

INTERDISCIPLINARY DISABILITY STUDIES



# Disability, Human Rights and the Limits of Humanitarianism

EDITED BY  
**MICHAEL GILL AND  
CATHY J. SCHLUND-VIALS**

DISABILITY, HUMAN RIGHTS AND THE  
LIMITS OF HUMANITARIANISM

# Interdisciplinary Disability Studies

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# Disability, Human Rights and the Limits of Humanitarianism

Edited by

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# Introduction

## Protesting “The Hardest Hit”: Disability Activism and the Limits of Human Rights and Humanitarianism

Michael Gill and Cathy J. Schlund-Vials

On 11 May 2011, an estimated 8,000 demonstrators took to London’s streets to protest proposed cuts to the nation’s Disability Living Allowance (DLA). Inaugurating the United Kingdom’s “Hardest Hit Movement,” marchers and activists warned that such austerity measures would put disabled people’s lives – along with their ability to live independently – at risk. In particular, the Coalition government’s fiscal amendments to the DLA (which involved major cuts and totaled £9 billion) would incontrovertibly affect the lives of 3.6 million individuals. Moreover, the government’s soon-to-be implemented Personal Independence Payment (PIP) program, intended to replace the DLA, would dramatically delimit aid to disabled persons, effectively making them the “hardest hit.” This new disability benefit initiative requires applicants to recertify their claims while cutting overall spending. Consequently, an additional 500,000 disabled individuals will be excluded (Kaye, Jordan, and Barker 2012).

Thus, notwithstanding the triumphal registers of the program, evident in the superficial emphasis on “personal independence,” the exact opposite will likely occur: less funding for personal care assistance will necessarily jeopardize independence for disabled people. The conservative politics that presage these measures – which emphasize individual responsibility over state culpability and eschew arguments about the “greater good” in favor of “bottom line” practices – on the one hand lays bare the extent to which the twenty-first century is increasingly marked by neoliberalism. On the other hand, policies of austerity disproportionately impact those most vulnerable and arguably most in need of social services. As Jaspal Dhani (Chief Executive of UK Disabled People’s Council and co-chair of the “Hardest Hit Movement”) rightly surmised: “Disabled people are the hardest hit and they are coming together to say loud and clear ‘stop the cuts and protect our rights’ (BBC May 11 2011, n.p.).

On 22 October 2011, similar demonstrations took place in 14 cities in the United Kingdom. Almost six months later, on 18 April 2012, the group “Disabled People Against the Cuts” staged a massive protest stopping traffic in Trafalgar Square. As international attention turned to the 2012 Olympics and Paralympics in London, disability rights activists once again accessed the public sphere, gathering

to challenge increased threats of welfare cuts and a spike in hate crimes against disabled people (Taylor and Van Steenberg 2012; Sale 2012). Ironically, as the world celebrated Paralympians in London, disabled people in the United Kingdom not only faced potential defunding with regard to governmental aid, they also encountered an unsympathetic public that increasingly eschewed government assistance for disabled people, who were marked by false and sensationalist characterizations as “benefit cheats” and “scroungers” in mass media outlets (Kaye, Jordan, and Barker 2012, 11–14).

Undeniably, the United Kingdom was not the only site for disability activism, which – in the aftermath of financial crises, banking fraud, and exorbitant debt – was increasingly fixed to threats inherent in proposed governmental austerity measures. On 2 December 2012, under the banner “SOS Disability: Save our Rights, Inclusion, and Welfare,” an estimated 10,000 disabled people and their allies took to the streets in Madrid, Spain to protest over €60 billion proposed in welfare cuts (Heckle 2012).<sup>1</sup> The next day, on 3 December 2012 (incidentally the UN International Day of Persons with Disabilities), disabled Greeks followed suit by staging a visually striking display comprised of prosthetic limbs, which were strategically hung on the fence that encircled Greece’s Parliament building. While such protests were often concentrated in specific nation-states and focused on particular government policies, they were by no means ideologically limited to one country or region. In a more global vein, these movements provocatively intersected with the theme for aforementioned 2012 UN International Day of Persons with Disabilities, titled: “Removing Barriers to Create an Inclusive and Accessible Society for All” (UN Enable 2012).

A truly global movement, the call to dismantle barriers against inclusion and accessibility was echoed by activists in Asia and Latin America. For example, in Seoul, South Korea, protests were staged in response to the Korean government’s disability rating system, which determined support according to levels of impairment and assumed ability to function without assistance (Park and Chung 2012). Responding to this unfair practice, then-presidential candidate Moon Jae-In potently maintained, “The classification system ignores their dignity” (Park and Chung 2012). In Bolivia, 50 demonstrators – in wheelchairs and on crutches – trekked 1,000 miles over the course of 100 days to demand increased state subsidies and state-sponsored initiatives to enhance disabled people’s employment opportunities and accessibility in public spaces (BBC 2012). Upon arriving at the nation’s capital (La Paz) these demonstrators were tear-gassed and violently beaten by state authorities. Such anti-activist violence prompted Amnesty International to call for an independent investigation of force and Bolivia’s inconsistent human rights record (Amnesty International).

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1 In Spain, healthcare spending is handled by regional governments, many under heavy levels of debt, thus requiring additional cuts to healthcare and support for disabled people. Additionally, infrastructure is left unrepaired further limiting access for those with mobility impairments.

Shifting from local movements to global affairs, the ongoing ‘War on Terror’ serves as a significant backdrop for protests by disabled people in Afghanistan, who struggle in an imaginary marked by ceaseless violence and unfulfilled governmental promises, particularly with regard to land claims and employment opportunities (Khitab 2013). In April 2013, disabled activists, dressed in shrouds and carrying coffins, gathered outside President Karzai’s office. As one protestor somberly remarked, “The government should either give us our due rights or kill us” (Khitab 2013, n.p.). Compounding the issue is a problem with international aid – two months later, in June 2013, the International Committee of the Red Cross (ICRC) significantly curtailed activity and involvement in Afghanistan following an attack at one of its facilities in Jalalabad (Al Arabiya 2013; TOLONews 2013; Welch 2013). In the absence of state-sponsored assistance, the ICRC became a primary source for prosthetic limbs and post-conflict rehabilitation.

Situated against this recent protest history and placed within the larger context of neoliberalism, war, and international disability movements, the ever-vexed notion of an “inclusive and accessible society for all” partially presages the focus of this volume, *Disability, Human Rights and the Limits of Humanitarianism*. On one level this collection of essays – notwithstanding the diversity of topics and approaches – is dialogically concentrated on the multivalent barriers disabled people face in an age troublingly determined by governmental decision-making. On another level, *Disability, Human Rights and the Limits of Humanitarianism* takes seriously the degree to which disabled people routinely struggle in having their equal rights recognized vis-à-vis material impacts of reduced disability support, culturally-sanctioned discrimination, socially-authorized isolation, and hegemonic violence. In so doing, the collection’s internationalist focus provocatively intersects with and critically engages the primary goals of the recently adopted United Nations Convention on the Rights of Persons with Disabilities (2006, CRPD), which begins with the assertion that disabled people across the globe largely live in poverty, face systemic oppression, and are subject to discriminatory violence. Such rights violations – as the essays in this collection make clear – are evident in the concomitant non-access to employment, education, healthcare, and housing.

Taken together, such diverse protests (at the level of the state), neoliberal models of humanitarian aid (with regard to multilateral agreements), and recent ratification of universalized rights (via the United Nations) encompass the political, theoretical, and historical stakes that undergird this volume’s essays, which consistently evaluate the limitations of human rights via the tension between discourses of specificity and universality. As disabled individuals and their allies continue to advocate for more accessible and less oppressive futures, important questions remain with regard to the necessity of human rights regimes and what support is most sustainable for disabled individuals impacted by segregation, reductions in state support, natural disasters, and warfare. *Disability, Human Rights and the Limits of Humanitarianism* resists a teleological narrative of progress in order to dwell upon the challenges and potentialities contained in discourses and praxes of human rights and humanitarianism.

## **Disability Studies, Human Rights, and Humanitarianism**

In establishing specific human rights standards, the 1948 Universal Declaration of Human Rights (UDHR) provides a normative foundation upon which to evaluate subsequent policies and laws that promote the rights of persons with disabilities. Specifically, Article 7 guarantees equality before the law and equal protection by the law for all individuals. Furthermore, Article 25 (1) establishes particular socioeconomic rights that foreground the contemporary imaginary of disability activism: the right to an adequate standard of living (including food, clothing, housing and medical care and social services) and the right to security (in the event of unemployment, sickness, disability, widowhood, and old age).

These terms and considerations foreground the types of work done in the emergent, interdisciplinary field of disability studies. This field (which marries law, social policy, public policy, literature, and science) “is the socio-political-cultural model of disability incarnate. [Disability studies] provides an epistemology of inclusion and integration, formulating ideas that could not have been imagined from the restrictive thresholds of the traditional canon” (Linton 1998, 526). Unquestionably, disability studies as a field has grown dramatically in the past two plus decades. Disability studies challenges medicalized and rehabilitative approaches to disability by articulating for a distinct epistemology. Such knowledge production recenters the experiences and perspectives of disabled individuals and their process of disablement by inaccessible landscapes, societies, and institutions. Illustratively, Rosemarie Garland-Thomson points out that disability like gender “is a concept that pervades all aspects of culture: its structuring institutions, social identities, cultural practices, political positions, historical communities, and the shared human experience of embodiment” (2002, 4).

Despite the rise of disability studies as a foundation for university curricula and programming throughout the US, Canada, Australia, the UK, and across the globe, the interstitial nature of the field (which enables multivalent conversations about bodies, (im)mobility, and hegemonic norms) has by and large been overlooked in scholarly evaluations of human rights and humanitarianism. Even though disability is specifically mentioned in the UDHR, it is often cast as a symptomatic rather than a root issue in human rights. Correspondingly, the question of “what to do” with those considered “disabled” necessarily accesses the problematical terrain of humanitarianism (replete with considerations of care and care-giving). This volume challenges those paradigms by relocating disability studies from the margins to the center. Expressly, the volume commences with a reading of disability studies as a field that must (to draw from Lisa Lowe’s work in *Asian American Studies*) “tirelessly” reckon with more established intersectional fields (e.g. *Ethnic Studies* and *Gender Studies*). Such “reckoning,” evident in the civil rights parameters of contemporary disability studies, simultaneously engages a more global imaginary comprised of war, relocation, environmental racism, state-authorized violence, and genocide.

Disability studies scholars and activists have long critiqued charitable approaches to disability. The telethon and the capitalization of individual disabled bodies to invoke pity are connected to paternalism and efforts to deny disabled individuals equal rights (Longmore 2003; Shapiro 1994). More recently, disability studies scholars are critical of international efforts to integrate disabled constituents, particularly around notions of development (Dingo 2007) and reduction of poverty (Dingo 2007; Groce et al. 2011). For example, Groce and colleagues question, “what becomes of impoverished people with disabilities when other members of their communities begin to benefit from successful international development efforts? Do their lives improve as part of general social and economic advancements, even if they have been left out of advances in education, economics and civil society, or are they left increasingly further behind?” (Groce et al. 2011, 1494). How are disabled people positioned in efforts to reduce poverty or address inequalities?

Connected to efforts to incorporate disabled people in development is the increased use of disabled bodies as “evidence” of harms done under capitalism, war, and other forms of conflict (Erevelles 2011). Humanitarian representational impulses, much like the telethon, often use disabled bodies, particularly disabled bodies of color, to generate resources for their humanitarian projects. Eunjung Kim (who is a contributor in this volume) previously discusses how the visualization of disabled bodies by human rights NGOs in the name of humanitarian aid reinforces a mode of representation where “disabled bodies signify the underdevelopment of their nation via its inability to provide a cure. Western or modern gestures to rescue people with disabilities from their own cultures strategically function to produce hierarchies between different societies and nations” (2011, 95). This mode of representation is connected to what Karen Halttunen (1995) calls “the pornography of pain” and Betty Plewes and Rieky Stuart (2006) refer to as the “pornography of poverty.” While NGOs use disabled bodies to generate resources for humanitarian programming, Mansha Mirza discusses how in refugee camps disabled individuals are excluded from humanitarian projects because of a view that sees disability requiring a certain level of specialization and professionalization (2011, 1528). As such, natural disasters (and warfare) often generate individually funded humanitarian responses. Donations through social media, text messaging, and online fundraisings are supplementing more traditional check mailing efforts.

Emblematically, after the 2010 earthquake in Haiti international communities mobilized to send goods, services, assistance, and financial aid. As Robert McRuer contends, the material existence of Haiti as one of the “poorest” countries in the world – with high levels of disability, illness (particularly HIV) – is inescapably connected to histories of colonialism, slavery, debt bondage, and neoliberalism (2010, 328–30). Conversely, in discussing Haiti, journalists, pundits, and politicians utilize metaphors of disability (Haiti is “disabled”) and able-bodiedness (e.g., Haiti will emerge “healthy” or “standing on two feet”) (McRuer 2010, 329). These metaphors have “the dual effect of naturalizing Haiti’s position as the poorest country in the western hemisphere and disallowing – as in other cultural locations where

banal disability metaphors circulate readily – other ways of imagining embodiment in general and disability in particular in this location” (McRuer 2010, 329).

Continuing with the “Haitian case,” confronted with images of disabled individuals and widespread suffering, efforts to donate prostheses, wheelchairs, and mobility aids from Canada, the US, and Britain “would turn their [disabled people outside Haiti] excess equipment into the accoutrements of Haiti’s regained mobility and the future ascendancy of a more modern, western-style, healthcare system” (Snyder and Mitchell 2010, 116–17). As Sharon Snyder and David Mitchell aver,

This display of disability largesse is an example of the kind of American exceptionalism whereby provisions are assumed to be excessive for institutionalized disabled people. The inadequacies of distribution of assistive technology and equipment are erased in Anglophone countries through a sort of Malthusian denial of the rampant rejection rates characteristic of insurance industries on behalf of people with disabilities. (2010, 117)

Global rhetoric of human rights protocols and nation-states as originators of disability rights (e.g. the Americans with Disabilities Act as the gold standard) further conceal material inequalities, despite multinational efforts to generate humanitarian relief for certain disabled bodies of color in the global south. Which bodies are recipients of aid and which bodies are not called into being?

Equally provocative, humanitarian impulses around disability are contrasted with global efforts to secure human rights for disabled individuals. Disabled individuals have long advocated for civil and human rights in various locations throughout the globe. At the 4th World Conference on Women in Beijing (1995), disabled women met to discuss their role in demanding national and international recognition of their rights particularly connected to issues related to education, reproduction, employment, and housing (Hershey 2003). Disabled People International (DPI) is an international network of disabled individuals that promote equal rights and full economic and social participation. DPI and other disability organizations, primarily non-western disability organizations, worked to secure passage of the CRPD. Disability rights are circulated through the convention encouraging governments to ensure the participation and actualization of human rights for their disabled citizenry. Disability studies scholars are examining the limits of global human rights rhetoric in relation to the UN Convention (Meekosha and Soldatic 2011; Muir and Goldblatt 2011).

It is this connection between civil rights and human rights, and this simultaneous relationship between national and international, that introduces this volume’s contention that disability studies is uniquely suited to conversations about humanitarianism. In a recent special issue of *The Journal of Literary and Cultural Disability Studies*, Sharon Snyder and David Mitchell, extending Jasbir Puar’s (2007) concept of “homonationalism” to disability, forward the notion of “ablenationalism” defined as “the degree to which treating people with disabilities as an exception valorizes able-bodied norms of inclusion as the naturalized qualification

of citizenship” (2010, 113).<sup>2</sup> They continue that ablenationalism is a prerequisite for inclusion for full citizenship:

Ablenationalism involves the implicit assumption that minimal levels of corporeal, intellectual, and sensory capacity, in conjunction with subjective aspects of aesthetic appearance, are required of citizens seeking to access the “full benefits” of citizenship. As such, most people with disabilities are excluded by falling short of this participatory bottom line and, as such, key guiding principles of democracy are left unrealized. (2010, 124)

As governments and municipalities throughout the world deal with shrinking budgets during a time of increased global conflict and fluctuating stock markets, calls for austerity are drastically affecting disabled citizens who depend upon social support for means of survival. Disabled individuals cast as “unfit to work” and thus “undeserving,” are further marginalized when work and productivity are constructed as contingent upon claims of citizenship. As mobility is restricted in the global north through calls for immigration reform, coupled with higher than average levels of unemployment, how are disabled, queer, poor, racialized, immigrant bodies cast out in the name of able/homo/national enterprises?

The “Hardest Hit” marches which open this chapter and volume provide tangible examples of disabled people challenging governmental efforts to reduce disability support and benefits. What are the lasting impacts of the reduction of disability benefits? How does ablenationalism threaten disabled individuals and their quality of life? Within a capitalistic system of production and labor, how are disabled bodies configured as “expendable” or “unnecessary” and in turn part of the “deserving poor”? How does the CRPD hold governments accountable for ensuring that their disabled citizens receive opportunities to access their rights?

## Challenges to Human Rights and Humanitarianism

To reiterate and expand, by resisting simplistic narratives of progress, the authors in *Disability, Human Rights and the Limits of Humanitarianism* explore challenges and possibilities of human rights in an age of inequality and rapid globalization. Additionally, this volume’s contributors are concerned with accurately documenting how groups of disabled individuals effect sustainable change in their lives. For example, Mark Sherry’s essay, “The Promise of Human Rights for Disabled People and the Reality of Neoliberalism,” traces contemporary neoliberalism that translates

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2 Puar writes that homonationalism is a type of “sexual exceptionalism” or “national homosexuality” that “corresponds with the coming out of the exceptionality of the American empire” (2007, 2). Homonationalism “operates as a regulatory script not only of normative gayness, queerness, or homosexuality, but also of the racial and normative norms that reinforce these sexual subjects” (2).

to reductions in disability benefits, increased poverty, and monitoring of people receiving benefits. Sherry sets the material conditions of disability against a human rights rhetoric that does very little for people experiencing homelessness, poverty, institutionalization, abuse, hate crimes, and discrimination, often due to the very neoliberal policies enacted by the state espousing human rights rhetoric. He astutely argues that this is a paradox of neoliberalism, wherein promises of freedom and human rights fail to change the day-to-day realities of disabled people, where basic rights remain unattainable.

Correspondingly, Maria Berghs, in her piece, “The New Humanitarianism: Neoliberalism, Poverty, and the Creation of Disability,” considers how efforts to “fight poverty” are linked to medical approaches of disability. Berghs maintains that this “new humanitarianism” extends neoliberalism through a commodification of disability. Continuing the analysis that Sherry offers, Berghs focuses on how organizations like the World Health Organization and efforts such as the United Nations Millennium Development Goals attempt to reduce poverty, while neoliberalism has exacerbated levels of poverty. As such, disabled people are often constructed as burdens, public health problems, and economic liabilities for a nation-state. In so doing, Berghs questions the benefits of humanitarianism instantiating that entire economies are built around disaster relief and humanitarian aid, while the aid does very little to change the material existence of disabled and poor individuals. Disabled individuals (and impaired body parts) are problematically deployed to generate pity and similar affective responses.

Continuing with the contemporary moment, Armineh Soorenian’s “Media, Disability, and Human Rights” traces the gendered impacts of ableist reporting in British media sources. As an example, in the last several years the number of articles in newspapers about supposed “benefit scroungers” have increased. As troublingly, so has the preponderance of high profile hate crimes against disabled women. Soorenian links these two phenomena as part of a growing public anger (and hatred) toward disabled people. Additionally, as the author contends, mainstream media continues to perpetuate stereotypes of disabled women as dependent, vulnerable, and in need of rescue. Soorenian juxtaposes a recent reality television show *The Undateables* as emblematic of the problems of disability messaging, especially when a growing percentage of the British public is hostile toward disabled individuals.

