mental health service users and psychiatric survivors (users and survivors) and their/our accounts of disability, madness, and distress, such as those articulated by the emerging field of Mad studies. The analysis considers the application of the rights to freedom of opinion and expression that are enshrined in the *International Covenant on Civil and Political Rights* and other international human rights instruments to the mental health context. The article explores the suppression of freedom of opinion and expression that is effected through the symbolic violence of psychiatry and the mental health paradigm. Focusing on Australian legal frameworks, the article discusses how the material violence and coercion characterising mental health laws compound this process. It is further argued that civil mental health laws, by codifying the tenets of psychiatry and the mental health paradigm so as to render them largely unassailable, validate the ontological nullification of users and survivors. The foregoing analysis exposes dangers of adopting a functional test of mental capacity as the pre-eminent legal standard for authorising involuntary mental health interventions. It is suggested that considering freedom of opinion and expression from the perspective of psychosocial disability and madness reinforces the Committee on the Rights of Persons with Disabilities' interpretation that such interventions are incompatible with international human rights standards.

Keywords: mental health law; Convention on the Rights of Persons with Disabilities; International Covenant on Civil and Political Rights; psychosocial disability; Mad studies; freedom of expression; freedom of opinion; coercion; symbolic violence; capacity

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1. Introduction

This article examines the suppression of freedom of opinion and expression by mental health (law). The international human rights to freedom of opinion and expression are understood to act as 'enablers' for a range of civil and political rights and 'the good working of the entire human rights system' (O'Flaherty 2012, pp. 629–31). International human rights bodies have long acknowledged the importance of these rights for political participation and the democratic process, in addition to the enjoyment of the rights to freedom of assembly and association (Human Rights Committee 2011, p. 1). Further, the value of freedom of opinion and expression for the protection of social, economic, and cultural interests is increasingly recognised (O'Flaherty 2012, p. 631), including the development of societies (Sen 1999, pp. 152–54), education, and women's ability to make informed decisions of particular relevance to them (Commission on Human Rights 2000). Their application in the specific context of disabled people, including people with psychosocial disabilities, has not been a focus in international human rights discourse. The new era of disability rights heralded by the advent of the

Convention on the Rights of Persons with Disabilities (CRPD),[1] which embodies the indivisibility and interdependence of civil and political rights and economic, social, and cultural rights (Degener 2016, p. 5), provides an opportune moment in which to reconsider these foundational human rights.

Sections 2 and 3 explain key concepts and terms that are used throughout this article, including symbolic violence, madness, and psychosocial disability. In Section 4, I outline components of the international human rights to freedom of opinion and expression and the relevance of these rights to disability. In Section 5, I consider how the views and experiences of mental health service users, survivors of psychiatry, and other people with psychosocial disability (users and survivors) demonstrate that denial of freedom of opinion and expression is implicated in psychiatry and the mental health paradigm at multiple levels. This extends to forms of colonial and cultural oppression operating at the global level. I also discuss the growing body of knowledge of users and survivors about madness, distress and psychosocial disability. The discussion shows how the symbolic power of psychiatry and the mental health paradigm operates to constrain and silence ways of knowing, expressing, opining, and being that may be vital to a person's sense of self, a process of symbolic violence that cultivates the ontological nullification of users and survivors.[2]

Australian civil mental health laws[3] provide for an individual to be detained, or made subject to a community treatment order, in order to force mental health interventions upon them. As a federation, Australia is comprised of states and territories, each of which has its own mental health statute. Focusing on Australian legal frameworks, Section 6 provides an overview of mental health laws and reflects on debates about their compatibility with international human rights standards, paying particular attention to the concept of (in)capacity.

Section 7 describes the coercive project of mental health law and the interrelationship between the material violence and symbolic violence that are inherent in this body of law. It is argued that mental health laws solidify restrictions on the freedom of opinion and expression of users and survivors. It is further argued that, by codifying certain tenets of psychiatry and the mental health paradigm so as to render them largely unassailable, mental health laws validate the ontological nullification of users and survivors. It is suggested that these suppressive processes radically diminish opportunities for individual self-expression and for the epistemologies of users and survivors to exert influence on societal systems and structures.

2. Symbolic Violence

An analysis of freedom of opinion and expression from the perspective of psychosocial disability and madness illuminates the 'symbolic violence' that is perpetrated by psychiatry and the mental health paradigm and reified by mental health laws.

Symbolic violence is perpetrated where an actor, usually the State, dominates symbolic struggles in a particular social sphere—struggles over the making of meanings and construction of social realities—and thus monopolises associated symbolic power (Bourdieu 1990, pp. 135–37). The processes by which psychiatry and the mental health paradigm push aside, diminish and nullify other understandings of experiences and interactions that are labelled as 'mental illness', are increasingly recognised as involving symbolic violence (Crossley 2004, p. 172; Lee 2013). The symbolic power thereby exerted is founded on a dominant ideology, including 'fundamental precepts, such as the existence of mental 'illnesses', the pathologisation of certain behaviours/beliefs deemed socially

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[1] *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) (CRPD).

[2] 'Ontological violence' or nullification occurs when a dominant ideology delivers an interpretation that 'determines the very being and social existence of the interpreted subjects' (Žižek 2008, p. 62).

[3] Although similar issues are raised by forensic mental health and disability laws, my focus here is on civil mental health laws. The term 'mental health laws' is used throughout this article when referring to civil mental health laws, which are termed 'civil commitment laws' in some countries.

unacceptable and the location and the causes of mental distress' (Kinouani 2015). Flick Grey has spoken of how this ideology comprises a 'specific biomedical, diagnosis-driven universe of meaning' which silences and marginalises 'the lived truth of those in contact with the mental health system' (Coopes 2017).

In referring to the 'mental heath paradigm' and the 'medical model', I am referring to systems of meaning that derive substantially from the discipline of psychiatry as a subset of medicine.[4] These systems of meaning, which dominate mental health service delivery, presuppose and privilege psychiatric understandings of madness and distress as involving 'illness' and 'disorder', which must be cured, fixed, and managed. The Special Rapporteur on the Right to Health has recently made recommendations aimed at addressing 'the imbalance of the biomedical approach in mental health services' (Human Rights Council 2017, p. 20). Aspects of psychiatry and mental health services may temper the excesses of this approach. For example, psychiatrists may be sensitive to their patients' social relationships and circumstances in making diagnoses, providing advice, and recommending treatment, and may attend most closely to experiences that actually seem to bother their patients. Clinicians in mental health services will reach different views, informed by their various disciplinary backgrounds and a range of ideas, which will influence real world decisions and outcomes. Certain critical strains within psychiatry emphasise 'the dangers of simply suppressing' madness 'with drugs or other means' (Critical Psychiatry 2017). Yet these forces would be hard-pressed to alter the tenets forming the very roots of these systems of meaning.

3. On Terminology

The CRPD was formulated after extensive deliberations, and, uniquely, input from a number of disabled people's organisations, including the World Network of Users and Survivors of Psychiatry.[5] The application of the CRPD to psychosocial disability is made clear in Article 1, in which it is stated that persons with disabilities include 'those who have long-term physical, mental, intellectual or sensory impairments'. Although the term 'mental impairments' is used in the CRPD, the associated disability is recognised in Article 1 as involving the interaction of such actual or perceived 'impairments'[6] with 'various barriers' that may hinder a person's 'full and effective participation in society on an equal basis with others'. This part of the CRPD is understood to incorporate the 'social model' of disability (see Degener 2016, p. 2).[7] The term 'psychosocial disability' is now commonly used by activists, advocates, and scholars applying the CRPD framework and provisions to protect the rights of users and survivors.

Madness and mental distress are in the process of being re-imagined as distinct from, and part of, disability. The choice of particular words to name and categorise a person, experience, or encounter in this context is a political choice that may operate tacitly to either preserve or resist the dominant paradigm (Burstow 2013, p. 82) and be indicative of heated conceptual battles (Diamond 2013, p. 64). Whilst 'mental health service user' and 'consumer' are terms commonly employed in government and public discourse, people on the receiving end of mental health services frequently use a variety of different terms to describe themselves. The term 'consumer', implying an acceptance of psychiatry's medical model by someone who has real choices in the marketplace, may be considered misleading given the reality of involuntary mental health interventions, and is insulting to those who have suffered psychiatric abuse (see Weitz 2003, p. 71).

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[4] On the hegemonic nature of psychiatric discourse see Burstow (2013, pp. 80–81).

[5] For the list of non-governmental organisations representing disabled people that participated in the CRPD negotiations, see United Nations Enable (2007).

[6] The role of the concept of 'impairment' within the social model of disability has been subject to criticism by disability theorists (for example Hughes and Paterson 1997) and doubt has been cast on the applicability of this concept to psychosocial disability (Penson 2015).

[7] The origins and development of the social model of disability are addressed in Barnes (2012).

Two terms that embody resistance to psychiatric discourse are 'Mad' and 'psychiatric survivor'. The term 'psychiatric survivor' has been embraced by many to show

> pride in our history of surviving discrimination and abuse inside and outside the psychiatric system, in advocating for our rights and in our personal and collective accomplishments—that psychiatric survivors are much more than a diagnostic label (Reaume 2008).

The term 'madness', which has in recent history been used in derogatory fashion, has been reclaimed since the emergence of the antipsychiatry movement and is used by some individuals and constituencies to affirm emotional, spiritual, and neuro-diversity (Menzies et al. 2013, pp. 10–11; Costa 2008). Rejecting the very categories of madness and sanity, Erick Fabris proposes the upper-case, proper noun 'Mad', to encompass people *considered* 'mentally ill', 'for political action and discussion' (Fabris 2013, p. 139).

'Madness' and its derivatives are controversial terms that may be considered offensive, including by many mental health service users. 'Disability', however, is far from achieving universal acceptance amongst users and survivors when it comes to self-identification (for example Beresford et al. 2010, pp 19–20). Jana Russo and Debra Shulkes, writing about the European user/survivor movement, have expressed concern about 'an implicit, and sometimes openly stated, demand that we all adopt the disability framework', particularly given that people's ability to self-define is often already diminished by the application of psychiatric labels and diagnoses (Russo and Shulkes 2015, p. 33).

'Mental illness' and 'mental disorder' are products of the diagnostic medical model, whereas 'psychosocial disability' aligns with the social model of disability and acknowledges the socially constructed nature of disability. 'Person with psychosocial disability' is a term that can be used to refer to people who may define themselves in various ways vis-à-vis their interaction with mental health services, including people 'who do not identify as persons with disability but have been treated as such, e.g., by being labeled as mentally ill or with any specific psychiatric diagnosis' (World Network of Users and Survivors of Psychiatry 2008). The political value of this term is captured by Tina Minkowitz who sees it 'as a bracketed space', allowing for individuals to identify needs for support and assert rights-claims when necessary (Minkowitz 2014, p. 461).

My choice to use the terms 'madness', 'mental distress' and 'psychosocial disability' in this article represents an attempt to heed the calls of Russo and Shulkes for 'an open-ended exploration of what different terms and concepts mean to different people' (Russo and Shulkes 2015, p. 34), and of Alice Hall that 'language is necessary in order to critique, challenge and re-write the stories and structures through which disabilities have been traditionally understood (Hall 2016, p. 8).'

4. The International Human Rights to Freedom of Opinion and Expression

The stifling of political dissent, workers' rights, media communications, artistic expression, and religious freedom are some of the areas that have been central to the development of domestic and international jurisprudence concerning the rights to freedom of opinion and expression. A number of international instruments have addressed threats posed to freedom of expression by expanded laws directed at combating terrorism and protecting national security and public order, such as offences of 'encouraging', 'praising' and 'justifying' terrorism, or engaging in 'extremist activity' (see Parmar 2015). A 2016 report of the Special Rapporteur on the promotion and protection of the right to freedom of opinion and expression stressed the potential for such measures to undermine the media, critical voices and activists (United Nations General Assembly 2016). Scholarship has taken up issues such as challenges that are associated with new information technologies, including internet governance (Benedek and Ketteman 2014), and the suppression of diverse gender identities (Nunan 2010).

The growing body of commentary about sharing and receiving ideas and information via digital technologies is particularly relevant when considering how to promote freedom of opinion and expression for people with disability (see Goggin 2017, p. 2). Yet, turning attention to disability in this sphere may yield valuable insights for theorising and implementing the rights to freedom of opinion and expression for all people, such as by destabilising assumptions about what constitutes 'normal' communications and expanding possibilities for activating communication rights (Goggin 2017). Confronting the meaning of the rights to freedom of opinion and expression specifically from the perspective of psychosocial disability and madness within disability human rights law may similarly enrich wider understandings of these rights. To date, there has been little consideration of the application of these rights to the mental health context, although concerns surrounding gross limitations on freedom of opinion and expression are implicit in much activism, advocacy, and research by users and survivors and their/our allies, as will be discussed in Section 5.

The first appearance of the rights to freedom of opinion and expression in an international human rights instrument was in Article 19 of the *Universal Declaration of Human Rights* (UDHR),[8] which states:

> Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

Article 19 of the *International Covenant on Civil and Political Rights* (ICCPR)[9] encompasses the right to hold opinions without interference and the right to freedom of expression, with the right to freedom of expression further enfolding

> freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of [a person's] choice.[10]

A notable difference between the UDHR and ICCPR formulations is that the UDHR treats freedom of opinion and expression as belonging to a single right, whereas the ICCPR demarcates two distinct rights and groups the subsidiary right to 'freedom of information', together with the right to freedom of expression. Whilst the term 'freedom of expression' dominates international legal discourse, assuming the subsumption of freedom of information within its parent right, there is a complex relationship between what may be seen as two 'contiguous' rights—to freedom of expression and to freedom of (access to) information (McGonagle and Donders 2015, pp. 2–6). In this article, I refer to the 'rights to freedom of opinion and expression' to refer to the body of rights and obligations enshrined in Article 19 of the ICCPR, which contains the 'principal global expression of the right' (O'Flaherty 2012, p. 633).

