Nothing About Us Without Us: Human Rights and Global Disability Empowerment

James D. Morgan

Sephanie Levin and Flavio Risech-Ozeguera

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Introduction
Abstract

Two major models govern the lives and bodies of persons with disabilities, the medical model and the social model. The medical model has in recent history been considered inadequate for respecting the human rights of disabled persons, and has been all but ruled out of policy considerations. The social model has emerged to fill its place, yet those concerned with the issue of disability cannot be uncritical of this development. The question of disability challenges classical liberal thought in unique and interesting ways. It is proposed here that a disability agenda that incorporates the feminist ethics of care might best formulate a meaningfully empowering and inclusive plan for respecting human rights. This insight is then situated in critical interpretation of the United Nations' current drafting of a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities.

Executive Summary

Within the field of human rights, four guiding principles characterise the legal protections that are the backbone of this kind of work. Solidarity, equality, autonomy, and dignity are the key values that lawmakers seek to incorporate, and ideas that politicians mobilise around. Recently, disability activists have called upon these moral pillars of liberalism to reinforce their demands for inclusion. Their success is enshrined in the current drafting of the Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities by the United Nations. As such, it is within this context that the question of disability must be considered.

Presented in the first portion of this work is an account of the evolution of a rights-based approach to disability activism. This introduction will focus first on the two major paradigms through which disability has been, and is currently seen. Central to both of these is a consideration of the ways that societies conceptualise and interact with impaired bodies. Tension arises between the two models in this light. The medical model sees the impaired body as an
abnormality, a limited form of normalcy, which must be cured of its ailments. The social model considers impairment a wholly different animal than disability; the former is corporeal and of individual concern, while the latter is a socially constructed and institutional response to impairment, which limits the capabilities of persons with disabilities, thus relegating them to the status of second-class citizens.

Each model advocates a lexicon of descriptors that define disability. These approaches use similar terminology in sometimes conflicting and confusing ways. The description and analysis here offers insight into this contestation over the definition of disability. The ways in which these words are defined impacts in a very real sense how disability is surveyed, and thus the kind of policy that is implemented.

The medical and the social model are both guides to how disability should be conceptualised, and to how policy should be implemented in response to it. The two are seen as diametrically opposed; two monoliths of equal and opposite proportions. However, considered by themselves, they are incomplete. Jerome Bickenbach has rightly noted that each has constructive and distorting elements. A reformulation of the question that disability poses to liberalism is thus in order.

Before we can rise to this challenge, however, it is important to note how states have responded to the question framed in classical terms. That is to say, states which have in place laws governing disability are emblematic of a paradigm shift from making policy considerations under the medical model to incorporating the insights offered by the social model. In policy, the social model translates into a rights-based approach to disability, focused on the removal of barriers to equal participation and the elimination of disability-based discrimination. In many
(especially Western) nations, efforts made by social model advocates have resulted in the recognition and acknowledgment of people with disabilities as a minority group. Different states have chosen to apply differing types of laws addressing disability. These have been enacted over time and around the globe to varying degrees of success. The second part of this paper focuses on the nature of the most popular response to disability, antidiscrimination laws, and the role the law plays in securing such protections.

International efforts have also been made to utilise human rights instruments in the context of disability. These predecessors to the pending Convention include binding treaties and non-binding statements of purpose. They reflect a growing international concern with disability, and exemplify another approach to the possible ways of solving the marginalised status endured by persons with disabilities.

Neither model has sufficiently righted the experience of disability as an obstruction to full participation in social, political, cultural, and economic affairs. The question of disability is an obstreperous thing for liberalism; the notion of equality purported by liberal theorists is akin to sameness, yet there are obvious and permanent differences of the most fundamental kind between disabled and nondisabled. As such, perhaps it is not the fault of well-intentioned models of incorporation, but the goal of liberal citizenship itself that has delayed justice for persons with disabilities. An alternative conception of citizenship, one offered by feminist supporters of the ethics of care, is developed in the third portion of this paper. When applied to disability, the issues precluding the resolution of marginalisation and discitizenship are made clear and solutions are made actionable.
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Chapter One
Disability and Human Rights Values

Traditionally, disability has been considered a strictly medical issue that identified the disabled as afflicted and in need of care. This welfare framework, known as the medical model, obstructed the view of the wider social needs of persons living with disability. As a result, they have suffered severe neglect and isolation. There has been a growing response to this social crisis, however, and the last quarter century has displayed an especially dramatic shift in the paradigm through which disability is seen. In line with this trend, individuals and organisations have worked globally to reposition disability as a human rights issue.

Across time and around the globe, persons with disabilities have led lives that were off the social map. In the best situations, the welfare framework provided by the medical model enabled persons with disabilities to sustain life, but offered little more. Disabled individuals have historically suffered political, economic, social, and cultural marginalisation. A combination of paternalistic attitudes about their participation in society and the character of a society accustomed to disabled persons' institutionalisation made a remedy for their situation unimaginable. Gradually, however, the welfare framework has come to be recognized as a form of oppression and a new model has emerged as a blueprint for empowerment. The alternative, known as the social model of disability, is based on the premise that disability oppression is similar in many ways to more widely recognized forms of paternalism and discrimination. Disability activists have learned from prior social movements that becoming part of the mainstream entails reforming society at large, not conforming to a predefined, marginalized and powerless identity. This means undoing the definitions of disability that maintain an oppressive hold on the disabled population. Positively defined, the goal is to provide a recognition of and
intention to address within an inclusive framework the rights and obligations of persons living with disabilities.

The rights-based approach to disability focuses on the removal of barriers to equal participation and the elimination of disability-based discrimination. At its core are the principles that have always guided human rights work. These four values are equality, dignity, autonomy, and solidarity, and offer an interesting theoretical framework within which to consider the issue of disability (Quinn, 9).

To date, equality has been the focus of attention for disability activists. In many (especially Western) nations, their efforts have resulted in the recognition and acknowledgment of people with disabilities as a minority group that is entitled to certain antidiscrimination protections. Nations which have achieved civil rights legislation for persons with disabilities exemplify the paradigm shift from the medical model to the social model. Legislation such as the Americans with Disabilities Act was enacted as a step towards the full recognition of human rights for persons with disabilities. Since the early 1980s, governments have been increasingly responsive to the needs of disabled individuals, and willing to codify their commitments into law.

At a basic level, these laws seek to address the issue of inequality between disabled and non-disabled persons. However, equality has been interpreted differently by countries in all regions of the world. There are three commonly accepted conceptual categories into which these variations fit. These are (1) formal or juridical equality, (2) equality of results, and (3) equality of opportunities, also known as structural equality. Together, these comprise what is referred to as the equality principle.
Formal, or juridical, equality seeks to prohibit unequal treatment based on difference. By de-emphasising a group's distinctive qualities, such as race, gender, or disability, it is thought that discrimination will be made arbitrary and thus less prevalent. This concept of equality is advantageous in that a denial of difference theoretically prohibits prejudice based on stereotypes and stigma. However, there are certain aspects of disability that require a recognition of difference. For example, a recognition of difference is integral to constructing a disability-inclusive built environment. Without certain, disability-centered considerations, accessibility issues could neither be sufficiently nor properly addressed.

Equality of results is based on the concept that all human beings are entitled to a basic level of dignity and value. This concept substantiates claims for equal distribution of resources, and is behind the notion that a difference-based unequal burden is discrimination. One example of this is the idea that equal pay is discriminatory when a person's impairment causes the work to be more burdensome. This concept of equality lacks two important details. First, it neglects to address the question of responsibility; who must right the inequality requires further explanation. For example, when an employer hires a person with a disability, and is forced to pay him or her more for the burdensome work s/he performs, should the state reimburse the employer, and become the agent and enforcer of equality, or should the employer? This concept of equality requires that the decision be situation-specific. Second, it fails to emphasise the process of achieving equality. There is much room in that process for erroneous treatment of a person based on stereotypes or a stigmatised idea of disability. Such a process does little for achieving justice, and likely discredits the end result of “equality”.

Structural equality is founded on the idea of “reasonable accommodation.” This principle
claims that disability must be taken into account when social or environmental changes must be made in order to achieve equality. The notion was hatched in US jurisprudence in the early 1970s, and has been adopted, defined and redefined by countries around the globe. It is currently the most widely used concept of equality in the area of disability.

The human rights value of dignity applies to persons with disabilities in the same way that it applies to the non-disabled population. The United Nations considers each human being endowed with a life of inestimable value, and entitled to a dignified existence irrespective of qualification, whether it is merit, economic status, gender, or any other type of status (“Universal Declaration of Human Rights”). As such, in the context of disability, an individual's dignity (and, thus, respectful treatment) must not be linked to their medical condition or functional capabilities. Neither should the determinant of their value be their economic viability (Office of the United Nations High Commissioner for Human Rights).

Autonomy, or self-determination, in the context of human rights means that individuals are entitled to self-direction, and ought to be the primary decision makers with regard to their well being. Socially, the autonomy of disabled individuals is typically seen from a highly stereotyped perspective. Given the degree of functional limitation, one's impulse is to assume that a disability precludes an individual from performing certain tasks, and thus caring for him or herself. This kind of opinion is supported by the medical model of disability. Supporters of this line of thought argue that nondisabled medical professionals should be permitted to direct the decisions regarding the capability of a disabled individual in their care. However, as certain disability activists have shown, independent living is not dependent upon one's capabilities, but rather on the facilitatory resources available to them. As such, the exercise of this principle
should not be tied to one's health status.

The principle of solidarity describes the interrelatedness of human experience, and the shared aspects of it that validate the demand for a basic level of rights. For disability, it means recognising the indivisibility of both sets of human rights (Degener, 152). Civil and political rights are crucial to empowering the voices of disabled individuals, whose demand for economic, social, and cultural rights are of equal value and deserve appropriate social support.

Together, the four human rights values named above are a point of unity amongst disability activists. Because of the efforts of such social reformers, these values find practical application in laws that govern disability in nations around the globe. This framework is effective for the evaluation of legal standards both within borders, in the form of domestic law, and across borders, in the form of past United Nations efforts, and the pending UN thematic convention on disability.

The Characterisation of Disabled Bodies

The definition of “disability” has been widely discussed and has changed drastically in the past few decades. In order to achieve consistency across this work, and to promote the interpretation of this sometimes confusing lexicon, it is necessary to summarise its variety.

The difficulty in pinning down a universal definition of disability lies in its multidimensionality. There is little commonality across disabilities, which inherently limits the span of any definition. Varying cultural conceptions of disability further complicate the process. Indeed, Majid Turmusani points out that the currently accepted international definition of disability does not address the aspects of culture that play a role in determining the level of
handicap, and are reflected in the political debate over resource distribution (Turmusani, 11). Cultures form different assumptions about disablement, he argues, and thus construct disability in varying ways. Turmusani notes that theoretical models have attempted to locate the lowest common denominator in order to classify, measure, and address disability. He describes, but does not take accurate note of the degree to which competition between these models has led to a politicisation of the definition. In turn, this has contributed to the confusion that surrounds disability terms and definitions.

Two schools of thought have developed coherent vocabularies about the determinants of disability: the medical model and the social model (Altman, 99). Both of these models have approached the subject of disability by offering differing interpretations of the body and its functioning. In 1980, the World Health Organisation (WHO) developed a clinical definition that has since been regarded by medical professionals as the standard. The model, known as the International Classification of Impairment, Disability and Handicap (ICIDH), recognises disablement within the context of health experience. The World Health Organization, then defines impairment as “any loss or abnormality of psychological or anatomical structure or function” (2). According to the WHO's definition, disability lies in

not being able to perform an activity considered normal for human beings: any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being (2).

Handicap is:

the inability to perform a normal social role and is defined as: a disadvantage for a given individual resulting from an impairment or disability that limits or prevents fulfillment of a role that is normal (depending on age, sex, social or cultural factors) for that individual (3).
As such, the WHO has laid out and defined three elements of disablement. The common thread between these is the personal, subjective experience of health. The definition relies on a standard of human health that is considered “normal.” Variation from that norm is considered an impairment, which in turn causes disability and handicap. Under the medical model, the body is considered only in physiological terms. It has no context beyond clinical treatment, and is thus singular, isolated, an abstraction. Such a conception actively denies what the social model asserts – that social relations play a role in constructing the disabled body.