Anna Mae Duane continues the materialist cultural studies analysis of disability and government support by contrasting *The Hunger Games*, a popular US young adult fiction trilogy with discourses of humanitarianism, and organ trafficking/donation. Similar to Berghs’ arguments about affect and pity, Duane in her essay, “Volunteering as Tribute: Disability, Globalization and *The Hunger Games*,” compellingly illustrates the growing trend of disabled children being used by international NGOs to garner donations and other forms of support. The materialist conditions in countries exacerbated through neoliberal models of heavy borrowing, structural adjustment, debt repayment, and reduced government expenditures render poor and disabled individuals more likely to seek nefarious means to gain financial independence, such as selling organs. Duane provocatively asks when, if ever, can

bodies be ethically sold, even by their owners? How might we rethink the rules in a system that insists that vulnerable people choose to “play” a game in which they have little to sell but themselves?

Moving from the cultural imaginary to the employment realm, Sarah Parker Harris, Randall Owen, and Karen Fisher evocatively examine if efforts to reform welfare in Australia are compatible with human rights discourses. In their co-authored contribution, “Structural and Cultural Rights in Australian Disability Employment Policy.” These reforms have largely embodied neoliberal principals, thus the success of increasing the overall employment of disabled individuals is negligible. Correspondingly, Parker Harris, Owen, and Fisher explore whether the CRPD and the discourse of right to employment is consistent with Australian disability employment reforms. Additionally, they determine to what extent current reforms embody measures to produce structural change and address discrimination regarding disabled workers. Using data collected from focus groups, the authors conclude that without efforts to change cultural views of disability, combined with structural change that incentivizes hiring of disabled workers, efforts to reform welfare will fail. Similarly, Vanmala Hiranandani’s essay, “Disability in Humanitarian Emergencies in India: Towards an Inclusive Approach,” critically considers the extent to which large-scale natural disasters such as the 2004 tsunami render visible the limitations of state-sanctioned humanitarianism vis-à-vis those who are disabled. Focused on India, Hiranandani productively and evocatively evaluates the multifold exclusions that emerge with regard to national, regional, and local policies concerning disaster relief efforts and services.

Tanya Titchkosky and Eunjung Kim take a more theoretical and archival approach in their respective considerations of what constitutes the human, humanitarianism, and notions of vulnerability. In “Monitoring Disability: The Question of the ‘Human’ in Human Rights Projects,” Titchkosky attends to the distinctions between those that “need” and those that can “provide” human rights. She concomitantly traces how there is a growing distinction that disability is socially produced, but also that impairment is produced globally warranting human rights claims. Titchkosky analyzes person-first language, discourses of impairment, separations of impairment from disability, models of disability, and conceptions of “human” to delineate how efforts to separate “nature” from “social” are intermixable and inextricably intertwined. She argues that there are three ways of making the category of “human” appear: 1) humans with actualized rights, 2) humans who can achieve their rights by being on the correct side of the human/not-human divide, and 3) those that are “naturally” without rights and exist on the margins of the category of human.

In “The Specter of Vulnerability and Disabled Bodies in Protest,” Eunjung Kim complicates discussions of materiality, and discourses of rights by exploring how vulnerability is deployed based on an assessment of yet-to-be manifested harm, as a type of intercorporeal affect. Historical events are considered alongside contemporary conditions to assess how bodies with supposedly similar characteristics are made vulnerable, or rather are constructed to be vulnerable. Kim analyzes representations of spectral vulnerability as reinforcing power differentials where

certain bodies (disabled, girls', immigrants', poor) are evidence of or seen to be a cause of harm. She traces how disabled and poor women in the non-western world are often seen as vulnerable and in need of protection from future vulnerability, often subject to impositions of "protections" that further cement the vulnerable status of these individuals. Ultimately Kim theorizes a vulnerability that resists identitarian imposition and humanitarianism in order to claim political and material agency.

While discourses of human rights are heavily critiqued, including by some of the contributors here, there are a group of essays (by Janet Lord, Ethan Levine, Jennifer Bronson, and Lydia Apon Strehlau) that contemplate if (and how) discourses of human rights can be utilized to improve the political subjectivity of disenfranchised individuals. For example, Janet Lord's in her piece, "Persons with Disabilities in International Humanitarian Law – Paternalism, Protectionism, or Rights?" considers how international humanitarian law casts certain populations, including disabled people, as highly vulnerable and in need of protection. The CRPD however deploys a social model understanding of disability requiring signatories to meet standards of inclusion, independence, and equality. Lord's *longue durée* reading of such legal frames – which involves sophisticated readings of militarized subjects and civilian non-combatants – underscores the vexed connection between war, disability, and human rights. Ethan Levine's "United Nations Policy and the Intersex Community" productively employs an intersectional analysis which considers the efficacy of intersex activists in calling upon the UN to address human rights violations, including childhood "corrective" surgeries. Noting that both disabled and intersex individuals have a vexed relationship with the medical industry, including often unnecessary and corrective surgeries, Levine also explores how the binary sex model in UN documents and conventions is a further obstacle to claims of human rights and equality. Given the fluid interpretation of disability in the CRPD, particularly with emphasis on environmental and social dimensions, Levine contends that a modification of understandings of the category of sex in ways similar to the CRPD and disability has the potential to resolve inconsistencies internationally for intersex communities. Levine's chapter provides the opportunity to think about the potential of coalitional politics in expanding human rights.

Analogously, Lydia Apon Strehlau also dwells upon coalitional potential, especially for people living with HIV (PLHIV) in South Africa. In "HIV/AIDS, Disability, and Socio-Economic Rights in South Africa" Apon Strehlau traces the relationship between discourses of socio-economic rights and human rights for people with HIV/AIDS. High unemployment, legacies of Apartheid, structural inequalities, and the prevalence rate of HIV in South Africa creates situations where individuals are not able to get their economic needs met (including government paid financial and housing assistance). Through a reading of the *Grootboom* case and the CRPD, Apon Strehlau delineates how a more holistic approach to HIV/AIDS including addressing housing and socio-economic concerns and disablement related issues could continue the progress made to date.

Jennifer Bronson's chapter, "The Overrepresentation of Black Children in Special Education and the Human Right to Education" traces how black children,

particularly boys, in the US receive more frequent diagnoses of certain impairments that result in placement in special education. Additionally, Bronson addresses how this overrepresentation strains limited resources effectively placing the efficacy of the educational services in jeopardy given growing student populations in special education classrooms. Bronson connects the contemporary overrepresentation of black and Latino children to the history of racialization in the US including Jim Crow and other state-sponsored modes of segregation. Culturally bound assessments of intellect, where whiteness remains hegemonic, also play a role in the overrepresentation. Bronson discusses the failures of US civil and social rights, and how human rights frameworks, with attention on structural change, have the ability to change decades of inequality, particularly for disabled students, disabled students of color and students of color.

Last, but certainly not least, Nirmala Erevelles forwards a historical material analysis of the ways bodies become disabled. In “‘Becoming Disabled’: Toward the Political Anatomy of the Body,” Erevelles attends to historical processes of exploitation, of bodies and labor, and how disability is a condition, or product of these modes of exploitation. Accordingly, Erevelles is cautious of the posthumanist celebration of bodies/organs/assemblages which fail to attend to the transnational capitalist material conditions that produce these disabled/impaired bodies. Drawing on colonial histories of slavery and enslavement, Erevelles forwards a theory of “the political anatomy of the body” to focus on how disability is not merely “anatomy gone awry” but “a historical materialist construct” that supports exploitative and productive occasions of race, gender, sexuality, and class.

Collectively, the essays resist simplistic narratives of progress, or challenge reductionist framing of human rights, disability, and humanitarianism. As such, we invite readers to explore the diverse offerings tracing the conversations and points of contention between the essays. While some authors are highly critical of human rights as limiting and exclusionary, others find claiming of human rights a necessary step to guarantee sustainability. Will the CRPD (and similar conventions) provide adequate and lasting protections for disabled people throughout the globe? As human rights are institutionalized (in universities in particular) coupled with professionalization and increased expansion of NGOs, how do poor and resource-less communities garner attention when their rights and wellbeing are violated? Will the protests, sketched out in the beginning, continue? And what are we to make of the rhetoric that countries are protectors or guarantors of rights, when these same countries enact gender, disability, sexuality, economic and race based violence and inequality?

Intertwined in these discussions of the role of human rights are material concerns. How are human rights and humanitarian impulses connected to denial of benefits, inability to gain employment, shrinking governmental budgets, structural adjustment, and neoliberalism that exacerbate poverty? As more communities rise up to make claims to the state, each other, and international bodies, including the UN, how can these claims be traced to mark a global uprising that seeks more accessible futures? While some authors invite us to contemplate the significance

of identity, especially as it pertains to equality and rights, other authors are highly suspect of any effort to delineate individuals along identity categories because of the nature of exclusion and power differentials embedded in these identity claims. Additionally, how does affect, pity, and other emotions, which are often intertwined with notions of power, get deployed in discussing human rights violations and humanitarian responses? Can disablement be celebrated even if it is due to warfare, poverty, human rights violations, or structural inequalities? Can the subversive potential of disabled individuals be utilized to transition ableist spaces to be more inclusive (and welcoming) of disabled, queer, and excluded bodies?

While this volume marks the end of a period of collaboration, in no way does it signal resolution to the questions posed here. We are incredibly proud of the various chapters collected, as we are certain the perspectives enrich and complicate the largely western cannon of disability studies theories and literature. Initially, we wanted to host a brief conference on the challenges that disability presents to human rights and humanitarianism. We envisioned an engaged dialogue, but we couldn't have imagined the theoretically rich, experientially grounded collection of essays that we present here. It has been an utter delight and privilege working with the authors in this volume. We are quite humbled by the opportunity. We hope that you find these essays are engaging and thought provoking as we do.

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## Chapter 1

# The Promise of Human Rights for Disabled People and the Reality of Neoliberalism

Mark Sherry

Over the last 20 years I have worked as an advocate with families of over 5,000 people with brain injuries, mainly in Australia and the United States. In that time, the vast majority of people I have met struggle to get their very basic needs met: whether it is being able to decide what time they eat if they live in a group home, or trying to have friends (even one friend seems a pipe dream for many of the most vulnerable and socially excluded people), or trying to get off the guaranteed poverty of the disability pension and into a position where they can actually make a decent living. With few friends, sometimes distant relationships with other family members, and few advocates, they are vulnerable to abuse and hate crimes. Feeling emotionally or physically safe is a basic human right, but in a wider context of everyday disability, social exclusion, and poverty, it seems this basic requirement for a decent life is not guaranteed to many disabled people.

In both Australia and the US, life as a disabled person usually involves poverty, social exclusion, prejudice, discrimination, and endlessly dealing with bureaucracies that require enormous emotional and physical effort, just to keep your head above water. I have seen some people succeed in this process, but I have seen far more fail, and I advocated for one man who committed suicide because the everyday face of disability discrimination got too much for him. This is the background, the mirror, against which I judge the everyday workings of the major political framework of our times – neoliberalism. Contemporary neoliberalism, which is dominant in both Australia and the US, has a nasty side – one that can be seen when people are forced to make difficult decisions about whether to buy food or pay the rent, when they spend years of their lives unemployed because no one is hiring disabled workers, or when they spend years in social isolation and feel as though they will never have any friends, such is society's exclusion of disabled people.

Against this background, the policies of contemporary neoliberalism mean more cutbacks to disability pensions, more hardship for the poor, more punitive monitoring of people receiving benefits, and all surrounded by less government intervention in the market economy and more tax breaks for the wealthy. The language of human rights and protecting human dignity – which is dominant in so much of the official policies of both Australia and the US – sounds remarkably hollow to people experiencing abuse, homelessness, institutionalization, poverty,

discrimination and social exclusion. This is the background against which I measure the empty rhetoric of neoliberalism on human rights.

Contemporary neoliberalism takes many forms, but is united around the demand for a reduced role for government in all sectors of political and economic life, including social welfare. Volunteerism, philanthropy, individual charity, corporate responsibility and a *laissez-faire* approach to the economy are upheld as the most effective mechanisms to address social issues, and to promote political and economic freedom (Bumiller 2008; Harvey 2007). The neoliberal agenda is dominant in the age of globalization; it is said to both provide improved economic outcomes as well as enhanced global protections for human rights. Indeed, governments committed to the neoliberal agenda have agreed to include disability provisions in national and international human rights law and politics.

One of the paradoxes of contemporary neoliberalism is that it promises freedom and human rights, but leaves most disabled people in impoverished, socially isolated situations, with few safeguards and protections, struggling for the basic dignities of life. Many disabled people are trying to achieve very basic things: a sense of control over what happens to them; a degree of economic security; being able to make important choices about their own lives; feeling physically and emotionally safe; having the chance to get a job, make a decent income or get a good education; and trying to form some sort of meaningful relationships with other people. We live in an age of globalization where neoliberalism reigns supreme; the lack of basic supports and safeguards for millions of disabled people is a reflection of the hollow promises of neoliberal discourse on human rights.

The language of “human rights” has been appropriated and incorporated by organizations promoting neoliberal globalization, and human rights organizations have also adopted neoliberal discourse in many cases (Erni 2011). The rhetorical commitment to human rights of neoliberal organizations, such as the World Health Organization and the World Trade Organization, is nevertheless contradicted—at least to some degree—by their commitment to free market economics (Feldman 2006). Feldman argues that free market, *laissez-faire* economics increase economic inequality, which in turn exacerbates poverty-related impairments and health disparities and may make it harder for poorer people to access health resources. Equally important, framing health and healthcare as simply another commodity on the free market misrepresents their true nature as “public and social goods” (Chapman 2009, 97). Coburn and Coburn (2007, 13) maintain that “market fundamentalism” generates economic/social/cultural inequalities which create health inequities, healthcare barriers, unaffordable medicines and other barriers to human rights: “The dogmatic application of neo-liberalism doctrines perversely increases those social inequalities that are among the basic causes of health inequities.” Indeed, they state:

Viewing health inequalities as part of the product of neo-liberal economic globalization and health and health inequalities as being caused by, and

covarying with other forms of inequality, connects health with much broader struggles. (Coburn and Coburn 2007, 29)

While Coburn and Coburn specifically focus on “health inequalities” (and the ways in which social inequality creates the conditions for inequalities in the experiences of various health and illness experience), their argument can easily be extended to include impairment and disability as well.

There is a danger, when the discourse moves from “disability” and “impairment” to “health conditions” or “illness” or “disease,” that the discussion will subtly slip from a social model of disability (Oliver 1990) into a medical model of disability. This is a concern for disability activists who have worked tirelessly to ensure that social exclusion, discrimination and disabling barriers are recognized as social problems, and are not a necessary component of living with an impairment. However, the fine line between disability and disease is complicated; AIDS provides a clear example of their overlap. People with chronic health conditions, like depression, chronic fatigue, back injuries, or autoimmune diseases, may be regarded as disabled. They experience many of the same disabling physical and attitudinal barriers as other disabled people. Their poverty puts them at risk, both for social exclusion and also for secondary health conditions. They may struggle to get appropriate medical diagnoses, to pay for treatment, or to find a job that pays enough to make a decent living – just like other disabled people. Their lives are similar to many other disabled people; they are struggling for basic human rights (respect, autonomy, economic security). This is the sad reality of “human rights” in the everyday lives of disabled people and people with chronic health conditions.

Some may wonder whether the international UN Convention on the Rights of Persons with Disabilities (2006) will address these problems. But to believe its promises is to buy into neoliberal rhetoric about human rights, outside of its wider political context of massive national and international economic inequality and the reality of cutbacks on the essential spending that disabled people need to achieve equal rights. The Convention itself even contains foreboding neoliberal rhetoric – under the heading “General Obligations,” the second point commits signatories to “take measures *to the maximum of its available resources*” (emphasis added). Given that the “maximum available resources” have been defined by dominant political perspectives that have imposed austerity measures and cutbacks which greatly reduce the rights of disabled people, there is little room to be optimistic. Of course, that does not mean one should abandon the commitment to “human rights” discourse; it does, however, mean that one must critically examine the deployment of such discourse in light of the material consequences of various economic policies. One must deconstruct the hegemonic connections between neoliberalism and human rights discourses so that a human rights discourse can be used to challenge dominant assumptions of neoliberal globalization.

## **Neoliberal Discourses, Individualism and Human Rights**

Neoliberal discourse on human rights commonly has a narrow individualist focus, with a strong assertion of civil and political rights, and much less emphasis on economic, social and cultural rights (Kirkup and Evans 2009; Weller 2009). Such a narrow, individualist conception of human rights is particularly problematic for disabled people, given their simultaneous exclusion in political, economic, civil, social and cultural spheres. It is impossible to separate the poverty experienced by the vast majority of the world's disabled people from inaccessible environments and prejudicial attitudes; it is equally impossible to imagine political and cultural empowerment without these broader changes. As one study of people with chronic illness in Columbia suggests, neoliberal healthcare systems exacerbate an unequal distribution of wealth and power, reinforcing the social exclusion of vulnerable groups (Pilar et al. 2012).

The state has a particularly important role to play in the human rights of disabled people. Governments make decisions about national healthcare schemes, which have major ramifications for most disabled people. Moreover, given its role in providing, regulating and funding social welfare programs, the state is responsible for maintaining welfare levels that impose and guarantee poverty for disabled people. Being on a disability pension (where it is available) is almost a guarantee of lifelong poverty, poor health care, and few opportunities for a better life. And yet the presence of such policies is often regarded as an informal indicator of the respect a government has for the human rights of its disabled citizens.

Governments also regulate access to voting rights – commonly using intellectual or cognitive status or psychiatric diagnoses as a basis for excluding some community members from political participation (Callard et al. 2012). Such policies commonly institute disablism, sanism and other forms of prejudice based on (certain assessments of) cognitive abilities as a gatekeeping mechanism within the political process. Interrogating the notion of “human rights” through the lens of disability further highlights the problems with traditional conceptions of human subjectivity that underlie many discussions of political rights. Such discussions tend to be based on individualism (rather than interdependence) and disembodiment (rather than recognizing that the body materially influences, and is influenced by, its social settings). The notion of “human rights” underpinning neoliberal discourse is a disembodied one: it fails to recognize that power is expressed through, in and upon the body.

Some disability organizations in the US are deeply committed to the rhetoric of “independent living.” And yet the rhetoric of “independent” living is inseparable from the wider influence of American individualism. In Australia, many disability advocates have asserted the importance of “interdependence,” rather than “independence,” as the foundational discourse of the disability movement. The rationale behind such a model of interdependence is that it is located within an ethics of relationality – emphasizing the two-way connections between disabled people and others in their lives. It has a parallel in some of the literature on disability and

care: again, recognizing that disabled people can be simultaneously providing and receiving care enables a richer understanding of the reciprocity and relationality involved in care (Deacon 2007). Such recognition is an important reminder for disability theorists: it is essential to move beyond a narrow, individualistic model of human rights and into a more complex examination of the relationships and social structures within which such rights may be realized. Part of that process will undoubtedly involve an exploration of power and the body.

Power and the body are deeply enmeshed (in both a physical and social sense). However, a disembodied approach to human rights masks the ways in which embodiment is influenced by, and reproduced within, wider social dynamics. For instance, it is virtually impossible to discuss disability without discussing social class. Whether one considers intellectual disability, asthma, autism, stroke, spinal cord injury, brain injury, blindness, deafness, or almost any other major health condition, people who are poorer are far more likely to experience impairment (Sherry 2008). Power materially shapes the body. And of course, the ability to deal with any impairment (or even to afford medical treatment) is deeply influenced by the amount of social and economic resources available; responding to impairment in the context of a society full of disabling barriers is refracted through the privileges and inequities of class. This basic connection between disability and inequality means that in order to change one, it is necessary to change the other. But neoliberal rhetoric about human rights is thoroughly individualist – immediately marginalizing any discussion of the collective nature of social inequality and the need for widespread social change.