The Human Rights Committee, which oversees the implementation of the ICCPR, published a new General Comment on Article 19 in 2011, *General Comment No. 34: Article 19: Freedoms of opinion and expression* (General Comment No. 34). This instrument notes the interdependence of the rights to freedom of opinion and expression, 'with freedom of expression providing the vehicle for the exchange and development of opinions' (Human Rights Committee 2011, p. 1). The only reference to disability is in the section on 'freedom of expression', which makes clear that 'all forms of expression and the means of their dissemination' are protected by Art 19(2), and mentions sign languages in the associated list (Human Rights Committee 2011, p. 3).

The re-articulation of the rights to freedom of opinion and expression in Article 21 of the CRPD displays a much-needed focus on freedom of information and communication rights. It supplements Article 19 of the ICCPR primarily by enumerating elements concerning seeking, receiving, and imparting information and ideas through diverse technologies, modes, and communication styles. Article 21 provides the following non-exhaustive list of actions States Parties must take to realise the rights to freedom of opinion and expression:

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[8] *Universal Declaration of Human Rights*, GA Res 217A, UN Doc A/810 91 (10 December 1948).

[9] *International Covenant on Civil and Political Rights*, opened for signature 19 December 1966, 999 UNTS 172 (entered into force 23 March 1976) (ICCPR).

[10] ICCPR, Art 19(2).

(a) Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;
(b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;
(c) Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;
(d) Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;
(e) Recognizing and promoting the use of sign languages.

Article 21, which includes a requirement for States Parties to take measures to ensure that people with disability can exchange information and ideas through all forms of communication of the person's choice, can thus be seen as vital to securing the participation of people with disability in all aspects of life. The emphasis seems to have been placed upon the technical and mechanical aspects of communication. This article is primarily concerned with the openness of the substance of communications and their epistemic underpinnings.

In the wake of the CRPD's entry into force, much of the debate about protecting the human rights of people with disability, including people with psychosocial disability, has focused on the right to equal recognition before the law contained in Article 12 and the requirements for States Parties:

- to recognise that people with disability 'enjoy legal capacity on an equal basis with others in all aspects of life';[11] and
- to take measures 'to provide access by persons with disabilities to the support they may require in exercising their legal capacity'.[12]

This debate has been substantially preoccupied with whether the CRPD permits substitute decision-making, such as guardianship and involuntary mental health interventions, and how States Parties can comply with the requirement to provide support in the exercise of legal capacity, as required by Article 12(3) (often termed 'supported decision-making'). The paradigm shift in the approach to legal capacity embodied in Article 12 of the CRPD (Beaupert and Steele 2015), as discussed in Section 6, has generated a vast body of commentary. A pivotal strand in the gradual broadening in scholarship to engage in more holistic fashion with the CRPD (for example, Arstein-Kerslake 2017; Beaupert et al. 2017) concerns the lawful material violence perpetrated against people with disability, violence that would not be tolerated in other contexts and against non-disabled bodies (Steele 2014; Steele and Dowse 2016; Spivakovsky, forthcoming).

Turning attention to the rights to freedom of opinion and expression offers promise for enhancing and complementing these enquiries in a number of respects. Applying these rights to mental health laws specifically may give additional insight into harms that are caused by the legal reification of the symbolic power of psychiatry and the mental health paradigm, including the lawful material violence constituted by involuntary mental health interventions. The Committee on the Rights of Persons with Disabilities (CRPD Committee), which is the body charged with monitoring the CRPD, has released a General Comment dealing with Article 12 of the CRPD, *General Comment No. 1: Article 12: Equal Recognition before the Law* (General Comment No. 1), concluding that substitute decision-making arrangements, including detention and other involuntary interventions pursuant to mental health laws, contravene Art 12 in addition to other provisions of the CRPD, and must therefore be abolished

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[11] CRPD, Art 12(2).
[12] CRPD, Art 12(3).

(Committee on the Rights of Persons with Disabilities 2014). One question that follows is whether an additional consideration supporting the abolition of mental health laws lies in the need to protect the 'negative' aspects of the rights to freedom of opinion and expression (i.e., non-intervention by the State). Given the manner in which the 'lives, experiences and opinions' of people with disability are fundamentally devalued and invalidated (Spivakovsky, forthcoming), the scope of States' 'positive' obligations to establish legal, policy, and administrative machinery to support freedom of opinion and expression (Kenyon et al. 2017) is equally relevant.

Freedom of opinion and freedom of expression are valuable concepts because they are not limited to speech, and are therefore well-suited to encompassing the diverse modes of communication and expression that people with disability may use to interact with other people and the world. Crucially, the notion of rights to freedom of opinion and expression holds potential for disrupting the symbolic power and epistemic authority of psychiatry by validating opinions and expressions of users and survivors that conflict with the mental health paradigm. Further, an approach from this standpoint may assist in preventing the (further) pathologisation of both their/our resistance to this dominant paradigm (see Hamilton and Roper 2006, pp. 420–21; Spivakovsky, forthcoming) and their/our wider socio-political dissents (for example Metzl 2009). In fact, struggles over the creation of 'truths' across Mad and disability activism and scholarship share groundings in resistance against assignments of impairment and illness through dominant medical epistemologies (Lewis 2013, p. 117). Karen O'Connell has interrogated the ambivalent position that eccentricity occupies in (disability) law, and the increasing tendency to pathologise eccentric behaviour, with a view to destabilising the categories of disability and normalcy (O'Connell 2017). Similarly, asserting the importance of 'freeing' the opinions and expressions of people with disability about their/our actual or perceived 'impairments' or 'illness'—whether regarding idiosyncracies, spiritual beliefs, unusual experiences, altered states of consciousness, distress, pain, discomfort, social needs, oppression, health, or desire to be left alone—may work to dislodge, enrich, and connect apparently fixed social and legal categories.

Freedom of opinion, according to General Comment No. 34, covers 'all forms of opinion', 'including opinions of a political, scientific, historic, moral or religious nature' (Human Rights Committee 2011, p. 2). Article 19(2) of the ICCPR on the right to freedom of expression protects the exchange of 'information and ideas of all kinds, regardless of frontiers'. In emphasising the inexhaustible nature of the forms of protected information and ideas, General Comment No. 34 lists political discourse, commentary on personal and public affairs, canvassing, discussion of human rights, journalism, cultural and artistic expression, teaching and religious discourse as being included amongst the expressions protected by Article 19 (Human Rights Committee 2011, p. 3). There is nothing to suggest that a person's opinions and expressions about their experiences of psychosocial disability or interactions with mental health services would be excluded. In light of growing concern about the questionable evidence base for mental health interventions (see Human Rights Council 2017, pp. 7–8; Whitaker 2010) and serious physical harms and lower life expectancies that are associated with these interventions (The Royal Australian & New Zealand College of Psychiatrists 2016; Lawrence et al. 2013), the imperative to protect an individual's ability to form their own opinions about what is happening, and should happen, to their mind and body—and to act on those opinions—is heightened.

The right to freedom of expression is subject to the restrictions set out in Article 19(3) of the ICCPR, specifically 'restrictions as are provided by law and are necessary':

(a) For respect of the rights or reputations of others;
(b) For the protection of national security or of public order (ordre public), or of public health or morals.

The circumstances in which freedom of expression will be protected under international law are circumscribed. The above restrictions to do not apply to the right to freedom of opinion, which, according to General Comment No. 34, may not be infringed even during a state of emergency (Human Rights Committee 2011, pp. 1–2). I am primarily interested in exploring the nature and implications of denial of freedom of opinion and expression for users and survivors; this article does not undertake legal analysis of whether mental health laws contravene Article 19 of the ICCPR and/or Article 21 of the CRPD. In particular, I do not examine whether restrictions that are imposed by mental health laws on the freedom of expression of people falling within their jurisdiction would come under the legally permissible restrictions.

The following section addresses the suppression of freedom of expression and opinion in the mental health context with reference to the views, experiences, and epistemologies of users and survivors and the symbolic violence that operates to marginalise these perspectives.

5. Unravelling the Symbolic Violence of Psychiatry and the Mental Health Paradigm

The symbolic violence of psychiatry and the mental health paradigm perpetrates diverse, sometimes blatant, and sometimes very subtle harms, by categorising the distress that people experience and facilitating a range of mental health interventions across institutional and community settings (Lee 2013). The deeply stifling and suppressive effects of psychiatry and the mental health industry have long been theorised.[13] Erving Goffman's work on mental asylums tracked the career of inmates and suggested that the asylum's structures, regimes, and rules imposed a status beyond the patient's control, whilst discrediting their story (Goffman [1961] 2007). Goffman's observations led him to describe asylums as 'total institutions', which radically altered inmates' personal identity (Goffman [1961] 2007). The following accounts of users and survivors confirm the thesis that psychiatry and the mental health paradigm can set in motion processes that destroy a person's sense of self.

Cath Roper has described the outcome of being psychiatrised, and co-opted into medical ways of making meaning of one's madness, and distress as follows: 'Our sense of self crumbles, our way of being in the world, what we know, how we make meaning, is disparaged and wrong' (Roper, forthcoming). Patricia Deegan, sharing her experience of being diagnosed with 'mental illness' at a young age, has said:

> Our personhood and sense of self continued to atrophy as we were coached by professionals to learn to say, "I am a schizophrenic"; "I am a bi-polar"; "I am a multiple". And each time we repeated this dehumanizing litany our sense of being a person was diminished as "the disease" loomed as an all powerful "It", a wholly Other entity, an "in-itself" that we were taught we were powerless over (Deegan 1996).

The notion that an institution or worldview can radically alter someone's identity implies that there is a reprogramming of thoughts and opinions about one's self and one's place in the world. The symbolic violence of psychiatry and the mental health paradigm can stifle thoughts, foreclosing possibilities for understanding and conceptualising one's own experiences. This process can preclude the forming and expressing of other opinions and understandings about what is happening, understandings that may be vital for a person to make sense of, work through, or embrace their experiences. Instead, it can instil a complete lack of self-confidence and faith in oneself, as elucidated by Ji-Eun Lee relying on descriptions by users and survivors of how they internalised the reality offered by clinicians of their 'resistance to treatment' and 'incompetence' (Lee 2013, p. 116).

Jana Russo has encapsulated the causal connection between the symbolic violence of psychiatry and the denial of the freedom of opinion and expression of users and survivors in describing how 'finding the right words', and even thinking through one's experiences, are challenging processes when 'we constantly meet psychiatry as a point of reference' (Russo 2016, p. 76). Katie Aubrecht's description of coercion in mental health treatment demonstrates how this encounter can destroy one's sense of self to the point of being completely uncertain about one's thoughts and opinions, or feeling almost possessed by the text of 'illness':

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[13] Scholarship in this tradition includes the following, among many others: (Szasz [1960] 1997; Goffman [1961] 2007; Foucault [1964] 2001; Chamberlin [1997] 2012); Fabris (2011); Rapley et al. (2011); Arrigo (2012); Newnes (2016).

> Under the watchful gaze of a physician, I was taught to read experiences, red cheeks, heavy hearts, and knots, as symptoms of mental illness and as tests of my character. I was constantly quizzed about how well I knew the experiences I had were actually true experiences. I couldn't be sure what I felt, liked, or wanted anymore. I did, however, become ever more familiar with what doctors felt, liked, and wanted, and that those would be the right things to feel, like, and want (Fabris and Aubrecht 2014, p. 191).

The impression that is created by such accounts is that when medical systems of meaning about madness and distress are imposed upon an individual this may actually suffocate thoughts and opinions that will enable them to express how they are feeling, what they are experiencing, and their views on what should happen and what supports—if any—they would find useful. Constructions of psychiatrised people[14] as 'disordered', 'incompetent' and 'dangerous' can entail epistemic disqualification of an individual as a legitimate 'knower' who can speak on their own behalf (Liegghio 2013). Further, supplanting an individual's thoughts and opinions with a system of meaning that destroys their very sense of self goes to the core of being and human dignity (see Liegghio 2013; Roper, forthcoming). This is a manifestation of 'ontological violence', described by Slavoj Žižek as occurring when a dominant ideology delivers an interpretation that 'determines the very being and social existence of the interpreted subjects' (Žižek 2008, p. 62).

Decades of resistance by ex-patients, psychiatric and mental health system survivors, consumers, mental health service users, advocates, practitioners, academics, and other allies have cultivated epistemologies grounded in experiential knowledge that challenge psy-based[15] understandings about 'mental illness' (Menzies et al. 2013, pp. 3–9). Whilst such dissents are often co-opted and manipulated to reinforce mental health industry agendas (Penney and Prescott 2016), different constituencies of users and survivors continue to work strategically to engage their/our own knowledge, histories and identities to build distinct visions and realities of healing, social justice, and political change (for example, Costa et al. 2012; Russo and Sweeney 2016). One spearhead of these initiatives is the emerging field of enquiry, Mad studies.

Mad studies operates as a praxis within which divergent perspectives and disciplines can connect as part of a collective project aiming to

> engage and transform oppressive languages, practices, ideals, laws and systems, along with their human practitioners, in the realms of mental 'health' and the psy sciences, as in the wider culture (Menzies et al. 2013, p. 13).