However, the medical model itself is evidence of such a relationship. By positing a narrow definition of the body, it establishes a dynamic of control over how disability is seen. Historically, this paradigm has been dominant. It is manifested in the control that medical professionals are granted over the bodies of their patients. Both the law and medical professionals have removed persons with disabilities from their families into institutionalised spaces that increasingly sought to control and regulate their bodies. The clinical model depicts persons with disabilities as solely medical creatures. The impulse is to “cure” the impaired body, or at least suppress its abnormality, and to prevent other like occurrences. In a word, such control served a wider social goal of “normalising” disability. The goal here is twofold eradication – the first component being the aim to undo the effects of impairment on the body, and secondly to remove its occurrence from society. Since disability is considered aberrant, an obstreperous condition in the course of human “normaley,” these efforts have at their heart a desire to make disabled bodies “normal.” When seen in this light, the insight of the social model becomes sharper; disability is a social relationship imposed on impaired bodies by society at
Recognising this power dynamic, it is easy to offer a conception of the body as a site of conflict. Social forces, such as attitudes and institutions, are more salient determinants of the body's reality than is biological fact. In other words, bodies are socially constructed, calling into question the dynamics at play in the definition of disability. The social model purports that the perception of bodies is influenced by socially dominant ideas, attitudes, and customs. The model posits a commonsense way of thinking about the ways in which people distinguish individuals who are not like themselves. It holds that the medical model is a tool used to construct the social perception of disabled bodies; in short, the medical model can be considered a weak form of social constructionism.

The social model itself can be described as a stronger account of constructionism. Its origins lie in a definition of disability offered by the Union of the Physically Impaired Against Segregation (UPIAS), a London-based organisation of disability activists that advocates for state assistance in achieving maximum independence in daily living activities. In the mid-1970s, UPIAS offered the following definition of disability:

disadvantage or restriction of activity caused by a contemporary social organisation which pays little attention to people with physical impairment and discounts their participation in the mainstream of social activity.

On a fundamental level, this definition reformulates the way in which disability is thought of. Instead of an issue only concerned with bodies and medicine, the definition offered by UPIAS situates disability in the context of “social organisation” and “participation.” Using these words to describe disability represents a radical break with traditional thinking about
disability. Instead of being rooted solely in the medical profession, disability became politicised. Under this definition, advocates could begin working toward drastic policy changes which codified and protected the rights of persons with disabilities. For this reason, the definition grew in popularity among organizations of disabled persons. It was adopted by the British Council of Organizations of Disabled People (BCODP) and Disabled People International (DPI). UPIAS later expanded it to cover other types of impairment, such as mental disabilities. According to these activists, disability is the result of constraints that social codes and norms place on bodies. Indeed, they see disability as the sum of poor social design and impaired human bodies. Cultural mores and physical obstructions in the built environment make adaptation to the dominantly nondisabled world difficult for impaired bodies. Essentialist attitudes attach stigma to disability; stairs impede access to buildings.

There is contention over terminology revolving around the distinction between impairment and disability (Turmusani, 12). UPIAS and BCODP concern themselves with impairment and disability, while DPI chooses to utilise the terms disability and handicap. These terms are more or less parallel visions; DPI's definition of disability is synonymous with impairment, and handicap is the same as disability. Jenny Morris has likened this kind of distinction to that used in the definition of sex and gender (10). According to this analogy, impairment, like sex, is an existential, biological element, naturally determined. Disability and gender, on the other hand, are socially constructed aspects of personhood. Similarly, UPIAS and others see impairment as a condition that applies at the biological level, and disability as defined socially.

Given the insights provided by such widespread criticism, the WHO circulated a revised
definition in 1997. Version two of the ICIDH changed the title of the classification system to reflect its focus. The International Classification on Functioning, Disability and Health (ICF), as it is now called, also uses a threefold description of disablement, but uses different terms: impairment, activity, and participation. Impairment, as it is defined here, is similar to its original formulation. The WHO now considers that impairment is:

- a loss or abnormality of body structure or of a physiological or psychological function.

Activity is considered to be:

- the nature and extent of functioning at the level of the person. Activities may be limited in nature, duration and quality.

Participation is defined as:

- the nature and extent of a person's involvement in life situations in relationship to impairments, activity, health conditions and contextual factors. Participation may be limited in nature, duration, and quality (“International Classification of Functioning, Disability and Health – ICF” 2).

This reformed set of definitions simply considers disability in positive terms. Impairment is discussed in terms of one's capability, rather than being considered inherently limiting. There is a rhetorical emphasis on involvement and participation, which is a definitional shift toward a stronger constructionism. However, the substance of the ICF lies in its similarity to the ICIDH. Both seek to “normalise” disability – the ICIDH for its abnormality, and the ICF for the social goal of participation. As such, it still treats the body as a singular entity, which ought to be considered primarily in physiological terms.
Quantifying Disability

The tensions between these two schools of thought, and the difficulty of finding an all-encompassing definition of disability are best exemplified by the efforts to quantify disability internationally. By popular estimate, there are 600 million disabled individuals in the world, and two-thirds of them live in developing nations.¹ Until recently, however, there has been no international standard by which to measure the prevalence of disability. Cultural differences, infrastructural incapacity, and discrimination have contributed to the lack of statistical data. As a result, the incidence, trends, and distribution of impairment and disability are not internationally comparable, and much national-level data, particularly in the developing world, is unreliable and out-of-date. The primary compendium of this data is the United Nations' Disability Statistics Databases (DISTAT-1 and -2.) There are several standards by which this data is classified and collected. Most data is drawn from national census surveys submitted to the United Nations Statistical Division, which also receives information from household surveys and registration systems.

In order to ensure international standardisation of this data, a number of efforts have been made to facilitate collection and analysis. These include the World Heath Organization's ICF system and its predecessor, the International Classification of Impairments, Disabilities and Handicaps (ICIDH). There is a strong need for the development and standardisation of inquiry measures to be applied in both censuses and representative surveys. This is complicated work,

¹ These numbers are supported by estimates that 10% of the world's population is disabled. The study that initially proposed this figure was funded by the WHO, and purported by the United Nations. The author of the study later wrote that his estimate would instead be between 4% of the population in developing countries and 7% in countries with advanced market economies.
given the multidimensionality of disability. The way in which disability is defined is directly related to the results of a survey of its prevalence. Judging the standards of living between disabled and non-disabled generally lends itself to a strictly medical definition of disability, as it focuses on impairment. A new approach where activity limitations and restrictions in social participation are treated as common phenomena has emerged, which lends itself to the definition purported by the social model. From the data analysis perspective, the research challenge lies in understanding disability as a multidimensional phenomenon that can be approached both as a dichotomous occurrence between abled and disabled, and as a continuous measure of activity limitations/participation restriction. In addition, these measures must be interpreted as relevant to the environment, society and culture from which they are derived. This will require an expanded view of disability data and effect substantially greater measurement challenges.

Achieving high-quality disability statistics is a prerequisite for designing a strategy for meaningful inclusion. In order to present a thorough picture of the situation faced by disabled people, any and all surveys must include two considerations. There need to be possibilities for comparison between groups (including disabled and non-disabled), and the surveys must document and analyse mechanisms explaining the close link between disability and other social issues, such as poverty or participation in government. These measures must be interpreted as relevant to the environment, society and culture from which they are derived. As a matter of human rights, these statistics are not only relevant, but also necessary to the monitoring of equality. These numbers are the rubric by which states are measured and held accountable for the economic, social, political, and cultural rights of disabled citizens.

The United Nations Statistical Division (UNSD) has kept official record of disability
statistics since the early 1980s. The impetus for action on this issue was the direct result of heightened international political awareness of disability issues (United Nations Statistics Division, 5). The UN declared 1983 the International Year of Disabled Persons, and began a Decade of Disabled Persons for the years 1983-1992. A World Programme of Action concerning Disabled Persons was established at that time to regulate and advise the UN in disability-related matters. One aspect of this Programme was the collection and dissemination of statistical information. In particular, the United Nations urges its Statistics Division, together with other units of the United Nations Secretariat, the specialized agencies and regional commissions, to cooperate with the developing countries in evolving a realistic and practical system of data collection based either on total enumeration or on representative samples, as may be appropriate, in regard to various disabilities, and in particular, to prepare technical manuals/documents on how to use household surveys for the collection of such statistics ("Guidelines and Principles for the Development of Disability Statistics" 3).

The UN issued a pioneer report that year titled Development of Statistics of Disabled Persons: Case Studies. In it, the disabled populations of five countries were examined retroactively. Each participating country submitted survey, census, and registration statistics for the years 1947-1981. The data collection process was convoluted; many countries had disability statistics embedded in other information that was not disability-specific, such as population surveys, or health and medical registration systems (2). As such, the report highlighted the need for international conceptual and methodological continuity. The first step, it recommended, was to create a disability-specific data collection system.

UN DISTAT-1 made its debut several years later, in 1988. Similar to the first UN inquiry into disability statistics, DISTAT-1 consolidated national data from national censuses, household surveys, and registration systems, and attempted to standardise the procedure for
international statistics gathering. The database includes socio-economic information regarding persons both with and without disabilities. These statistics were gathered using the World Health Organisation’s ICIDH classification system, including marital status, level of education, and economic characteristics. Sixty-seven studies were submitted to the database, representing the status of disabled individuals in 55 countries between 1975-1987. The data were organised into six subtopics:

(i) General description of the census or survey methodology in each data source;
(ii) Demographic characteristics and urban/rural residence;
(iii) Assessing the equalization of opportunities, i.e., socio-economic characteristics such as educational attainment, economic activity, occupation, industry and employment;
(iv) Social integration, household and family membership;
(v) Describing the disability experience; and
(vi) Other special topics (United Nations Statistics Division 3).

As such, some of the definitional problems that previously hampered comparison of disability statistics were eliminated. Still, however, the existing data were inadequate, the numbers deemed too scarce, and inconsistent for analysis.

In 2001, DISTAT unveiled a second version of its database. DISTAT-2 gathered 179 national studies from all regions of the globe, and initiated a system of regular observation that is currently published annually in the UN's Demographic Yearbook. As was true for DISTAT-1, international standards (namely the ICIDH) were used where applicable, and socio-economic and other variables were included for comparison with the non-disabled population. Currently published statistics, however, deal only with the prevalence of disability. The data are grouped by age, sex, and country, and expressed as a number per 100 of the population. The results concerning the prevalence of disability vary greatly and are sometimes misleading. In order to
facilitate understanding of the data, UNSD provides information on the question(s) used in its study. Furthermore, data submissions to DISTAT-2 were varied with regard to their coverage. For example, some studies included statistics on persons with disabilities aged 10 or more years, while others collected data on individuals aged 15 or more years (United Nations Statistics Division 3). The differences in classification and collection strategy, in other words, have not been smoothed out by this second version of DISTAT.

While the multidimensionality of disability makes it an extremely difficult subject to quantify, there is an urgent necessity for standardisation. Informed policy making is contingent upon such data. Activists and politicians alike find the information useful for strategising responses to the social issues caused by disability. Recognising this, in 2005, the UNSD initiated another round of data collection. This effort includes a disability-specific questionnaire that should better inform the United Nations, and which will be published in the Demographic Yearbook. It is currently being tested and developed in the areas of tabulation and dissemination.

**Policy and the Analysis of Disability**

The two major theories of disability, the medical model and the social model, have been described above. These approaches find practical application in legal codes that govern disabled bodies. Societies have chosen to respond to disability in numerous ways throughout history. Generally speaking, there are three categories into which one can separate these responses: isolation, welfare, and empowerment. The first of these is a policy of isolation. Especially in highly religious societies, disability is seen as a punishment for some type of sin or wrongdoing.
It follows from this mode of thinking that disabled individuals ought to be excluded from the mainstream. Their medical conditions are highly stigmatised and programs receive few resources, if they exist at all. Impairment is, at best, a cause for charity in these societies. Turmusani has noted that all the major religions take an ambivalent stance on disability (Turmusani 6). These religions look negatively upon the condition and the person that supposedly committed the sin deserving of such impairment. The societies in which one of the major faiths dominates political discourse depict disability as either something to be pitied and carefully tucked away from sight, or an example or warning to followers that divine retribution can be visited upon one’s body for committing a sin.