Another related issue is that disabled bodies are often devalued – to the point where disability is often still assumed to be a life not worth living. This flawed cultural assumption is most evident in the attitudes towards the abortion of disabled fetuses. Eugenics has effectively been privatized in the modern world (Kerr and Shakespeare 2002). Large numbers of disabled bodies are still being aborted – but the decision to do so has moved from the public (state) sphere to the privatized one of doctor’s rooms and people’s homes.

In short, the individualist assumptions which underpin neoliberalism threaten the human rights of disabled people because the experience of disability is both collectively shaped through social inequality, and because many forms of prejudice (such as the desire to abort disabled fetuses) are masked in a neoliberal ideology as “individual choices,” even though they systematically threaten the human rights of disabled people.

### **“The Human Right to Health”**

In recent years, there has been an increasing tendency to include “the right to health” in human rights discussions at a regional, national and international level (O’Connell 2010). While seemingly uncontroversial, this valorization of health as a “human right” places some disabled people at particular risk. Many disabled

people are healthy, certainly – but there are others who are not “healthy” and who never will be “healthy.” If a person’s very being situates them outside the realm of a discourse of “human rights,” then surely it is the discourse, rather than the person, which needs to change. Both at an individual and population-level, the incitement to health – as both a material benefit and a presumed “right” – has unintended consequences. As Metzl comments, “Health is a desired state, but it is also a prescribed state and an ideological position” (Metzl 2010, 2). Moralism and prejudice lurk silently in the background during many discussions about “health,” often reflecting underlying experiences of power and privilege. Health is not simply an embodied experience; it is often a form of cultural capital.

There are significant problems associated with assertions of “the human right to health” and the operation of market hegemony, particularly policies of privatization, reduced government spending, and commodification of healthcare. O’Connell (2010, 198) believes that these policies “serve, first and foremost, to open up new avenues of profit realization,” and that “systemic denials of the right to health” occur when healthcare is governed by the market. The discrepancies between those who can afford healthcare and those who cannot, “is literally a matter of life and death,” O’Connell (2010, 201) states. Similarly, Dominelli (1999) suggests that the application of market principles to health and welfare issues changes the relationship between the state and citizens, particularly for those who are poor and may lack the ability to pay for essential services.

Dominelli does not explore the particular advantages which citizens experience (and non-citizens do not experience) in such a context, but this theme is addressed by Gottlieb, Filc and Davidovitch (2012) who highlighted the contested “deservingness” of non-citizens. Sargent (2012), exploring the same theme of “deservingness,” comments that “immigrant health is a product of policies of entitlement and exclusion.” The rights of non-citizens raise a number of political and humanitarian issues associated with the vulnerability of those who lack governmental recognition. Such people include asylum seekers, undocumented workers, and many short-term migrants, all of whom require what they would call “medical humanitarianism.” Disabled people within these groups face particular vulnerabilities and highlight the need for political advocacy for those who are non-citizens; their experiences highlight the fragile nature of “the human right to health” outside of market contexts and government protections.

## **Neoliberalism and Social Change**

Neoliberalism offers piecemeal change, not systemic change. Questions of economic justice – and their relationship to embodiment – do not arise within narrow neoliberal discussions of “human rights.” Furthermore, even though the disembodied language of “human rights” is deployed extensively within the discourse of contemporary neoliberalism, neoliberal policies (such as welfare cutbacks and privatization of social services) produce the antithesis of such rights.

The outcomes of the neoliberal agenda include increased global and national inequality, higher levels of poverty, and reduced safety nets for those who fall outside the employment/social welfare system. For disabled people specifically, neoliberal policies have failed to challenge physical and attitudinal barriers, reinforced long-established patterns of social exclusion and discrimination, and privatized issues that the disability movement had previously sought to place squarely on the public agenda (such as the importance of government funding of social services, rather than a reliance on corporate or individual charity).

Disability organizations have never collectively argued for reduced government funding and support; less regulation and oversight of service providers; less government spending on making the physical or social environment accessible; or a replacement of government entitlements with individual and corporate charity. To do so would compromise the very rights that the disability movement seeks to secure. But this is precisely the neoliberal agenda which the disability movement confronts – even though it is soaked in the rhetoric of “human rights.” Disabled people are facing massive levels of poverty, a cultural climate of disablism, strongly-entrenched prejudice and discrimination, and an epidemic of abuse and disability hate crimes. Disabled people face these challenges within a context where their welfare entitlements are continually under attack. This is the everyday reality against which neoliberal discourse about human rights should be judged.

Neoliberalism has been deeply connected with “welfare to work” (or “workfare”) programs, and these programs have been significantly criticized by disability advocates. For instance, following the implementation of punitive workfare programs in the US, similar programs were developed in Slovakia. A review of this program by Gould and Harris (2012, 1) concluded “welfare to work (workfare) policies present substantial barriers to participation in the open labor market for people with disabilities.” But the effectiveness of neoliberal workfare programs is only one part of a much larger story. Equally importantly, it is essential to note that disability organizations have consistently argued against neoliberal policies in the welfare area. My own research on welfare reform in Australia demonstrates this opposition to neoliberalism. In 2002, the Federal Government solicited community input into reform of the disability sector, and there was unprecedented input from disabled people and disability organizations, highlighting the barriers which must be removed to ensure disabled people have the right to participate fully in society (Sherry 2002).

Despite this unparalleled outpouring of support for what some would call a “social model of disability” perspective, the response of successive governments was not wholesale removal of disabling barriers, but standard neoliberal policies. Punitive crackdowns on “welfare fraud,” accompanied by a reconfiguration of the roles of disabled people to that of a “consumer” of disability services, simply added more barriers, more stigma, and more difficulty for already vulnerable people. As has been argued with regard to people with mental health issues:

The consumer label, while attempting to free the patient/client from an unequal relationship to her or his doctor or health care worker, has merely traded one inequity for another. For persons with a chronic mental illness who are either unemployed and/or welfare dependent, the consumer label has potentially negative consequences. Not only does it fail to address the sometimes involuntary nature of mental healthcare, but within the current political climate, the neo-liberalist user-pays philosophy is imposed onto a group whose spending power and freedom of choice is already heavily compromised. (Holdsworth et al. 2004, 1)

So after disabled people and disability organizations indicated, in the clearest possible way, that neoliberal policies were the antithesis of what they needed, the end result was reform of disability pensions, aimed at cutting expenditure and eliminating certain entitlements. Essentially, this was a classic case study in neoliberalism: the rights and needs of disabled people (along with many others) were sacrificed amid the rush to cut spending, stigmatize welfare recipients, and the underlying problems of poverty, high rates of unemployment, vulnerability to abuse, negative cultural stereotypes, and other disabling barriers were left unchecked. This is a microcosm of neoliberalism and disability, which has been played out in many countries across the globe.

In Britain, for instance, a similar workfare program has been resoundingly criticized. One of the criticisms relates to the way work is valorized in these programs, as if the capacity to work is the key criteria for full citizenship rights. Obviously, such a perspective leaves those who cannot work with little respect, and few resources. Likewise, the punitive elements of workfare programs are often criticized for pressuring disabled people to change, rather than businesses, employers or governments:

Policies in neoliberal states tend to downplay rights to welfare, focusing instead on the need for individuals to change rather than structural changes needed to enable more people to move into the workplace, such as greater access and adaptations by employers. (Stevens 2012, 5)

The negative effects of neoliberal globalization in India have been highlighted by Hiranandani and Sonpal (2010). They suggest that neoliberal cuts to welfare have increased inequality and left vulnerable groups such as disabled people struggling for basic human rights – food, water, health, education and employment. They further argue that the foundational premise of neoliberalism is “the abdication of government responsibility for essential services” (2010, 13), and the results of such abdication of state responsibility are large-scale human rights violations in the Global South, particularly for vulnerable, excluded and stigmatized groups such as disabled people.

## **Neoliberalism and Governmentality**

It is also important to recognize that “neoliberalism” also involves a form of governmentality in which individual citizens are exhorted to “conform to the norms of the market” (Larner 2000, 12). In other words, not only is welfare state spending cut back, but individuals on welfare are encouraged to take responsibility for their own situation. The inequitable social effects of such policies have been discussed elsewhere; essentially, the outcomes of neoliberal economic and welfare policies are the redistribution of wealth away from poorer people and towards the wealthy (Harvey 2007). Taking “individual responsibility” sounds like a reasonable thing to do, in many areas of one’s life. But it is not a panacea for all social problems, particularly those caused by social inequality. Further, when it comes to disability, there are long-standing and deeply problematic individualist messages about self-sufficiency and the need to individually “overcome” a disability. Such messages immediately narrow the frame of reference for disabled people – the challenge is not to create a barrier-free environment for all people, not to stamp out the collective aspects of disability prejudice, and it is certainly not to emphasize overlaps and connections between disability and racism, sexism, classism, heterosexism or other forms of social exclusion.

Instead, a key theme of neoliberal governmentality is for an individual to succeed “against the odds.” “Triumph over disability” narratives can make great news stories, for some audiences, because they fit neatly into broader cultural narratives about succeeding against the odds, overcoming adversity, and achieving success in a capitalist society more broadly. However, these stories are always individualist, never collectivist. Narratives about the need for wholesale changes in the economic position of disabled people throughout society are not nearly as seductive and do not evoke such sentimental responses from an audience.

That is not to suggest that some individual disabled people do not succeed against the odds, or that their achievements are any less commendable because they have experienced disabling barriers. But the “triumph over adversity” narrative has well and truly run its course. It is time for another, collective narrative that focuses on social justice, social change and collective action to take the place of this narrow, individualist perspective.

## **When “Human Rights” Discourses are Useful**

This analysis has suggested that neoliberalism and broader social inequalities are deeply connected, and that it is necessary to challenge hegemonic discursive connections between neoliberalism and a human rights discourse. However, that does not mean a human rights discourse is not useful for disability advocacy. Far from it: a human rights discourse which foregrounds notions of empowerment, participation and accountability can be a useful tool for political mobilization against hegemonic neoliberalism (Chapman 2009). Farmer (2003) makes a

more direct connection between human rights violations and the unequal risks of experiencing illness, disease, and disability, suggesting that the same forms of political and economic inequality which lead to the spread of diseases like HIV also create the unequal risks towards human rights violations.

A progressive human rights discourse is clearly a valuable tool for social change. Such a discourse might argue (for instance) that every citizen of the world has the right to clean water (and that it is not just another product to be sold on the free market), or might highlight the human rights abuses (and risks of disability and illness) associated with war or starvation. Or it might highlight the ways in which neoliberal policies reinforce the poverty of the Global South, thereby actively harming the health and lives of millions of people. In such a context, a human rights discourse might be crucial to protecting the living conditions of the most disadvantaged individuals, and challenging neoliberal policies which disproportionately benefit the wealthy—both at an international and local level.

The impulse for disability advocates to get behind international human rights conventions is perfectly understandable – there is a desperate need to address the discrimination, prejudice, lack of access, hostile attitudes, alarming levels of abuse and hate crimes, social barriers, and widespread social exclusion that affects everything from opportunities for work to interpersonal relationships. But the question remains: is the discourse of human rights – wrapped as it is in contemporary neoliberalism – the most useful way of advancing this cause? Given the power of neoliberal organizations such as the World Health Organization or the World Trade Organization within international treaties, as well as the dominance of neoliberal ideas among countries in the Global North, there is every reason to be suspicious.

Bumiller (2008) has argued that the feminist movement's current reliance on the state to achieve justice regarding sexual violence is problematic because of its expansion of state power over the lives of women. Moreover, the strategies adopted by the state tend to be individualistic rather than collectivist (another effect of neoliberalism). A similar argument could be made with regard to disabled people. The effect of neoliberalism has been to narrow the range of options which are considered in order to protect the rights and freedoms of disabled people.

Returning to the issue with which I opened this essay, my attitudes towards disability have been indelibly shaped by my work in disability advocacy in both Australia and the US. I have been deeply influenced by the stories of the thousands of people who I have worked with – stories that have occurred against the backdrop of an ascendant neoliberal human rights ethos. I have heard countless stories of abuse, social isolation, disrespect, poverty, and injustice. These stories have emotionally scarred me, but also left me deeply angry at the hypocrisy of a neoliberal agenda which promises human rights and delivers social exclusion, prejudice and discrimination. The answer is not a *laissez-faire* approach to economics and a crackdown on welfare fraud; these are policies in the interest of the wealthy and the privileged, at the expense of poor people and disabled people. The answer is not a rhetorical commitment to human rights against a backdrop of ignorance, abuse, and thinly-disguised indifference. If a human rights discourse is

to make meaningful change in the lives of disabled people, it must break free from the shackles of neoliberalism. Human rights are worth fighting for – not just in the Global North, but internationally. But the struggle for meaningful human rights cannot be realized in a context of policies shaped by neoliberalism. The promise of real human rights for disabled people requires a far more radical change than that.

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## Chapter 2

# The New Humanitarianism: Neoliberalism, Poverty and the Creation of Disability

Maria Berghs

Due to the efforts of disabled people's organizations and activism, 'disability' has now become part of supernational policy, practices and language. This has meant a move away from a medical model of disability where impairment was seen as the cause of disability to one that acknowledged the social creation of disability and thus the need to change social and political conditions to ensure inclusion of disabled people. In an effort to reflect such broad understandings of disability or a 'bio-psycho-social' model, the World Health Organization (WHO) now uses an International Classification of Functioning definition of disability where:

Disability is the umbrella term for impairments, activity limitations, and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors). (WHO 2011, 4)

The efforts to ensure that disability become a global issue began in the 1980s by ensuring that the United Nations (UN) gained awareness of the needs of disabled people, for example, in terms of rehabilitation or accessibility (Yeo 2005). By the 1990s, there was a move towards human rights to ensure legislative protection and social changes to ensure inclusion. The culmination of this human rights and social model approach was the UN's Convention on the Rights of Persons with Disabilities (CRPD), which came into force in May 2008. Article 11 of the CRPD specifically outlines obligations of nation states to disabled people to ensure their human rights and protection during situations of risk or humanitarian emergencies.<sup>1</sup>

A legislative instrument linked to development aid, the CRPD elucidates how disability 'mainstreaming' is now an integral part of many policies, projects and sustainable development. Disability mainstreaming:

is a strategy for making disabled people's concerns and experiences an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes in all political, economic and societal spheres, so disabled

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<sup>1</sup> 'UNCRPD', United Nations Enable, <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> (accessed 28 Nov. 2012).

people benefit equally and inequality is not perpetuated. The ultimate goal is to achieve disability equality. (Albert and Harrison 2006, 6)

Development is a contested term, defined by international institutions such as the World Bank (WB) and International Monetary Fund (IMF) (Escobar 2012). Disability thus remains shaped by a teleological worldview that posits governance of aid, biomedical intervention and imposition of neoliberal norms and values on the global south. At its heart is still a 'racial discourse' tied to a history of eugenics that has not changed much since colonial times (McClintock 1995; Duffield 2007). This 'civilizing' mission, integral to a colonial governing project over bodies and land, was tied to Social Darwinism and medical making of 'fit' and 'unfit'.

Just as the colonial conquest revealed the polemical intersections between religion, gender, class and 'race', the current focus in foreign policy associated with disability reveals a neo-colonial (dis)ablism discourse predicated upon a healthy white rich able-bodied norm. Generally speaking, disabled people have not been included in development aid nor poverty reduction work as active and equal partners (Albert and Harrison 2006). Notwithstanding the emphasis on disability mainstreaming in the CRPD, in development discourses, and international debates, disability is chiefly connected to the fight against poverty. Kate Manzo (2008) explains how all rights based models now encompass the alleviation of poverty as a basic human right. This imposes a subtle hierarchy, wherein poverty must be alleviated first in order to access other rights. A delimited understanding of disability is formed; where it is viewed as an economic 'problem' and this underlies humanitarian aid.

According to the World Health Organization (WHO 2011, 29), an estimated 15.3 per cent of the world's population has 'moderate or severe disability'. While disability encompasses a wide variety of impairments, mental health diagnoses, and chronic conditions, it disproportionately affects 'vulnerable' people such as those living in low income countries with women, children, aged and minority groups particularly affected (WHO 2011, 27). The word 'vulnerability' in this context is contentious when applied to these groups of people due to its paternalistic overtones, which imply that there is a need to prevent or protect without ascription of agency. By contrast, Rebecca Yeo (2001) elucidates this 'vulnerability' in terms of susceptibility, arguing that a chronic poverty-disability cycle exists because living in poverty makes people more susceptible to impairments, due to such factors like hazardous working and living conditions. Correspondingly, Yeo maintains that people incur more costs as a result of their impairments and are more prone to poverty due to 'institutional, environmental and attitudinal discrimination', resulting in a lack of inclusion and disablement (4). Despite moot points on language and models of disability used, most disabled people's organizations (DPOs), activists and charities have affirmed a commitment to fighting poverty and thus disability.

Following suit, Simon Maxwell (2003) observes that combating poverty has now become part of international institutional policies, instantiating a revised

poverty agenda. According to Maxwell, the anti-poverty agenda includes five identifiable elements (5–6):

1. Millennium Development Goals (MDGs) with their 8-point plan to reduce poverty
2. International agreements on how to reduce poverty set by the World Bank
3. Poverty Reduction Strategy Papers (PRSPs) or the agreed actions each country would take to reduce poverty as a condition to aid
4. Technologies for delivering aid in form of budget support to a government
5. Commitments to results based management of aid.

In this way, finances and aid to rebuild after a conflict, reconstruct after a disaster, or combat poverty are regulated by institutions such as the WB and IMF (working with the World Trade Organization) necessitating ascription to neoliberalism. Neoliberalism is a capitalist economic and political system extolling free market trade, deregulation, privatization and the rolling back of the welfare state. This demands that an agenda to combat poverty is now linked to neoliberalism and affirms management style techniques but also consumerism. A good example of this is the United Kingdom Department for International Development (DfID) (2011) conducting evaluations of their multilateral aid to see if their poverty targets are being met. The post 2015 agenda will see greater diffusion of the concept of poverty in terms of determinates of health that can be measured more easily.

Notwithstanding the emphasis on fighting poverty, neoliberalism has thus created new ‘geographies of poverty’ with increases in inequality in both north and south (Kitson et al. 2011). Neoliberalism mainly advantaged large multinational corporations and simultaneously led to the dismantling of welfare state structures and access to services that typically acted as a safety net. In addition, neoliberalism has benefited those with some kind of capital such as education, money or skills appropriate to emerging post-Fordist economies. To be sure, disabled people are not all vulnerable, poor or unemployed. However, neoliberalism has disproportionately negatively affected disabled people and globally created more unemployment and impairment (Hiranandani et al. 2011). It is worth remarking that, even for those benefiting from neoliberalism, any negative changes in social, cultural, political, legal and economic environment can quickly shift from enabling environments to disabling.

For example, economic booms have negative consequences by engendering impairment through social upheaval and increases in pollution affecting chronic, neurological or mental health conditions limiting the ability to work. Austerity too can mean cuts in services, jobs, devices and technologies specifically for disabled people and their families. Discounting the fact that there have always been groups of severely disabled people who will never be able to ‘work’, there are now new geographies of disability and poverty, as indicated in the intersectionality of groups affected by neoliberalism who are typically disabled people who are; uneducated, women, children, elderly and from ethnic minority groups or living in areas of

deprivation. These same groups of people have always been more 'vulnerable' to poverty and disability.