Mad studies is particularly relevant when considering freedom of opinion and expression from the perspective of psychosocial disability and madness because of its explicit focus on deploying the opinions and experiences of Mad constituencies, and celebrating their expression, in order to 'contest regimes of truth' (Menzies et al. 2013, pp. 14–15). In working to transform and transcend dominant medical approaches to madness, Mad studies does not deny that users and survivors may experience 'psychic, spiritual and material pains and privations' and want help in dealing with these experiences:

> To the contrary, it is to acknowledge and validate these experiences as being authentically human, while at the same time rejecting clinical labels that pathologize and degrade; challenging the reductionist assumptions and effects of the medical model; locating psychiatry and its human subjects within wider historical, institutional and cultural contexts; and advancing the position that mental health research, writing, and advocacy are primarily about opposing oppression and promoting human justice (Menzies et al. 2013, p. 10).

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[14] The term 'psychiatrisation', which refers to processes that construct and produce people as 'mentally ill', subverts understandings of madness and mental distress as individualised pathologies (LeFrançois and Coppock 2017, p. 165).

[15] Rose (1998) contends that the psy sciences (psychology, psychiatry, and other disciplines that designate themselves with the prefix psy) constitute techniques for the disciplining of human difference.

In discussing possibilities for harnessing the individual and collective experiences and knowledge of users and survivors, Peter Beresford emphasises that users and survivors have different and diverse *knowledges* and that experiential knowledge takes many forms (Beresford 2016, p. 42). Some of these knowledges are comparatively well-established (see Mills 2014, p. 144), such as the hearing voices movement, which positions the experience of hearing voices, and other unusual beliefs and experiences, as something real and meaningful (Intervoice The International Hearing Voices Network), thereby subverting explanations of such experiences as symptoms of 'mental illness' or 'psychosis'. Others are emerging, such as the 'Mad approach to grief', which Jennifer Poole and Jennifer Ward offer up to 'start a conversation' about 'getting under', 'feeling', and 'claiming' grief, in part to challenge the increasing medicalisation of grief through the development of a broadening array of psychiatric diagnostic categories (Poole and Ward 2013). Research conducted on mental health service users' views about their experiences of mental health issues and interactions with mental health services revealed limitations the medical model places upon people's ability to truly make sense of the wider social context of madness and distress (Beresford et al. 2010).

Whilst such knowledges diverge in important ways, many of them share in common a dissatisfaction with the dominant medical model and the constraints that it imposes on their/our abilities and opportunities to name and make meaning of our experiences. Some users and survivors consider certain experiences labelled as symptoms of 'mental illness' to be meaningful processes that they wish to explore rather than numb through the use of medication (Spandler and Calton 2009, p. 245). Thus, Poole and Ward speak of 'grief liberation practices' run by people who have been constructed as disordered 'because of how they expressed and communicated the pain' and who 'know what it is to break open the bone of grief and story it from down deep' (Poole and Ward 2013, p. 103). These knowledges indicate that experiences that are frequently classified as symptoms of 'mental illness' are for some users and survivors forms of expression in and of themselves, which need to be felt, voiced, and lived through on one's own terms. Helen Spandler and Tim Calton posit the 'right to *experience* psychosis ... without *forced* treatment/medication ... but with maximum *support*' in response to this need (Spandler and Calton 2009, p. 246), throwing into sharp relief the denial of freedom of opinion and expression that can accompany an approach which predominantly seeks to eliminate or dull such 'symptoms'.

Article 21 of the CRPD does not explicitly direct itself to this outlook on expression and the interconnection between expression and the different epistemologies and ways of being of people with disability. On one level, the exploration in this article points to the potential limitations of the CRPD in addressing fundamental injustices connected to deference to medical epistemologies that enact 'mental illness' as a negative attribute residing in the mind and body in framing the social needs and political demands of people with psychosocial disability. On another level, I am using the concept of freedom of opinion and expression as a springboard to interrogate concerns which underlie and give further content to articulations and theories of rights under the banner of the CRPD. Degener writes that the CRPD provides for a new concept of 'transformative equality', which goes beyond combating discriminatory behaviour, structures, and systems to require positive measures that change the offending structures and address hierarchical power relations (Degener 2016, p. 24). Further engaging the substantive dimensions of the concept of freedom of opinion and expression for disabled people—in addition to procedural aspects relating to modes of, and technologies for, expression and communication—may enliven this project.

Whilst there are unifying threads in the experiences and histories of users and survivors, the potential for the Mad movement—particularly through (sometimes unwitting) attempts to universalise experiences of madness and mental distress—to itself subjugate the knowledges of marginalised individuals, communities, and identities (Gorman 2013) should be acknowledged as part of the complexity of denial of freedom of opinion and expression at work in this context. Within different constituencies of users and survivors, hierarchies that privilege and centre certain experiences can trivialise the process of meaning-making for people for whom there is no well-established knowledge base (Grey 2017). Every person's experience of seeking access to, using, or being abused by, mental health services, and how this experience interacts with their identities, relationships, and social positionings, is unique. Yet, allowing for the expression of unique experiences may require a conscious broadening in outlook to address certain commonalities within marginalised communities. Colin King, for example, explains how the invisibility of whiteness within European psychiatry serves to obscure the neo-colonial processes underpinning diagnoses of 'psychosis' and 'schizophrenia' assigned to African and black men (King 2016). In cautioning against 'the solidification of an 'essential' Mad identity', Rachel Gorman exposes a troubling lack of engagement by the Mad movement and disability studies with analyses of race, poverty, migration, and the global (Gorman 2013).

With the onset of the Movement for Global Mental Health (Movement for Global Mental Health 2017), and the World Health Organization's prioritisation of global mental health promotion (Wildeman 2013), considerations of freedom of opinion and expression expand beyond individual and collective expressions and experiences of user and survivor constituencies towards ethno-cultural expression and freedom. In her exploration of how global mental health policy can be read as a form of colonial discourse, China Mills uncovers how psychiatric practice can become an instrument of rights violations masked as benevolent health interventions in parts of the global South (Mills 2014, pp. 4–6). Mills concerns about Global Mental Health lead her to ask: 'as this knowledge is exported as a universal standard, a global norm, what other ways of knowing are lost, or forced to speak in whispers?' (Mills 2014, p. 7). The racism and colonialism that in many respects underpins psy discourses can threaten 'the cultural survival of Indigenous spirituality and healing', impacting ongoing struggles for Indigenous sovereignty (Tam 2013, p. 297). Users and survivors in India are utilising the framework of the CRPD to contest the colonial impositions of the asylum, mental health law, and practices of segregation and exclusion that have become 'inextricably mixed into the project of providing mental health services' (Davar 2005).[16] The next steps in reform of laws and policies relating to mental health and disability in the global North thus have pressing socio-political implications both within and beyond its borders.

The discussion in this section has hinted at the breadth of the denial of freedom of opinion and expression that is effected through the symbolic violence of psychiatry and the mental health paradigm. It has also been suggested that such suppression of different ways of knowing, expressing, and opining cuts to the essence of being and humanness, manifesting as a form of ontological violence against the inherent human dignity that forms the foundation of international human rights.[17] Before considering how these harmful suppressive effects are compounded by civil mental health laws in the final section, Section 6 provides an overview of these legal frameworks and debates surrounding their compliance with the CRPD.

6. Civil Mental Health Laws, the Convention on the Rights of Persons with Disabilities and (In)Capacity

The trajectory of law's relationship to madness when it comes to civil confinement and control of people with psychosocial disability is often characterised as involving a central tension between 'rights-based legalism' and paternalism or clinical discretion (McSherry and Weller 2010, pp. 4–5). Mental health law reform in the global North has tended to oscillate between allowing medical professionals substantial discretion over the treatment and detention of people with psychosocial disability and requiring more extensive legal oversight of these processes (Bean 1986, p. 14). A persistent assumption underlying these reforms has been that some level of formal involuntary psychiatric intervention in the lives of individuals with psychosocial disability is necessary in order to

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[16] The scope of this article precludes a fuller account of the relationship between freedom of opinion and expression and global mental health promotion and Western medical imperialism (see (Davar 2005; Jayawickrama and Rose 2017; Bayetti and Jain 2017; Mills 2014), for exploration of relevant intersections).

[17] See ICCPR, Preamble: 'Recognizing that these rights derive from the inherent dignity of the human person'.

protect health and safety. The advent of the CRPD has eroded this assumption. At present, however, mental health laws in many jurisdictions typically make provision for two classes of compulsory intervention, which are effected through a legal 'involuntary order':[18] (a) inpatient commitment or detention in a mental health facility; and (b) outpatient commitment or a community treatment order (CTO), requiring submission to mental health interventions and compliance with other conditions whilst living in community settings. Another element of formal coercion pursuant to mental health laws is the administration of unwanted drugs and procedures to individuals subject to an involuntary order.

In Australia, the statutory criteria that must be satisfied for a person to be made subject to an involuntary order[19] include core prerequisites that: (a) the person has 'mental illness' or 'mental disorder' variously defined;[20] and (b) owing to that condition, 'treatment' is required in order to protect the person or other people from harm. The immediacy and level of seriousness of the requisite harm varies between jurisdictions and typically extends to a risk of deterioration in the person's condition or health. An additional requirement, often termed 'the least restrictive alternative principle', is that there must be no less restrictive means of providing the 'treatment'.[21] Secondary statutory criteria relating to the proposed intervention may also apply, such as the need for immediate or efficacious 'treatment' to be provided (see Carney et al. 2011, p. 58).

A more recent arrival in four Australian jurisdictions—Western Australia, Tasmania, South Australia, and Queensland—is a requirement that the person lacks 'decision-making ability' in relation to, or the capacity to consent to, the proposed intervention.[22] Although a lack of decision-making ability is not a prerequisite to making an involuntary order in the other jurisdictions, the relevant mental health statutes do now incorporate important provisions and requirements regarding obtaining consent and consideration of decision-making ability that limit the circumstances in which involuntary mental health interventions can occur.[23] The closely related concepts of mental capacity and decision-making ability discussed further below, which have become pivotal in disability human rights discourse, go to the heart of the rights to freedom of opinion and expression. This is because their formulation in and through mental health, disability, and capacity laws implies that the opinions and expressions of people considered to lack mental capacity or decision-making ability are so unworthy of being taken seriously that they can be overridden.

Decision-making about involuntary mental health interventions under Australian mental health laws is primarily shared between clinicians, in particular, psychiatrists and other doctors, and MHTs (or an equivalent body such as a generalist tribunal).[24] MHTs are multi-disciplinary quasi-judicial bodies that are established in each state and territory, sitting at the apex of the primary decision-making

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[18] I adopt this term to refer to the various orders that authorise involuntary mental health interventions pursuant to civil mental health or commitment laws throughout this article.

[19] *Mental Health Act 2014* (Vic), s. 5; *Mental Health Act 2007* (NSW), ss. 12–15 (detention) and 53–54 (community treatment order); *Mental Health Act 2015* (ACT), ss. 58 (psychiatric treatment order) and 66 (community care order); *Mental Health and Related Services Act* (NT), ss. 14–15A (involuntary admission) and 16 (involuntary treatment in the community); *Mental Health Act 2016* (Qld), s. 12; *Mental Health Act 2009* (SA), ss. 10, 16 (community treatment orders), 21, 25, 29 (inpatient treatment orders); *Mental Health Act 2013* (Tas), ss. 39 and 40; *Mental Health Act 2014* (WA), s. 25.

[20] Some Australian mental health statutes broaden the scope of involuntary intervention beyond people considered to have a 'mental illness' to cover other people with disability, such as people who are considered to be 'mentally disordered' or to have a 'mentally disturbance' or 'cognitive impairment' in certain circumstances: see, for example, *Mental Health and Related Services Act* (NT), ss. 15–15A; *Mental Health Act 2007* (NSW), s. 15.

[21] This principle does not form part of the statutory criteria that must be satisfied in order for an involuntary order to be made by the MHT in Tasmania, although it should be factored into decision making under the *Mental Health Act 2013* (Tas) by virtue of ss. 12(d) and 62(a).

[22] The terminology and formulations used for this criterion vary: see *Mental Health Act 2016* (Qld), ss. 12(1)(b), 14; *Mental Health Act 2009* (SA), ss. 5A, 10(1)(c), 16(1)(c), 21(ba), 25(ba), 29(ba); *Mental Health Act 2013* (Tas), ss. 7, 40(e); *Mental Health Act 2014* (WA), ss. 18, 25(1)(c).

[23] See *Mental Health Act 2014* (Vic), ss. 68–76; *Mental Health Act 2007* (NSW), ss. 68(h1); *Mental Health Act 2015* (ACT), ss. 78, 56. In the Northern Territory and the Australian Capital Territory one of the prerequisites is that the person lacks decision-making ability, *or* has refused, treatment; in the Northern Territory the standard lifts to unreasonable refusal: *Mental Health and Related Services Act* (NT), s. 14(b)(iii); *Mental Health Act 2015* (ACT), ss. 58(2)(b), 66(2)(b).

[24] The term mental health tribunal (MHT) will be used to refer to the MHT or equivalent body in each jurisdiction.

hierarchy (Carney et al. 2011). MHT decisions may be appealed to the courts, although appeals are not a frequent occurrence in most jurisdictions. Typically, an interim period of involuntary detention for assessment purposes can lead to a longer formal period of involuntary intervention. The MHT is in most cases responsible for making the initial involuntary order and conducting further hearings to determine if the person continues to satisfy the relevant statutory criteria on the order's expiry or the next review date. Similar criteria apply for authorising detention and making a CTO. Uniquely, in NSW, a separate lower threshold test is prescribed for making a CTO in some situations,[25] comparable to the standard applying to preventive outpatient commitment regimes in place in some United States jurisdictions (Player 2015, pp. 175–81).