The medical model has been the model of choice for Western welfare states. Its social goal is to promote the welfare of disabled persons by allocating resources to prevent, treat, and cure disability. However, since disability biologically impacts individual's functional ability to perform an economic role, is situated within a singular body, and is seen as a physiological occurrence (as opposed to divine punishment), society must provide a support system. In other words, under the medical model, disability enters the political realm at the intersection of funding and advocacy. Legislation based on this model is largely allocative, and provides for research, benefits, and services. The research that receives funding has highlighted the incapacity of disabled persons, reinforcing the notion that such individuals are unable to help themselves. Advocacy for services is done in a similar manner. Lobbies become largely emotional, appealing to tales of victimisation and moral entitlement to benefits and services. Efforts spearheaded by charities and politicians have used token poster children that were socially, politically and economically disadvantaged by their varying conditions.
The social model has molded a fundamentally political retort to the welfare mentality of the medical model. Its strength lies in seeing beyond the specific impairment of individuals and embracing the social, political, and economic dimensions of disability from a human rights perspective. The model suggests that persons with disabilities have historically suffered, and currently experience, marginalisation based on the stigma attached to their bodies. A proper disability policy, in this view, would focus on empowering persons with disabilities to reclaim their right to be treated with dignity, and to fully participate in society.

Identity politics are at the forefront of this discussion: the social model creates a group identity, and posits that the group has been oppressed. Historically speaking, this was a landmark shift for disabled persons. Politicisation offered a sense of commonality, a tie that could form the basis for a disability identity, and, thus, collective action. The isolation and dependency experienced by persons with disabilities are not natural results of their impairment, but rather the result of social attitudes and institutional choices. To remedy the limitations faced by disabled persons is to change the face of cultural mores and decision-making institutions. Primarily, this change is brought about through antidiscrimination legislation. Borrowing from materialist (neo-Marxist) perspectives, which have been arguably successful for such other contemporary social movements such as race, gender, and sexual preference, the social model assumes that by changing the material conditions of disability, a change in exclusionary social relations predicated on discrimination would naturally follow. Disability activists developed a politics of disability, in which persons with disability demanded wider engagement and inclusion.

Each of these models is a paradigm through which advocates argue for policy
implementation. The medical model and the social model in particular can be seen as ideologies that are opposed to one another. Proponents of both consider theirs to be the proper way of conceptualising disability, and have attempted to refute elements of the other’s position. Jerome Bickenbach has sharply criticised either paradigm, noting that each has components that are simultaneously constructive and distortive (“Physical Disability and Social Policy” 60). This is most clearly illustrated within the medical model. There are obvious benefits to having a clinical definition of disablement. The medical model offers a systemic and reliable foundation for disability policy. The notion that there is an element of disability that is not socially constructed constrains lawmakers within certain bounds. Scientifically derived evidence is difficult for lawmakers to refute or to politically manipulate. Further, without a clinical conception of disablement, some daily necessities in the lives of persons with disabilities would not be possible. Assistive technologies, such as wheelchairs, and regular medication are prime examples. To its credit, the medical model simultaneously gives a reason for policy and aptly defines a goal; once clinically recognised, an individual's needs can be correspondingly stated and a conversation can begin about how to allocate to meet those needs.

This model, however, fails to recognise the full range of what disability means. It is a gross understatement to claim, as this model does, that disability can be reduced to impairment. By claiming that the only social relevance that disability has is allocative, and by claiming that medical professionals should be the sole judges of the capabilities of a person with a disability, the model prevents public discourse about disability and has the effect of stifling any debate that might serve to redefine disability. Politicians have often signed onto remedial legislation out of the fear of being deemed insensitive to the plight of such marginalised and “afflicted”
individuals. In this way, many conditions have been “medicalised,” legally defined through the lens of the medical model so as to entitle those “deserving” enough to receive services.

More, in welfare states, a prerequisite for full participation in public affairs is economic activity (Turmusani 7). Disabled individuals, however, find it difficult to procure and maintain jobs given discriminatory attitudes and barriers in the built environment, and are often seen as welfare dependent and a drain on resources.

The social model posits that exclusionary attitudes are the cause of discriminatory policies in education, housing, employment, transport, social interaction, cultural expression, and personal behaviour. As a result, the social model recognises that disabled citizens are treated as second-class citizens. The model uses the common thread of social exclusion to unite persons with disabilities. Organisers were thus able to look to the social model of disability to construct cross-cultural and pan-historical categories of disability. In this way, the discussion prohibited by the medical model was been brought to the fore.

The politics of the social model focus less on distributive concerns and more on the social roles played by disabled individuals. Under the social model, activists and advocates were able to formulate a plan to transform decision-making power, traditionally held by medical professionals, into direct participation in advocacy, policy-making, and program implementation. UPIAS made the following demand in 1976:

Disability is a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people (3).
UPIAS made a political claim – that persons with disabilities inherently deserve to control
decisions made about them, and their inclusion in the decision-making process should be
immediate and complete. Their call created the possibility for a unified political voice, to be
expressed in the variety of institutions in which power is manifested. Such a challenge to
traditional political structures and values is central to the social model.

The social model is a distortive lens for considering disability policy because of its neo-
Marxist assumptions. The social model culminates in antidiscrimination legislation. Activists
and advocates that adhere to the social model have assumed that the attainment of rights would
deliver respect and accommodation, and that inclusion in all spheres would flow naturally from
the heightened stature of disabled individuals. In countries that have enacted antidiscrimination
legislation, the status of disabled citizens suggests that this is, at best, illusory.

There is a long history of legal disability advocacy that follows in this vein. Past social
movements have successfully argued for antidiscrimination legislation based on their social
exclusion and minority group status. The most famous of these include the American cases of
racial desegregation and women's liberation, which were, to a significant degree, fought through
state and federal courts. Building on this ground, the disability rights movement launched
several class action suits in the 1970s, some of which provided the grounds for later legislation
(Scotch 37). In the United States, the push for civil rights culminated in the Americans with
Disabilities Act (ADA) of 1990. Certainly the most far-reaching of this type of legislation, the
ADA was lauded by disability rights activists at the time, yet has been critically analysed since
its codification. The legal reasoning behind the ADA drew upon prior civil rights legislation, in
particular the Civil Rights Act of 1964, and has afforded disabled individuals significant advances in the social, economic, and political mainstream (Scotch and Schriner, 150). Similar legislation has been achieved in numerous countries around the globe. Israel, Canada, New Zealand, India, Australia, and the United Kingdom are examples of nations that have derivative forms of the ADA in place today. These laws, of course, differ in subtle ways, but the governing principles of the social model are the same across the board (Shakespeare and Watson 569).

Like other rights struggles, however, the reach of social change promised by such legislation has been limited, and the experience of rights constrained to a certain population. Such is the case with African American civil rights; while formal equality has been achieved, it can be argued that little has been done to improve standards of living or equality of outcome. Bickenbach has noted that after the ADA, more than half of all Americans living with disability still live in poverty (“Disability Human Rights, Law, and Policy” 551). This poses an impasse for the social model. The stature of persons with disabilities has been heightened by legislation such as the ADA, however, respect, inclusion, and accommodation are still limited in many spheres. The current status of disabled persons points out the false assumption that the attainment of rights would naturally dissipate these phenomena. Unfortunately, the ADA has not been enough to solidify empowerment beyond formal bounds.

For the reasons discussed in the following section, some critics have been active in providing reasons for this failure. These critical accounts ultimately revolve around the minority group status of disabled individuals, in which the pursuit of antidiscrimination laws as the means to a civil rights policy is paramount.

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2 See, for example, Albrecht (2001), Bickenback (1993), Scotch and Schriner (1997), Zola (1989).
Minority Group Status and Discrimination

The social model categorically states that persons living with disability constitute a minority group. Since persons with disabilities have been marginalised due to discrimination, the first step toward disability empowerment has been the codification of rights under antidiscrimination legislation. A primary aspect of minority group status is an idea of what it means to identify as disabled. The social model is able to deliver this by providing common ground on the basis of shared experience. Difference between disabled individuals may exist, especially when comparing medical conditions, or other, more salient identities such as race and class, but the social model posits that the political marginalisation and social exclusion of such individuals via discrimination is grounds for a group identity (Devlin and Pothier 3).

It is true that individuals commonly experience marginalisation, but not in the same ways as other minority groups have historically been persecuted. Racial identities, for example, are premised upon physical commonalities, as is the case with gender or religious identities. Disability, however, lacks such overlap. The degree of stigma attached to mental and physical disabilities vary widely. Moreover, many individuals, especially those with learning disabilities, refuse the label; to be called disabled is to accent the marginalising aspect of their otherwise mainstream human condition. As such, there is little ground beyond politics for forging a unified disability identity. Within disability it is true that subcultures have been able to forge a politically charged language and culture. One need only look to the Deaf community for evidence of this trend. However, the lack of transdisability rhetoric considerably slims the chances for a serious, identity-based political culture.
The ADA and its derivations around the globe are evidence that governing bodies are willing to address the issue of disability discrimination. These are important guarantees, and such constructive criticism serves to better, not undercut these achievements. However, within these statutes there remain unresolved issues of problematic language and processes for protecting rights.

By definition, antidiscrimination laws are two-fold; they include a description of the grounds for discrimination and a list of physical areas or social situations to which the protection applies. These laws are typically complaint-based, and in order to be practically and fairly enforced, the legislation must have a device to determine first whether an individual qualifies for such protection, and second whether any unlawful discrimination has occurred. Legislators refer to this process as “gatekeeping.” As such, the nature of antidiscrimination provisions is to be reactive, and requires a cumbersome and costly administration. The main criticism levied at the ADA and similar antidiscrimination statutes is the inordinate amount of time and resources that have been spent on gatekeeping.3

Moreover, the process itself forces the social model to individualise disability. In order to qualify under the law, one must have a medically defined condition that confers disability status. This is a process that forces individuals to identify with the most stigmatised aspect of their condition in order to qualify for “special treatment.” Bickenbach notes that a number of cases brought under the ADA have been thrown out due to insufficient or ambiguous medical evidence (“Disability Human Rights, Law, and Policy” 577).

So far, the criticisms leveled against antidiscrimination policies have focused on thier

3 Bickenbach (1993, 2001) is one outspoken critic of this sort.
inherent theoretical contradictions and their costly, problematic administration. Unfortunately, a larger problem lies categorically beyond the scope of antidiscrimination policies. The root cause of inequality is found not only in the maldistribution of power and resources, but also in the politics of recognition. Underfunded medical research prospects, lagging assistive technology, and minimal policy influence are examples of decisions that have an effect upon the lives of persons with disability. These are not direct forms of discrimination, but rather are results of social arrangements that deny participatory parity. The social model was right to address discrimination as a social ailment, but was wrong to assume that protections against such attitudes would somehow also solve these problems.

**Conclusion**

Disability has been defined in several ways, each of which has a distinct effect on policy. Each has benefits to offer the disabled community, but each also incurs a loss of some form. The primary model used to empower individuals living with disability in recent decades has been the social model. Its implementation, primarily achieved in Western nations, has had a generally positive effect, despite its theoretical and administrative shortcomings.
Chapter Two
Disability antidiscrimination laws have been enacted around the globe. These laws enumerate the successes of the social model. Their lobbyists have established a working definition of disability, and manoeuvred to decide the proper policy response to the social issues that arise in the context of disability. Such civil rights legislation has been achieved in varying ways. There are several ways of conceptualising equality, and many more ways of codifying its definition. Nations that have constitutional amendments to protect persons with disabilities, for example, think of equality in different terms than nations that have passed civil laws. The variety of laws that nations have enacted begs the question of which ways are most successful for providing meaningful protection for persons with disabilities.

To respond to this question, one must survey the ways protections have been afforded, and how these countries have responded to the conditions of disabled individuals within their borders as a result. Presented here is a comparative look at these statutes in order to inform efforts to discuss disability as a subject of international human rights law. Governments worldwide are in the process of drafting provisions that will be internationally binding. A look at these laws should inform the drafting of this international convention.