Why are these groups of people being disproportionately affected? Despite the WHO definition of disability as social and the UN's emphasis of a 'person first approach' in the CRPD, these institutional foci occur at the cost of disability and prevention of impairment. In the UK, austerity has led to a rationing of care, leading to more poverty. The label of 'disability' within this context is limited to only the severest forms of impairment (Roulstone and Prideaux 2011; Oliver and Barnes 2012). Defined as a public health and an economic problem, disability is closely connected to interventions and even humanitarian aid. Indeed, the emphasis is not on inclusion but rather on impairment as a particular and at times preventable problem that costs money and affects state resources (Garthwaite 2011). Additionally, the idea of 'prevention' is in keeping with a 'new humanitarianism' that is being shaped by new foreign policy. That policy has as its goals a tactical approach that seeks to intervene to stop conflict, prevent causes of violence, and ensure neoliberalism. In such an understanding of the global, violence and conflict are viewed as inevitable risks that need to be controlled but similarly as opportunities to increase governance (Duffield 2001).

Humanitarianism in global neoliberal discourses and imagery connected to the fight against poverty and disability has – under the influence of rationing of care – become commodified. The earliest signs of this were in the late 1990s, with the inclusion of indicators of cost-effectiveness, evidence, and the use of Disability Adjusted Life Years (DALYs) as measurement of disability (i.e. Griekepoor et al. 2000; Banatvala and Zwi 2000). Concomitantly, there was an increased focus on the monitoring and evaluation of humanitarian aid, impact assessments and military interventions where the apolitical and 'gift' aspect of humanitarianism was left behind in favour of the measurement of cost-effectiveness of practices and value for money. There was also an increase in bilateral aid going directly to governments but with conditions to budget allocations and outsourcing by non-governmental organizations (NGOs), as well as the privatization of aid and care in public-private partnerships.

Situated adjacent to this process, Mike Duffield (2001) argues that there has been a move away from aiding states to those seen as most vulnerable and poor within specific population groups such as children, mothers, old or disabled people. Adding to this, Maria Kett explicates a move away from a 'blanket' towards a more 'targeted approach' that she says is only used, 'for food and emergency non-food item distribution' (2010, 347). Yet, she overlooks the specialised NGOs and corporate services now dealing with rehabilitation, reconstruction, and research for disabled people. These NGOs and corporations are also a part of public-private partnerships where their services are (sub) contracted because they are not seen as part of the general rehabilitation and reconstruction of the nation state (Binder and Witte 2007). To ensure that these public-private partnerships between institutions, states, and the myriad organizations contracted are overseen, there was a need for 'new contractual regimes' (Duffield 2001). Maxwell (2003) avers, these new

technologies certify that aid is delivered to budget priorities according to principles of management; correspondingly, Duffield (2001, 308) cites; ‘standardization, benchmarking and performance auditing’ as given assurances.

Within the humanitarian sector, there have been efforts to ensure accountability, such as the Active Learning Network for Accountability and Performance in Humanitarian Action (ALNAP) and the Sphere Project – both a guidebook and charter to disaster relief.<sup>2</sup> Since the late 1990s, mechanisms have been put in place to ostensibly guarantee accountability of humanitarian aid such as the Sphere Project’s Charter and the Red Cross/Crescent Code of Conduct. The Overseas Development Institute (ODI) (2003) note that in light of exploitation in refugee camps in West Africa in 2003, rules and codes of conduct have also become attractive to NGOs themselves with a Humanitarian Accountability Project (HAP) instantiated. Likewise, there have been greater calls to understand budgets and finances, so an International Aid Transparency Initiative has begun.<sup>3</sup> Even with these provisions, the political and legislative oversight over these initiatives is unclear due to lack of culpability (e.g., who is doing the measuring) and the ambiguity between surveillance, security and measurement.

Both Naomi Klein (2007) and Linda Polman (2010) show how legal and illegal economies are still built up around disasters, conflict, genocide, and humanitarian emergencies and aid does not always benefit those who need it most. Likewise, HelpAge and Handicap (2011) reviewed financing of humanitarian aid projects in 2010–2011 and they found that only 1 per cent of humanitarian aid went to people with disabilities and older people. The primary tool used was the Financial Tracking Service (FTS) implemented by the UN’s Office for the Coordination of Humanitarian Affairs (UNOCHA) which reviewed data from over 6,000 projects in the context of 14 UN Consolidated Appeal Processes (CAPs) and four Flash Appeals.<sup>4</sup> It should be noted that this was several years after the CRPD came into force. These assessments raise the question of what is really meant by the ‘new humanitarianism’ and why technologies of measurement and management are not working, especially if they are becoming increasingly specialized. Ideally, such apparatuses should increase control over humanitarian aid, improve performance, and target aid to those who need it the most such as those who are deemed most ‘vulnerable’ to poverty and disaster. A related question involves the implementation and enforcement of the CRPD, which is at present reliant on mainstreaming of disability.

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2 Active Learning Network for Accountability and Performance in Humanitarian Action (ALNAP), <http://www.alnap.org/> (accessed 28 Nov 2012). Sphere Project, <http://www.sphereproject.org/> (accessed 28 Nov 2012).

3 Aid Transparency, <http://www.aidtransparency.net/> (accessed 28 Nov. 2012).

4 According to HelpAge (2011: 5), ‘CAP and Flash Appeal documents are used as planning tools for donor support’. They are approved by the UN and form a basis for funding humanitarian aid.

## Commodifying Disability

This lack of inclusion reveals that new neoliberal humanitarianism is built on a commodification of disability founded on a new technological rationalism and refined medical model of disability. At the heart of this rationalism lies a virtual world which seeks to map data in order to offer top down evidence to justify policy and practice in humanitarian aid. For instance, the UN's Global Pulse initiative seeks to 'map' or offer data analysis solutions to real life problems; while commendable, the work is inherently positivist.<sup>5</sup> Based on Western-Enlightenment understandings of knowledge, the initiative posits that the more we know or dissect something, the more we understand it and therefore the more malleable and controllable it becomes. In this worldview, impairments are likewise 'virtual' problems that need to be overcome by practical solutions such as medical intervention or rehabilitation (Barnes 2003). This is reminiscent of a medical model of understanding the world; within this refined model, an individual subject's world can be controlled and changed virtually and practically, if not by themselves then by others. Such analysis eschews structural and historical conditions of inequality, the sociocultural nature of people within communities, and the specificity of disability. Moreover, cognitive impairments or mental health difficulties which problematize data solutions and rational choice theory are summarily ignored. And, the focus is increasingly on physical impairment or public health prevention. Prevention of impairment poses the easiest solution in offering medical aid which can be measured, evaluated and followed up with public-private partnerships of care. As Rajeev Patel and Philip McMichael (2004) elucidate, this practice of humanitarianism is controlled by market forces and privatized:

In the current global trajectory of privatization of services, access to healthcare, for example, heightens the policing of bodies – payment systems demand an accounting system at the level of individual bodies, and with that accounting system a prior history of health and of access to cash (and hence paid labour) for the patient. It invokes an entire system of state monitoring, evaluation by capital and control of individuals, individuating bodies as repositories of asymmetrical and delimited (market) rights. (240)

With an internationalist focus on healthcare in public health, one would expect a wealth of data on disability but there is a dearth, particularly with regard to humanitarian contexts such as disasters or conflicts (Kett 2010; WHO 2011).

The absence of useable information reflects an imbalance of power in terms of data-collection, which remains top-down and occurs without the participation of disabled people advocating their needs. The data-analysis solutions presupposed are correspondingly short-term in order to make immediately discernible but not necessarily sustainable. This is due to the fact that solutions are offered within a

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5 United Nations Global Pulse, <http://www.unglobalpulse.org/> (accessed 5 Nov. 2012).

policy landscape wherein long term political support and funding is not always assured in austere times. Despite the fact that austerity is linked to the volatility of the free market, data or numbers have a scientific gloss and are seen as incontestable. They appeal to the shorted attention span of a humanitarian consumer who has to feel a new kind of moral engagement that comprehends change in terms of ‘giving’, ‘counting’, and ‘fighting the tragic’. Typically, it is the consumer’s choice of how much to give and thus clear indicators need to be publicized between budgets and aid (e.g., £30 will provide food for a child for a month). Following suit, in times of austerity, NGOs have begun giving breakdowns of how each pound is spent and promoting smaller monthly contributions.

Philippe Calain, drawing on Didier Fassin’s (2007) work, notes how public representation has shifted to a bio-political victim–agency debate wherein those suffering are viewed as ‘others’ or victims who need another person to bear ‘witness’ and ‘give’ (Calain 2012) or save. Correspondingly, disabled people are medicalized and objectified to ensure economic support for aid.<sup>6</sup> While there is undoubtedly a need for medical aid, bearing witness, and documenting injustice, Manzo (2008) and Calain (2012) assert that the same norms regarding informed consent, use of imagery, and dignity in photography should apply in the global south. Likewise, we must interrogate why virtual technologies are not used in humanitarianism to engage a more critical dialogue that relocates representation and the act of witnessing to local people (children and adults).<sup>7</sup> Even in cases where this is done, data is collected to serve as ‘evidence’ for what people voice but this has to be in terms of the work of the NGOs or their conceptions and understanding of disability. Similarly, Peter Retfield (2006) contends that the need for evidence to justify policy and practice instantiated the creation of MSF’s Epicentres in the 1990s to collect epidemiological data.

Evidence also needs to be given for the donations that people make so when voices of disabled people are used to highlight inclusive practices it is still within a charitable, medicalized or neoliberal context focusing on employment and not necessarily social justice. Examining the webpages of major NGOs reveals a profound absence in terms of real data about disability; instead these sites are primarily constructed for fundraising purposes. World Vision, Oxfam, Save the

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6 The ‘disabled’ body also acts as a metaphor for a ‘disabled’ state and fits within the security apparatus of humanitarian interventions. Likewise, there is a long history of using disabled children in charities, telethons and aid work to gain access to funds. This is despite the inherent contradictions in using disablist imagery to supposedly enable and prevent disability, see, for example, John Davis and Nick Watson, *Countering Stereotypes of Disability: Disabled Children and Resistance*, in Mairian Corker and Tom Shakespeare (eds) *Disability/Postmodernity* (London: Continuum, 2002) 159–74.

7 While there have been spoofs, such as Radi-Aid, <http://www.africafornorway.no/> (accessed 28 Nov. 2012) or Pimp my Aid Worker, <http://www.pimpmyaid.org/> (accessed 28 Nov. 2012) these have come from the north and not the south and are just as decontextualized as the campaigns they ironically critique.

Children, International Rescue Committee (IRC), Médecins Sans Frontières (MSF) and Concern are among some of the NGOs that have signed up to the humanitarian guides and charters. They have promoted working with disabled people using the social model of disability. For instance, Oxfam promotes a training manual on how to include disability rights and equality for development and humanitarian organizations. By contrast, public bodies such as institutions dealing with humanitarian aid like the European Commission's ECHO or UN's OCHA offer more information and data mainly because their mandate as public bodies requires them to do so.

Most NGOS now have specific webpages for humanitarian responses targeted to gain aid for vulnerable and poor children as well as their families. Some NGOs make an effort to ensure information linked to poverty or disability and take seriously disability mainstreaming. For example, Oxfam does illustrate the plight of Sudanese refugees with a picture of a group of refugees sitting down near a tree and amongst the group is a man with a crutch.<sup>8</sup> While passive, the image of a male disabled person in such a setting is rather unusual. When disabled people do appear on websites they are still linked to children and not ascribed agency (i.e. as breadwinners). World Vision too has a picture of an emaciated African child sitting down with a person with folded feet and legs behind it. The gender, nationality and other information linked to the child or person sitting behind the child is not given. The text near the picture indicates that by donating money you are aiding people to 'wholeness'. Likewise, Women's Refugee Commission has a lot of children on its website but uses an image of a smiling disabled woman in a wheelchair to highlight an appeal for 'voices of courage'. The image still uses a 'black' child next to an attractive 'black' disabled woman who is represented as passive and missing a leg.

The polemical connection to 'courage' underscores a representation politics that strategically uses concepts of 'race', religious charity, pity and heroism (with regard to impairment). Denis Kennedy (2009) explains that images that are accessible, like children, need to be used to sell a 'distant other'. Concomitantly, the iconography of children is deployed to signal humanitarian value of neutrality and impartiality as a kind of branding exercise that makes the link to human rights (Burman 1994). In much of the online imagery about the Syrian humanitarian crisis, children as traumatized victims persist and dominate.<sup>9</sup> These images often touch on tropes of suffering, death and lack of dignity but in a decontextualized, neo-colonial, paternalistic and ethically problematic way, especially if they are connected to disability (Manzo 2008, Wehbi et al. 2010). If disabled people are represented it is also still in distorted terms where specific impairments or lack of a

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8 Oxfam, <http://www.oxfam.org.uk/what-we-do/emergency-response> (accessed 5 Nov. 2012).

9 RedCross, <http://www.redcross.org.uk/About-us/News/2012/September/Humanitarian-situation-rapidly-deteriorating-in-Syria-and-bordering-countries> (accessed 5 Nov. 2012).



**Figure 2.1** Afghan refugees in Jalozei camp, Pakistan

*Source:* (UNHCR/C. Shirley, 2001)

body part are used as symbols of a crisis: ‘Disabling stereotypes which medicalise, patronise, criminalise and dehumanise disabled people’ (Barnes 1992).

In sum, (dis)ablist imagery are drawn on to affectively structure feelings of pity, despair, and disgust. I deliberately use the term ‘affective’ to convey a physiological intentionality that problematically structures a negative emotional response (Massumi 1995). This physiological reaction and negative emotional judgement is engendered through the distance created by the use of images that dehumanize. It is insidious in that it provokes a negative bodily response, as well as emotional judgement, through the loss of authentic portrayal. Body parts become ‘othered’ or sites of spectacle and sensation while embodiment and personhood is lost. This is reflected by the UNHCR which has a special page on ‘Persons with Disability’ about how they are invisible and largely forgotten.<sup>10</sup> While seemingly trying to address flaws of past NGO or institutional campaigns excluding disabled people or using (dis)ablist imagery, the site replicates a narrative of objectification. For, example, the page features a picture of the bottom part of a body with a missing leg, reinforcing the invisibility of a person while increasing the visibility of impairment in terms of ‘lack’.

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<sup>10</sup> United Nations High Commissioner for Refugees (UNHCR) /C.Shirley (2001) Afghan refugees, in Jalozei camp, Pakistan. <http://www.unhcr.org/pages/4a0c310c6.html> (accessed 5 Nov. 2012).

What is generally focused on is the impairment as a kind of ‘fetish’ (Shakespeare 1994) of the physical body or the voice of ‘trauma’ (Fassin and Pandolfi 2010). A commodification of the body and its parts is engaged in (Scheper Hughes and Wacquant 2000), because, as Fassin (2007) has described, it is only the ‘suffering’ body that is according legitimacy or a person in pain. It only becomes legitimate to participate in humanitarian action on reductive or essentialist grounds expressed as ‘bare life’ (Agamben 1994). Why that ‘bare life’ or state of biological exception is located in the global south or constructed on the site of what is defined as disabled or impaired is never really investigated (Patel and McMichael 2004; Overboe 2007). Nor as Paul Gilroy (2000) has examined, are the bio-political consequences of reducing people to their bodies and the kind of far reaching governmentality that espouses.<sup>11</sup> If a body can be dissected into ever smaller parts or measured as object, it is replaceable and replicable and thus open to any (i.e. genetic and/or medical) intervention. Yet, disability is something that has to be immediately visible (impairment) or articulated (suffering) which is problematic and can lead to the intentional creation of disability as this becomes a condition for aid. This kind of objectification also has consequences for how subjectivities linked to disability are being fashioned and understood in delimited unrealistic terms.

### **The New Consumer and Moral Control**

Virtually, there are seemingly no boundaries and borders between ‘us’ and ‘them’. However, disability becomes an object of pity when the consumer and their body are the sites of the norm or normal. The control is also in the hands of the consumer who is always posited as in a virtual space, ‘white’ and with the ability to give money to the ‘other’. In this way, the ethical imperative of ‘the Other’ (Levinas 1984) gives way to consumer-driven and essentialized remote moral imperative. The privatization of services and a delimited welfare state give rise to an ‘entrepreneurial self’ aligned with consumerism that manages identity through economic actions (Giddens 1992, Peterson and Lupton 1996). This coheres with the tenets of neoliberalism, which encourages a teleological project of self-fashioning, now virtually and through others. Globally, moral subjectivities are imbricated in a narrative of neoliberal individualism that perceives ethical action through bodily-influenced gift control and gift making.

Correspondingly, ‘giving’ must both be simplified and targeted towards an ethical appeal in order to refocus attention on the giver. An example is the Just Giving website which allows individuals to set up a personal webpage but also gets users to control and target their monetary donations.<sup>12</sup> The website includes advice about social networking like Facebook and how to increase donations to your fundraising appeal or charity with an easy click of the button or direct text.

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11 I am thinking of ‘remote’ control and governmentality, such as the use of drones.

12 JustGiving, <http://www.justgiving.com> (accessed 5 Nov. 2012).

The website is unique in that it; firstly, offers a more select and targeted approach to gift giving, secondly, there is an interactive and more personalized approach to fundraising, and thirdly it is simple to use and does not really require engagement.<sup>13</sup> This is because it falsely reduces and reconstructs the distance between giver and recipient. Disabled people have also set up pages but often in English and using the global scripts that donors can understand, for example, ‘disability is not inability’ or for a specific project like a water pump. While it is democratic, it also does away with idea of ‘gift’ in that certain socio-cultural, political and ethical norms, values and expectations are encountered in the act of making donations of money. Gift giving aligns a fundraiser, charity or humanitarian appeal to a ‘humanitarian’ identity perceived as positive in their terms. There are also more links to social media and the understanding that engaging in humanitarian action also reveals something about a person’s identity, politics and social networks as aspirational. In a sense, Zygmunt Bauman’s (1998) synopticon shifts back onto the viewer (now donor), with the few not only observing but wanting a specified form of action from the many.<sup>14</sup> The new neoliberalism posits a new form of governmentality through the creation of institutional affect and desire (Deleuze and Guattari 1987).

Hence the UN also focuses its fundraising, information and activities around the idea of a consumer whose humanitarian ‘gift’ is intentionally self-reflective. The clearest illustration of this was in the campaign to raise awareness of World Humanitarian Day (19 August). The UN website states, ‘This year’s campaign “I Was Here” is about making your mark by doing something good, somewhere, for someone else’.<sup>15</sup> In such a campaign, there is a focus on the ‘I’ or individual wanting to do ‘good’ for an ‘other’. The campaign reveals a belief in an ability to control the world and act towards change through individual actions, located on the site of bodies. Ideas of ‘governmentality’ and ‘docile’ bodies that can be kept under surveillance, fixed and fashioned within neoliberal regimes put the emphasis back on an individual as body and consumer as desiring certain bodies (Foucault 1995). The unhealthy or disabled body represents disorder and deviance from normality which must be prevented (Davis 1995). The responsibility for fighting against such visible inequality or aiding in disasters is thus moved towards the individual from the state. You can argue that due to the insurmountable aspect of such as responsibility, a distance is necessarily evoked and needed, as individual responsibility is also understood in terms of a moral project of risk prevention.

This need for control is linked to current anxieties related to ‘managing’ risks of poverty, vulnerability and disability in a time of austerity. Ulrich Beck (1992) argues

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13 This extends into the work of development and humanitarian aid where a certain distance is also instantiated. See, Fechter, Anne-Mieke, ‘Living Well’ While ‘Doing Good’? Missing (Debates) on Altruism and Professionalism in Aid Work, *Third World Quarterly* 33(8) (2012): 1475–91.