One distinct trend in recent mental health law reform in the global North has been towards a stronger due process model, or increased procedural protections, such that laws provide for more stringent and frequent oversight by courts or quasi-judicial bodies (Carney et al. 2011, p. 5). However, recent reforms have expanded the situations in which involuntary psychiatric interventions may be authorised in several respects (Gooding 2017, p. 31). The introduction of CTOs, for example, has extended the locus of involuntary mental health interventions into the community. Whilst CTOs are now well-embedded in the Australian mental health law landscape, they have sparked controversy in other jurisdictions where they have been only relatively recently established, such as Scotland (Taylor 2016) and many parts of the United States (Player 2015, pp. 162–63). Outpatient commitment has far-reaching coercive implications, intruding into many aspects of a person's life (Fabris 2011, pp. 136–49), and the presumption that CTOs are a less restrictive alternative to detention has been called into question (Callaghan and Newton-Howes 2017, pp. 908–10). The situational context in which involuntary mental health interventions can be authorised has also broadened in some jurisdictions through changes to the relevant statutory criteria (Appelbaum 2006).

Given this trend towards *expansion*, it is imperative to continue grappling with questions surrounding the compatibility of mental health laws with human rights standards and the wider ethics of involuntary mental health interventions.

The Convention on the Rights of Persons with Disabilities and Involuntary Mental Health Interventions

Historically, mental health laws largely grounded the authority for their involuntary interventions in 'mental illness' and 'dangerousness' criteria. The shift towards 'incapacity' or 'lack of decision-making ability' as an additional or alternative rationale has commonly been viewed as a progressive development (Fistein et al. 2009). The entry into force of the CRPD has destabilised this perspective.

There is now a sharp divergence between mental health laws depending upon whether they incorporate a prerequisite that the person lacks the capacity to consent to the proposed intervention. Many commentators have pointed to the seemingly anomalous nature of mental health laws that do not include such a criterion. It has frequently been argued that this position discriminates unjustifiably against people with psychosocial disability, since informed consent is foundational to laws governing health care generally (Large et al. 2008, p. 878; Callaghan et al. 2013). Long before the entry into force of the CRPD, similar reasoning led commentators to propose the abandonment of separate mental health legislation in favour of generic health care or incapacity legislation applying to anyone lacking the capacity to consent to proposed medical treatment (Gordon 1993; Szmukler and Holloway 1998; Wand and Chiarella 2006). Thus the creep into mental health laws of incapacity-related prerequisites to involuntary interventions is often understood to be a delimiting, rights-respecting measure (Fistein et al. 2009).

The CRPD prescribes a regenerated outlook on (in)capacity, as epitomised in Article 12 (Equal recognition before the law). Article 12(1) states the underlying principle that 'persons with disabilities have the right to recognition everywhere as persons before the law'. The remaining provisions expose

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[25] *Mental Health Act 2007* (NSW), s. 53(3), (5).

how domestic formulations of legal capacity have undermined this principle in its application to people with disability. Article 12(2) demands recognition of the 'legal capacity' of people with disability on an equal basis with others. Legal capacity is a constitutive concept in numerous legal systems, encompassing an individual's ability to hold rights and duties (legal standing); and their ability to exercise those rights and duties (legal agency) (Committee on the Rights of Persons with Disabilities 2014, p. 3). Article 12(3) provides that States Parties 'shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity'. The short-hand term 'supported decision-making' is often used to describe measures contemplated by Art 12(3), although this term does not appear in the CRPD's text. Different understandings of this term indicate that 'supported decision-making' 'refers to a collection of various demands . . . [which] centre upon boosting the agency of persons with disabilities, offering them resources for making choices among good options about how to live' (Gooding 2017, p. 11).

Denial of the legal capacity of people with disability on the basis that they lack the mental capacity to make decisions about their/our own lives, or to participate in various private and public processes, has been endemic throughout history. People with disability who are considered to lack mental capacity have been legally prevented, for example, from getting married, voting, entering into contracts, and deciding what happens to their/our bodies and minds (Committee on the Rights of Persons with Disabilities 2014, p. 2). Laws in numerous countries continue to effect deprivations of liberty and denials of legal personhood on the basis of distinct approaches to mental capacity, known as the 'status approach', the 'outcome approach' and the 'functional approach' (Committee on the Rights of Persons with Disabilities 2014, p. 4). The status approach to mental capacity denies legal capacity purely on the basis of a person's status as a person with disability, or a medical diagnosis, whereas the 'outcome approach' attributes incompetence on the basis that a person has made a decision that is considered to have negative consequences (Committee on the Rights of Persons with Disabilities 2014, p. 4). A third, highly-contested approach, is the 'functional approach', which denies legal capacity where a person is considered to lack mental capacity on the basis of a specified assessment process, which often involves attempting to determine 'whether a person can understand the nature and consequences of a decision and/or . . . can use or weigh the relevant information' (Committee on the Rights of Persons with Disabilities 2014, p. 4).

In General Comment No. 1 on the right to equal recognition before the law, the CRPD Committee interpreted Article 12 of the CRPD as requiring the abolition of substitute decision-making regimes, such as guardianship and mental health laws (Committee on the Rights of Persons with Disabilities 2014, p. 6). The Committee's view is that Article 12 is contravened when people with disability are denied legal capacity on the basis of mental capacity tests, including tests adopting a functional approach to mental capacity. This interpretation therefore inverts the long-standing view that various disability-specific regimes providing for substitute decision-making grounded in an incapacity rationale are protective, and instead casts them as discriminatory measures (Beaupert and Steele 2015, p. 162). Historically, as Linda Steele explains, 'through the division of human rights subjects on the basis of mental capacity and incapacity, human rights *accommodated,* and, in fact, were *premised upon* the differential and discriminatory treatment of people with mental incapacity' (Steele 2016, p. 1014). Further, General Comment No 1 ascribes multiple violations of the rights of people with psychosocial disability to mental health laws and other substitute decision-making regimes applying to people with disability, including contravention not only of Art 12 of the CRPD, but also Art 14 (Liberty and security of person), Art 15 (Freedom from torture or cruel, inhuman or degrading treatment or punishment), Art 16 (Freedom from exploitation, violence and abuse), Art 17 (Protecting the integrity of the person), and Art 25 (Health) (Committee on the Rights of Persons with Disabilities 2014).

The CRPD Committee's interpretation has precipitated candid debate about whether States Parties are under an obligation pursuant to international human rights law to absolutely prohibit involuntary mental health interventions and other substitute decision-making regimes that regulate the lives of disabled people. However, much academic and public policy discussion in the wake of General

Comment No 1 proceeds on the assumption (or reaches the conclusion) that substitute decision-making for people with disability is warranted in some circumstances, and rather considers the bases on which such arrangements are permissible in light of the CRPD's provisions. Indeed, a number of States Parties to the CRPD have entered interpretive declarations, indicating their understanding that substitute decision-making regimes do not breach the provisions of the CRPD.[26] A prominent interpretation of Article 12 is that a functional approach to mental capacity is the dividing line between laws that are consistent with, and those that infringe, the CRPD (for example Dawson 2015). This position corresponds in many respects with earlier analyses that general incapacity or health care laws, rather than mental health laws, should govern the situations when others can make decisions about the lives and bodies of people with psychosocial disability with a view to providing health care.

In 2014, the Australian Law Reform Commission (ALRC) completed a landmark review of equal recognition before the law and legal capacity for people with disability, which considered the implications of the CRPD for domestic law reform (Australian Law Reform Commission ALRC). The Commission noted the interchangeable nature of a functional approach to mental capacity and a test of 'decision-making ability' (see Australian Law Reform Commission ALRC, pp. 71–72), variations of which now form part of the prerequisites for making an involuntary order in the mental health statutes in four Australian jurisdictions, alongside various combinations of the core and secondary criteria, as noted above.[27] A test of 'decision-making ability' assesses a person's mental capacity based on factors such as their ability to understand, retain, and weigh information that is relevant to a specific decision and to communicate that decision (Australian Law Reform Commission ALRC, pp. 200–1). The ALRC considered that an assessment of 'decision-making ability' that delinks this concept from diagnosis or disability and focuses on assessing the support a person needs to exercise legal agency avoids the pitfalls of a status approach to mental capacity (Australian Law Reform Commission ALRC, pp. 70–73). According to the CRPD Committee, a functional approach to assessing mental capacity (or decision-making ability) is flawed, firstly, because it is discriminatorily applied to people with disability, and, secondly, because it 'presumes to be able to accurately assess the inner-workings of the human mind and, when the person does not pass the assessment . . . denies ... [them] a core human right' (Committee on the Rights of Persons with Disabilities 2014, p. 4).

Functional abilities in the mental health context are determined with reference to medical and psy-based epistemologies that defer to psychiatry, via a process turning in large measure on a person's 'mental illness' diagnosis and status as a person with a psychosocial disability that judges their views about interventions proposed by psychiatrists and other clinicians. For example, the first requirement of the Queensland incapacity criterion is that the person must be 'capable of understanding . . . that the person has an illness, or symptoms of an illness, that affects the person's mental health and wellbeing'.[28] This formulation demands that a person, to be considered as having mental capacity, must form and express opinions about their experiences that align substantially with medical conceptions of 'mental illness'. It is unlikely that delinking decision-making ability from diagnosis or disability in the wording of a mental health statute would disturb these mechanisms. Accordingly, Steele and I contend that a test of 'decision-making ability' to determine whether involuntary mental health interventions are warranted is a veiled status approach to mental capacity (Beaupert and Steele 2015, 2017).

As discussed in the following section, the gradual encroachment of an incapacity or 'lack of decision-making ability' prerequisite to involuntary mental health interventions carries with it significant risks associated with codifying the notion that there is in an intrinsic association between incompetence and psychosocial disability.

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[26] For example, Australia, Ratification (with Declarations), registered with the Secretariat of the United Nations 17 July 2008, 2527 UNTS 289 (date of effect 16 August 2008).

[27] *Mental Health Act 2016* (Qld), ss. 12(1)(b), 14; *Mental Health Act 2009* (SA), ss. 5A, 10(1)(c), 16(1)(c), 21(ba), 25(ba), 29(ba); *Mental Health Act 2013* (Tas), ss. 7, 40(e); *Mental Health Act 2014* (WA), ss. 18, 25(1)(c).

[28] *Mental Health Act 2016* (Qld), s. 14(1)(a)(i).

7. Juridical Denial of Freedom of Opinion and Expression: Interlocking Material and Symbolic Violence

Whilst much of this article is concerned with symbolic violence, the denial of freedom of opinion and expression that occurs in the mental health context is deeply bound up in material violence. As Steele has written, non-consensual medical treatment, detention, and physical and chemical restraint are exceptionally legally permissible when applied to people with disability under particular legal frameworks, comprising forms of 'disability-specific lawful violence' (Steele 2014). Mental health laws form one such legal framework, which legalises acts that would amount to civil and/or criminal wrongs, such as the crimes of battery and assault, if perpetrated in other contexts and against nondisabled people (see Steele 2014). This section, firstly, considers how the (threat of) material violence produced by involuntary mental health interventions intensifies the denial of freedom of opinion and expression that is effected through the symbolic violence of psychiatry and the mental health paradigm. Secondly, it is argued that the medico-legal discourse of mental health laws, by consecrating this symbolic violence, operates to manipulate and nullify individual ways of knowing and being, and to radically diminish opportunities for the epistemologies of users and survivors to exert influence on societal systems and structures. Constructions of people with psychosocial disability as lacking capacity and 'insight' are central to these processes of dehumanisation.

7.1. The Suppressive Effects of Mental Health Law's (Threat of) Material Violence

The coercion, control, and force effected upon users and survivors through Australian mental health laws operate at multiple levels. A formal involuntary order provides the overarching mandate for the forced administration of specific drugs and procedures to an individual. On a day to day basis, clinicians are for the most part responsible for authorising the administration of drugs and other interventions.[29] MHT or other independent authorisation is typically only mandated for the performance of more exceptional procedures, such as electroshock and neurosurgery, in specified circumstances.[30] Even where clinicians are obliged to consult individuals who have involuntary status before providing or administering drugs or undertaking procedures, or to seek their informed consent in the first instance,[31] there is an expectation that 'treatment' will be provided. Drugs and procedures may be forced upon a person against their will, and even if they are considered to have the capacity to give informed consent, with the exception of electroshock and neurosurgery in some jurisdictions.

Many users and survivors characterise their interactions with mental health services and detention in mental health facilities as involving violent, torturous assaults on their bodies and minds (for example Lee 2013, p. 110). The experience of being in a psychiatric ward, which may include being placed in seclusion and administered with unwanted drugs, can be physically, psychically, and emotionally harmful and oppressive. Being forcibly administered with drugs or procedures has been described by users and survivors as a terrifying and degrading experience that 'breaks the spirit' (Lee 2013, p. 112). Forced administration of drugs also produces painful and damaging physical effects. Fabris uses the term 'chemical incarceration' to describe the prolonged imposition of drug treatment without a person's consent, regardless of whether the treatment is administered pursuant to mental health laws or in other contexts such as schools, prisons and hospitals (Fabris 2011, pp. 114–31). Drugging of individuals in nursing homes or of people with cognitive disability or intellectual disability in residential homes, for example, would equally be covered.

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[29] In the Northern Territory and Tasmania, the MHT is responsible for pre-approving treatment to be provided to a person subject to involuntary treatment, although clinicians can administer treatment outside this authority in specified circumstances: *Mental Health and Related Services Act* (NT), s. 55; *Mental Health Act 2013* (Tas), s. 41(2)(c).

[30] *Mental Health Act 2014* (Vic), s. 96 (electroshock), s. 102 (neurosurgery); *Mental Health Act 2007* (NSW), s. 96 (electroshock); *Mental Health Act 2015* (ACT), s. 157 (electroshock); *Mental Health Act 2016* (Qld), s. 236 (electroshock), s. 239 (non-ablative neurosurgery); *Mental Health Act 2009* (SA), s. 42 (electroshock), s. 43; *Mental Health Act* (WA), Pt 21, Div 6 (ECT), Pt 21, Div 7 (neurosurgery).