**Antidiscrimination Laws in Comparative Perspective**

These principles are useful tools for analysing the legal protections afforded to persons with disabilities around the globe. As was noted above, the equality principle has received far more legislative attention than the other three human rights values. Of its variants, structural equality has been favored by more governments worldwide than any other. Two legislative events have contributed to this trend. The first was the passage of the Americans with
Disabilities Act (ADA) in 1990. Since many laws in other nations were soon after enacted to serve similar purposes, using language similar to the ADA, Theresia Degener holds that codification of the ADA was arguably more influential internationally than it was domestically ("Disability as a Subject of International Human Rights Law and Comparative Discrimination Law" 154). The second factor, the 1993 United Nations' Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Standard Rules), ensued heightened international awareness about disability issues caused by the passage of the ADA. These two documents have inspired the implementation of antidiscrimination provisions around the globe, and as such, will serve as the basis for comparative analysis. It should be noted that, since disability law is a new field, and its study an even more recent occurrence, limited information is currently available on the provisions enacted, especially in developing nations. As such, the cross-section of laws analysed here will have, for the most part, a European focus. Laws from outside this region will be included where it is possible and appropriate.

Employment lies at the heart of the ADA, and as such, it is the archetypal example of reasonable accommodation. The ADA defines disability as a “physical or mental impairment that substantially limits one or more of the major life activities” ("Americans With Disabilities Act"). It has three qualifications that one must meet to qualify for protection under its provisions. First, an individual must have a major limiting physiological disorder or condition. Second, there must be medical record of the impairment; and third, the person must be regarded as substantially limiting in one or more life activities. Since the ADA has employment as its primary focus, it uses qualification for work as a second means of gatekeeping. Individuals who qualify for employment, with or without reasonable accommodation, are those covered by the
As international non-binding, or “soft” law, the UN Standard Rules were intended to serve as a model for developing domestic law. In most countries that ratified the document, disability movements were able to use Rule 15 of the Standard Rules to pressure governments to adopt similar, binding, domestic legislation:

States have a responsibility to create the legal bases for measures to achieve the objectives of full participation and equality for persons with disabilities. . . . States are under an obligation to enable persons with disabilities to exercise their rights, including their human, civil and political rights, on an equal basis with other citizens. States must ensure that organizations of persons with disabilities are involved in the development of national legislation concerning the rights of persons with disabilities, as well as in the ongoing evaluation of that legislation (“Standard Rules”).

Rule 15 also suggests enacting disability-specific laws, mainstreaming disability clauses into existing and new laws, establishing affirmative action quotas, or a combination of these techniques to incorporate disability legislation.

The domestic laws that have resulted from the precedent set by the ADA and Standard Rules approach codification in one of four ways. These are antidiscrimination protections in criminal law, in constitutional law, in civil law, and in social welfare reforms (Degener 160). These laws are all designed to uphold the principle of equality, but the commonalities often stop there. Given the multidimensionality of disability, and the myriad different cultural conceptions of it, this phenomenon should be expected. Some of the laws in question lack enforcement mechanisms, others leave out a plan for accommodation, while still others embrace the equality principle in full and impose strict penalties for its violation.
Finland, France, Luxembourg, and Spain have chosen to protect persons with disabilities under their criminal law. France and Luxembourg are of note for having chosen to treat disability-based discrimination exclusively this way. Finland, Luxembourg, and Spain have an administrative government body, such as a human rights commission or ombudsman that oversees enforcement and hears grievances (Michailakis 55-56). Legislation in both countries guarantees due process, or legal remedy through the courts, to disabled persons. While France has not legislated any new provisions since the adoption of the Standard Rules, Luxembourg has outlined a national program for disabled persons, with a coordination committee that represents several government Ministries (Michailakis 56). Nations that protect their disabled via criminal law hold that discrimination is only illegal when it was direct and intentional. In other words, there must be an action or event that is perpetrated against an individual. There is reason to believe that this kind of enforcement is ineffective, because many violations may go unreported. Moreover, criminal law protections neglect to address indirect or unintentional discrimination. As such, it is a selective treatment of disability-based discrimination. Other provisions are required to regulate accessibility in the built environment and media, as well as the right to organise and lobby government.

Constitutional protections are more prevalent than are criminal law statutes. At least thirteen nations worldwide have constitutional provisions that explicitly deal with disability. The language used to prohibit negative discrimination in these constitutions is broad; the definition of discrimination is left open for the courts to interpret. Disability issues achieve high visibility in these countries, as antidiscrimination is enshrined in the highest law of the land. As

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4 These countries are Austria, Brazil, Canada, Finland, Fiji, the Gambia, Ghana, Germany, Malawi, New Zealand, South Africa, Switzerland, and Uganda.
opposed to nations that use criminal law, some of these countries have chosen to mention direct and indirect forms of discrimination. For example, Article 9, Section 3 of the Constitution of South Africa provides that:

> The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth (DREDF International).

Most of these constitutions require that congress or parliament make further protections via legislation. The majority also provide for quota systems, or affirmative action, based on disability. Nine of the aforementioned thirteen seek to eliminate structural or institutional discrimination by requiring that a certain number of individuals with disability be part of decision-making processes (Degener, 165). These quotas apply to both employment and political representation. In Brazil, public employment is regulated by Article 37 of the Constitution, which reads: “the law reserves a percentage of public offices and positions for handicapped persons and defines the criteria for hiring them” (Brazil – Constitution). Pursuant to Article 29 of Ghana's Constitution, a National Council on Disabled Persons was established in 1993, with the stipulation that its Executive Secretary be a person with a disability, appointed by the nation's President to “be responsible for the administration, organisation and control of [the Council's] functions” (Ghana – Constitution). Uganda has passed several acts to raise the quota of persons with disability in its senate. Degener cites the Local Government Act of 1997, which earmarked a certain number of seats for persons with disabilities at all levels of government (167).

There are reasons why constitutional antidiscrimination clauses are strongly favoured for
creating actual, lasting change in societies, but there are also drawbacks. On the one hand, their strength lies in their definition; since the constitution is the highest form of law, a constitutional provision has the effect of rendering conflicting legislation unconstitutional and, thus, void. Moreover, it sets a standard by which all new case law must adhere, and opens the way for reform as a result. However, such rights are only valid in public law. This means that the scope of protection is limited to protection from discrimination by state entities while private employers and providers are not held accountable for discriminatory practices they might perpetrate. Finally, and this is true of all laws, the narrow range of protection against state discrimination is open to interpretation by the courts, the discretion of which can vary widely. The courts are subject to sway depending on the atmosphere of the legal culture that surrounds them, and are subject to political motivated, activist appointees.

Theresa Degener describes the civil antidiscrimination laws which have been enacted by at least twenty-seven nations (170). This type of law is usually broader in scope than constitutional provisions, and better defines discrimination and the enforcement mechanisms used to counter it than does constitutional law. Indeed, a handful of countries impose criminal penalties on violators of such laws. Australians face a six-month prison sentence or a fine for harassment or other discriminatory practices. Similarly stiff laws are on the books in Hong Kong, Mauritius, Israel, the Philippines, Zambia, and Zimbabwe (171). Twenty-six of the nations, Chile being the exception, deal with employment in their antidiscrimination statutes (171). One third of these countries deal exclusively with employment discrimination, through

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5 These countries are Australia, Canada, Chile, Costa Rica, Ethiopia, Germany, Ghana, Guatemala, Hong Kong, Hungary, India, Ireland, Israel, Korea, Madagascar, Mauritius, Nambia, Nigeria, the Philippines, South Africa, Spain, Sri Lanka, Sweden, the United Kingdom, the United States, Zambia, and Zimbabwe.
labour laws. Ethiopia is one instance of this type of legislation. Disabled Ethiopians are granted protection under two, very short laws. These are Labour Proclamation N/42 OF 1993, and The Rights of Disabled Persons to Employment Proclamation nß 101/1994. This latter piece of legislation is a comprehensive document detailing the rights of disabled persons in Ethiopia.
What is interesting about the former is its brevity. The relevant antidiscrimination portion of the Labour Proclamation states simply that it is unlawful for an employer to “discriminate between workers on the basis of nationality, sex, religion, political outlook or any other condition” (Ethiopia – Labour Proclamation). There are other ways of legislating employment-related discrimination laws that have a more disability-centered statement of purpose. Indeed, Ethiopia has passed such a bill. In another example, disabled Australians can expect protection under the Disability Discrimination Act of 1992, which has thoroughly comprehensive disability antidiscrimination provisions. In addition to employment, the Australian law forbids discrimination in the provision of goods and services, housing, education, land possession, access to built environments, sports, clubs, and similar facilities (Australia - Disability Discrimination Act 1992). Most civil law protections fall somewhere in between the general protection of Ethiopia's labour law, and Australia's broad set of protections. Most focus particularly on employment.

A handful of nations still have disability-centered social welfare laws in effect. Some are less reform minded, while others have enacted additional antidiscrimination laws. Bolivia, China, Costa Rica, Finland, Germany, Korea, Nicaragua, Panama, and Spain have laws that focus on disability prevention and rehabilitation (Degener 179). These laws focus more attention on providing services and mainstreaming individuals with disability than on empowerment and
Nations legislate differently depending on their legal systems, and how the rights of disabled persons might best be protected. As has been shown here and in the previous chapter, antidiscrimination provisions that target disabled persons as a group are the most popular way of doing so. Generally speaking, employment laws, constitutional provisions, and criminal laws treat the rights of the disabled as group rights. Ghana is the only country surveyed here that does not follow this pattern. Civil antidiscrimination protections are designed exclusively for individuals with disabilities. Persons who were once disabled, who may be disabled in the future, or are regarded as having a disability are protected under these laws. Some nations protect the family members and associates of disabled individuals against discrimination. Australia, Hong Kong, and New Zealand are particularly noteworthy for their protections of this variety (Degener 179).

Of these types of law, then, which is the most desirable, and which falls closest to the kind of justice advocated by the social model? Structural equality is certainly the most prevalent form of empowerment. Twenty-five percent of the countries surveyed here use the concept of reasonable accommodation as it was formulated under the ADA. Fourteen nations seek structural equality through affirmative action. These generally apply to employment, rather than political representation. Nigeria and the Philippines are the only two countries to legislate quota systems targeting civil and political empowerment. It is true that at first, the movements for racial and gender equality both sought antidiscrimination provisions that enabled their civil and political rights. These examples make antidiscrimination provisions a tempting first step toward

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6 Canada, Ethiopia, Ghana, India, Israel, Mauritius, Nigeria, Philippines, South Africa, Spain, Uganda, USA, Zambia, and Korea.
the full realisation of disability rights, however problematic their definition and implementation may be.

Equally important to the process of informed legislation is the question of what prior attempts have been made, and the degree of success each has enjoyed. Since its origins, the United Nations has been at the forefront of international human rights legislation and protection. Some of its efforts have been disability-specific, while others deal with the rights of both disabled and non-disabled simultaneously.

The UN and Disability Rights

Disability has been an object of attention at the United Nations since the middle of the twentieth century. Under the auspices of the United Nations Charter, the Universal Declaration of Human Rights, the International Covenants on human rights and other related instruments, the UN has ventured many programs to assist persons with disabilities to exercise their civil, political, social and cultural rights on an equal basis with non-disabled persons.

The Preamble to the United Nations Charter affirms the dignity and worth of every human being (“Charter to the United Nations” 1). The Charter does not explicitly aim to protect the rights of the disabled, but offers de facto inclusion in a general affirmation of focus. The document's commitment to international social justice and fundamental human rights was the originative statement of purpose on which all other disability-specific human rights instruments have been based.

The first of the disability-centered programs were established in the 1940s, and offered infrastructural support to governments through advisory missions, training workshops, and the
opening of rehabilitation centers. The efforts focused on disability prevention and rehabilitation – in short, for three decades, the UN used the medical model of disability as the basis for its outreach.