14 Note that I do not use the word ‘interaction’ or ‘engagement’.

15 United Nations Humanitarian Day, <http://www.un.org/en/events/humanitarianday/> (accessed 28 Nov. 2012).

that modernity means that we live with increased concepts of risk and the adoption of diverse strategies to mitigate those feelings. Those feelings are acutely highlighted by media messages about living through times of increased risks such as; economic austerity, breakdown of the state, terror, poverty, conflict, environmental disasters and so on. At the same time, the development of new security apparatus, (bio) medical, technical and research specialisms (i.e. social determinates of health) mean that we can expect greater biological and technical governance which we express in neoliberal humanitarianism. Self-fashioning posits choices and preferences in terms of management of 'risks' and 'control' revealing that moral intervention is now part of our personal responsibility of an ethics of care.

Ananta Kumar Giri and Philip Qarles Ufford (2004) note that there has been a shift towards results based development where we only engage in actions if they are simple to do and we know that they will have real ramifications. We infer from our perception of a 'malleable' self that all selves are malleable and that ethical action should be interventionist disciplining and preventively fashioning bodies. We also engage in actions according to 'our' ethics and norms influenced by neoliberalism so they get an economic slant, for example, microcredit or microfinance has been viewed as a means to aid empowerment of women. Donors want money to go to specific women or women's groups to 'help' themselves out of poverty focusing on economic action and gender relations. Yet, critical case-studies from areas with long histories of microfinance, like South Asia, illustrate complexities. While disabled people are typically excluded, Vandana Chaudhry (2011) illustrates when included in neoliberal community practices, the intersectionality of disablement with structural, material and political factors is ignored and emancipatory 'pedagogies and frameworks' are 'co-opted and depoliticized' with damaging outcomes. Meghan Moodie (2008) too nuances that microfinance may not 'work' in terms of empowerment of gender relations or economic gain but is refashioned and accepted by women due to other webs of political and social relations of indebtedness within female networks. Both illustrate resistance as well as how people have no real choice but to engage with neoliberalism.

In humanitarian aid the idea of freedom of choice or giving choices (a principle of consumerism) is neglected and instead personal responsibility for governmentality of others is enforced by using simple symbols such as the iconography of a child or body part to ensure the consumer understands a message quickly. It is related back to messages that are a part of simplified campaigns that they have heard before i.e. 'Make Poverty History' or discourses linked to disability they understand, such as disabled people as tragic and needing charitable aid.

## **Conclusion**

The above illustrates the limits of the disability rights movement and the CRPD in how neoliberalism creates disability in post-modernity. There is a neo-colonial flow of information and aid towards the global south or poor people in the north,

typified by an absence or tokenism of disabled people and messages geared towards a virtual world of gift-giving to fight poverty. This is typified by an individual need for control of risk linked to management of current anxieties about austerity and 'disorder' aligned to disability. Management of gift giving is hyper rational and linked to a refined medical model which constructs disability as a problem on the site of a body part that needs to be targeted but with evidence for a cost-effective intervention. Interventions usually target either medical or economic aid, in line with priorities of neoliberalism, simplified in a message of giving towards NGOs or programmes that aid or rehabilitate disabled people to become economically viable citizens. Yet, they also act as a metaphor of insecurity which needs control. The role of the state and idea of new humanitarianism as political intervention to stop the escalation of conflict or a disaster, or even understandings of conflicts as opportunities to gain geopolitical and economic power is disguised. The conception of hegemony or analysis of power, racism, sexism and (dis)ablism is done away with in humanitarian aid and there is often no examination of a legacy of neo-colonialism, political influence of donor or previous international economic policies; such as learning from the mistakes of the structural adjustment policies. Instead the focus is strictly on aiding a humanitarian disaster or crisis aligned to a new neoliberal humanitarianism often linked to messages about combating poverty to instigate a new economic regime. Combating poverty is never understood as part of neoliberal project or what Patel and McMichael (2004) term the 'financial discipline' or surveillance of states as bodies.

Post-modernity shows a greater fluidity in how poverty, vulnerability and disability are embodied and encultured illustrating widening inequalities between people and how those are formed and understood (Connell 2011). An essentialist and reductive focus on how those inequalities are symbolised on the site of a missing body part, pain or prevention of disability erases understandings of how those inequalities are formed by various conflicting discourses, practices and policies both nationally, transnationally and supranationally. Colin Barnes and Alison Sheldon (2010) have argued that without fundamental structural changes at an international level, globalization will just lead to the perpetuation of greater inequalities. Neoliberalism is based on policies by the WB and IMF and the links between these macro policies and humanitarian aid, conflict and crises have not been explored. The implementation of the CRPD and disability mainstreaming is not a reality and again posits a neo-colonial move of rights, models and images to the global south. The effects of those policies on local people or whether rights can function within non-existent, weak state structures, patrimonial exchange systems and/or dictatorships are rarely examined (Meekosha and Soldatic 2011). Often there is a disjunction between policy and practice, for example in the case of illiberal foreign policy where economic rights of states have more clout in the new humanitarianism than human rights. A paradox thus exists in humanitarian efforts to rehabilitate the nation state and promote democracy, in that those very efforts may (re)fuel inequality, create violence, impairment and disability or ensure the

status quo (James 2010; Berghs 2012). Alex de Waal (2011) explains that elements of cruelty and suffering can become a part of humanitarianism.

Disabled people can be created and be symbolic of a conflict or disaster but they are never humanitarian aid priorities in the rehabilitation of a state, NGO or donor funding. The state's apparatus does not change or come into existence just because there has been a disaster or crisis. Other visible and invisible flows of information, exchange, bodies and money exist side by side with new budgets, people and norms that are being imported and thus refashioned, rejected and resisted. In many countries or borderlands, economic 'management' or discipline of self or selves is just not possible and disabled people are included regardless or remain open to discrimination and misfortune. Legislation or a state's adherence to the CRPD on a macro level may not trickle down to the micro level of individuals trying to survive a crisis. Post-modern biopolitical governance and ascription of rights are now linked to suffering, body parts and trauma which invalidate transnational, global and local ascriptions of personhood, identity and the role of the state.

Disability is still seen as a separate issue that needs supranational medical specialization from particular NGOs. Data has to affirm how disability is being prevented or people integrated economically. At its heart, the new humanitarianism will never affirm the human rights of disabled people, partnership or inclusion. Instead, it is concerned with the neo-colonial and neoliberal surveillance of 'bare life' and suffering due to its links to poverty. Humanitarian actions are part of globalization coming into contact with states and populations, sometimes ensuring more inequality. A new humanitarianism promotes an apolitical project of aid that does away with the structural, institutional and individual interplay and networks which constitute the disablement of people and states.

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## Chapter 3

# Media, Disability, and Human Rights

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In a 2010 op-ed entitled ‘Iain Duncan Smith on Benefits Britain’ that appeared in *The Sun* newspaper, political editor Tom Newton Dunn (2010) cited Iain Duncan Smith’s claims that disabled people were responsible for the UK deficit (Jolly 2011). The article commented on an interview with the Work and Pensions Secretary where he drew a direct link between UK economic turmoil and the ‘workless’. The article claimed that the officials at the Department for Work and Pensions had told Duncan Smith how easy it was to simply fill in a form, send it off, ‘sign on’ and cheat the system in order to get the ‘hand-out’ of up to £91.40 a week. He discussed a cultural shift, from days when Britain had been the workshop of the world, which gave everybody the free market and the industrial revolution, to today’s ‘shirkers’ paradise’ in which ‘a block of people’ like the Brazilian singer Wagner Carrilho, have become ‘conditioned to be users of services, not providers of money’. Carrilho was voted off *X Factor*; nevertheless according to *The Sun* article he performed his energetic dance routines on the show whilst claiming incapacity benefit for an injured shoulder. In his interview Duncan Smith went on to say ‘This is what the benefits system has become – a deep incentive for people to do no formalized work’. Such misleading claims about Disability Living Allowance (DLA) and Employment Support Allowance (ESA) have fuelled and reinforced the public’s negative attitude towards disabled people.

To be sure, this negative portrayal of disabled people coheres with a larger trend in British print media; as Emma Briant, Nicholas Watson and Gregory Philo (2011) have documented, a total number of 713 disability-related articles appeared between 2004 and 2005. Five years later, between 2010 and 2011, the amount of published articles about disability increased to 1,015. Not only were disabled people more ‘visible’ in mainstream British media; their bodies formed the basis of an increasingly volatile debate over state-sanctioned, state-authorized benefits (Briant et al. 2011). Missing from these pieces were accounts of disability discrimination, societal attitudes, and physical, social and economic barriers. This shift in emphasis reflects a wider attitudinal change, characterized by ‘society’s growing antipathy towards disabled people’ (Riley-Smith 2012, unpagged), and hence negates the gains in social acceptance won by the Disabled People’s Movement over the last several decades. This has also been argued by Scope (a UK-based disability charity) and a coalition of 50 other third-sector organizations (Briant et al. 2011).

The exploitative portrayals of disabled people in general and disabled women in particular have engendered a pervasive culture of fear with a number of high profile cases wherein disabled women are the targets of violent attacks. As Ben Riley-Smith states, ‘The number of disability hate crimes reported to police has reached a record high, sparking concerns that the Coalition’s ‘anti-scrourger’ rhetoric is fuelling hostility to the most vulnerable members of society’ (2012, unpagged). Many scholars maintain that negative representations of disability have reinforced the rise in incidents of disability hate crime, which has almost doubled since the start of the financial crisis in 2008 (Briant et al. 2011; Clark 2012; Kaye et al. 2012). It is this link between negative portrayals of disability and disability hate crime that foregrounds this chapter, which considers the relationship between disability, media, and human rights. In particular, I am interested in the ways in which the hostile treatment of disabled women in Britain is attributable to the mass circulation of ableist images of ableist bodies. I conclude the essay by discussing how the British Coalition Government’s ‘Reform for Welfare Provisions’, a large-scale comprehensive spending review introduced in May 2010, is leading to the intensification of these violent crimes and is exacerbating the existing discrimination against disabled women’s human rights.

### **Gender, Representation, and Disability**

Despite the British government’s claims to welcome ‘media’s challenge to stereotypes and the portrayal of women in a positive manner’ (Convention on the Elimination of all forms of Discrimination Against Women Report 2011, Paragraph 49), there nevertheless exists no positive role model for disabled women in literature, films, commercial and media imagery (Scarlet 2012). Consequently, ‘for many women, particularly those who become disabled later in life, it is difficult to learn to incorporate wheelchairs, prosthetics, scars, and braces into their ideas of what ‘sexy’ is’ (Kafer 2000, unpagged). Indeed, disabled women have conventionally been portrayed in a lonely, dependent and pitiful state (Lonsdale 1990). Their inability to have ‘normal’ friendships/relationships with others, specifically with the opposite sex (Kent 1987), has often been reinforced by other women’s overprotective behaviour. In short, disabled women’s imagery has been utilised to trigger pitiful responses whilst discouraging emotional identifications by other women.

Conversely, the attractiveness of non-disabled women with ‘perfect’ physical appearance, wearing fashionable clothes, and often involved in some kind of ‘sweet’ romantic encounter in such films as *Pretty Woman* directed by Garry Marshall in 1990, and *Legally Blonde* directed by Robert Luketic in 2001 suggests success in every aspect of life, something to strive for. As Susan Peters characterizes, ‘In today’s world, the mass media has influenced a widely accepted norm of physical beauty as womanly svelte curves’ (2000, 596). Correspondingly, James Charlton argues that this emphasis on the ‘importance of body and sexual

imagery' can be 'especially bad for women with disabilities' (1998, 59). To conform to this code of perfection and the powerful 'ideal' image of womanhood set by the dominant culture, disabled women are encouraged to use alternative methods, and are provided with a range of cosmetics to change their appearances and conceal deformities. Such pressure, predicated on bodily transformation, leads to feelings of constant dissatisfaction with their body-images and decreased self-respect. As Alison Kafer summarizes, 'The cultural construction of women with disabilities as asexual, deviant, and unattractive affects the self-perception and self-presentation of disabled women, impelling them to disguise – and be ashamed of – their physical differences' (2000, unpagged).

Set adjacent such sociocultural stresses, women who have 'imperfect bodies' and who do not conform to the 'arbitrary values' are rendered outcasts: as one disabled woman emphasized, 'I was ugly and I would get uglier as my disability progressed' (Hall 1992, 134). Such reflections make visible the critical impact social messages about 'disability' have on a woman's feelings of self-worth and confidence and beliefs about the kind of relationships she deserves (Thomas 1999). Accordingly, disabled women continuously manage negative and discriminatory social reactions both at an interpersonal level and when confronted with layers of degrading images of themselves in the media and other cultural discourses (Thomas 2006).

More often than not, the primary goal of these cultural productions for the young, healthy female protagonist is to find a happy marriage/relationship partner and to form a family. Therefore, the single disabled woman who remains unmarried throughout the storyline, like in *Her Name is Sabine* directed by Sandrine Bonnaire in 2007 is perceived to be a dependent and emotionally dissatisfied individual. Alternatively, in such films as Douglas Sirk's *Magnificent Obsession* (1954), and Leo McCarey's *An Affair to Remember* (1957), if an often non-disabled 'Prince Charming' arrives to 'rescue' her, the disabled woman tries to 'protect' herself and her lover from future disappointments by turning down the possibility of a 'bright' future, by 'freeing her lover' (Kent 1987). Her impairments and the society's doubts in her being a qualified confidante, friend, partner, wife and mother is often the focus of these works. The male is more often than not either attracted to her 'mysteriously heroic character' and/or wishes to fulfil his own needs in being protective of the 'vulnerable girl' as in *Love and Other Drugs* directed by Edward Zwick in 2010. In terms of a master narrative, the masculine subject fetishizes vulnerability. In valorising disabled women, the male protagonist, like the 'devotee community', seems to disregard prevailing ideals of beauty, 'choosing women that other men had rejected as not sexy or desirable' (Kafer 2000, unpagged).

Alternatively, a male protagonist (within these narratives) may be revolted by her sheer physicality. Set adjacent a commodified reading of romantic relationships, Deborah Kent observes that 'frequently the man feels he will be diminished in the eyes of others if he can only acquire a substandard partner' (1987, 15). Correspondingly, as Kent avers, the primary creator of such fantastic disability narratives are non-disabled men, who to varying degrees project their negative attitudes and specific values in their depiction of disabled women.

Such perceptions about and characterizations of the disabled body are evident in a particularly notorious television show. In January 2013, the British TV company Channel 4 broadcasted the second series of *The Undateables*, which trades on sensational entertainment through the spectacularization of disability. The advert presents six people with various impairments, surrounded by such slogans as ‘Love is blind, disfigured, autistic’. As the UK Disabled People’s Council and European Disability Forum (2012, unpagged) surmises:

If *The Undateables* seems an offensive title for a show, then that is probably the marketing aim for a TV channel in the quest for an audience. Through a patronising voiceover, viewers are told from the opening that they’re about to see a group of ‘extraordinary singletons’ when in fact we see the opposite: six single people who happen to be disabled.

Returning to the show, the opening voiceover avers, ‘In the world of matchmaking, people with disabilities can be a hard sell’.

Focused on sexuality as commodity (e.g., ‘a hard sell’), the voiceover likewise underscores a dominant reading of difficulty with regard to disability. A first premise for the voiceover and show is that the disabled participants’ ability to go on a date and form romantic relationships is undeniably affected by their impairments. As Sharon Brennan argues, ‘the programme builds on the assumption that disability is automatically a negative condition that makes it highly unusual to find love and, at the very least, will always remain a burden inflicted upon a potential partner’ (2012, unpagged). Conversely, the programme’s gradual movement in focus, from disabled subject to general public, makes possible a potential (albeit less apparent) critique of disability-based discrimination. Whilst a programme in this area can be helpful in changing perceptions, the format of using an agency to match the participants over a period of a few weeks based on their shared interest of music only, for example, presents the danger of oversimplifying the issue and perpetuate the assumption that disabled people are best suited for each other. This then leads to the production of ‘exploitative, cheap TV’ reflected in the show’s advertising, specifically the abovementioned poster (Jo 2012, unpagged). Furthermore, the perceived financial ability of the disabled participants in *The Undateables* to date at a time of benefits backlash when most people struggle financially may be questioned, criticised and even resented by non-disabled people. In short, instead of trying to bring disabled people’s romantic and sexual needs into the mainstream, the programme does the opposite, setting the disabled participants apart from the non-disabled society. This division is critical when considered alongside negative representations of disability in the British print media, the backlash instantiated by the economic downturn, and the increase in hate crimes against those who are disabled.

Such patronizing, dehumanizing and negative stereotypical assumptions of disabled men and women – which encompasses characterizations of difference, dependence, asexuality, and unattractiveness – are ingrained in our culture and provide a bedrock on which institutional discrimination and exploitation

rests (Cochrane 2008). The false perceptions persist because of their constant reproduction in print and visual media (Barnes 1992; Scarlet 2012). This is significant considering the role media plays in raising disability awareness amongst members of the public, many of whom have little or no personal experience of 'disability'. Thus, despite major efforts by disabled activists to engender increased integration or inclusion, disabled people remain (via their vexed representations in the media) largely absent from British social and cultural life.

Returning to the present-day article that begins this chapter, disabled people are consistently vilified and falsely labelled in the media as outright benefit scroungers (at worst) or (at best) social burdens unable to contribute to society in any meaningful way (Boffey 2011). To reiterate, as Debbie Jolly observes, disabled people are repeatedly and increasingly termed 'burdens', 'scroungers' and 'cheats' in print media (2011, unpagged). Concomitantly, descriptions and stories about their real life experiences have almost disappeared in the tabloid press such as the *Daily Mirror*, *The Sun*, the *Daily Mail*, and the *Daily Express* (Jolly 2011).

The use of criminalized language with regard to disabled individuals makes visible a discourse of fraud that is uniquely fixed to benefit claims. Stories about benefit fraud abound in tabloids like *The Sun*, which claims that over 70 per cent of those receiving these benefits are cheating the system (Briant et al. 2011). *The Sun*, more than any other tabloid, dramatically increased the proportion of its articles that defined claimants as 'undeserving' from 18.8 per cent during 2004–5 to 26.9 per cent in the same period in 2010–11 (ibid.). Variations were also found in the way different impairment groups were depicted; those with learning disabilities and other invisible impairments were more likely to be presented as 'undeserving' and receive scrutiny from the media than other groups including people with a physical or sensory impairment. For example, people with 'depression' and 'stress' were often represented as unworthy of benefit. The reader is provided with some stereotypical contextual details about a claimant's background to portray them leading a certain life style undeserving of the benefit system.

Reflecting the views of the media, societal attitudes appear to be of a kind that disabled people must be 'lazy' and get 'something for nothing' as a 'Lifestyle Choice' (after George Osborne's – the current Chancellor of the Exchequer – repetition of the phrase in a key interview [Wintour 2010]). Addressing 'people who think it is a lifestyle to sit on out-of-work benefits', Osborne promised that 'that lifestyle choice is going to come to an end. The money will not be there for that lifestyle choice'. Yet, the barriers disabled people have to overcome if they are to participate in the job market on equal terms are substantial and will become more severe still if crucial benefits such as DLA are reduced or removed. DLA helps disabled people and their support-workers to remain in work, therefore the loss of this support could mean many of disabled people leave employment. Without individually tailored support, and fairer conditionality and sanctions for claimants going through the Work Programme, participating in paid employment will remain an unreachable dream for disabled people whilst simultaneously contributing to their oppression and further stigmatization.

Summing up this situation in the British press, Briant et al. have written that ‘by simply replicating the government’s position on disability and disability benefit without checking either their statistics or the basis on which the claim is made, the partisan approach they adopt has the danger of further adding to the oppression disabled people are experiencing’ (2011, 70). Because of its capacity to legitimize some views and trivialize others, the news media, specifically, is positioned to play a significant role in the construction of disabled people’s marginalization. Regardless of the accuracy of the news, media coverage allows the general public to categorize, label, and manage a variety of world events (Surette 2007). More often than not, the word selections, in both the title/headline and throughout an article, are being internalized by disabled people and reinforce social stereotypes, as well as creating barriers, and contributing to the discrimination against disabled people in all areas including the job market. Many disabled people are not cheats, nor are they workshy (DPAC 2010), but are rather excluded by physical and attitudinal barriers in the work place. In 2009, 1.3 million disabled people in the UK were available for, and indeed wanted to work (Office for National Statistics 2009).