[31] For example, *Mental Health Act 2014* (Vic), s. 70.

The process of chemical incarceration, which is an embodied, visceral, physically violent process induces physical effects, such as numbing, fatigue, and cognitive restriction, which render an individual malleable and weaken their ability to resist; the chemical impact of the drug on the brain 'leads to pacification' (Fabris 2011, p. 115). It appears that the physical effects of drugging can reinforce the oppression involved in the 'textual' diagnostic and 'treatment' process, through suppressing abilities to form opinions and to 'seek, receive and impart information and ideas'.[32] Thus one's own body can become an alien place of interlocking material and symbolic imprisonment, as evidenced by Aubrecht's description of coercion in mental health treatment:

> What you describe as chemical incarceration, for me, meant being restrained in what felt like someone else's body. Pharmaceutical reason confined me within a glass bubble that separated me from my body and my body from the world. Voices were muffled, and responses were delayed and over determined. Within a biomedicalized world of one, I was encouraged to imagine the medication as a guide that would lead me to adjust to the timelines of respectable 'reality' (Fabris and Aubrecht 2014, p. 191).

Not everyone who is subject to involuntary mental health interventions is administered with drugs through the use of physical force. Some people 'consent' or 'acquiesce'. Yet, the coercive project of mental health law manifests in pernicious fashion at this point, where a person may be faced with a 'choice' of refusing proposed interventions and being detained or subject to a CTO for even longer, or 'agreeing' and being returned to a situation that more closely resembles their daily life.

Choice is limited in the mental health context, where medication is presumed necessary and service provision is predicated on the ability to use physical force to ensure compliance. Sjöström's work has shown how the 'coercion context' of the mental health paradigm can be leveraged so as to secure individuals' 'consent' to mental health interventions across both involuntary and voluntary settings, blurring the boundary 'between coercive measures and patients' voluntary acceptance of treatment' (Sjöström 2006, p. 37). A study of patient perceptions of 'leverage' in community mental health settings showed that the pressures experienced by users and survivors come not only from within mental health services, but also beyond, and extend beyond pressure to comply with 'treatment' as an end in itself, to pressures to maintain 'treatment' and 'stay well' in order to secure other 'gains' (Canvin et al. 2013); access to critical social services, such as housing support or social security, may effectively be contingent upon individuals' compliance with psychiatric interventions in some cases. Even where clinicians do not actively use informal coercion to secure their patients' compliance, knowledge that formal coercion is a possibility can lead people to 'internalise' the notion that drugs and medical procedures are necessary (Rogers 1998). The nature of 'informed consent' becomes particularly tenuous where formal coercion is legally permissible (Carney et al. 2007).

Mental health laws embed coercive forces throughout numerous aspects of the lives of users and survivors. These forces extend to lawful violence prior to the making of an involuntary order, such as where police are empowered to apprehend a person and transport them to a mental health facility. Social and relational pressures and informal coercion may be overlayed upon the numbing effects of medication, which are sometimes administered deliberately to induce compliance with other drugs (Minkowitz 2007, p. 424). Further, methods of inducing compliance can extend to coercing individuals to adopt particular behaviours to demonstrate their recovery, such as women being 'pressured to put on makeup and present a more feminine appearance as a sign of 'getting better' (Minkowitz 2007, p. 424). Guilaine Kinouani concisely captures the catch-22 situation users and survivors who seek to resist hegemonic forces within mental health services can find themselves in:

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[32] See ICCPR, Art 19(2) (enshrining the right to freedom of expression).

> I can choose to accept a diagnosis of psychosis and find it useful. However, the fact remains that not doing so may well mean that I cannot access services, that I am deemed to lack insight and thus subjected to more oppressive forms of 'treatment' (Kinouani 2015).

The domination of lawful violence in the mental health context can thus wear down an individual's will to resist, constraining the ability to express one's opinions and potentially 'changing the personality' by destroying 'identity, self-concept, relationship to the world, and inner subjective experience' (see Minkowitz 2007, p. 421) through an elaborate interplay of formal and informal coercion.[33]

7.2. Medico-Legal Incapacitation of the Expressions, Opinions and Epistemologies of Users and Survivors

Fiona Campbell's work on the relationship between law and disability explains how law partners with medicine in rendering disability within 'official' realities that reinforce negative attitudes and stereotypes about disability, for example, through narratives of tragedy, suffering, and catastrophe (Campbell 2009, pp. 34–37). The dialectic relation between law and psychiatry similarly encodes medico-legal expressions which invalidate people 'for their articulated and lived difference' (Arrigo 2012, p. xxii); for people with psychosocial disability oppressive medico-legal narratives frequently revolve around 'risk' and 'incompetence' (Liegghio 2013). Legal rendering of disability can impose official definitions and categories of 'deficiency' based on medical categorisations which deny the private realities, opinions and expressions of people with disability (Campbell 2009, p. 37). Mental health laws providing for involuntary mental health interventions operate to embed psychiatry's configurations of madness and mental distress, to the exclusion of other understandings.

MHTs have been observed to 'mould' the information presented to them by the parties to their proceedings into a form that satisfies the prerequisites for involuntary intervention, frequently deferring to clinical opinion. Jill Peay's study of MHTs operating under the *Mental Health Act 1983* (Eng and Wales), concentrating primarily on 'restricted' or forensic patients, found that the tribunals routinely endorsed clinical recommendations, 'almost irrespective of the content of the recommendation' (Peay 1989, p. 209). The study observed the misapplication of the relevant statutory criteria via a 'back-to-front' process, whereby some MHT panels reasoned backwards to a pre-determined outcome, heavily influenced by pragmatic considerations, such as subjective assessments of risk (even very low level risk) and available support options (Peay 1989). According to a later study conducted in the same jurisdiction by Elizabeth Perkins, clinical judgments about a person's 'insight' into their alleged condition and compliance with proposed interventions tended to be uncritically accepted by MHT panels operating under civil mental health laws, and witnesses and narratives were placed on a 'credibility' spectrum, which positioned patients' narratives as least credible when weighing up the evidence (Perkins 2003).

Turning to Australian MHTs applying civil mental health laws, research on the use of the concept of 'insight' by Victorian MHT panels found that this concept allowed panels to 'medicalize arguments put forth by persons subjected to mental health review board hearings, thereby framing the person's self-perceptions and choices as evidence of pathology' (Diesfeld and Sjöström 2007, p. 98). Observations of MHT hearings conducted by Carney et al.'s comparative study of Australian MHT operations found that even where the opinions of the person at the centre of proceedings were sought by panels, they were 'sometimes ... treated as an exhibit, in that their performance and behaviour at the hearing [was] judged as evidence pertaining to their mental illness' (Carney et al. 2011, p. 215). In these situations, the person's opinions and expressions were largely used as a means of establishing evidence of mental illness, lack of insight, and non-compliance with clinical advice. Constructions of people with psychosocial disability as 'incompetent' are a primary mechanism by which they/we are marginalised, silenced, and, ultimately, 'disqualified as legitimate knowers' (Liegghio 2013, p. 126). Maria Liegghio has described how such 'epistemic disqualification' effectively

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[33] On law's violence, and the violence and coercion that inhere in judicial interpretive acts, see Cover (1986).

renders individuals out of existence (Liegghio 2013, p. 124). Further embedding a functional approach to mental capacity in mental health laws as a pivotal prerequisite to involuntary mental health interventions, by codifying the association between psychosocial disability and incompetence that is already implicit in these laws, risks exacerbating this invalidation of the ways of knowing and being of people with psychosocial disability.

General Comment No 34 states that the rights to freedom of opinion and expression in the ICCPR prohibit 'any form of effort to coerce the holding or not holding of any opinion', and that 'freedom to express one's opinion necessarily includes freedom not to express one's opinion' (Human Rights Committee 2011, p. 3). In maintaining that involuntary mental health interventions contravene the universal prohibition of torture, Minkowitz has comprehensively described the abusive nature of the process of obtaining information and a 'confession' from people who resist psychiatric diagnosis and treatment (Minkowitz 2007, pp. 421–25). MHT processes can entail a further element of coercion of individuals into particular admissions and understandings of their situation, and the consolidation of these admissions and understandings as the official version of events that justifies making an involuntary order. For example, a process of intense questioning in pursuit of a certain response was observed by Perkins' study where MHT panels felt that clients were hiding something. Perkins termed this approach a "catching out' technique': leading questions were asked to lure patients into revealing the presumed truth regarding their condition and their understanding of their condition (Perkins 2003, p. 72). Some MHT panels go to great lengths to establish whether a person *accepts* that they have a mental illness and need medication to alleviate their condition. If a person does not succumb completely to the medico-legal understanding of the compliant, 'insightful' patient, mental health law may re-invent them as 'incompetent', and therefore eligible for involuntary mental health interventions.

Historically, users and survivors who seek to resist the medical model and the mental health paradigm have frequently been denied the symbolic capital that is necessary to make their/our own meanings about psychosocial disability, experiences of madness and mental distress, and encounters with mental health services.[34] Mental health laws reinforce this process of epistemic invalidation, which is so deeply embedded within laws and cultural practices that it is largely invisible. This legal interpretive process causes a kind of 'overlock', that strengthens and prevents fraying of the symbolic power of psychiatry. Official discourses can stabilise and compound the appearance of 'lawful violence' in the disability sector as therapeutic and necessary at the structural level (Spivakovsky, forthcoming). I suggest that one consequence of the denial of freedom of opinion and expression that is effected through mental health laws is to systematically wrest symbolic power from people with psychosocial disability by conferring an 'absolute, universal value' on the symbolic capital that is possessed by psychiatry (see Bourdieu 1990, p. 136).

Dinesh Wadiwel has analysed how systems of violence against people with disability both 'materially produce disability' and constitute an 'epistemic problem', where regularised violence and torture are simultaneously concealed and reconstructed as benevolent and necessary (Wadiwel 2017; see Steele 2014). Wadiwel suggests a connection between the failure to name material acts of violence against people with disability and the epistemological construction of people with disability as 'not having a dignity to violate' (Wadiwel 2017, p. 389). The epistemological struggle that is demarcated in this article similarly implicates a denial not only of legal personhood, but also an ontological nullification of humanness—the designation of a border between who is and is not considered a human to be treated with dignity and whose experiences, opinions, thoughts and feelings should be respected and acted on (see Roper, forthcoming). Further, the legal codification of people with psychosocial disability as lacking capacity, through mental health laws, may materially construct

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[34] See Bourdieu regarding the situations in which people are denied the ability to imprint meaning upon the structure of social space through the operation of symbolic violence (Bourdieu 1990, pp. 134–35).

individuals as not having a dignity to violate, weaving these negative constructions into both a person's sense of self and the official records that will influence future legal and administrative decision-making about that person.

In affirming that people with disability are rights-holders who enjoy legal capacity on an equal basis with others in all aspects of life, the CRPD arguably strives towards contestation of the symbolic violence that has pervaded society's relationship with disability and madness. This is evident from the statement of the Committee on the Rights of Persons with Disabilities in General Comment No. 1 on Article 12 of the CRPD that mental capacity is 'contingent on social and political contexts, as are the disciplines, professions, and practices, which play a dominant role in assessing mental capacity' rather than being 'as is commonly presented, an objective scientific and naturally occurring phenomenon' (Committee on the Rights of Persons with Disabilities 2014, p. 4). Acknowledging the contingent nature of 'mental capacity' not only exposes as discriminatory the historical denial of the legal capacity of people with disability, but also disrupts the very categories of mental capacity and incapacity and any attempts to define legal capacity with reference to these categories.

It is unsurprising that reflection on denial of freedom of opinion and expression in this context animates the debate about the right to equal recognition before the law enshrined in Article 12 of the CRPD. The demand of Article 12 targets the coercion underpinning and effected through mental health (law) at the points of convergence between the material violence and symbolic violence of this body of law. The analysis in this article suggests that allowing the State to inflict material violence upon its citizens, and other people within its territory, in the form of involuntary mental health interventions systematically stifles attempts to think, feel, opine, express, and imagine outside of psychiatry's schema. This may hinder recognition and further development of the epistemologies of users and survivors, as well as stifling individual self-expression. Ending involuntary mental health interventions may significantly expand possibilities for the lived truths of users and survivors to shape the responses and support options that are available to people with psychosocial disability at individual and structural levels. These considerations add weight to the interpretation of the Committee on the Rights of Persons with Disabilities that substitute decision-making pursuant to mental health laws contravenes Article 12, and other provisions, of the CRPD.

8. Conclusions

This article has examined aspects of the relationship between the rights to freedom of opinion and expression and madness and psychosocial disability. I explored how the symbolic violence of psychiatry and the mental health paradigm operates to suppress the opinions and expressions of people with psychosocial disability. This enquiry was in part guided by experiences and epistemologies of mental health service users and survivors of psychiatry. I discussed how the denial of freedom of opinion and expression that is effected through the symbolic violence of psychiatry and the mental health paradigm is compounded and consecrated when wielded as part of the coercive project of mental health law. I argued that codifying 'incapacity' as a prerequisite to involuntary mental health interventions may further amplify this process. I also argued that mental health (law) may produce a form of ontological violence, fundamentally altering the opinions, expressions, and ways of being of people with psychosocial disability. Finally, I suggested that these combined considerations reinforce the interpretation of the Committee on the Rights of Persons with Disabilities that Article 12 and other provisions of the CRPD require the absolute prohibition of involuntary mental health interventions.