The 1948 Universal Declaration of Human Rights (UDHR) was the first to include rights-based protections for the disabled. The Declaration uses general language to define fundamental human rights, setting forth both positively and negatively defined rights including those to privacy, work, equal pay, equal access, education, and the right to be free from torture. Particularly of note is Article 25, in which the UN grants each person “the right to security in the event of unemployment, sickness, disability, widowhood, old age, or other lack of livelihood in circumstances beyond his control” (“Universal Declaration of Human Rights”). While the UDHR is nonbinding, it is often argued that it has indirectly affected legislation in member states.

On 16 December 1966, the UN passed two binding covenants on human rights. The International Covenant on Economic, Social, and Cultural Rights (ICESCR) and the International Covenant on Civil and Political Rights (ICCPR) are worded similarly to the Universal Declaration of Human Rights. The documents highlight the interrelatedness of human rights, a subject that the context of disability perhaps best evidences. Stanley Herr reports that at the recommendation of advisers reporting directly to the UN, the organisation now recognises that the ICESCR covers disability rights, which, since the document is a binding treaty, is cause for domestic legislation that realise these rights in practice (“From Wrongs to Rights: Internataional Human Rights and Legal Protections” 117).

According to the United Nations 1971 Declaration on the Rights of Mentally Retarded
Persons, intellectually disabled individuals are entitled to the same rights as the non-disabled. The Declaration names seven such desirable protections, including one's access to “proper medical care, education, economic security, training, rehabilitation, social security, and the right to live with his/her own family or with foster parents” (Zaldo, 3). Interestingly, and aptly, the right to due process is written into the protection against exploitation, abuse and degrading treatment. Unfair treatment before the criminal justice system has been a widely discussed problem facing individuals with intellectual disabilities, hence its inclusion in this rule. It is important to note that this document is the first international declaration that evidences the paradigm shift from welfare legislation to human rights. Indeed, the UN Declaration was inspired by a 1968 article published by the International League of Societies for the Mentally Handicapped. The group, comprised of parents and other allies, released their Declaration on the General and Special Rights of Mentally Retarded Persons following their fourth World Congress. Its assertion that “The mentally retarded person has the same basic rights as other citizens of the same country and the same age” (International League of Societies for the Mentally Handicapped) can be seen as the inspiration for the two disability-oriented UN Declarations that followed.  

Almost exactly four years later, the UN passed a Declaration of the Rights of Disabled Persons that aimed at hastening the process of social integration or reintegration. Slightly longer than the previous disability-specific declaration, this document affords rights to the intellectually and otherwise disabled, including the right to self-reliance, and to be included in economic and

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7 See, for example, Kebbell, Mark R. and Graham Davies, “People with intellectual disabilities in the investigation and prosecution of crime.” Legal & Criminological Psychology. Vol. 8 (2002).

8 It should be noted that the Declaration of the Rights of Disabled Persons even uses similar phrasing. Its third proclamation guarantees the “same fundamental rights as their fellow-citizens of the same age.”
social planning. This more general statement reiterated the call for binding international and national legislation, and affirmed the rights previously promised only to the intellectually disabled under the 1971 Declaration on the Rights of Mentally Retarded Persons, adding the right to social and creative endeavor, and the right to avail one's self of legal aid (United Nations Department of Economic and Social Affairs, 7).

With regard to disability, the 1979 Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) is similar to the UDHR, ICESCR, and ICCPR, in that only tangential reference is made to discrimination based on capacity. In Article 11(e) the United Nations guarantees protection against discrimination based on “incapacity to work” (“Convention on the Elimination of All Forms of Discrimination Against Women”). Since its adoption, the lack of attention paid to disability has been raised by international NGOs, and much attention paid to the visibility of women in discourse related to disability rights.9

General Assembly resolution 31/123 dedicated 1981 as the International Year of Disabled Persons (IYDP). The decision substantiated the international dedication to the visibility and integration of persons with disabilities with programmes, policy considerations, and research opportunities. While not yet fully embracing the social model, the IYDP is the first United Nations effort that conceptualised handicap as a relationship between individuals with disabilities and their environment.

In 1982, the UN adopted the World Programme of Action concerning Disabled Persons (WPA). The Programme emphasised disability prevention and rehabilitation, and an equalisation of opportunities (Quinn 18). The day of its adoption, December 3, is currently

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marked as the annual celebration of the International Day of Disabled Persons. The furtherance of equality and participation for the disabled during this decade was enacted through fundraising, devising long-term domestic policy strategies for socio-economic development, promoting the development and use of rehabilitative and preventative technologies, and encouraging adoption of domestic antidiscrimination laws. State members of the UN recognised the value of disabled persons’ direct participation, and in 1984, a Special Rapporteur was appointed to the Subcommission on Prevention of Discrimination and Protection of Minorities to study disability discrimination and its link to human rights violations (The UN and Persons with Disabilities: The First 50 Years” 9).

The primary aims of the WPA can be categorised into three actionable parts: the prevention of disability, rehabilitation, and the equalisation of opportunities for persons with disabilities (Quinn, 20). This is the first explicit evidence of a paradigm shift in the conception of disability to appear in international literature. Paragraph 12 of the WPA defines the equalisation of opportunities as:

the process through which the general system of society, such as the physical and cultural environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities, are made accessible to all (“World Programme of Action concerning Disabled Persons” 1).

Further, paragraph 21 states that:

Experience shows that it is largely the environment which determines the effect of an impairment or a disability on a person's daily life. A person is handicapped when he or she is denied the opportunities generally available in the community that are necessary for the fundamental elements of living, including family life, education, employment, housing, financial and personal security, participation in social and political groups, religious activity, intimate and sexual relationships, access to public facilities, freedom of
movement and the general style of daily living (“World Programme of Action concerning Disabled Persons” 2).10

As such, the WPA addressed the concept of equality in structural terms, treating disabled persons as a group entitled to specific rights. The Programme is reviewed every five years, and despite its definition of disability being the most prevalently adopted in all regions of the globe, the predicted outcomes have been hampered by poor dissemination of programme goals and state failure to act upon them. This is partly due to poverty, war, and other grave complications.

During this decade, heightened awareness led to the inclusion of disability-specific provisions in the 1989 Convention on the Rights of the Child. Rehabilitation services and special care, as well as empowering educational programs are called for in Article 23 of the document (“Convention on the Rights of the Child” 3). The Convention also advocates for disabled children's active community participation.

The World Programme of Action culminated in the 1993 United Nations Standard Rules on Equalization of Opportunities for Persons with Disabilities. As has already been made clear, the document sets forth guidelines for the implementation of policy, and catalyzed efforts in several states around the globe to codify rights for the disabled population. The 22 rules provide a framework which defined the preconditions for the equalisation of opportunities, the essential main policy areas, and established a Special Rapporteur to monitor implementation (Zaldo 12). The rules encourage the foundation and development of disability NGOs and their participation in dialog with UN member states and intergovernmental organisations. Other groundbreaking areas of interest are written into the document, including Rule 9, which expresses the right of

10 Emphasis added.
disabled individuals to experience their sexuality and parenthood. Rule 8 outlines means of enticing the domestic population to work via social security incentives (“Standard Rules”).

The Need for a Thematic Convention

This survey has provided a snapshot of disability-specific United Nations legislation. Some nations have focused their efforts to protect the rights of the disabled on mainstreaming provisions into more general human rights legislation. Elsewhere, disability issues have been highlighted exclusively. Disability rights have primarily been mainstreamed into other thematic treaties. This effort was made in order to avoid the phenomenon of invisibility. Invisibility is the result of non-application or misapplication of existing legal protections. This occurs when an individual is a member a minority group, and considerably more often when a person is a member of more than one minority. With regard to disability, the topic of invisibility is complicated by the fact that, despite the prevalence of disability, and its theoretical constitution as the largest minority group, the UN Subcommission on Prevention of Discrimination and Protection of Minorities has declared that only ethnic linguistic and religious groups can be deemed minorities (Swedish Organisations of Disabled Persons International Aid Association 8).

Relatedly, at present, no binding international instrument directly and exclusively addresses the rights of disabled persons. As such, disabled persons find themselves at a disadvantage to women, children, refugees, and other vulnerable groups whose rights have been protected by thematic, binding treaties. No international body is dedicated to their protection, and no one directly hears grievances. Many NGOs have lobbied to change this. A thematic treaty on disability rights, it has been argued, would fill what is still a large gap in the
international monitoring of human rights. Preparatory work for such a treaty began at the Interregional Seminar and Symposium on International Norms and Standards Relating to Disability (Herr 130). Held in Hong Kong during December of 1999, the event finished with a commitment to initiate discussion between the UN, its member states, and international disability NGOs to foment ideas.

A World NGO Summit on Disability followed the year after, producing the Beijing Declaration on the Rights of People with Disabilities in the New Century (Quinn 181). The Declaration was a call to action, and a dedication on the part of international NGOs to see the effort for a binding convention through. Five leading international disability organisations\(^{11}\) that maintain consultative status with the UN requested the active support of all UN Permanent Missions, and provided the text of the Declaration to the UN General Assembly as proof of their dedication (Disability World).

Action on these recommendations will have many positive results. The first instance of any thematic convention is the increased visibility of the marginalised group. As it stands, disability has been incorporated into other thematic conventions whose focus is on a different minority group. With such a broad array of issues facing each minority group, the amount of attention that persons with disabilities can receive is minimal. Binding international law will force the hand of inattentive states to recognise and legislate on behalf of their disabled population. A disability-oriented regulatory body will be more readily able to handle issues specific to the experience of disability, without being hampered by other concerns. As such, a thematic convention could be seen as an extension of the Standard Rules.

\(^{11}\) Disabled Peoples International, Inclusion International, Rehabilitation International, World Blind Union and World Federation of the Deaf
Expertise in this field would ensure dedicated and consistent application of legal protections, and raise awareness across interrelated issues. Moreover, it would streamline the handling of disability rights. Presently, these protections are scattered over several declarations and conventions, the facts of which may mask obligations to their signatories.

A thematic convention would also emphasise the interdependence and interrelatedness of human rights. The International Covenant on Economic, Social, and Cultural Rights and the International Covenant on Civil and Political Rights have spotlighted the general agreement that rights are mutually reinforcing. A holistic treaty could wed social justice to the headway that has been made in economic and social freedoms, and provide the means to uphold human rights values without compromising the needs of persons with disabilities. It could also emphasise and potentially counteract the lack of domestic law addressing the human rights principles of solidarity, dignity, and autonomy.

Most recently, efforts at the UN have been made to mainstream the issue of disability into all social and economic concerns. Considerations are being made toward rectifying past instances of discrimination, and utilizing advances is assistive technologies to help disabled individuals participate in society as fully empowered citizens.

The decision to draft a thematic UN Convention was taken by the UN General Assembly in 2001. An Ad-Hoc Committee was later established, inviting “States, relevant bodies and organizations of the United Nations system... as well as intergovernmental and non-governmental organizations with an interest in the matter to make contributions.”12 True to the social model, some of the Ad-Hoc Committee members are international disability activists who

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12 The General Assembly resolution number was A/C.3/58/L.78. (International Disability Alliance)
are themselves disabled.

To conclude, the prevalence of domestic antidiscrimination laws following the passage of the ADA and the adoption of the Standard Rules shows that attention to disability issues is on the rise. While much remains to be worked out, a great deal has been achieved in the short history of international attention to disability issues. Both the comparative study of successful domestic empowerment and a commitment to the furtherance of human rights values should inform the treaty making process, which offers many benefits to the international disability community.
Nothing About Us Without Us: Human Rights and Global Disability Empowerment

Chapter Three
Beyond Dichotomies

While efforts have been made in international and domestic law to include persons with disabilities, there is much to be desired. Disability poses difficult questions for liberalism. The way in which disability is conceptualised has different implications for what it means to be a citizen. The medical and social models propose different sources of disability; one is rooted in the body, and the other in the perceptions and reactions to the body. These positions are dichotomous, but share the fact that neither has been able to fully resolve the second-class status of disabled citizens. The medical model is entrenched in professionalism, and thus unable to address the social concerns that are real and present in the lives of persons with disabilities. The social model has failed to deliver full empowerment due to its too-narrow vision of what constitutes citizenship.