### **The Current State of Disability Rights in Britain**

Due to the intense work of British disabled activists over the last three decades, disability has been recognized as an equality issue through the implementation of the 1995 *Disability Discrimination Act* (DDA). Following the Prime Minister’s Strategy Unit document of 2005, the Disability Equality Duty (DED) required 45,000 public sector organizations to plan, publish and implement a three-year Disability Equality Scheme (DES) by 4 December 2006. By consulting disabled people in the preparation and implementation of the document, the scheme obliged institutions to facilitate equality and address any barriers to disabled people’s equal participation in mainstream life. In October 2010, in the public sector, as a single equality act, the *Equality Act* (EA) came into force. This act replaces and in some respects extends the existing anti-discrimination laws for race, disability and gender. The term ‘protected characteristics’ (including age, disability, gender reassignment, race, religion or belief [or none], sex, sexual orientation) was introduced as grounds upon which discrimination is unlawful. The Act also includes ‘a combined discrimination’ section (section 14) for the first time, which is claimed to protect people who experience direct discrimination based on a combination of two protected characteristics. Subsequently, the Public Sector Equality Duty (PSED) came into force across Great Britain (GB) on 5 April 2011. This duty requires public bodies to have due regard towards the need to eliminate discrimination; advance equality of opportunity; and foster good relations between different people when carrying out their activities. These policies and plans underscore the degree to which disability issues have become issues of civil rights that have equal footing claims of discrimination on grounds of gender, sexual orientation and ethnicity.

Internationally, the British government has also signed and ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Consequently, the government has legal obligations under Article 19 of the CRPD to take effective and appropriate measures that will facilitate disabled people's full enjoyment of key rights to independent living. The government is likewise internationally committed to guaranteeing their full inclusion and participation, as dictated by Article 14 of the CRPD, which notes, 'States Parties shall ensure that persons with disabilities, on an equal basis with others enjoy the right to liberty and security of person'. Nevertheless, the prevalence of anti-disability hate crimes, coupled with the previously discussed problematic media representations, militate against such wholesale equality. Indeed, in the current British socio-political context, disabled women's human rights are violated on a frequent basis with little respect for their 'liberty and security' and capacity for 'independent living'.

Disabled women have expressed fear in leaving their homes because of physical threats and accusations of benefit frauds. The climate of fear is working. They are feeling the effects of societal prejudice and it is impacting on their own feelings of security and safety, which in turn contributes to their social isolation and victimisation. In a piece in *The Guardian* entitled 'Comment is Free readers on ... negative attitudes towards disability' readers told their experiences of disability abuse received. Philippa Willits (a disabled woman) wrote, 'A few months ago, I was followed by a man I had never met before. For the length of the street where I live, he shouted 'fucking DLA stick!' at me every few seconds'. Willits explained that the man concerned was referring to the crutch she uses to help her walk which he thought she was using fraudulently, 'In his eyes, I was stealing taxpayers' money with my wily use of fake neurological problems, and as such, I deserved everything I got' (Willits 2012, unpagged). What is more Willits expressed her concerns about this stranger reappearing and subjecting her to similar abuse, which made her feel vulnerable. Another contributor, Isobel Glenelg (also a disabled woman), surmised her experience, 'On days when the media runs anti-disabled stories, it's safest to stay indoors' (Glenelg 2012, unpagged).

As the above examples illustrate, while progress on legislation and rights has occurred by way of rhetoric, what remains an issue is a rampant discrimination which is troublingly linked to disability benefits. Correspondingly, demands for equality with regard to disabled citizens have yet to be actualized (Briant et al. 2011). While disabled men and women face discrimination, the latter are doubly subjugated due to their gender and impairment. Indeed, despite the passage of anti-discrimination legislation over the past 15 years, disabled women are still targeted in daily life and in mainstream media. The stereotyped and victimized image of disabled women (in shows like *The Undateables*) does little to help their integration and equal participation in mainstream society. As will become even clearer, disabled women increasingly feel negatively stereotyped by police, politicians and media; such institutionalized modes of discrimination make this population feel threatened, marginalized and excluded from social, political, and economic life.

## **Disability Hate Crime and Equality Before the Law**

In accordance with the Home Office (2009) (a department of government concerned with domestic affairs, legal issues, immigration and broadcasting) definition, a hate crime is any criminal offence, which is viewed by the victim or witnesses to be ‘motivated by hostility or prejudice based on a person’s actual or perceived race, religion, sexual orientation, transgender or disability’. Among those aged 16–34, 38 per cent of disabled people reported they were a victim of crime compared to 30 per cent of non-disabled people (Papworth trust 2011). Among those who define themselves as disabled, more than 20 per cent have experienced harassment in public because of their impairment. Harassment is the most common crime, followed by verbal abuse (while away from home) and repeat burglaries. Sixty-six per cent of those diagnosed with a learning disability were regularly bullied; 32 per cent claim that bullying was a daily or weekly occurrence (Papworth Trust 2011).

To reiterate and expand, disability hate crime has steadily increased in recent years. This is attributable to a highly inflammatory atmosphere and associated with the ideological message of the media strategy on the demonizing of disabled people (Jolly 2011). Although disabled women may experience the same forms of violence non-disabled women and disabled men experience, there is an intersectional difference. As Stephanie Ortoleva explains, ‘when gender and disability intersect, violence takes on unique forms, has unique causes, and results in unique consequences’ (2012, 14). Consequently, abuse against disabled women is not merely a subset of gender-based violence; it is a multivalent mode of violence which is gender-based *and* disability-based (International Network of Women with Disabilities 2010). Forty-three per cent of disabled women felt very or fairly worried about being physically attacked by strangers, compared to 39 per cent of non-disabled women. In contrast, 30 per cent of disabled men expressed similar worries compared with 25 per cent of non-disabled men (EHRC 2011).

Physicality becomes a focalizer in these hate crimes. Many disabled women who do not conform to idealized beauty standards; their dress and hygiene operates at times in contrast to mainstream social norms. As ‘othered’ female subjects, disabled women often find themselves the target of hatred, resentment, and abuse. For example, in a reported hate crime, an attacker thought a young disabled woman, due to her facial disfigurement, looked ‘disgusting’, and subjected her to an unprovoked assault (Crown Prosecution Service 2012). In another instance (which took place in March 2011), four people were charged with assault and sentenced to a 27-year prison term after brutally attacking a disabled woman, Louise Hewitt, in her flat in Devon. Hewitt described her traumatic experience in graphic detail, ‘I was beaten with saucepans and plates. They dumped a big plant pot over my head. They broke my nose. They cut me with a kitchen knife behind my ear and on my arm. One of them tried to strangle me’ (Riley-Smith 2012, unpagged). To be sure, such crimes are not limited to those with physical impairment. As Helen Carter narrates, Gemma Hayter, a woman with learning disabilities, was led to a

railway embankment, forced to drink urine, stripped, and was viciously beaten by five alleged friends. In addition to being victims of hate crimes, disabled women are also vulnerable to other types of abuse. The financial dependency and daily needs of disabled women (including reduced community inclusion and a deeper dependence on intimate partners for assistance with daily needs), may result in living arrangements that subject them to mental abuse, physical assault, and sexual violence, thus multiplying their vulnerability (Thiara et al. 2011). Illustratively, there is the case of James Watts, a ‘care home’ driver, who was recently charged with ‘four counts of sexual activity with a person with a mental disorder ... and two counts of sexual assault’ (CPS 2009, unpagged). Reporting such crimes becomes an issue if the victim has cognitive and speech impairments. Indeed, as witnesses, disabled women may require a skilled intermediary to negotiate multiple facets of the Criminal Justice System (CJS).

In some cases, police officers are inadequately trained in terms of professional and personal attitude; this lack of competency with regard to disability leads to what Eric Levy observes is a wholesale neglect of disabled women’s needs ‘at all levels’ (2012, unpagged). This sense of neglect is exemplified in the case of Fiona Pilkington. In October 2007, Pilkington killed herself and her daughter Frankie, who had learning disabilities, following a hate campaign wherein local youths in the Leicestershire area targeted Frankie’s learning disability. Local police recorded Ms. Pilkington’s complaints as evidence of anti-social behaviour, not as an on-going hate crime concern and ‘cry for help’. James Sturcke observes that ‘the jury blamed poor sharing of information between the police and councils for contributing to the deaths, but also noted Pilkington had neither ‘sought nor accepted’ help on occasions’ (2010, unpagged). Similarly, a case of harassment involving a disabled mother in London – which lasted a total of five years – was recently dismissed as hate crime. Despite her attacker admitting to calling her a ‘spastic c\*\*\*’, the Metropolitan Police remarked that the complainant was treated as ‘vulnerable’ but that the case was not a hate crime concern (Disability Now 2009, unpagged). Last, but certainly not least, is the case of Christine Lakinski, a disabled woman with a visual impairment, who collapsed near her home in 2007 in Hartlepool (Disability Now 2008). Her neighbour, Antony Anderson, refused to help and instead urinated over her as she lay dying. Anderson had encouraged a friend to film the event. In the face of such evidence, the Crown Prosecution Service (CPS) nevertheless chose to not pursue criminal charges. The CPS stated instead that the ‘Defendant claimed that he thought that the victim was drunk or on drugs and there was no evidence to suggest that the defendant knew she was disabled’.

In a related vein, research confirms that a woman’s status as a testifying witness is afforded less respect/weight than that of a man (Ortoleva 2011). When a disabled woman’s legal capacity is limited in this way, she is denied her rights to be equal with men and also to report and address disability/gender-based violence. Even when reported, the CJS does not always investigate the cases of people with mental health issues fairly before they reach court (Mind 2007). Societal responses and perceptions of ‘disability’ are a significant barrier to the CJS, when a disabled woman’s testimony

is not accepted as credible, due to the pervasive stereotypes about her intentions and intellectual capacities (Mitchell and Buchele-Ash 2000). Moreover, lighter sentences are given to those who commit hate crimes against disabled people as opposed to those who commit similar offences against non-disabled victims. For Mark Sherry (2000), this suggests that crimes against disabled people are perceived to be less important. Similarly, Christopher Williams refers to the trivialization of disabled women's abused experiences, remarking that 'women with learning disabilities are "sexually abused" – other women are raped' (1995, 111).

While the new Strategic Vision of UK Department for International Development (DfID) claims to support 'survivors of violence to seek legal redress' (CEDAW report 2011, Paragraph 231), this remains elusive in most cities (e.g. Coventry), where legal aid concerning welfare benefits, education, medical negligence, domestic violence, housing, and immigration has been cut (Stephenson and Harrison 2011). The situation has worsened in some English counties, which have removed all funding to rape crisis and domestic abuse refuge services (UK Joint Committee on Women 2011). The police and CPS are facing budget cuts, and the voluntary organizations fear that the support available to victims and survivors of violence may be reduced (Stephenson and Harrison 2011). Due to extremely limited resources, most disability organizations do not offer any specific domestic violence services (Thiara et al. 2011). It could therefore be argued that abused disabled women remain marginal within both sectors of 'women' and 'disabled people', and as such 'lose out on both counts' (ibid., 75). A paradox is thus created; the current economic crisis constructs disabled women as benefit cheats, whilst essential services like rape crisis refuges are cut which in turn heightens disabled women's vulnerability. In the context of council budget cuts and the National Health System (NHS) being under considerable pressure, disabled women's human rights and needs could remain unmet elsewhere.

As these examples make clear, despite claims that 'all CPS Areas and CPS Direct [have] implemented a disability hate crime action plan to improve performance and engagement with disabled communities' (CPS 2012, 24), disabled people are less likely than their non-disabled peers to find justice. Indeed, fewer disabled individuals regard the CJS as fair (54% as opposed to 61% of non-disabled people) (Papworth trust 2011). Past experiences with the CJS (Scott et al. 2009) and the institution's lack of awareness with regard to human rights (Berzins et al. 2003) contribute to such mistrust. Feelings of post-attack humiliation, the inability to articulate the criminal offence, advice from others to ignore such incidents, and fears of retaliation underscore the human rights stakes embedded in issues of dependency and unequal power relations (with the state and vis-à-vis perpetrators) (Sin et al. 2009).

## **Human Rights, Disabled Persons, and Austerity**

The wider reshaping of social policy and reform of public spending has undoubtedly increased the existing social and political inequalities of many minority groups,

including disabled people and women. Disabled people have experienced a £500m cut in income since the Emergency Budget of 2010, and face the ‘perfect storm of benefits cuts and cuts in local care and support’ (Kaye et al. 2012, 19). In introducing a ‘cap’ on all benefits, the Coalition’s plans are accused of neglecting the higher costs faced by disabled people (James 2010). DEMOS (2010) warned that disabled people will be hit with more than £9bn in welfare cuts over the next five years. Furthermore, the Labour Party’s Work and Pensions spokesperson, Yvette Cooper, highlighted that women will bear more than 70 per cent of the cuts in benefit and services. These cuts will have a lasting effect on women, leaving them unemployed, forced to remain in abusive relationships, and pushed to the margins. As ‘disabled’ and ‘women’, this population is further threatened by changes to benefits and services, restrictions in local authority (LA) eligibility criteria for social care support, the replacement of the DLA with Personal Independence Payment (PIP), the closure of the Independent Living Fund (ILF) and changes to Housing Benefit (HB).

The Chartered Institute of Housing has calculated that the cumulative effects of the coalition’s proposals mean that by 2020 every tenant’s HB (both in social housing and in the private sector) will be too low to cover their rent. Consequently, renting in the social housing sector will become unaffordable in many higher priced areas of the country. Disabled people may therefore be forced to rent in the cheapest properties in an area, which are more than likely to be inaccessible and unsafe. This will increase the difficulties disabled women face in finding suitable accommodation to live independently, increase homelessness and push them further into poverty. It will also exaggerate and reinforce concerns about women being more likely to lose their jobs (Stephenson and Harrison 2011). The recent changes in the employment benefit system are equally critical for disabled women. Disabled people are gradually being moved from Incapacity Benefit (IB) to ESA and will have to be re-assessed. Those whose impairment is ‘severe’ will be in the ‘support group’, and will not be expected to work. Those whose impairments are judged (by largely non-medical Atos staff), to be less ‘severe’ are placed in the Work Related Activity Group (WRAG), and are expected to take part in work focused activity, and pushed to undertake employment which is not necessarily supported by suitable adaptation (Soorenian 2012). The changes to disability benefits will lead to a significant drop in income for those disabled women, who were receiving IB but are assessed as not being entitled to ESA. One consequence of such a move is that more disabled women will be trapped in long-term unemployment and poverty, with implications for their human rights.

Parallel to these negative changes in employment-related benefits, recommendations have also been made to cut 20 per cent of the DLA claimants. DLA has thus far supported a large number of disabled people to participate in work, and have an equal footing in the employment market. Since DLA is an allowance paid for the extra costs of ‘disability’, including transport to and from work, higher fuel bills to pay for extra lighting and heating, and the costs of hospital visits, the reduction will restrict disabled people’s freedom to manage their own

spending. This clearly contradicts the Government's agenda of implementing personal budgets. The DLA claimants will need to be reassessed for the new benefit, the PIP. The PIP will have no equivalent low-rate care payment, meaning that the 643,000 people receiving this support from DLA are now at risk of losing help with getting to their work place, taking part in leisure activities, attending important appointments and participating in everyday life (Kaye et al. 2012).

Therefore, with the rising cost of living in general and the extra costs of disability in particular, disabled women living on benefits will be even more limited. More importantly, the PIP consultation has failed to account for extra costs related to being a woman. Disabled women have higher costs for 'personal care' issues, and thus can be further disadvantaged. Moreover, older disabled women's impairments may significantly affect the quality of their lives (Banks et al. 2006), yet they may not satisfy current DLA criteria for age-related reasons. The uncertainty surrounding the continuation of ILF to help more than 21,000 'severely' disabled people, who live in their own homes, is another major cause for anxiety for disabled women using this fund. In the ILF consultation, the Government has made it clear that they want to transfer the current users' funding to the LA and close ILF as it stands. This move will put many women back into residential institutions, where they were before ILF began, thereby taking away their independence in the mainstream community.<sup>1</sup> It is estimated that by 2015, 98,170 single disabled people will lose £127m, which can force many disabled women to stay in abusive relationships and endure hardship with increased dependency (DEMOS 2010; Kaye et al. 2012). One of the hidden but damaging effects of cuts on disabled women is their increased isolation (Kaye et al. 2012). This then intensifies their vulnerability, subjecting them to heightened levels of verbal, physical, psychological and sexual abuse, a situation which most certainly challenges human rights instruments.

Article six of the UNCRPD asserts: 'States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms'. Nevertheless, as discussed throughout this essay, to be made to live with the daily reality of hate-filled and offensive media coverage, mirroring the impact of Government cuts on disability benefits is in breach of disabled women's human rights under this Article of the UNCRPD. Disabled women therefore seem to be ignored when human rights issues are discussed in today's Britain, a situation which ought to be thoroughly challenged by all those

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1 Furthermore, from October 2013, the Government has contemplated the process of bringing together working age income-based benefits, including income-based ESA, in a new Universal Credit (UC). Whilst it has been claimed that this plan intends to involve a shift in resources to better target disabled people with the greatest needs, the abolition of the 'severe disability premium' (SDP) is said to mean even those with the greatest level of impairment will receive £28 less a week if they live on their own (Kaye et al. 2012).

concerned with continuing the legacy of the disability movement against those who would seek its demise.

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## Chapter 4

# Volunteering as Tribute: Disability, Globalization and *The Hunger Games*

Anna Mae Duane

In 1994, the United States government found itself having to refute an accusation that the rich were stealing poor children for their organs. In what the *New York Times* called ‘an extraordinary wave of panic’ Guatemalans, fueled by rumors about missing children, were convinced that American tourists and scientists had come to their country to “kidnap children, cut out their vital organs and ship them to the United States for transplantation.” In three separate incidents, Americans were attacked by crowds of Guatemalan villagers. In the worst case, a 62-year old Alaskan woman was accused of stealing a local eight-year old boy and was stabbed eight times by a crowd that was said to reach nearly a thousand people (Samper 2004). In response, Todd Leventhal of the US Information Agency submitted a report to the United Nations Special Rapporteur on the Sale of Children, Child Prostitution, and Child Pornography. Leventhal’s report, marked by strikingly literary language, argues that the persistent narrative of foreign child/organ trafficking to the US was “a myth, that embodies in fable form, some of the most potent anxieties of modern life [such as] fear of and resentment at wealthy foreigners who are perceived as extremely powerful.” Leventhal’s analysis further suggests anxieties residing at an “even more visceral level,” which included “fear of wrongful mutilation and death, which has subconsciously been stimulated by the dramatic advances that have occurred during the past ten to fifteen years in the field of organ transplantation” (Leventhal 1994). Faced with such “visceral fears” Leventhal suggests, poor people in developing countries succumb to superstition, conjuring white bogeymen as embodiments of terror.

Almost two decades later, during the 2011 holiday season, a Facebook meme took hold that circulated another vision of an endangered child.<sup>1</sup> Beneath a photo of a sleeping, heavily bandaged toddler in a hospital bed, was a caption asking all who saw the heart-wrenching image to Please hit share. If this little angel gets 100 shares,” the caption promised, “he gets a heart transplant for free!:)” There is no explanation of how sharing this affecting image will get this child the organ transplant that Facebook insists the child desperately needs. Is there a mysterious rich benefactor who somehow needs proof that the child is worthy before he writes

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1 This meme was by no means unique, though this version was particularly popular.