My exploration of the rights to freedom of opinion and expression from the perspective of psychosocial disability and madness ultimately folded back into mental health law's problematic of coercion. This problematic entails a mutually reinforcing relationship between the material violence that is immanent in denial of legal personhood under civil mental health laws and the symbolic violence of psychiatry and the mental health paradigm. It also connects to scholarship and debates about the deployment of medico-legal and psychiatric epistemologies in ways that silence the political resistance and claims of marginalised groups at the intersections of different coercive legal frameworks, such as people in immigration detention (Joseph 2016) and incarcerated people labelled as ‘mad Muslim terrorists’ (Patel 2014).

Probing the contours of the denial of freedom of opinion and expression that permeates involuntary mental health interventions holds value, for people with psychosocial disability and beyond, because it demands, in the first instance, a ‘stripping bare’ to the immediate wishes, feelings, concerns, and communications (or attempts to communicate) of individuals and constituencies. This may assist in delineating physical, psychical, social and political aspects of these opinions and expressions and their connections to different political and historical struggles. Giving effect to the requirement in Article 4(3) of the CRPD to ‘closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations’ in developing and implementing laws and policies to implement the CRPD calls for direct and genuine engagement with the opinions and expressions of disabled people.

Acknowledgments: I want to thank Linda Steele for her comments on earlier versions of this article, in particular regarding the relationships between different forms of violence operating in the disability and mental health contexts. I am also grateful to the three anonymous referees for their helpful comments.

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6

Living on the Global Peripheries of Law: Disability Human Rights Law in Principle and in Practice in the Global South

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Abstract: This article develops the notion that poorer nations of the Global South are particularly disadvantaged in terms of realizing disabled people's human rights in practice. This is because they are situated in what is termed the global peripheries of law. These are peripheries in which very limited human and financial resources are available to practically realize disability human rights (reflecting processes such as the outmigration of trained professionals, devaluation of currency as a condition of debt repayment, and dependence on agricultural exports and imports of expensive manufactured goods, including medicine, from the Global North). Being on the global peripheries of law also reflects legacies of colonial and neo-colonial violence and oppression in an unequal global capitalist order, such as ongoing and widespread violence against women and unsafe working conditions—both of which result in death and the geographically uneven production of impairment. This uneven production of impairment also needs to be considered as an important part of understanding disability human rights law in a global context. Following a brief overview of the U.N. convention on the human rights of disabled people and the U.N. Covenant on Economic, Social and Cultural Rights to provide a global legal context and of the Inter-American Human Rights System to provide a regional legal context, the article illustrates why it is so difficult to realize disabled people's human rights in practice in the Global South, through a case study of Guyana.

Keywords: global peripheries of law; disability; human rights; production of impairment; U.N. Convention on the Rights of Disabled People; Guyana case study

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We live in extraordinary times and places. These are characterized, in part, by globalization, the concentration of wealth amongst an elite few, a deeply unequal neo-liberal global capitalist order, a rise in precarious employment particularly amongst younger persons, ageing populations in developed nations and ongoing struggles to assert the human rights of persons with impairments and illnesses, who are disabled by attitudinal and social barriers to inclusion in the Global North and South. In this article, I am particularly concerned with what it is like to be on the global peripheries of law in the poorer nations of the Global South and this is illustrated through a case study of disabled people's rights and lives in Guyana.

In this article, I conceptualize global peripheries of law as places in the world where it is particularly difficult to realize human rights in practice. Historically, these peripheries are the legacies of imperialism, and colonial and neo-colonial oppression. As such, they also reflect the deeply unequal and unjust neo-liberal capitalist global order in which we live today. I argue that this helps us to make sense of why some countries are particularly disadvantaged in terms of their capacity to improve disabled people's lives through disability human rights law. This conceptualization also builds on my earlier work on legal peripheries in disabled people's human rights in Canada (Chouinard 2001) and the notion that living the law in principle and in practice are often fundamentally at odds when we are located at the peripheries of law.

I develop these arguments as follows. First, I provide a conceptualization of what it means to be situated on the global peripheries of law. Then, in order to provide a global human rights context, I consider the development of the United Nations Convention on the Rights of Persons with Disabilities and the U.N. Covenant on Economic, Social and Cultural Rights and some of the human rights they enshrine and aspire to. Next, I provide a regional human rights context for the subsequent case study of disabled people's human rights and lives in Guyana. I do this by considering the development and limitations of the Inter-American Human Rights System. This is followed by a case study of how disability human rights law is being lived, in principle and in practice, in the developing nation of Guyana.

1. Conceptualizing Global Peripheries of Law

What does it mean to be situated at the peripheries of law? For some legal scholars, it refers to occupying especially disadvantaged places in law and society (see for e.g., The Griffith Law Review (2015) special issue focusing on the links between disability and criminal law). I concur with this general meaning but with a geographer's caveat that those at the peripheries of law are also spatially disadvantaged in important ways. Still, there is more to experiences of being on the peripheries of law than this.

As the following quote suggests, being situated at the peripheries of law is also about encountering tensions or contradictions between how law is lived in discourse and in principle and how it is lived in practice:

> . . . the socio-spatial production of legal peripheries or places in which law as discursively represented and law as lived are fundamentally at odds. These are places of 'shadow citizenship and entitlement'—important to the cultural representation of neo-liberal democracies as inclusionary and tolerant of diversity, but lived as places of profound exclusion in which basic human rights are routinely denied. It is from such peripheral, disempowered locations that disabled Canadians are struggling to claim their places in society and space. (Chouinard 2001, p. 186)

Countries of the Global South are particularly disadvantaged in this regard as a result of centuries of colonial oppression and exploitation and their disempowered positions in the current neo-liberal global capitalist order. This means that they have especially limited human and financial resources to draw upon in realizing legal rights in practice. This is reflected in processes such as the outmigration of trained professionals, including lawyers, to the Global North, historically high national debt loads and devalued currency that makes it difficult or impossible to purchase commodities such as medicine or mobility and other aids for persons with illnesses or impairments, from countries of the Global North despite depending upon these countries for such goods. As the feminist philosopher and bioethicist Jaggar (2002) explains, countries of the Global North and elites in those countries (as well as elites in the South) continue to benefit from a post-colonial neo-liberal capitalist order in which developing nations' labour power is exploited, natural and agricultural resources are exported, and in which countries are forced to buy manufactured goods (such as medicine, fertilizer and agricultural machinery) from the Global North. Such imbalances in power fuel widespread poverty and poor health, particularly amongst more vulnerable groups such as women (Jaggar 2002).

Being on the global peripheries of law is also about experiencing especially severe disjunctures between what people aspire to achieve through law and what is actually achieved in practice. I discuss and illustrate this in the case study analysis of Guyana presented later in this paper—drawing on interviews I conducted with disability activists in the country.

Existing on the global peripheries of law also involves being in especially marginal places of 'shadow citizenship'. These are places in which the state and legal system may appear to recognize and assert the human rights of vulnerable citizens such as disabled people and in doing so help to create the illusion of an inclusive society. At the same time, however, shadow citizens lack the means (e.g., financial, insufficient access to legal expertise and to mobility and other aids) to claim those rights in practice.

This is not to deny that there are important legacies of colonial exploitation and oppression, and life on the global peripheries of law in countries of the Global North. This is the case with respect to indigenous people and especially women and girls in countries such as Canada, for instance, who have had to struggle for legal recognition of traditional rights to land, self-governance, for Indian status, and also for freedom from oppressive practices such as forced education in church-run residential schools aimed at 'killing the Indian in the child' and assimilation, and the disappearances and murders of indigenous women (for further discussion, see for example: Bell and Anderson 2017; Hanson 2008). Violence against indigenous women is higher than that experienced by other women in Canada (Kubik et al. 2009) and has prompted a National Inquiry into Missing and Murdered Indigenous Women and Girls that commenced in 2016. Aboriginal people in countries of the Global South, such as the Amerindian people of Guyana, are arguably in even more disempowered and disabling locations on the global peripheries of law—struggling to deal with human rights abuses arising through human trafficking, very limited access to health care and education in their relatively isolated hinterland communities, contamination of water supplies (through mining of bauxite and gold), and insufficient access to resources such as culturally appropriate teaching materials that would aid in the preservation of communities' cultural heritages. Here the gap between the human rights that Amerindian people aspire to (such as equality of opportunity and the preservation of culture) and what can be delivered in practice is especially severe (Cultural Survival 2015). As I argue later in this article this is also true with respect to non-indigenous disabled persons' rights in Guyana.

There is no doubt that disabled people also remain on the margins or peripheries of law in countries such as Canada. Indeed, the Canadian Human Rights Commission (CHRC), in its 2016 report to the Parliament of Canada, noted that 60% of all human rights complaints it receives concern discrimination on the basis of disability (and many of these are related to employment) (Canadian Human Rights Commission 2016). But these are arguably not global peripheries of law in the sense of directly arising from colonial exploitation and oppression except for disabled aboriginal people who experience poorer health and greater impairment than many non-aboriginal Canadians. However, this situation is especially dire and difficult to address in countries situated on the global peripheries of law, such as Guyana, owing to very limited financial and human resources.

One advantage of conceptualizing disabled people's human rights in terms of global peripheries of law is that this helps to frame the realization and denial of those rights as matters of global injustice. This in turn encourages recognition that impairment and disability issues are intrinsically linked to people's places in a profoundly unequal global capitalist order and lends a political urgency to addressing these issues in this wider context.

2. Getting Global and Regional: The U.N. Convention on the Rights of Persons with Disabilities and the Inter-American System of Human Rights

The United Nations Convention on the Rights of Persons with Disabilities (CRPD), after five years of consultation between U.N. officials and states in the Global North and South and disabled persons' organizations, was adopted in December 2006. Following initial ratification by a record number of states (81) as well as the European Union, the convention came into force in May 2008 (Harpur 2012; Kayess and French 2008). The international convention was the first to explicitly address disabled people's human rights although some rights were interpreted prior to this in relation to general human rights conventions. In addition, the U.N. Convention on the Rights of the Child (which came into force in September 1990) mentioned disabled children once. In this context, the CRPD is frequently seen as a milestone in international disability human rights law and in global disability activism. There is also an Optional Protocol to the Convention that established a U.N. Committee on the Rights of Persons with Disabilities. The Committee is responsible for assessing individual and group complaints of violations of the rights of persons with disabilities in states that are party to the Convention and recommending courses of action to remedy them. States are also obliged to regularly report on the implementation of disabled persons' human rights to enable the Committee to monitor implementation of the Convention over time and space (Office of the High Commissioner on Human Rights 2018a). All but one of the 18 experts serving on the committee are disabled persons.

Scholars and activists, however, do not always agree on the significance and promise of the CRPD. Harpur (2012) argues that it has facilitated a paradigm shift in disability human rights law whereby there is, as in the social model of disability, recognition that people with impairments are disabled by environmental and social barriers. However, and unlike early radical social models of disability pioneered in the U.K., there is also recognition of the need to address the experiences and ramifications of impairment in disabled people's lives (such as the need for government support for rehabilitation and other services and housing that accommodates living needs). He also points out that the CRPD has helped to reinforce the importance of involving disability organizations in the development and implementation of the Convention. Degener (2016) argues that with the CRPD we have moved from a social model of disability to a human rights approach. She sees a number of advantages to this, including recognition of disabled people's inalienable right to dignity, an understanding that human rights are to be respected despite differences in mental and bodily status, and scope to think about the affirmation and denial of rights in terms of the intersectionality of identities. Megret (2008) contends that the Convention contributes not just to the recognition of universal human rights as applying to persons with disabilities but also recognizes rights, such as the right to full and equal participation in society, that reflect the specific circumstances of disabled people. Others, such as Kayess and French (2008, p. 34), are more guarded and critical in their views of the CRPD and its potential. In the conclusion to their article they argue:

> If there is truly to be a shift to a coherent new disability rights paradigm in international law, it will be important that CRPD interpretation and implementation efforts penetrate beyond populist social model ideas to a more sophisticated understanding of impairment and disability in its social context. Additionally, it must be recognised that despite the CRPD's extensive exposition of disability rights, some crucial areas, including bioethics and compulsory treatment, are barely grazed by the CRPD text. The CRPD is therefore a crucial buttress and facilitator of a disability rights agenda, but it is not a proxy for that agenda. Some disability rights issues still remain untouched or undeveloped in international human rights law. Consequently, it will be important that disability human rights activists neither undervalue, nor overestimate, the role and scope of the CRPD and its potential contribution to securing the human rights of persons with disability into the future.

Others share such concerns. Freeman et al. (2015) argue that the U.N. committee attempting to oversee implementation of the CRPD, in its statement on article 12, went too far in asserting that all individuals at all times have the capacity to make decisions regarding matters such as treatment that would further other human rights goals such as receiving the best health care possible. They note that at least some disability organizations in countries such as South Africa and India have overwhelmingly supported the notion that people with mental and physical disabilities are sometimes unable to make informed decisions, for example when delusional or in a coma. In response to such criticisms, the Committee on the CRPD has insisted that in extenuating circumstances, such as when a person is in mental distress and a danger to themselves or others, that supported decision-making should take the place of decisions made by others such as health care professionals (Office of the High Commissioner of Human Rights 2018b).

Nonetheless, the legal principles of the CRPD are lofty and ambitious. As the World Health Organization (2011, p. 9) puts it:

> A range of international documents have highlighted that disability is a human rights issue, including the World Programme of Action Concerning Disabled People (1982), the Convention on the Rights of the Child (1989), and the Standard Rules on the Equalisation of Opportunities

> for People with Disabilities (1993). More than 40 nations adopted disability discrimination legislation during the 1990s. The CRPD—the most recent, and the most extensive recognition of the human rights of persons with disabilities—outlines the civil, cultural, political, social, and economic rights of persons with disabilities. Its purpose is to "promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by people with disabilities and to promote respect for their inherent dignity".