The central tenet of liberal thought, namely the universalist ethics it espouses, are at the source of the social model's failure to fully accommodate disabled people. The model has as its goal liberal citizenship, a concept which upholds the false notion that equality and difference cannot coexist. Through the lens of feminism it is possible to see the many failures of liberal universalism. Rather than construct a reactionary and dualistic conception of citizenship that will accommodate persons with disabilities, it is argued that such a reformulation should be pluralistic.

As its central precept, liberalism posits the self as sovereign, and assumes it as the foundational unit for analysis. The ideology emphasises autonomy and choice as dichotomous to dependence and reliance. Persons with disability typically experience a constricted range of such liberties. The very nature of disability begs a reconsideration of the analytical and strategic utility
of this prioritisation. Is it not best to emphasise that all citizens, regardless of ability, tend to need support and care? The point here is not to eliminate the focus on liberty – indeed disability rights movements have utilised such notions to their benefit quite often. Rather, the point is to hedge-out a space for discussion of the varied focus that sometimes mutually, sometimes exclusively, bars persons with disabilities from substantial participation.

**Dis/Citizenship**

Conferring disability as a status applied to impaired bodies is, under the social model, diametrically opposed to the status of nondisabled. Impairments are produced by congenital abnormalities, either genetic or nonhereditary, or are acquired from disease, wounds, accidents, senescence, or a combination thereof. Having an impaired body, or a body which is considered impaired, is grounds for classification as disabled. As has been previously stated, the essential claim is that disability is a social construction; individuals are seen as the “other” due to their difference, and are pigeon-holed into predefined social roles. People with disabilities thus develop a sense of self that is contingent upon dominant norms and expectations placed on them.

The social model has argued that the marginalisation of persons with disabilities constitutes a lack of citizenship. Arguments made from this position have emphasised equality, justice, and independence. In this way, the social model has been informed by and upholds the set of key assumptions that underly liberal thought. The uniting characteristic of disability rights movements has been the adherence to and support for the four core human rights values: equality, autonomy, solidarity, and dignity. Achievement of these is seen as a prerequisite to gaining citizenship. In this way, the focus has largely been on acquiring citizenship status; in
many nations, even the formal act of voting is curbed for disabled persons. To be fair, the social model has advocated for more substantial participation, as well. It has addressed issues of access, inclusion, rights, equality, and redistribution of resources. However, it has prioritised these claims in such a way that reinforces the dualism inherent in Western liberal thought. Antidiscrimination provisions aim to neutralise difference, valuing instead equality; independence from others is valued above recognising and reciprocating the caring tasks that often accompany disability. Unpacking the concepts inherent in liberal thought is necessary for understanding why the priorities set by the social model are problematic.

**Universalist Liberal Ethics**

Liberalism has at its core ethical considerations; these take form in the everyday notions of individuality and the “common good.” Its focus is on universalism, the belief that legitimate rules, norms and principles should be understood by and applied to every rational thinker. The purpose of a universalism of ethics is to differentiate between contesting claims of what is in society's best interest. This task makes it necessary to prioritise basic human rights, creating a hierarchical distinction between claims and rights. “Neutrality, impartiality, rationality, abstraction and objectivity are the most important requirements for acquiring insight into the correct criteria” for which claims are valid and which are not (Sevenhuijsen 40).

Universalist ethics considers three primary principles: equality, autonomy, and justice. Equality under this rubric is thought of in terms of sameness. Equality-as-sameness is an Aristotelian notion that assumes like object should be treated alike, and those that are unlike treated differently. The basis for this reasoning lies in the assumption that every individual is
born equal; it follows that all persons must be treated equally in all circumstances. Inequality and difference become indicators of something gone wrong. Underlying this vision is the notion that persons are, in principle, the same, and that there is a uniform human standard. If people are treated equally, then there will be equality of results. It is because people are treated differently that the natural sameness dissipates, and difference ensues.

As such, this universalist dualism makes difference and equality appear as opposites. Those individuals who conform to the human standard are considered equal, while those that are unlike are not. Persons should aspire to be like the norm and, if difference is insuppressible, it should be temporary. In other words, this view posits difference as self-executing; once a claim grounded in difference is righted, difference ceases to exist.

Another principle of universalism is the notion that moral judgments can best be orchestrated from the perspective of a singular moral subject, which is apart from and above empirical reality. Kant was the first to describe this situation, positing that such autonomy would enable judgment of what constitute moral universal obligations. Also, in this way, the moral subject can be held accountable for freely made choices. Therefore, the central moral question is how to best satisfy universal obligations. Doing so entitles the subject to rights. Obligations and rights, then, are contingent upon one another. Kant and other moral philosophers relate this to the notion of a social contract. At the base of liberal citizenship, then, is the premiss of abstract moral reasoning. Each individual, it is assumed, is capable of making rational moral judgments. By way of Kantian moral philosophy, such individuals are contractually tied to involvement in the polis. In this way, morality forms the basis for citizenship.

In current political debates, the notion of citizenship takes many forms. In most
discussions, the definition put forth by T.H. Marshall is the starting point for debate:

The civil element is composed of the rights necessary for individual freedom – liberty of the person, freedom of speech, thought, and faith, the right to own property and to conclude valid contracts and the right to justice. The last is of a different order from the others because it is the right to defend and assert all one's rights on terms of equality with others and by due process of law. This shows us that the institutions most directly associated with civil rights are the courts of justice.

He continues, “By the political element I mean the right to participate in the exercise of political power, as a member of a body invested with political authority or as an elector of the members of such a body. The corresponding institutions are Parliament and councils of local government.”

He concludes:

By the social element I mean the whole range from the right to a modicum of economic welfare and security to the right to share to the full in the social heritage and to live the life of a civilised being according to the standards prevailing in the society. The institutions most closely connected with it are the education system and the social services (Marshall 10-11).

Thus, Marshall recognised a multilayered, process-oriented citizenship bestowed to the population via civil, political, and social rights. His inclusion of the relevant institutions implies that there are obligations associated with such rights.

Citizenship highlights the nature and relationship between the self and society. It is mediated by membership in the polis, and participation in the community. Recent scholars have expanded Marshall's thesis, arguing that the way in which different groups have struggled to gain recognition and autonomy informs its analysis. How a society deals with difference, in other words, is central to its notion of citizenship.

Selma Sevenhuijsen has noticed that interpersonal judgment is located at the intersection
of equality and difference (28). Alterity must be handled within this context by recognising individuality and diversity while simultaneously affirming equality. This is precisely the nature of the problem posed to liberal thought by disability. How, then, does difference play out in the context of disability, and can liberalism cope with it? The feminist ethics of care offers some intriguing insights to this question.

**Ontology and the Ethics of Care**

Feminist critiques of liberalism conversely postulate a less atomistic ontology. Rather than focus on the presupposed sameness of individuals, such criticisms borrow from social constructivism the notion that individuals experience concrete relationships wherein interactions shape behaviour, perceptions, interpretations, and ultimately identity. There is no such thing as a pre-social self, but instead a processual self, continually learning and reevaluating its position and values.

Under liberalism, difference is seen as deviant, the binary opposite, the “other.” Feminism has been the chief critic of dualistic comparisons, noting that they contribute to an epistemic hierarchical system of control and exclusion. This follows from the idea that in every binary situation, the “other” is labeled “inferior”. Its opposite, then, constitutes the dominant subjective norm, objectifying the “other,” and denying its subjectivity. The dominant norm constitutes “true personhood.” Critical theorists have ably pointed out that dominant traits such as whiteness, maleness, ability, class privilege and heterosexuality have historically characterised “true personhood.”

Additionally, the focus on autonomy in universalist ethics marginalises and makes inferior
claims of need and dependence, whereas an ethics of care listens to and substantiates subjective interpretation of such claims. In other words, individuals can know their own subjectivity, and make claims from it; what should be valued are the narrations of need and dependence expressed by such subjects. Nancy Fraser has called this the politics of needs-interpretation (Fraser 10).

Universalism is thus inclined to privilege the autonomous self. Recognizing this, Charles Taylor proclaims that liberal citizens' sense of the importance of potentiality reaches so far that we extend this protection [of liberal rights] even to people who through some circumstance that has befallen them are incapable of realizing their potential in the normal way – handicapped people...for instance (qtd in Erevelles 9).

In other words, Taylor and his followers contend that persons with disabilities are able only by “extension, or derivation or fiction” to enjoy full citizenship. This is clear-cut evidence of “othering” within universalist liberalism; in order to account for the agency of persons with disabilities, its source must lie in the able bodied individual experiencing “true personhood.”

These concerns have led some proponents of feminism to reformulate citizenship under the prescript of an ethics of care. This line of argument began with the notion that women posses unique moral qualities and perspectives given their role as nurturers; as such, they have useful and interesting opinions to offer in public discourse.

Authors writing on this subject highlight the false dichotomy between public and private endeavours. The ethics of care highlights the fluidity of the public/private “divide.” Without caring work in the private sphere, there would be no possibility for public life. Further, the divide has been gendered. As an historically women's role, care (and thus the private sphere) has been

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stereotyped as sharing the characteristics of “particularity... and dependence,” whereas the public sphere (historically gender male) represents “universalism, justice, and independence” (Lister 17).

In particular, mothering has been a central focus for supporters of an ethics of care. Traditionally, the notion of motherhood has been far removed from the political sphere; at times it has also been taboo within discussions of feminist ethics and theory, since its construction has been so readily used to reinforce patriarchy and heterosexism. Some feminists, however, have used aspects of motherhood, especially the mother-child relationship to criticise the individualistic perspective offered by liberalism. Particularly, the mother-child relationship is built upon dependence and nurturing. The mutual respect, intimacy, and trust that mark such a relationship should be moved to the center of debates over belonging and entitlements; the atomistic view of legal rights under contractual principles is incomplete for considering such situations.

Selma Sevenhuijsen has concentrated her criticism on one of the original philosophies of this type, offered by Virginia Held (11-25). She notices that because Held offers an abstraction – a “mother-figure” or “motherly metaphor”, she avoids essentialising women. Yet, she criticises Held for falling into a reversal of liberal “true personhood.” In other words, feminist theorists have correctly pointed out that the universal moral subject supposed by liberalism is indeed gendered by the way in which he upholds dominant (male) traits. Sevenhuijsen acknowledges, however, that Held's approach falls into the trap of binary, Western thought. Such a framework risks a reification of “moral motherhood,” and runs contrary to gender equality and the eradication of gender binaries, in short, important feminist goals.
What is Care?

If it is not a reaction to the gendered liberal moral subject, then what does the ethics of care pose as an alternative? In her book *Love's Labor*, Eva Kittay utilises what she titles the *dependency critique* to call attention to the marginalised position persons in situations of dependence have historically experienced, in liberal theory. Kittay relates the backgrounded status of dependent persons to the treatment of the public/private divide in liberal theory. Concerns of this type, she argues, have primarily belonged to the private realm, where individuals are personally responsible for their own care. More, liberalism categorically denies claims of dependence and interdependence, since “correct” moral judgment cannot be made from such “inferior” viewpoints. The ethics of care, rather, suggests that these perspectives should be recognised and validated as an existential reality, without reifying them. Possessing an autonomous moral self, then, is founded upon a different norm – avoidance of objectifying the “other.” It implies that the self is a competent actor and subject without qualification, and certainly without the doubts at agency that accompany the label “inferior.”

Dependence is an unavoidable human experience, according to Kittay, often experienced in infancy, old age, and temporarily or permanently in the form of impairment over the course of one's life. In her view, a theory of equality that neglects to account for the position of dependents is incomplete, and will not be able to enact justice for all citizens. It is in this way that disability forces a reconciliation between autonomy and dependency. The work of a care provider, then, is integral to the functioning of a society. All individuals experience dependence, and human existence is characterised as an experience of temporary independence at best.
Care has been the province of second-class citizens historically; slaves, servants, and women have been socialised and coerced into caring roles (Tronto 113). In caste societies, such duties have been dealt to the lowest caste. This trend is mimicked in modern, industrial societies where persons on the lower rungs of the social hierarchy are responsible for tasks of “cleaning up” - low-paying and stigmatised jobs such as janitorial work, private servants, or household child care workers. In short, care-giving and care-receiving are jobs relegated to the less powerful. In this way, care is influenced by complex relations of class, gender, and race.