#### Mobile Uploads

Please hit share. If this little angel gets 100 shares, he gets a heart transplant for free!:)

**Figure 4.1 Facebook Meme**

the check to the doctors? Will God somehow make a suitable heart available if He sees that enough people were moved by this one child's suffering?

The first story, dismissed as a fiction, features powerful figures, moved by insatiable appetites that greedily aid and rapaciously adopt doomed children. The second story conjures its own fiction featuring powerful forces moved by benevolence that swoops in to save children. The tension between these two conflicting but complementary stories of violence and rescue, of death and cure, resonate through other narratives we are much less willing to identify as myths: that strong adults protect weak (white) children, sympathy can work miracles, and American munificence can contain and cure disability (and even death). In the story of benevolent progress and gift-giving that informs the Facebook meme, there is no talk of the costs of cure, the resources required to keep death and disability at bay, or the way the odds are stacked in favor of certain bodies identified as redeemable and others as expendable. The silence surrounding these questions in the popular depiction of a sympathetic, phenotypically Western child, elide the very uncomfortable answers suggested in the story about threatened Guatemalan children. Who is going to supply a child's heart? Where, exactly, will it come from? In many ways, such stories are two versions of the same posthuman fantasy, in which the old structures of private empathy, prayers and charity now circulate through allegedly neutral technology designed to remake bodies and banish pain.

These two phantom stories wherein virtual child bodies are stolen, sacrificed and saved constitute a subset of countless narratives that ostensibly reside in the realm of science fiction, but that actually provide keen insights into how bodies are circulated, connected and commodified in our present moment. This essay focuses on the wildly popular American young adult *Hunger Games* trilogy (2008–2010) as a means of tracing the causal link between the rumored voracious foreigners who want to consume children and the benevolent Facebook clickers who want to rescue them. The fantastic premise of the *Hunger Games* dramatizes how long-standing attitudes towards both disability and altruism create a powerful, but largely invisible source of coercion in global markets. Underlying both the

fiction found in the novels and the fantasies that govern much of our discourse on disability, audiences are pitched affecting images and stories of vulnerable and disabled bodies in the hope that they will open their wallets in response.

To be precise, I draw from the futuristic premise of *The Hunger Games* trilogy to explore how a nineteenth-century model of sympathetic giving honed in medical and humanitarian approaches to disability has become layered with a modern neoliberal story of plucky individuals who can win the competition for resources and applause, regardless of how the game might be rigged. It is this combination of Dickensian morality and reality-show competition that renders the coercion prompting the widely disabling work of organ trafficking invisible. Disability studies show us how such forces emerge from the economic disparities of the developing world and the quixotic desire for perfection that permeates the culture of the overdeveloped world. Enamored by a story in which individual initiative and gambled bodies can win an escape from suffering, even the best-intentioned human rights activists can seek to celebrate agency of individual players at the expense of ignoring the systemic power of what we could well call the global hunger games.

Deploying the provocative idea of “bioslavery,” Priscilla Wald (2005) suggests that the public claim to certain bodies, or even body parts, evokes the dangerous precedent of slavery in which individuals were denied the right to claim their own bodies as private property. Yet, as in the days of antebellum slavery, the language of altruism and care often provides cover for such appropriation. Proslavery arguments repeatedly depicted the slave plantation as a paternalistic institution, wherein fatherly slaveholders provided for the enslaved in ways they themselves could not. There was, the argument ran, a trade-off in which self-sovereignty was relinquished to gain security and care. A not dissimilar model of benevolent appropriation animates the 2011 Facebook meme. To garner needed outside resources, the child’s body circulates as a common property we can claim with tears, clicks, and possibly, checks.

Current disability studies scholarship focuses on how prejudicial narratives can create disability where there need not be any. When this model is turned upon developing countries in need of aid, the narratives of “saving” the disabled create cover for an unjust economic system that creates disability itself. As Michael Davidson contends, globalization poses several problems for scholars in disability studies, including the need to reassess some of our own assumptions about access and individual rights that don’t translate well beyond the West. We need to remember Davidson writes, “the structural violence that maintains” – and I would add, creates – “disability through seemingly innocuous economic systems and political consensus” (2006, 118). Indeed, disability studies’ most powerful social critique may actually emerge when we as theorists consider the material impacts of globalization with as much attention as we have brought to disempowering local cultural narratives.

*The Hunger Games* trilogy illustrates how the seemingly innocuous habit of altruistic appropriation can link the oldest form of slavery (in which children, like

the ancient slaves of Rome, are forced to fight for popular entertainment) to the newest forms (wherein impoverished people are lured by promises of gain and the language of altruism to forfeit self-ownership). In fact, the requirement to relinquish self-ownership to maintain self-preservation permeates the language of both slavery and altruism. John Locke and Hugo Grotius, among other philosophers, helped establish the belief that self-preservation and self-ownership must be mutually constitutive. The idea that self-sovereignty and self-preservation are two sides of the same coin emerged as part of the natural rights theory that underwrites much of human rights discourse today (Tierney 1999). “As regards the individual himself,” Grotius suggested, “everybody is obliged to preserve as best he can his own life, safety and health” (in Tierney 1999). The desire to preserve one’s health and one’s bodily integrity correlates seamlessly with the need to maintain control over one’s own body. Thus, as the UN Declaration of Human Rights insists, every human being is entitled to “life, liberty and security of person” (1948, Art 3). Yet, in scenarios that manifest in increasingly popular reality shows, the fictional *The Hunger Games* trilogy and, less visibly, in the real-world markets of organ trafficking, the “sacred” instinct to maintain one’s health and bodily integrity *requires* abdicating self-ownership. In a neoliberal regime of free markets and allegedly free choice, individuals are encouraged to gamble with whatever resources they have. Put simply, since the body is valuable property, it makes sense to use that property as the stakes that might win a bigger prize.

### **The Medical Model and the Poster Child**

Disability theorists have long argued that medical and technical knowledge can alter the relationship between self-preservation and self-ownership in ways that transfer, or at least defer, ownership of the body to those with expertise, rather than the patient whose body is in question. As Richard K. Scotch describes, the medical model assumes that disability is “the natural product” of material “impairments” (2000, 214). The “corollary to this assumption,” Scotch points out, is our approach towards people with disabilities, which involves “help[ing] in the repair and rehabilitation of their damaged bodies and mind” (ibid.). Ideally, this repair would not only alleviate suffering, but would allow the recipient to more fully participate in the labor market, thus making themselves more “productive” within a capitalist system (Garland-Thomson 1997, 46–55).

Faced with physical suffering or physical imperfection, the medical model contends that our collective obligation is to fix it. Disability activists have pointed out the flaws within this model, not least of which is its erasure of the perspective of the person with impairments. Rather than being a problem to fix, they argue, people with disabilities simply have different capabilities that deserve accommodation. “From a doctor’s perspective,” Nancy Mairs writes, “a disability is wrong because it deviates from the ideal norm built up during years of training and practice. Yet for the patient, disability simply *is* the norm” (2002, 161). From

resisting prosthetics to arguing against the tyranny of neuronormativity, people with disabilities have argued that the medical model flattens out human diversity in pursuit of an ideal – and illusory – norm (Lorde 1980).

Through the transfer of self-sovereignty often required by the medical model, those whose bodies or minds do not match up to the ideal of a mature, autonomous adult becomes conflated with the helpless dependence we have come to associate with childhood. Children, after all, are not commonly assigned full ownership of their bodies, at least in part because parents and other authorities are assumed to be better positioned to keep those bodies safe and healthy than children themselves are. Much like liberal theory's take on other forms of property, the owners must be able to properly maintain their own possessions, or they are in danger of losing it to more fit stewards. For Locke and others, Native Americans' supposed failure to tend their lands in a suitable manner rendered it just for better farmers to appropriate those lands (Bishop 1997; Arneil 1996). Thus, someone like Mairs, whose MS renders the work of self-preservation a medical matter, finds herself faced with the expectation to hand over her self-ownership, much like a child, for "her own good." The infantilizing abdication of sovereignty seems a reasonable gamble in the hopes of winning a better shot at self-preservation. "To some extent," Mairs argues, "paternalism infects [medical professionals] relations with all their patients – a word that doesn't share its root with 'passive' by accident – because [physicians'] apparent (and often real) power over life and death reduces us all to a childlike dependency on their superior knowledge. We reinforce their dominance through our docility" (2002, 161). In other words, people with disabilities are cast as grateful recipients of superior knowledge and technology. Much like children who treat Santa's presents with unquestioned delight, the recipients of medical largesse should not question – and certainly are not responsible for – the ways in which those presents are generated or delivered.

The child in the Facebook image beautifully represents this sort of surrender – tragically unable to manage the project of his own self-preservation, he becomes the common property of hundreds, perhaps thousands of Facebook users, who will work feverishly to accomplish what he himself cannot. An entrenched medical model of disability, deeply intertwined with our models of childhood, creates a logic in which the instinct for self-preservation must come at the cost of self-ownership. The Facebook post urging readers to click a sickly child back to health is part of a cherished Western narrative in which endearing, vulnerable bodies win needed resources by wringing the hearts of generous breadwinners. It's no coincidence that some of the most famous disabled characters in literature have been children, and vice versa. From Dickens's Tiny Tim and Little Nell to Harriet Beecher Stowe's Little Eva to the plucky little cancer patient whose smiling young face appears on talk shows and supermarket fundraising posters, small and helpless bodies have long encouraged the strong to cry, and to give.

In both Tiny Tim's and Little Eva's case these sickly, but nonetheless winning, children are able to change the hearts of wealthy men. Because Tiny Tim's illness-wracked frame moves him, Scrooge loosens his purse strings, benefiting

Tim and his whole family. Little Eva's moving deathbed pleas wrings expensive promises from her slaveholder father. The narrative of self-surrender has material consequences outside the fictional texts that have enshrined it. Much of the power of the supplicant's appeal depends on reaffirming the donor's own privileged position by contrasting it with the horrors of disabled imperfection (Garland-Thomson, 2004). As Carrie Sandahl reminds us, "People with disabilities know that playing the 'supplicant' does not win one civil rights or even common respect. Indeed, one can play the supplicant for pity all too well, as the prevalence of the phrase 'Better dead than disabled' and the growing interest in physician-assisted suicide among the nondisabled population suggest" (2003, 42). As long as aid is distributed through the sentimental logic of individually plucked heartstrings rather than a sense of mutual universal obligation, the object of that aid inevitably becomes construed as less valuable than the giver of it.

### **The Disabled Child in Global Humanitarianism**

The narrative in which adults are convinced, through a child's charming vulnerability, to feel some investment in that child's welfare, has been deftly adapted by various nongovernmental organizations (NGOs) that have realized that the combination of childhood and disability makes for a potent emotional appeal. Organizations like UNICEF, Save the Children and Save Orphans and Disabled African Children (SODAC), and the recently notorious Invisible Children (KONY 2012) have all, to differing extents, promoted a narrative that, in Rosemarie Garland-Thomson's words, enables "viewers' own narratives of progress, improvement, or heroic deliverance and contains disability's threat in the sympathetic helpless child for whom the viewer is empowered to act" (Garland-Thomson 2002, 63; Invisible Children, 2012). To be fair, the UN and other NGOs are cognizant of problems raised by offering the suffering child up as an emotional hook for potential donors. Save the Children for example, has admonished its photographer to avoid creating a series of poster children: "*Do not* show children as helpless victims – e.g. closely cropped pictures of children with sad eyes looking up to the camera. We should be truthful, not sentimental" (qtd in Manzo 2008, 638). Yet these organizations do need to keep funding streams open, and the appeal of the poster child continues to deliver (Manzo 2008, 638). Thus children facing the threat of diseases such as AIDS, malaria, and the disabling effects of starvation generate much of the fundraising copy about developing countries in Africa and Asia.

A fundraising email issued by UNICEF on Mother's Day 2012 rhetorically unfolded the hunger caused by lack of adequate resources into a classic narrative of passive vulnerable disability:

SUBJECT: A child's 600 muscles, breaking down

Young children don't realize that they have over 600 muscles in their bodies – contracting and releasing with amazing sensitivity and precision. All the children

know is the delight of their bodies moving however they want them to: running, jumping, and playing.

But when children have severe acute malnutrition, their bodies don't have enough fuel – so they start breaking down the muscles instead of food. **That's why they can't run or play. That's why they lie there, numb and unmoving.** (bold in original)

UNICEF's image of agentless, idiopathic affliction sidesteps a much more troubling set of factors that indicate how we as sponsors are often, albeit indirectly, contributing to the very suffering we congratulate ourselves on alleviating. To take only a few examples among many, our appetite for oil, diamonds, and other resources found on the African continent have helped contribute to political instability, which in turn creates disability through war and poverty (Ransom 2005; Baaz 2005). In a causal chain that is often unremarked, hunger is the mechanism by which self-ownership becomes impossible, and by which the work of self-preservation is handed over to other, abler hands. To make economic disparity worthy of the sympathy required to preserve this virtual child, the figure must appear within the logic of disability rather than simply of hunger: "unmoving" bodies and useless muscles render these poor children candidates for distributed ownership. Once portrayed as disabled, rather than simply poor, the child is fully eligible for the sponsor's gift, a contribution towards a publicly offered body in need of preservation.<sup>2</sup>

Rather than drawing attention to the systemic ways in which Western demand for cheap resources create the very conditions that require rescue in the first place, the logic of sponsorship privatizes childhood suffering so that it is easily contained, indeed owned, by individuals. In a cannily commodified process, Western sponsors can "shop" for the perfect child, moving through a website's collection of adorable photos featuring children as young as three looking pleadingly into the camera (Christian Foundation, Save the Children). Once the benefactor decides to invest, they are entitled to a personal bond with that child – the rhetoric of adoption is never far away – in which the child writes grateful letters replete with charming details of a life improved by the benefactor's largesse. The child saved from disability and death by individual generosity earns her keep by providing emotional payoff for the donors. Through the orchestration of the charity, both givers and receivers play a role in the narrative of a willing gift – defenseless virtual bodies are volunteered, if not for consumption, then for benevolent appropriation.

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2 Much of this work is well-intentioned. My larger point is that by addressing symptoms rather than causes, many well-intentioned people are inadvertently exacerbating the very problems they wish to solve.

### ***The Hunger Games and the Logic of Tribute***

If the work of NGOs evokes the Facebook meme of heartfelt giving that opened this essay, *The Hunger Games* trilogy reverberates with the story of terrified Guatemalan villagers who worried that the rich had come to steal their children. Criticized for graphically depicting the violent deaths of child-tributes, *The Hunger Games* trilogy would seem, at first, diametrically opposed to the comforting tale of rescue and recuperation told by childhood charities, a story that assures rich Americans that their strong bodies and full pocketbooks have the power to save poor, disabled and otherwise threatened children in the developing world. Rather than choosing appealing children to help by alleviating their pain, adults in *The Hunger Games* randomly choose poor children to provide amusement through their suffering. As Katniss Everdeen, the protagonist and eventual “winner” of the Hunger Games reveals, the logic behind of the game blends coercion and competition:

The rules of the Hunger Games are simple. In punishment for the uprising [in which impoverished districts rose up against the wealthy Capitol], each of the twelve districts must provide one girl and one boy, called tributes, to participate. The twenty-four tributes will be imprisoned in a vast outdoor arena that could hold anything from a burning desert to a frozen wasteland. Over a period of several weeks, the competitors must fight to the death. The last tribute standing wins. (Collins 2010a, 18)

Like the stories that unfold on US reality shows, charity appeals, and tales of lottery hits, the winners of the Hunger Games are richly rewarded for their gamble. “The last tribute alive,” Katniss explains, “receives a life of ease back home, and their district will be showered with prizes, largely consisting of food. All year, the Capitol will show the winning district gifts of grain and oil and even delicacies like sugar while the rest of us battle starvation” (Collins 2010a, 19). The system of economic inequality that keeps the district populations hungry and (often) sick is overwritten by the Hunger Games’ emphasis on random luck, hard work, and appealing bodies. If one only has the right stuff, the Games promise, one can rise above the systematic oppression of their districts and live like a rich Capitol resident. Thus the concept of tribute, of a willing gift, has explanatory power both for understanding the horror of *The Hunger Games* and the circulation of resources that it charts. If we buy the argument that an individual is capable of overcoming the odds, the tribute’s act of self-surrender becomes a reasonable gamble.

The organizers of *The Hunger Games* downplay the coercive nature of the event in favor of a narrative featuring plucky young contestants competing for glory and fortune. In a pivotal moment in the first novel, Katniss’s younger sister, Primrose is selected as a tribute. When Katniss protectively moves forward, volunteering to take her sister’s place in the Games, the organizers are eager to spin her act of self-sacrifice as a savvy gamble. Capitol representative Effie Trinket applauds Katniss’s entrepreneurship as she volunteers to take on the deadly games in order

to save her sister. “Well bravo!” Effie exclaims, “That’s the spirit of the games! We don’t want her [Prim] to steal all the glory, now do we?” (Collins 2010a, 23). Effie recasts Katniss’s desperate response – the surrender of her own body, and, most likely, her own life – as a voluntary act of daring that will ultimately benefit her future self, well-fed and famous.

The motto of the game, and a catchphrase Effie repeats every year, is the wish that “the odds be ever in your favor,” implying that, with the right amount of luck and grit, the “tribute” could win big. And indeed, there are some players who buy into this fantasy. Each year, we learn, there is a contingent of “Career Tributes” from richer districts who train from early childhood for the chance to play, and who are most likely to win (94). Among this set, being chosen is considered a great honor, and “people are eager to risk their lives” (22). Yet, most of the tributes, like Katniss, realize that their name being called is almost certainly a death sentence. Nonetheless, they go. And it is this act of abdication – interpreted by the self-interested Capitol citizens as an eagerness to compete for prizes, and interpreted by Katniss as a necessary sacrifice, that sets the novel’s events into action.

The Games’ organizers have realized that spectators are far more likely to be engaged if audience members can influence the games in favor of those who pluck their heartstrings most effectively. A key part of the Games’ narrative of individual accomplishment comes from being able to appeal to rich sponsors who can help tributes out of tight spots by providing needed supplies at dramatic moments. An appealing tribute, Katniss obtains several of these life-saving gifts. At one juncture, Katniss, immobilized by severe burns on her leg, returns to her sleeping bag to find “a small plastic pot attached to a silver parachute. [Her] first gift from a sponsor!” It turns out to be valuable medicine possessing an “almost magical” effect, instantly relieving the pain and greatly accelerating the healing process. “This is not an herbal concoction my mother grinds up out of woodland plants,” she realizes, “this is high-tech medicine brewed up in the Capitol’s labs” (2010a, 188). Without the sponsored windfall, Katniss would almost certainly have perished.

The “high-tech medicine” that saves Katniss is central to the Capitol’s posthuman ethos, in which bodies can be endlessly remade through resources that no one bothers to trace to their origins. In the run-up to the games, the youths’ bodies are subject to expert makeovers to make them more appealing to the audience and to sponsors. Welding a nineteenth-century logic of sentimental childhood with a futuristic ability to drastically rework the body, Hunger Games “stylists” are vital allies in the quest to cultivate the right look, to create the winning sales pitch that will help pluck certain endangered children from obscurity, if not death. “The Hunger Games aren’t a beauty contest,” Katniss explains, “but the best-looking tributes always seem to pull more sponsors” (58). Luckily for Katniss, her stylist Cinna possesses an artistic eye and a keen awareness of what will sell. As the prep team waxes, tweezes, and generally beautifies Katniss’s body, Cinna’s costumes and theatrical coaching help the underdog tribute win over the crowd. Although the expensive beauty treatments lavished on attractive young bodies might seem far removed from the sad-eyed child supplicants that populate humanitarian appeals,

both are motivated by the intoxicating idea that money will allow us to buy our way out of suffering and into perfection. The money given by well-intentioned sponsors from the US and the money donated by the voyeuristic sponsors in the Hunger Games respond to an emotional pull that empowers them to ease the lives of appealing young people. It is this same seductive belief that we can buy our way out of suffering that animates the global organ trafficking system.