But, as indicated above, there are challenges and unresolved issues in terms of further articulating, and realizing in practice, the human rights of disabled persons. Outlining all of these is beyond the scope of the present paper (but for more detailed commentary on the Convention, see (Della et al. 2017). However, to help to put disability human rights law and disabled people's lives in Guyana in a global context, I now want to turn to a critique that is long overdue—namely, the efficacy of applying a disability human rights approach developed in relatively affluent nations of the Global North, such as the U.S. and Canada, to advancing the rights and well-being of disabled people in the Global South.

The dominance of Northern discourses that frame disability issues as matters of human rights at the global scale is, as authors such as Meekosha and Soldatic (2011) point out, a key legacy of a long historical trajectory of colonial and neo-colonial oppression. This oppression included taken-for-granted practices of valuing the ideas, social practices and societal organization of Northern nations (e.g., as modern and progressive) over those of poorer nations in the Global South (e.g., as more 'primitive' or traditional). This hegemony is illustrated, for example, by the fact that many Southern nations embraced this disability human rights campaign. This was undoubtedly important in forging international solidarity amongst disability activists and building networks for future action. What it arguably did not do, or did not do enough of, is pushing the boundaries of how disability issues are understood and addressed in nations of the Global South. Disability scholars point out that disability issues in the Global South need to be understood in terms of how nations and bodies are situated in an uneven global capitalist order that still bears the marks of colonial and neo-colonial oppression. So, for example, Meekosha and Soldatic (2011) note that one of the legacies of this oppression is the often especially deep poverty in which people in the Global South live. This poverty not only causes impairment (e.g., through malnutrition) but also causes especially severe barriers to inclusion such as lack of access to transportation, education and adequate health care.

To address such issues Meekosha and Soldatic (2011) suggest the need for a deeper, richer conception of disability issues as involving an uneven politics of impairment that is as important as disabling barriers to inclusion and well-being. In a similar vein, Chouinard (2012, 2014) insists on considering disability to be as much about the geographically uneven production of impairment (e.g., through war, violence against women, the organ trade, poverty and especially unsafe conditions of work in poorer nations) as it is about barriers and the violation of human rights.

There are two fundamental problems here. The first is that an exclusive focus on human rights can encourage exaggerated confidence in the power of law alone to improve disabled people's lives since it fails to explicitly critique the uneven geography of access to the resources needed to realize such rights. The second problem is that, in failing to recognize the links between the uneven production of impairment and disparities in capacities to enforce rights due to global inequality, scholars and activists miss important opportunities to explicitly frame disability issues as matters of global injustice. Some may argue that the problem is not so much the hegemony of Northern conceptions of disability as matters of human rights as it is an overly narrow conception of those rights, which fails to address issues such as violence and gender. While there is some merit to this view, it arguably remains important to look beyond human rights per se to adequately contextualize disabled people's lives and struggles for social change.

The U.N. Covenant on Economic, Social and Cultural Rights was adopted in December 1966 and opened for ratification and came into force in January 1976. Its articles outline general human rights principles and goals and as such, provide a general international framework for protecting and advancing the human rights of diverse groups such as disabled and indigenous people. Among the general human rights it enshrines are the rights to adequate food and freedom from hunger, to not be forcibly or otherwise removed from one's home, to enjoy the right to work and to have favourable conditions of work, to ensure the equal right of women and men to enjoy the economic, social and cultural rights set out in the Covenant, and the right to adequate health care. Article 2.2 of the Covenant commits signatory states to ensuring freedom from discrimination on various bases of human difference:

> The States Parties to the present Covenant undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. (U.N. General Assembly 1966, p. 2)

It is important to note that the concept of the progressive implementation of economic, social and cultural human rights, which arguably simplistically assumes that these rights will be realized over time as states, even poorer nations such as Guyana, gain economic resources and the government and legal infrastructure needed to enforce them, informs the Covenant. The only caveat is that states will only be expected to act 'within the means available to them'. Specifically, Article 2.1 states:

> Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures. (U.N. General Assembly 1966, p. 2)

The Inter-American System of Human Rights pre-dates the International Convention on the Rights of Persons with Disabilities by many years. It began with the creation of the Inter-American Commission on Human Rights in 1959. This was followed in 1978 by the entry into force of the American Convention on Human Rights and establishment of the Inter-American Court of Human Rights. The articles of the American Convention cover a wide range of human rights including the right to life, security of the person, freedom, protection from inhumane treatment and the progressive implementation of economic, social and cultural rights. It also sets out the roles of the Inter-American Commission on Human Rights and the Inter-American Court, the former being responsible for investigating alleged human rights violations and determining which cases proceed to the Court (Organization of American States 2018)[1]. A key challenge in its early years, which coincided with the Cold War and fears about the potential spread of communism in Latin and Central America and the Caribbean, was dealing with authoritarian/military regimes responsible for murdering or 'disappearing' activists who opposed their regimes. Goldman (2009) contends that if the success of the Inter-American system is measured in terms of the reparations made for this flagrant violation of human rights in countries such as Argentina and Guatemala then it can be seen as remarkably successful. It has, however, also been plagued by on-going problems. It is seriously under-funded relative to the activities it undertakes. Despite growing needs to investigate alleged human rights abuses in the region and growing caseloads, the Commission and Court receive less than 10% of OAS funding. In the 2007 fiscal year the Commission's budget was $3,845,100.00 (U.S. dollars) and the Court's was $1,656,300.00 (U.S.). This compares to a budget of $72,171,000.00 (U.S.) for the European Court of Human Rights in the same fiscal year (Dulitzky 2011, p. 134).

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[1] The Organization of American States was founded in 1948 in part to bolster security amongst member states in the Western hemisphere and in response to perceived threats of the spread of communism. Headquartered in Washington, D.C., the OAS gradually took on other roles such as dispute resolution between member states (e.g., regarding borders, trade) and promoting better economic, political and cultural conditions in member states. Some leaders, such as Hugo Chavez of Venezuela, have denounced the OAS as a 'puppet' of the United States. Nonetheless with the entry into force of the American Convention on Human Rights and establishment of the Inter-American Court of Human Rights, both in 1978, the OAS signaled an intent to strengthen its role in monitoring and addressing human rights issues in the region (Editors 2018).

Under-funding has forced the Commission and Court to seek additional external funding for their activities (e.g., from Europe) but still funding falls far short of demands to investigate, document, process and litigate cases. This has resulted in insufficient personnel and a growing backlog of cases (Dulitzky 2011). It has also helped to limit the capacity of the Commission to make site visits to assess the human rights situations in some of its OAS member nations (there are 35). In the case of Guyana, it was only in 2016 that the Commission visited the country for the first time on a fact-finding mission on human rights (Rivero 2016). This is despite rampant human rights abuses such as police violence, domestic violence, violence against LGBTI youth, trafficking in women and the severe impoverishment of many vulnerable groups including disabled people. It was also six years after disability activists finally, after approximately a decade of struggle, succeeded in getting the Guyana Government to pass a Disability Act aimed at protecting disabled persons' human rights.

With these points in mind, I now illustrate why a deeper and more global conception of impairment and disability is needed in the context of understanding disabled people's rights, lives and struggles in the developing nation of Guyana.

3. From Principle to Practice? Impairment and Disabled People's Human Rights in Guyana

Guyana is a lower middle-income country (Gjaltema et al. 2016, p. 14) located on the northeastern coast of South America. Colonized first by the Dutch and later the British, the predominately Afro-Guyanese and Indo-Guyanese population, many descendants of slaves and indentured servants who labored on sugar plantations, is considered culturally part of the Caribbean. As of 2016, Guyana had a total population of 773,303 (World Bank 2016). Due to outmigration, there are now more Guyanese living abroad than in the country.

According to U.N. estimates 7–10% of the population of developing countries are disabled. This means that approximately 73,000 people in Guyana are disabled. In 2005, the National Commission on Disability, established in 1997 as an advisory body to the Government of Guyana, released the results of a survey of 1485 disabled people (Mitchell 2005). It noted that poverty was widespread and contributed to the production of impairment as well as financial barriers to accessing services such as health care and education (Mitchell 2005). Unemployment is widespread with 40% of the unemployed disabled people surveyed reporting that they had lost their jobs as a result of becoming impaired. Another 9% were trained and skilled but lacked opportunities to do paid work. Negative attitudes toward and treatment of disabled people were common (affecting 79% of respondents) and included people feeling ashamed of disabled family members and keeping them hidden from public view (Mitchell 2005). These problems and others persist today (e.g., Chouinard 2014).

Guyana signed the U.N. Convention on the Rights of Persons with Disabilities in 2010 and ratified the international treaty in 2014. The treaty is meant to encourage signatory nations to enact and enforce human rights laws for disabled people. It also has established an international committee to deal with complaints about violations of disabled people's human rights. Also in 2010, after many years of lobbying by disability activists and organizations, the Government of Guyana passed a Disability Act meant to protect the rights of disabled people to accessible environments, equal opportunity in education and employment, access to services such as health care and rehabilitation, and freedom from discrimination on the basis of disability. Unfortunately, however, disability organizations and other civil society groups report that the Act is not being enforced (Worth et al. 2017).

As argued above, one of the difficulties of addressing the oppression and exclusion of disabled people in terms of human rights is that this often does not take into account the geographically uneven production of impairment at the global scale. So, for example, people in Guyana experience severe and multiple forms of violence resulting in impairment or death. Police violence against civilians is endemic with the highest rate of police shootings of civilians in the world (Chouinard 2012). There is also violence in the illegal narcotics trade. Racialized violence remains an ongoing problem. Reflecting a violent colonial past and patriarchal oppression, there are also cutlass attacks (cutlasses being used to harvest sugar cane) resulting in impairment or death. Women are most often the victims and the perpetrators are usually men (Chouinard 2012). According to the Guyanese organization Help and Shelter (2011) as many as two out of every three women in the country are victims of domestic violence.

With the help of three female Guyanese interviewers (named in the acknowledgements to this article), from 2007–2015, 110 disabled women and men shared their life stories. At least four of those stories were about becoming impaired as a result of violence. Three different women reported being attacked with a cutlass by male partners or acquaintances. One lost her right arm in the attack, another lost both forearms and the third lost the use of one of her hands. A fourth interviewee reported losing his sight as a result of acid being thrown in his face by members of a drug cartel (Chouinard 2012). These are criminal acts producing impairment or death and are violations of basic human rights (e.g., to security of the person), and yet such acts remain very prevalent in Guyana. It is important to recognize, as well, that these acts are harrowing and traumatic and cause not only physical but also psychological impairment. A case in point is that of Cora (pseudonym) whose story is outlined below.

Cora arrived at her daughter's house one day and hearing her screams went upstairs to a bedroom. There she found her son-in-law chopping her daughter with a cutlass. She tried to intervene but was unsuccessful. Then moments later her son-in-law chopped her daughter in the head. Her daughter moaned, "Ah me dead" and dropped to the floor. Cora fled downstairs. Even though her daughter's body was lifeless Cora continued to hear her son-in-law chopping the body upstairs. In shock, she tried to flee the house but was accosted by the son-in-law who began chopping one of her hands. Bleeding profusely, she begged him to stop saying "look at all this blood—why do you want to do that?" To her surprise he stopped and she ran next door to a friend's house for help.

Cora's story illustrates just how terrifying these instances of domestic violence can be; resulting in this case, in one woman's death and in another woman's serious physical impairment.

Why, despite laws in place that in principle protect women's human rights do these kinds of attacks persist? Part of the explanation lies in the limitations of judicial and police services. A recent report by the U.S. State Department (2015, p. 10) on human rights in Guyana had the following to say about domestic violence:

> Domestic violence and violence against women, including spousal abuse, was widespread. The law prohibits domestic violence and allows victims to seek prompt protection, occupation, or tenancy orders from a magistrate. The police received 2170 reports of domestic violence cases, and 1131 persons were charged. Penalties for violation of protection orders include fines up to 10,000 Guyanese dollars (GYD) ($50) and 12 months' imprisonment. Survivors frequently were unwilling to press charges due to a lack of confidence in obtaining a remedy through the courts. Some preferred to reach a pecuniary settlement out of court. There were reports of police accepting bribes from perpetrators and other reports of magistrates applying inadequate sentences after conviction.

Marta, another woman who became impaired as a result of a cutlass attack by her male partner, lost both of her forearms. Her case illustrates the personal toll that lenient sentences take on women who are victims of chopping violence. Her partner was sentenced to seven years in jail even though Marta's impairments, impoverished conditions of life (e.g., lack of electricity and piped water in the home), and only very temporary access to extremely basic prosthetic devices meant that she would be disabled for the rest of her life. She was further disabled and excluded by attitudinal barriers that blamed her for the violent attack (e.g., gossip that she was promiscuous) and associated acts of 'shunning' and she said sadly that because of this she no longer felt a part of Guyanese society. With only one niece to assist her in her home she lived in terror that her male partner would return once he was released from jail and further injure or kill her. Such fears about vulnerability to violence were further accentuated by difficult living conditions. Dependence on her niece to assist with tasks such as turning on a generator for lighting meant that Marta had to wait alone in the dark in the evenings for her niece to return before she had light in her home.