In this sense, care is thus a social, ethical concern. Bernice Fisher and Joan Tronto offer a working definition of care:

On the most general level, we suggest that caring be viewed as a species activity that includes everything that we do to maintain, continue, and repair our “world” so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, live-sustaining web (Tronto 40).

Caring is an inclusive activity, in the sense that it transcends individual activity; it is not dyadic, but exists in a general sense. It is a culturally defined norm, that is both a practice and a status. It is processual, involving first the recognition of needs and an appraisal of how to approach them, second, assuming responsibility for providing care, and finally receiving care and the response that entails such a process. Including this final step is integral to understanding whether needs have been met.

Considering care in this light has interesting implications for citizenship and the social arrangements that it entails. The failure of liberalism to recognise and account for care-givers and care-receivers, it has been shown, is integrally related to the sense of self that it purports.
John Rawls' (1998) definition of citizenship is useful here. He considers a citizen to be:

a fully cooperating member of society...[with] the capacity to understand, to apply, and to act from the public conception of justice... and to rationally pursue a conception of one's rational advantage or good... for our purposes here I leave aside permanent physical disabilities or mental disorders so severe as to present people from being normal and fully cooperating members of society in the usual sense (Rawls, 19).

As such, the autonomous moral subject is free from situations of dependency, and thus able to make rational decisions that are integral to his citizenship. Within the ethics of care, care-givers inhabit a position of “other,” such that when an individual needs care it can be delivered without impacting his autonomy. Care-receivers, too, are “othered;” deprived of his autonomy, it is said, the moral subject is weak and incapable of making reasoned decisions – he is thus outside of the liberal conception of citizenship.

The treatment of “others” as well as the ways in which social structures shape the ways in which care is socialized are political questions. Tronto and Sevenhuijsen have rightly noticed that, as such, it has become necessary to formulate care as a political ideal.

According to Sevenhuijsen, The feminist ethics of care, by reorienting the concept of the self, is able to pose different moral questions than those which serve as the basis for liberal citizenship. Instead of querying “What are my obligations to others?”, one may ask “What is the best way to deal with dependency and my relationship to it?” Needs and the response to them are narrated by the moral subject. Individuals, it is assumed, are capable of knowing and expressing their needs. Liberal discourse denies such expression by rooting it in traits of the “other,” which must be transcended in order to discover “good” or “true” ethical concerns. Rather than locating the self in a vacuum of moral detachment and objectivity, this reformulation presumes that individuals are morally engaged. This is a necessary step in recognising the best course of action.
in addressing needs. As such, judgment of moral dilemmas is enhanced, and decisions pertaining to issues of equality and difference are better informed by this sense of “being in the world with each other.” Sevenhuijsen argues further that such a position enhances one's autonomy since the moral subject is exposed to a diversity of moral considerations.

Citizenship, then, is tied to the public discussion of needs. Tronto notes the implications that integrating care as a political practice might have on power relations; the question “who cares for whom?” challenges individuals to notice the demarcations that race, gender, and class have on liberal societies (Tronto 112-117). She believes that serious discussion of the needs that followed would entail a

vision not of autonomous, equal, rational actors each pursuing separate ends, but [a vision] of interdependent actors, each of whom needs and provides care in a variety of ways and each of whom has other interests and pursuits that exist outside the realm of care (167-168).

This conception owes much to the neo-republican sense of active citizenship wherein the public sphere is a centre for the exchange of narratives and opinions, and this dialectic permits reformulations of “self” and “other,” shaping identities around doing rather than being. In this way, identities are not static, but “are interpreted and judged in specific contexts of action” (Sevenhuijsen 13).

Imbuing the ethics of care with the notion of active citizenship is necessary to keep discussions of power dynamics at the fore. The assumption that moral subjects must be engaged debunks the notion that all human beings are necessarily “created” equal. Indeed, it posits that they are not – some exist in varying states of dependency, while some are able to provide care.
Engaged moral subjects, however, are conscious of this inequality, able to recognise it and to set the achievement of equality as a political goal. Equality thus becomes something concrete and practical, something to be considered and reconsidered in light of shifting circumstances, rather than immutably rooted in moral selfhood.

Under the ethics of care, citizenship is seen as both a status and a practice. Ruth Lister has formulated a critical synthesis of liberal and neo-republican citizenship that is of value to the ethics of care (1). She roots citizenship-as-status in rights granted to particular groups, and in the notion of need. Moral subjects are granted citizenship by way of their knowledge of their own subjectivity. Needs are expressed from this perspective, and such claims are codified into rights that simultaneously value the group and the identity/identities of the individuals that comprise the group. Such a distinction is necessary because “a group-differentiated politics which asks the individual citizen to identify with just one aspect of her identity runs the risk of fragmentation at the individual as well as the group level” (Lister 10). Such fluidity is granted by the ethics of care; the emphasis on doing rather than being permits identity-based categories that claim a differentiated sort of universalism.14 The focus is on a politics of difference that constructs notions of equality.

Citizenship as a practice, then, must recognise the political subject as being comprised of varying identities. Two commitments mark the perception of citizenship-as-practice; the political subject must value difference, and there must be dialogue so as to promote the development of view and the exercise of judgment. These commitments are met by the ethics of care in the reformulation of the moral subject.

14 I borrow this term from Ruth Lister.
Disability, Differentiated Universalism, and the Politics of Recognition

We have thus arrived at a critical synthesis of liberal and neo-republican notions of citizenship via the feminist ethics of care. This new conception comes to bear on disability by challenging the notion within the social model that the tensions between equality and difference, and those between dependency and autonomy are mutually exclusive, and cannot be formulated in creative ways.

Also, as part of the landscape of the social model's politics of recognition, disability activists have suggested that there is a “disability culture”. Expressed in film, writing, theater, and academic discourse, disability culture stresses the shared sense of difference that is inherent to the identity politics theorised by the social model. It is a level of understanding across disability types and national boundaries that gives meaning to the struggle and rewards of living with disability. Disability culture provides a means of self-identity, affirmation, solidarity, and personal autonomy, while challenging the definitions of bodily normalcy and function, as well as their resultant social relations. Disability culture uses disability as a universal category. Like the treatment of women as a universal category, disability culture posits that persons with disabilities are outside of the mainstream, and should be allowed access to it because of what the group has to offer society at large.

While the idea of culture does promote solidarity, the price is diversity. There is a risk of fragmentation in shifting from disability politics to disability culture. By creating a unified disability identity, and treating it as a static group norm, disability as a universal category could be split along lines of other, more salient identities; the triad of race, class, and gender come to
mind. This is a particularly dangerous subject for disability, given its multidimensionality. One could imagine the group splitting along lines of impairment as well; consider a Deaf culture lobby pitted against a campaign for accessibility in public transit. With this in mind, it is clear that a universal conception of disability needs to be more fluid. The social model has neglected to recognise to a proper extent how differences within the category influence the group's relationship to citizenship. There has been some discussion of women with disabilities, but this mostly focuses on their “double exclusion,” not on their relationship to disability as a category.

This is not necessarily to say that disability culture should be denied; there is strong evidence that it would be an effective strategy to argue in its favour. However, without a fluid conception of disability as a universal category, one that is tempered by a recognition of inter-group differences, holding such a group together would be tenuous. Further, its relationship to citizenship would be ill-advised if it overlooked such diversity.

The ethics of care further informs disability by recognising the importance of maintaining citizenship as a political objective. Rather than abandon the idea, or formulate a binary response to it, the ethics of care suggests that disability move beyond the limited focus of the social model and adopt a pluralistic alternative to liberal citizenship. Central to this approach is the perception that citizenship can only maintain political force if it appeals to a universal category premised on moral commitment to the “equal moral worth and participation and inclusion of all persons” (Lister 9).

Such a perspective is also valuable for distinguishing that equality and difference are only incompatible when equality is seen as sameness. By making the moral subject the arbiter of needs, the ethics of care move the achievement of equality from a presocial, assumed location, to
a place where its characteristics can be debated and constantly reevaluated. This is important
within the context of disability because currently, care and the tasks associated with it are
marginalised and “othered.” Renegotiating the position of care in society means reordering social
institutions to accommodate carers and dependents. More, it means actively debating equality,
and ensuring that the relationship between care-givers and care-receivers remains a healthy and
constructive one.

More, the ethics of care points out that justice and care are not irreconcilable. In order to
mitigate the unequal relationship between care-givers and care-receivers, a theory of justice must
be employed. If economic and physical autonomy are derived from a situation of
interdependence, one must be careful about and critical of situations of dependency. A theory of
justice like the one offered above is also important for overseeing the distribution of caring tasks
within a society.

**Recognition and Redistribution**

Becoming an active citizen entails access to resources. As such, a politics of recognition
implies a politics of redistribution. Similarly, justice requires social arrangements that permit
participatory parity. Fraser offers two conditions that must be met in order to fulfill this
requirement for justice (3). First, the distribution of material resources must be such that all
participants have an independent, empowered voice. Second, the institutionalised patterns of
cultural interpretation and evaluation must ensure equal respect and opportunity.

Targeting antidiscrimination legislation as the sole solution to the social injustice suffered
by persons with disabilities is a misrepresentation of the needs of that social group. In other
words, the question of disability requires more than antidiscrimination legislation for persons
with disabilities to become full partners in social interaction. Disability is a multidimensional issue that requires the mechanisms of redistribution and facilitation, as well as goals of inclusion and social justice. Conceptually, the social justice-oriented goal of redistribution has been divided, and seen as mutually exclusive from the politics of recognition. However, this is a false dichotomy; justice cannot follow one without the other.

**The UN Convention: Incorporating an Ethics of Care**

As was shown above, full access to citizenship is limited for disabled persons. In order to qualify for antidiscrimination protections, as well as to receive medical and social care, economic remuneration, etc., persons with disabilities are forced to repeatedly deny their own moral subjectivity. Such laws are maintained by a process of gatekeeping which narrowly defines disability, and then requires that all applicants negotiate their relationship to the polis and to civil society within those terms. As Erevelles writes:

> Recognizing [the inherent] contradictions [that disability exposes in liberal thought], disability theorists are now grappling with the ideological terms and material conditions necessary to (re)negotiate their participation in civil society without reifying the hegemonic structures of ableism that they argue still persists in liberal democratic society and that support limiting definitions of citizenship (15).

The point here is not to undo or demean the valuable work that has been achieved in the way of liberal citizenship. Rather, this “(re)negotiation” aims to negate the conflict between equality and difference, as well as reformulate hierarchical differentiation between claims and rights in more inclusive terms.

To do this, the ethics of care must be tailored to directly bear upon the issue of citizenship. Feminist discussion of the public/private divide is one way to bring this topic into
focus. As an historically women's role, care (and thus the private sphere) has been stereotyped as sharing the characteristics of “particularity... and dependence,” whereas the public sphere (historically gender male) represents “universalism, justice, and independence” (Lister 17). An ethics of care sheds light on this false dichotomisation. Without caring work in the private sphere, there would be no possibility for public life. Indeed, the criticism goes further – public life is misconceived of in its current form. It needs to be tempered by instilling the conditions of dependence and interdependence as values of equally inestimable social worth.

Thus, when asylum laws governing the status of women fleeing sexual persecution are guided by the public/private divide (as has been the subject of much Australian work on the subject) the gendered nature of the laws' construction, and thus its' relationship to care is highlighted (Jakubowicz and Meekeeshoa 241). Similarly, disabled immigrants are denied formal citizenship because of their condition. Such laws can thus be considered ableist, as they directly limit the experience of citizenship by persons with impaired bodies. Often, the state invokes a variation of the public/private divide in its reasoning; one's health status is within their individual purview, rather than a responsibility of the state. Admitting a disabled citizen, it is argued, would create a strain on the public sphere (services, etc.). As such, the care associated with impaired bodies is marginalised, and relegated to a secondary status. In essence, this kind of approach is mired in the same patronizing way of thinking that characterise the medical model and its correlative welfare state response that it purports to undo. An informed UN treaty could work to undo this practice by addressing the topic of disabled persons' immigration rights. It is easy to imagine the adoption of the antidiscrimination principle here, given its salience in domestic law around the globe.
Bearing the public/private divide in mind, the principle of antidiscrimination is also helpful for postulating what a citizenship-oriented ethics of care might look like. The social model and the ethics of care share a focus on the dominant norms and expectations placed on persons with disabilities, which construct the “disabled” sense of self. However, the social model falls victim to logic in its pursuit of antidiscrimination provisions. It is impossible to create a positive group identity (remembering that this is an objective of antidiscrimination tactics) if each individual is forced to identify their “abnormality” in order to qualify under the law. No wonder, then, that the social model has stalled at antidiscrimination legislation, and not further remedied the second-class status of disabled citizens; each protected individual is forced to deny his or her own subjectivity, the very basis of citizenship. This is the second step the pending UN convention should take if it is to fully embrace the notion of disabled persons as full citizens; attention must be paid to the framing of laws that ensure the right to work and to work in an hospitable, accessible environment, so as to avoid falling in to the same trap.