Violence also in some cases worsened impairment and, along with barriers such as poverty and negative attitudes, worked to further marginalize and exclude disabled women in public and private spaces of life. Sarah, a woman who was mentally ill, was unable to communicate with her interviewer and so her mother was interviewed instead. Her mother related how Sarah was subjected to violence such as name-calling and having stones thrown at her if she ventured outside the home and into the local community because people recognized her as "not right in she head". Sarah also experienced violence in the home. It was not unusual for her children to beat her when they thought she had done something wrong in places such as the kitchen. Such experiences of abuse added to the trauma associated with being mentally ill. Sarah was also not receiving the medical treatment she needed—her home was located in a village a considerable distance away from the capital city of Georgetown and her family could not afford the transportation to either the National Psychiatric Hospital in Canje, Berbice or the Georgetown Public Hospital psychiatric ward where, at the time of the interview, only two psychiatrists were available. Guyana has a chronic shortage of psychiatrists and psychiatric support workers due to a combination of outmigration and limited resources for training. A 2013 newspaper report (Alleyne 2013), summarized the situation in the country in the following way:

> It has been twenty years since the PPP/C government took office against a backdrop of increasing numbers of mentally ill persons on the streets, but still there does not appear to be a comprehensive plan to address the problem. Mental health experts spoken to by this newspaper point out that the numbers of doctors and the facilities available remain woefully inadequate, in addition to which law reforms have not been made [there is a separate mental health act that dates from 1930]. At one point there was a mass rounding up of the mentally ill so that they would not be visible on the streets during a major event, but this was not followed up by any attempt to secure treatment for them.

Not surprisingly in such circumstances, the human rights of mentally ill people are repeatedly violated in practice as they face widespread stigma and discrimination in terms of employment and economic well-being, lack of cultural acceptance, and lack of access to services such as the judiciary, education and health care. In 2016, the Ministry of Health announced that it would open a new mental health unit in Georgetown with five psychiatrists as well as support staff (Disabled People's International, Department of Public Information 2016). It remains to be seen, however, how far this will go in diminishing mental impairment and securing human rights in practice for people with mental illness in Guyana. Concerns are already being raised that the five psychiatrists with the new unit have to service approximately 100,000 patients each and that social work and other staff are also scarce. This is in a country that has the highest rate of suicide in the world (Bhagirat 2017).

People with physical impairments also reported being abused in and/or outside the home. Mark, who was partially paralyzed on his left side as a result of a stroke, talked about the verbal abuse he was subjected to if he ventured outside his home and into the local community and how it made him feel hated and excluded. Another stroke survivor, Jim, noted how he was now shunned by and isolated from family members—with at least some believing that strokes were contagious. This meant he could not look to family for the assistance he needed with activities such as cooking and cleaning. Karen, who was missing a foot at birth, recounted how, as a young child, she overheard a nurse advising her mother to have her killed. It was a deeply traumatic experience that denied even her right to exist. As a young woman, she lived with her aunt and suffered psychological and physical abuse at the hands of the aunt's daughter and nephew. She was treated as a 'defective' outsider and mocked for not having a foot. She was told she did not have the right to make decisions in the home —even about her own belongings—and was beaten when she tried to assert this right. In desperation, she turned to the police for help but, despite physical evidence of the beatings, they did not assist. Finally, she took the only escape route open to her and moved out. Such acts of hate and devaluation, isolation and neglect, and violent oppression clearly violate disabled people's human rights to inclusion, respect, safe and secure environments, and in cases such as Karen's even the right to life itself.

Extreme economic disadvantage was a fact of life for many of the people with impairments and illnesses interviewed. Of the 81 interviewees for whom employment status is known, only four were in full-time employment: Bob was mobility impaired and used a wheelchair and worked at shoe repair in a market stall in Georgetown, Nigel, also mobility impaired and a wheelchair user, worked in an office staff position at Guyana Power and Light, Jody was visually impaired and worked as a local radio host in Georgetown, and Trisha, who was mobility impaired and a wheelchair user, also worked in an office job. Three interviewees reported sporadic employment (e.g., selling small items, tiling, making chair backs) with two of these (both wheelchair users and visibly impaired) noting that customers paid them less than their able counterparts because they were disabled. The remainder of the interviewees struggled to survive on meager government income assistance (the equivalent of one to two U.S. dollars per day). In three cases, this was augmented by periodic small remittances from family living abroad but this source of income was unreliable.

Poverty and discrimination act as barriers to mobility and accessing spaces such as those used for disability activism and the provision of health care. Representatives of disability organizations based in Georgetown interviewed by the author noted that their membership declined quickly due to the high costs of transportation to meetings. Guyana does not have public or paratransit systems and relies on private mini-buses or taxis for persons who cannot afford private vehicles or who are unable to drive. The mini-buses are highly profit-driven and focus on having as many passengers as possible as well as quickly arriving at destinations so that more passengers can embark and pay for transit. The former is a problem because mini-bus drivers frequently refuse to stop to pick up visibly impaired people such as those using wheelchairs or walkers. This is because their aids take up space that could otherwise be filled by paying passengers. The latter emphasis on arriving and departing quickly also contributes to impairment and death as a result of accidents. The problem of being refused mini-bus transit service was sufficiently severe to prompt disability organizations to launch a ‘right to ride’ campaign. Unfortunately, the campaign was unsuccessful for the most part and so disabled people continue to be denied rights to the mobility they need to be able to access spaces that could help to empower and enable them in their daily lives.

Widespread poverty amongst disabled people also acts as a barrier to accessing aids such as wheelchairs and walkers and the prostheses made in the single rehabilitation centre in Georgetown. Costs to import aids such as wheelchairs are high and this means that most are provided by charitable organizations such as Food for the Poor. Even so, these aids are not available to everyone who needs one. It is also expensive to import materials for prostheses, and with patients expected to cover the costs of materials (with the government and donors covering overhead and labour costs), lack of income acts as a barrier to accessing the prosthetic devices that people, such as Marta, need to mitigate impairment and lead more enabling lives. The Ptolemy Reid Centre in Georgetown, a rehabilitation centre, which now houses the only prosthetic unit in the country, estimates that since this service commenced in 1994 it has assisted 2000 people with prosthetic devices (Charles and Chigbo 2017). Still, access to prosthetic aids remains a problem for people such as Marta.

Cultural attitudes and practices also contribute to the violation of the human rights of persons with disabilities in Guyana. Rights to inclusion and equal opportunity are often compromised in practice when family members feel ashamed of a disabled family member, and as a result, hide them away in the home. It is not uncommon for disabled children to be kept hidden and out of the educational system for life. In some cases, disabled children are even chained to heavy furniture such as beds so they cannot leave the house. Such forced isolation also helps to explain why facilities such as the Open Doors Centre, a national job training centre for disabled people located in Georgetown, has had difficulties recruiting students for its programs—even though these are badly needed (Kaiteur News 2017). Disability activists interviewed as part of this study also point out that such practices contribute to low turnouts at public disability events, perceptions that there are not many disabled people in Guyana and politicians who have been slow to act on disability issues. Activists believe these are some of the reasons why it took almost a decade of lobbying to pressure the government into enacting a national Disability Rights Act in Guyana.

Whatever the challenges of realizing disabled people’s human rights in practice in Guyana, the ten leaders of disability organizations who were interviewed as part of this study insisted that progress on disability issues would only be made once a national Disability Human Rights Act was in place (as noted above this happened in 2010). This in part reflects the global hegemony of a human rights framework for understanding disability issues. But it is also a significant 'leap of faith' that the Act will be enforced through the courts and government agencies. Also civil society organizations, as noted above, report that to date this has not been the case. This is perhaps not surprising in a context in which financial and human resources to address disability issues are very scarce, reflecting processes such as dependence on the importation of expensive manufactured goods from the Global North, the devaluation of currency as a term of debt repayment, and the outmigration of trained professionals from the country. This is not to say there is no progress on disability issues. The disability movement has developed over time in the country and leaders of such organizations as Young Voices of Disabled People contend that awareness of disabled people and their rights is on the rise (Admin 2013). Still, there is, arguably, a pressing need to consider the situation in Guyana in terms of the globally uneven geographic production of impairment. Legacies of a violent and patriarchal colonial past persist in pervasive violence, particularly against women—violence that results in impairment and even death. The high cost of importing aids such as wheelchairs or materials for prostheses mean that not all who need these aids to mitigate impairment receive them. This is also exacerbated by the outmigration of trained medical professionals in search of better wages and working conditions. Transportation costs, a chronic shortage of mental health professionals, and high costs of some medications, mean that people with mental illness also do not receive the treatment they need to diminish mental impairment. Many disabled people face poverty and discrimination in terms of access to transportation compounding their limited mobility and excluding them from potentially empowering and enabling spaces of life such as disability organization meetings.

4. Where Do We Go from Here? Towards Enabling Geographies of Impairment and Disability in the Global South

In this article, I have argued for a richer and deeper understanding of the geographically uneven production of impairment and disabling conditions of life at the global scale, and in countries of the Global South. Such an approach recognizes the legacies of a long and violent history of colonial and neo-colonial oppression manifest, for instance, in the chopping violence against women that still occurs in Guyana and results in impairment, death, the lack or loss of employment, deepening poverty and other disabling conditions of life. Patriarchal oppression is also at work here as manifest, for example, in tendencies to blame women for the violence they experience and related practices such as 'shunning' or avoidance. This too, has disabling consequences such as socio-spatial isolation. Marta, the woman who lost both forearms to chopping was, for instance, also deeply distressed to learn through the grapevine that one of her nephews was threatening his girlfriend with the same form of violence if she did not 'stay in line'. As the Guyana case study helps to show, cultures of disability are also geographically uneven and this is important to consider when assessing why human rights enjoyed in principle are not being realized in practice. While there are some cultural commonalities between Guyana and countries of the Global North, such as activists embracing a human rights perspective on disability issues, there are also divergences as well. The latter include the especially severe stigma and shame associated with mental and physical impairment and associated practices such as keeping disabled family members hidden away in the home. We also need to be cognizant of people's and nations' places in the uneven global political-economic order, as shown in Guyana's case by widespread and deep poverty that both causes impairment and exacerbates disabling conditions of life (e.g., through lack of access to prostheses, medicine). Disabled people in Guyana are also disadvantaged by the outmigration of trained professionals such as lawyers and doctors and the strain this puts on already very limited training resources. Nor is it surprising that rampant human rights abuses persist given the country's disadvantaged place in the international human rights system, as illustrated in this article with respect to the Inter-American system. There are, of course, internal factors at work here, such as corruption and bribery. The RefWorld (2016) report on human rights in

Guyana notes that it is not uncommon for magistrates to be bribed in exchange for imposing lighter sentences on violent offenders, or for women who are victims of violence not to report it to the police because they do not think justice will be served in court.

One advantage of thinking about disability human rights laws and issues in terms of global peripheries of law is that it also encourages us to understand that the production of impairment and disabling conditions of life are both global justice issues and need to be considered in that wider context. This approach also allows us to problematize both impairment and disability as about more than simply the violation of human rights. The Rana Plaza collapse in April 2013 in Bangladesh, for example, killed almost 1300 people and injured and impaired more than 2500 others (mostly as a result of the need for amputation of crushed limbs). This tragedy occurred because plant owners/managers valued profit over human safety and forced workers to continue to labour in a garment factory that they believed to be unsafe as a result of cracks in the walls that they had noticed the previous day (The Guardian 2015). The case drags on in the courts in Bangladesh but critics argue that too little is being done to make conditions in garment factories safer and prevent injury, impairment and death (Jazeera Media Network 2016). The case illustrates how the production of impairment in the Global South goes hand in hand with treating workers as cheap, exploitable and easily replaced. It also shows how the violation of human rights to a safe and secure workplace can have profoundly disabling consequences. Many of those injured in the collapse can no longer work due to psychological trauma as well as physical injuries—this in turn contributes to poverty and an inability to purchase necessities such as medicine, food and transportation.

Taking the uneven production of impairment and illness seriously also allows us to better appreciate the complex interconnections between violations of human rights, impairment, and disabling conditions of life across a wider range of phenomena. Women forced into the global sex trade, for example, often have documentation such as passports confiscated by traffickers and pimps to help ensure that they do not try to flee. In the country illegally, they are afraid to turn to the police for help because of the threat of deportation. Threats of violence are also sometimes made against family members back in the women's countries of origin as a way of 'keeping them in line'. The sex trafficking of women, as well as children, violates human rights to life, liberty and security of the person (UN Women 2017), but it also often results in psychological and physical impairment. It is worth noting that trafficking often occurs from poorer, less developed nations to more developed ones—this is because of disabling conditions of life such as widespread poverty that make women and children more desperate for income and jobs, and thus more vulnerable to traffickers.

Finally, if we consider the production of impairment and illness and disabling conditions of life such as poverty, global inequality and discriminatory acts that cause impairment and violate disabled people's human rights, to be matters of global injustice, then we can begin to imagine a more enabling and inclusive world. But building such a world in practice will take courage and the determination to do things differently by, for example, challenging ableist practices of evaluating job performance in terms of quantity rather than quality and failing to recognize the extra work that disabled people often do to be part of our workplaces in the first place. It will take a redistribution of wealth from the Global North to the South to sustain more enabling conditions of life (such as better working conditions, access to prostheses and other aids) in the long-term. It will also require a fairer distribution of wealth between the elite few and most people in countries of the Global South, such as Guyana, so that barriers to disabled people's inclusion and well-being, such as grinding poverty can be eliminated. Also, it will take ongoing efforts to 'think outside the box' of framing disability issues exclusively in terms of human rights as conceived of in countries of the Global North. Nations in the Global South have a critical role to play in encouraging a more expansive, encompassing view of the issues at stake in our highly unequal global capitalist order—an order which disproportionately impairs, sickens and disables people in the Global South. Scholars, political leaders and disability activists in these countries are well positioned to raise awareness about the human suffering and denial of rights that a globally unequal geography of impairment and disability entails. It is high time that we work toward the kinds of changes that will help to make being on the global peripheries of law a thing of the past.

Acknowledgments: I would like to thank the disabled women and men in Guyana who shared their life stories and the three Guyanese women who assisted with interviews with them: Cora Belle, Halima Khan, and Norma Adrian.

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