In its present draft form, the UN Convention attends to five primary guiding principles: dignity/autonomy/independence, nondiscrimination, equality of opportunity, full inclusion, and respect for difference. The latest draft is the result of seven plenary sessions. It is unlikely that this framework will change. Drawing from the two citizenship-oriented criticisms above, and seen from the perspective of the ethics of care more generally, some of these principles are cause for concern. In particular, the focus on dignity/autonomy/independence is the first suggested guideline. Given both the multidimensionality of disability, and the non-dichotomising ethics of care approach, problems arise from the binary nature of such an approach. The reasoning that backs the calls for “autonomy” and its primacy in the hierarchy of rights makes it tempting to
overlook the problem it creates – the goal is to empower persons with disabilities to function as participating decision-makers in the relationships that directly impact them. However, it is an admirable end with poorly formulated means. The authors of the Convention have, in classic liberal form, suggested that one's independence is threatened by the limited functioning of their body. What is needed, it is suggested, is more independence – to indemnify the “other,” to condescendingly appease her with promises of more freedom. It is true that decision-making about the systems that govern the lives of persons with disabilities has been both the source of and symptomatic of marginalisation. Such empowerment needs to be invested in. A better approach would considerably alter the perception of in/dependence, however. Persons with disabilities would be considered capable by way of their knowledge of their own subjectivity to articulate their needs and to reciprocate what obligations may arise therefrom.

The clauses that address nondiscrimination are found in Draft Article 7. The language is straightforward: “Discrimination shall mean any distinction, exclusion or restriction which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise by persons with disabilities, on an equal footing, of all human rights and fundamental freedoms” (UN Enable 13). Since the Convention seeks approval as an internationally binding treaty, the above cited clause would mean that states were responsible for incorporating such provisions into domestic law, and overturning such legislation that might conflict with the state's obligation to the treaty. In short, this principle seeks to further internationalise the principle of equality as sameness that haunts disability-specific antidiscrimination legislation.

The third guiding principle in need of reformulation is the guarantee of equality of opportunity. As with prior UN efforts at equality between disabled and nondisabled, the guiding
light for the draft clauses on equality of opportunity is “reasonable accommodation.” This principle illustrates nicely the feminist critique of the self-executing liberal conception of difference. The Draft Convention explicitly states that accommodations “shall in no way entail as a consequence the maintenance of unequal or separate standards; those measures shall be discontinued when the objectives of equality of opportunity and treatment have been achieved” (UN Enable 16-17).

Difference here can only exist as an abnormality. The political aberrance suggested by disability can be assimilated by “leveling the playing field.”

Contradictorily, the treaty names two less-distortive principles on which the human rights of persons with disabilities should be founded. These others recognise the importance of active citizenship, and the necessarily positive identity that is its prerequisite. Draft Article 18 concerns Participation in Political and Public Life. It principally serves to facilitate participation in the polis and civil society by guaranteeing the right to vote with or without assistance, run for and hold public office, and to form organisations that inform the decision-making processes that are sometimes beyond direct voter control. This emphasis enables the type of “doing” that is necessary for active citizenship and the ways of identifying that accompany it. The wording itself leaves much to be desired – the emphasis could fall more on participation than on empowerment. However, this clause enables discussion around how to conceptualise citizenly activity, and thus has constructive elements.

The second such curious principle is that which aims to promote respect for difference. The treaty suggests that public awareness campaigns be launched in signatory nations, promoting a healthy self-conception and a positive perception on behalf of the nondisabled. Article 2, which

15 Emphasis added.
states the general principles of the Convention announces as a fundamental goal “respect for
difference and acceptance of disability as part of human diversity and humanity.” An article
describing perceptions of persons with impaired bodies follows soon after, yet the actual word
“difference” appears only in Article 2, which establishes the document's theoretical framework.
It is difficult to evaluate the presence of this effort to promote respect for diversity. Ultimately,
the document assumes fundamental sameness between disabled and nondisabled persons. It is
precisely this contention that disallows the construction of a positive disabled identity before the
law. As such, while this principle and the articles that are uphold it are well-intentioned, their
purpose is oxymoronic.

While the content of the Convention is somewhat problematic, having guiding principles
that are simultaneously empowering and limited, it is important to note that it achieves much
headway in the direction of codifying rights in ways which express their interrelatedness. Draft
Article 1 stresses that the purpose of the Convention is to “ensure the full, effective and equal
enjoyment of all human rights and fundamental freedoms by persons with disabilities” (UN
Enable 4). The Convention reaffirms the importance of a litany of other internationally binding
treaties and non-binding UN statements, ranging from the Convention on the Rights of the Child,
to the International Convention on the Protection of the Rights of All Migrant Workers and
Members of their Families. More, the writers have expressed that the incorporation of a gender
perspective into the treaty, in both explicit and implicit terms, is of considerable importance.
Such concerns have been raised especially in regards to the articles addressing the right to work,
Draft Article 22, and the right to social security and an adequate standard of living, Draft Article
23. So far explicit mention of the importance of gender considerations is only inscribed in Draft
Article 23. It ensures access to social security and poverty reduction programmes, and also enables women and girls to participate in their formulation and implementation.

The Convention has also achieved a furtherance of the four human rights values, sometimes to the determent of a perspective that incorporates an ethics of care. Equality has been the mainstream lens through which disability has been addressed in domestic laws around the globe. The Convention focuses considerably more on dignity and autonomy, but does not deal with the notion of solidarity. Dignity is the human rights value that receives the most attention in the text. Indeed, the drafters chose to single out the principle in the title of the Convention for explicit mention; as such it enjoys a higher worth in its protection and promotion than do the other four human rights values. In the text, the principle is mentioned explicitly with regard to several situations, which vary greatly. Collection and distribution of statistics about persons with disabilities is to be done in a way that ensures the privacy and dignity of those participating in the census. Disabled persons who are deprived of their liberty are to be treated in a dignified manner, and efforts should be made to meet the needs caused by their unique situation. Disabled children are to receive education that values their inherent worth and reaffirms a positive sense of self. Health and rehabilitation professionals are to receive education so as to respectfully deal with their patients and clients. In these four situations, three are reactive – protections against conditions under which the dignity of a person with a disability might be threatened. In the case of children's education and sense of self, the danger is that such a positive identity might never develop. These protections, especially the concern for the development of a positive identity in children, are in line with an ethics of care.

Often, the principle of autonomy is tied to these calls for dignity. The drafters concentrate
on the marginalisation of disabled persons in decision-making about political and economic issues. The document emphasises the contributions made to society by disabled persons in the past, and denotes the hope that the Convention will empower further progress in this regard by way of their “full participation” (UN Enable 3). The independence and autonomy of individuals with disabilities are emphasised in their public and private lives. “The freedom to make their own choices” is mentioned in the preamble, and autonomy is mentioned with regard to the right to ethical public and private health care. This is an instance where the ethics of care would problematise the straightforwardness of liberal autonomy. The realm of public and private heath care is intimately informed by and representative of the values propagated by the ethics of care. Instead of placing such a stern emphasis on ensuring “that the services and conditions of public and private health care and rehabilitation facilities and institutions are well monitored” to provide the most autonomy possible, the Article could be reformulated to represent the value of work that care providers give, and respectfully denote that some conditions require for their eradication, diminution, or maintenance, a situation of inter/dependence.

The word “solidarity” never appears in the Draft Convention. The notion is conspicuously absent throughout the text. Its absence serves to illustrate a principle point that has been suggested in this chapter – that disability is a difficult concept for liberalism to respond to. Solidarity between disabled persons is cause for their recognition as a group whose needs are distinct and separate from other citizens. If, as liberalism suggests, citizens are autonomous moral subjects who are inherently equal and the same, a distinction of this kind would create an impasse. To promote solidarity in this Convention would be to suggest that no degree of incorporation could fully bring disabled persons back into the fray of citizenship from their
“momentary” departure that sought redress for their difference.

To conclude, the Draft UN Convention has elements that are shared by the ethics of care, but its overarching principles often run contrary to the observations made by such feminists as Sevenhuijsen and Tronto. An ethics of care is regrettably missing from considerations of the rights of persons with disabilities, as it offers a better framework and plan for inclusion (via citizenship) than traditional liberalism.
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Conclusion
There are several important points to summarize before concluding this work. The criticisms presented above are pointed at antidiscrimination legislation, and at the social model for making such laws its principal goal. It has been argued that a perspective from the feminist ethics of care can assist the social model; both because its emphasis on interdependence better characterises situations familiar to persons with disabilities, and because it avoid the problematic conception of difference that traditional liberalism offers.

It is important to stress the issue of identity in this context. Positive group identity is integral to creating a meaningful, participatory political atmosphere. In other words, it is a central prerequisite for citizenship. Antidiscrimination legislation has been retrograde in this regard. It is impossible for a group to create a positive group identity if each individual is forced to identify “abnormality.” In part, this has to do with the concept of liberal equality. Traditional liberalism focuses on the inherent sameness of persons. Difference is a temporary matter, because the brand of equality endorsed by this philosophy is structural equality (represented around the globe by employment legislation that endorses the notion of “reasonable accommodation.”) Thus, when disability activists posit that persons with disabilities represent a group that is different from the population at large, their governments respond with laws that will “level the playing field.” While the gains that have stemmed from these laws are indispensable, the laws are inherently limiting in this way. More, most of these laws are employment codes that focus on mainstreaming individuals with disabilities, and pay more attention to providing services than to empowerment via human rights.

One tenet of the social model is that persons with disabilities develop a sense of self that is contingent upon dominant social forces. This insight is accurate; there are norms and
expectations in every society as to what a disabled person is capable of, and what s/he ought to do with his or her life. Antidiscrimination legislation is a representation of social and cultural mores embedded in law. These laws seek to remedy the unfair advantages that abled persons have over disabled persons in the labour market. In doing so, these laws are designed to undo claims of difference within liberal societies. This is a limiting conception of citizenship because it denies the use of difference to justify other claims. The authenticity of claims made by disabled persons, in other words, is limited in two senses; they are pigeonholed and forced to deny their moral subjectivity in order to qualify for antidiscrimination protection, and are simultaneously expected to have no further qualms about their relationship to society or the polity that governs it.

To construct a binary response to this problem would be to fall victim to the equal and opposite wrong done by liberal theory. Instead, the ethics of care promotes a dynamic vision of citizenship, wherein the moral subject does not need to couch claims for redistribution of resources or meaningful inclusion in terms of their difference from the rest of society. Citizens are recognised as having varying identities, and are committed to dialogues about them which develop the multiplicity of viewpoints and the exercise of judgment that are essential to democratic participation. Joan Tronto's ideas are valuable here; equality is a politically contestable notion, and locating it in a political sphere precludes assumptions that it is equivalent to sameness. Difference, in other words, is essentially assumed; it is a fact of life which can strengthen citizenship and participation.

A poignant conclusion lies in the application of differentiated universalism to citizenship. Ruth Lister revises a classic phrase about citizenship to reflect the definitional change offered by
the ethics of care. In stead of talking in terms of “rights and obligations,” she speaks of “rights and opportunities.” This seems a fitting reformulation of citizenship for persons with disabilities. Since previous claims at empowerment, namely antidiscrimination legislation, have limiting effects, the focus in the context of disability should be on whether conditions of citizenship undermine or promote its expression.
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