In the attention the novels lavish on Katniss's repeated makeovers, *The Hunger Games* trilogy illuminates how beauty and disability are formulations managed through medical expertise determined to erase imperfection. If theorist N. Katherine Hayles considers it a nightmare to envision a "culture inhabited by posthumans who regard their bodies as fashion accessories rather than the ground of being," then her fears are fully realized in Panem (Hayles 1999, 5). In this world, bodies – or at least the bodies of those lucky enough to live in the Capitol – have no limits. They can be healed, augmented, and refashioned at will. The stylists who prep Katniss and the other contestants sport dyed green skin, gold tattoos, orange corkscrews, and purple lipstick. Their outrageously constructed appearance conflates the nineteenth-century freak show with twenty-first century obsessions with makeovers.

But if the endlessly malleable bodies of Panem might worry Hayles, they would likely thrill Giles Deleuze and Felix Guattari. In their famous formulation of the body without organs – partially metaphorical to be sure, but also deeply conversant with posthuman fantasy that influences medical models – they celebrate a new body with endless virtual possibilities and contingencies that can be activated through imagination and experimentation. "The body without organs," they explain, "is an egg," brimming with limitless possibility. "[The BwO] is crisscrossed with axes and thresholds, with latitudes and longitudes and geodesic lines, traversed by gradients marking the transitions and the becomings, the destinations of the subject developing along these particular vectors" (Deleuze and Guattari 2004, 19). To be de-organized, untied to stultifying logics and boundaries, they suggest, is to engage in "freeing lines of flight, causing conjugated flows to pass and escape and bringing forth continuous intensities" (178).

The stylists of Panem would surely concur with such a celebratory vision of the body as a conduit for uncontained creativity. For them, the human form is an endlessly rewritable text on which previous markers of age, race, and beauty can be continually reimagined and reshaped through technology. Cesar Flickman, the television personality who interviews the child-tributes in the run-up to the Games, is "a little scary" to Katniss because "his appearance has remained unchanged for over forty years" ... "They do surgery in the capital," Katniss explains, "to make people appear younger and thinner." The body's chronology, the body's history, and certainly the body's supposed flaws, are something to be beaten back, and with luck, erased with technology. Back home in District 12, Katniss tells us, "looking old is something of an achievement since so many people die early. You see an elderly person, you want to congratulate them on their longevity, ask the secret

of survival.” In the Capitol, however, “it is different. Wrinkles aren’t desirable. A round belly isn’t a sign of success” (Collins 2010a, 125).

The body’s usual biological markers – signs of satiety, aging, or other physical processes – have no home in the Capitol’s posthuman regime of endless reinvention. In the place of the bounded, material body, the Capital offers a truly Deleuzian dream: an idealized, highly technologized, free-flowing body that correlates with celebratory visions of global cosmopolitan exchange in which culture and people move freely, without the old restrictions of nation, kin and race (Appiah 2002; Nussbaum 2002). The Hunger Games themselves both reveal and reinforce the costs of such freedom. Within the Capitol, the most eagerly anticipated spectacle, with conceivably the most intense affect, comes about as privileged viewers experience the vicarious horrors of exposure, disease, hunger, thirst and violence as these forces dismantle the vulnerable bodies of the young participants. Citizens rest easy in the knowledge that the Capitol’s medical technology protects them from such fates. The costs for maintaining such perfection are, for most of the year, invisible to those signing up for skin tinting and body polishes, until the Games remind them of the terrors of the unmedicalized body.

As *The Hunger Games* depicts the construction of both idealized and disabled bodies, it illuminates how the first both figuratively and literally causes the second. In Panem, as in the real world’s medical marketplace, the relentless demand for ageless bodies often requires the sacrifice of other, supposedly less valuable ones. The Capitol’s sumptuous wealth is propped upon the labor, resources, and people of outlying districts, which in turn supports medical and technological prowess to which its citizens feel entitled. While the occupants of the wealthy Capitol are able to engage in Deleuzian experiments to give free reign to potential desires, people in the Districts are firmly grounded in the material, their bodies exposed to dangerous working conditions while being denied medical care. Thus the people in Katniss’s home District 12 are utterly constrained by illness, hunger, physical impairment and early death. Katniss’ father, like many of the men of the district, had succumbed to a deadly cave-in at the dangerous mine where all are expected to work. Katniss’s mother, a healer, succumbed to a paralyzing depression with no access to medication that could have alleviated her symptoms. In the meantime, her children nearly starved to death. Once she recovers, Katniss’ mother struggles mightily, and often unsuccessfully, to attend to her neighbors’ many injuries and illnesses with the most rudimentary techniques and tools.

In the Capitol’s highly medicalized society, the differences of race, ethnicity and nation are replaced by a division between two types of bodies – one imagined as physically unbounded, and endlessly malleable, and another trapped in what William Gibson might term “meatspace” and Deleuze might call a highly organized realm. While conceivably the posthuman body could offer escape from the old traps of race, age and ability, in reality emerging medical technologies often reiterate, rather than refute, the binaries that privilege Western, white male bodies. In *The Hunger Games*, the “natural,” unreconstructed body occupies the subject space previously assigned to those imagined as hopelessly, inescapably embodied –

namely, people of color, women and people with disabilities. In this world, having an unreconstructed body is to be marked as inferior. In fact, physical disability is directly imposed on the worst outcasts in order to permanently mark them as part of a different order, ineligible for healing and renewal. Political dissidents have their tongues cut out and are forced to spend the rest of their lives working for their Capitol overlords. In a world of polished and perfected bodies, the physical disability of the Avoxes, as they are called, functions as a clear dividing line between the citizen and the slave.<sup>3</sup>

### Real World Hunger Games and the Work of the Tribute

The bodily division depicted in *The Hunger Games* between the rich Capitol and the poor Districts is far from science fiction: of all the social forces that exacerbate disability, none is more powerful than poverty (Fremstad 2010). Within the United States, nearly half (47.4 percent) of all working-age adults in the US who experience poverty have a disability. The relationship is reciprocal. Often having a disability makes it difficult to find employment. But being poor also makes it difficult to get medical care for conditions, that untreated and unaccommodated, become disabling. Globally, the correlation is even more profound. As figures by the World Health Organization and the United Nations indicate, eighty percent of people with disabilities live in developing countries (Davidson 2006, 117). As Michael Davidson writes, “the developing world carries 90 percent of the disease burden, yet these countries have access to 10 percent of world health resources” (2006, 117). These statistics echo the mutually constitutive relationship between the power of medicine and the power of capital found in *The Hunger Games*. In the novels and in our current global marketplace, the remarkable treatments, the regenerative surgeries, indeed the extreme makeovers that offer miraculous cures to people in the West are simply unavailable to the majority of the world’s population.

The antics of Capitol citizens tap into the suppressed narrative that somehow all bodies can be endlessly regenerated, fulfilling Americans’ posthuman fantasies of bodies made of exchangeable parts that circulate as an endless, value-free movement of resources. But the novel’s bleak premise also refutes the notion that these resources come at no cost. Katniss’ sacrifice illuminates what is hidden in the Facebook post and indeed in many hospitals throughout the globe. The happy ending promised to the sweet little boy featured in the meme, and indeed to all of us who have access to transplant technology, is made possible by invisible

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3 Thus disability in this novel often serves the function of race, marking off those who get to consume from those who must produce. See Lawrence Cohen, 2001 for a fascinating discussion of how modern immunology has altered the dynamics of physical otherness that enabled race-based slavery. Now, with body parts emerging as useful resources, immunology drugs have effectively rendered impoverished bodies “alike enough” to amalgamate with the rich (often) white bodies that can pay for their distribution.

“tributes” that come forth in to play a dangerous game in which they hope their sacrifice will earn them the much-needed capital they need for themselves and their families (HRSA).<sup>4</sup>

“Human organs are not spare parts,” insists Dr Howard Zucker, the World Health Organization’s assistant director general of health technology and pharmaceuticals. His assertion comes in direct contradiction to the posthuman embrace of the body as interchangeable information that manifests in global organ trafficking. In the world of organ trafficking, or as it is more euphemistically known, transplant tourism, wealthy people visit countries in the developing world to access “donated” organs that are sold to hospitals through brokers. “No one,” Dr Zucker argues, “can put a price on an organ which is going to save someone’s life” (CBC 2007). According to journalists’ reports, a price is regularly affixed and paid for precisely this: donors are often offered US \$2,500 for a kidney but may receive only half because of the broker’s cut (ibid.).

Landing in the very countries in which charities often package cute, appealing bodies of impoverished children looking for donors, wealthy patients seek to benefit from the physical “donations” of members of that same endangered community they might well sponsor. The language of donation, I suggest, belies the coercion that underwrites such decisions on behalf of the donor. And here perhaps is the most disturbing parallel between the dystopic world of *The Hunger Games* trilogy and the benevolent world depicted in a well-meaning charity appeals on behalf of disabled children. In both Collins’s fictional world and the equally fictional narrative of medical miracles dispensed by disembodied benefactors (and, more to the point, disembodied resources), the vulnerable are told that their sacrifice is merely the entrance fee to a game they can ultimately win. There is no need to rely on the gothic horror story of monsters ravaging children’s bodies that the Leventhal report dismisses. Globalization renders hunger a keen motivator for relinquishing one’s health in ways that often benefit the wealthy. The rich don’t need to steal organs; they need only partake in a system in which the hungry have little option but to offer them up.

The act of “donating” a vital organ is often portrayed as a laudable act of altruism, in which the strong and healthy are moved to help preserve the bodies of those in need. That model can be accurate when donations are made between peers, though even then the decision is often constrained by a host of factors. Anthropologist Nancy Scheper-Hughes has explored the ways in which the “gift of life” – in which an organ donor sacrifices bodily integrity for promises of money and security, for themselves or for members of the family – represents a form of “sacrificial violence” that benefits the strong at the expense of the weak (Scheper-Hughes 2007). Here the very logic used to help the less fortunate operates in reverse, in which the less powerful feel both emotional and financial compulsion to help a suffering patient.

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4 Much of this analysis correlates with Marx’s analysis of ownership in *The German Ideology*, 2004, particularly pages 42–7.

The rhetoric of the gift that underlies organ donation masks a number of unpleasant realities, in which “the odds” are firmly fixed in the favor of the privileged. “In general,” anthropologist Nancy Scheper-Hughes writes, “the flow of organs follows the modern routes of capital: From South to North, from Third to First World, from poor to rich, from black and brown to white, from female to male” (2000, 193). The US Organs Procurement and Transplantation Network lists 2299 females and 1637 males who have donated organs in 2006 (HRSA, in Scheper-Hughes 2000). In earlier years, the gender gap was still larger. Journalist Scott Carney upon visiting a refugee camp in Banda Ache, Indonesia, reports that almost every “adult woman” has a scar testifying to her decision to donate a kidney in the hopes of gaining money to support her family (Carney 2012, 62).<sup>5</sup> Anthropologist Lawrence Cohen describes an area of India he deems the “*kidneyvakkam*,” in which so many villagers sell their organs that the buying and selling prices of kidneys are publicly posted (Cohen 1999). In Pakistan, from 40 percent to half of residents in some villages have only one kidney each because the other was sold to a wealthy person, likely from another country, according to Dr Farhat Moazam of the Sindh Institute of Urology and Transplantation in Karachi, Pakistan (CBC 2007).

Following the money renders the sacrifices of organ donors, like the sacrifices of Panem’s tributes, coerced “gifts” packaged as a mix of altruism and entrepreneurship. Like Capitol residents who chose to cast tributes as eager young people anxious to win fabulous prizes, some theorists contend that organ donation represents a reasonable gamble. If we are truly the owners of our bodies, as ethicists such as Deryck Beyleveld and Roger Brownsword have argued, then “a person’s own body is par excellence the kind of thing that might be treated as one’s property” (2000, 88). Within such a model selling off bits of the property can be spun as a reflection of autonomy. A man placing an ad in a Sao Paulo newspaper in 1981 reflects this narrative in which self-harm is written as altruism. “I am willing,” the ad reads, “to sell an organ of my body that is not vital to my survival and that could help save another person’s life in exchange for an amount of money that will help me feed my family” (in Scheper-Hughes 2000). Journalist Ivo Patarra found the man who placed the ad, and the interview reveals that the author was well aware of the deadly game he was playing. “I know that I would have to undergo an operation that is difficult and risky,” he acknowledged. But the promise of winning is a powerful incentive: “If I could sell a kidney or an eye for that much money I would never have to work again” (Patera 1982; Qtd in Scheper-Hughes 2000, 7). Beyleveld and Brownsword, among others, might applaud the man for making the most of the resources he has available to him, and argue that he has the right to access and commodify those resources as he sees

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5 The data on organ trafficking is notoriously difficult to obtain and has yet to be aggregated in comprehensive ways. The WHO has indicated that, in the absence of comprehensive scholarly analysis, journalists’ reports provide one of the most valuable sources of data. For this reason, I rely on journalistic reports more heavily than one might expect for a scholarly paper.

fit. In other contexts, feminist scholars have made compelling arguments that our squeamishness about selling bodily resources can reify oppressive ideas about the body's supposed purity, thus marginalizing women who are voluntarily engaging in sex work that could well prove advantageous to them.

Even so, a posthuman neoliberal narrative applauding people's ability to market their vital organs on an open market writes a reality-show gloss over systemic economic injustice. The often-laudable desire to recover the agency and dignity of those in constrained circumstances can, if we are not careful, divert our attention towards the romance of the gamble and away from the forces that make such a desperate throw of the dice seem like a valid idea. By lauding the pluck and initiative of a willing tribute, we can render it even more difficult for that tribute to articulate the injustice of the sacrifice required. As Walter Johnson maintains, to applaud choice and ignore the circumstances that surround that choice, to apply "the jargon of self-determination and choice to the historical condition of civil objectification and choicelessness," we can too easily shove to the side "a consideration of humanness lived outside the conventions of liberal agency" (2003, 115). In other words, when Effie Trinket's cheers for Katniss' "spirit" as she volunteers to act as tribute in her sister's place, she insists on a narrative where Katniss had a free choice, and chose to act with spirit. So too, when we celebrate either the altruism or the moxie of impoverished organ "donors," we will them into the sort of liberal citizen-actors that we would like to see, but that does not reflect the circumstances in which they find themselves. Those circumstances are created in part by the West's ravenous desire for bodily perfection and a pervasive fear of disability.

By most accounts, the windfall the man in the Sao Paulo ad envisions is highly unlikely. Even if a donor were to receive a great amount of money, his or her health could well be too compromised to enjoy its benefits for very long. Donating a vital organ is always a risk, but to do so in conditions of great poverty exacerbates the danger. An article in the *Bulletin of the World Health Organization* tracked organ donors in three countries and reported that they overwhelmingly experienced deteriorating health after the operation (Shimazano 2007). To suggest that the market in organ trafficking reflects a market of free exchange, Miran Epstein writes, to spin these resources as either willing gifts or savvy sales, conceals "the coercion underlying all dilemmas involving the option of selling one's organs. Free, uncoerced people do not choose to face such dilemmas" (2004, 473). To pretend otherwise, as if acts of literal self-sacrifice are canny acts of speculation or marketing, is, for Epstein, to covertly support the very "political and economic environments which impose tragedy on individuals by forcing them to choose between horrible options – either poverty or selling body parts" (ibid.). Put another way, poverty enacts its own grim Hunger Games – forcing the participants to engage in a competition where the odds in your favor are vanishingly small.

The tragedy of casting the sacrifice of impoverished and vulnerable bodies as pieces in an exciting competition is played to devastating effect in the final novel of *The Hunger Games* trilogy. After a series of twists, in which Katniss emerges as a leader in an army rebelling against the Capitol, and thus against the Hunger

Games, there is a final battle. The battle takes place outside the Capitol President's house. In the midst of a chaotic scene of fighting between rebel and Capitol forces, we learn that child refugees from the Capitol are led to the grounds of the president's mansion, where they allegedly could be protected. Soon, however, it becomes clear that the children are there for another reason altogether:

Everyone inside the barricade is a child. Toddlers to teenagers. Scared and frostbitten. Huddled in groups or rocking numbly on the ground. They aren't being led into the mansion. They're penned in, guarded on all sides by Peacekeepers. I know immediately it's not for their protection. If the Capitol wanted to safeguard them, they'd be down in a bunker somewhere. This is for [President] Snow's protection. The children form a human shield. (Collins 2010b, 346)

While the Capitol guards are allegedly the villains of the conflict, it turns out that the revolutionaries from the Districts are just as good at manipulating images of children to political effect as their Capitol overlords. In a stunning visual maneuver that evokes the sponsor parachutes that brought much-needed supplies to favored players in the Hunger Games, "a hovercraft marked with the Capitol's seal materializes directly over the barricaded children." The children, Katniss tells us, "know what silver parachutes contain. Food. Medicine. Gifts. They eagerly scoop them up, frozen fingers struggling with the strings" (346) Then the parachutes explode. Many children are killed, including the younger sister Katniss had first joined the Games to save. Worst of all, the hovercraft dropping bombs had come from the rebels, not the Capitol. Having learned from "the same playbook" that created the Hunger Games in the first place, the rebels know that the sight of snow "red and littered with undersize body parts," will turn public sentiment irrevocably against the Capitol (*ibid.*). And they are right. The Capitol is defeated, and the war is won.

The brutal scene of sacrificed children provides the novels' most salient critique of the gift as it emerges in twenty-first century logic of suffering, rescue and sponsorship. These children, displaced by war, have been trained by the televised Hunger Games to hope for help floating in from the sky. But these descending presents reveal the destructive nature of any "gift" that is given solely on the merit of emotional appeals. The exploding sponsor parachutes provide a painfully apt metaphor of how the gift, set into motion by a logic in which appealing disabled bodies can win the largesse of the more fortunate, often harms the recipients. Raised to expect aid from wealthy donors to arrive with no strings attached, the children never imagine that these gifts are in fact the means by which their bodies become appropriated as part of politically advantageous photo-op. And indeed, people in the developing world might well recognize the dynamic in which money floating in from paternalistic wealthy benefactors, first a lifesaving balm, is transformed years later into a destructive force. Like Panem's deadly parachutes, the money rolling in from rich nations towards children circulates through a narrative that marries altruism with commodification. Such gifts can indeed bring lifesaving food, water

and medicine. Once the needs of the benefactors change, however, reaching out for Western offerings – such as the cash provided by medical tourism – becomes a life-threatening gamble.

Katniss, a witness to the deadly parachutes, is badly burned by the explosion. Luckily, as the leader of the winning side of the war, she has access to the miraculous medical treatments formerly reserved for Capitol citizens. “In the dazzling white Capitol hospital,” she relates, “the doctors work their magic” (350). They provide her with new skin, regenerate damaged cells, and tell her that she “will be as good as new” (350). Yet, the resolution of the Hunger Games makes clear; being as good as new is simply not possible. Katniss is denied the healing, happy endings found in other popular recent young adult series. Unlike the heroine of the *Twilight* Series, she does not learn that the power of love provides the key to eternal youth and beauty. Unlike Harry Potter, she doesn’t get to enjoy a contented postwar future replete with a happy marriage and magical children. Instead, the book provides a protagonist who must cope, imperfectly, with a damaged mind and body.

Rather than a world without scars, which requires only the proper resources to perpetually restore beauty and health, Katniss retires to a world in which her scars shape her life. After a lifetime of being on display, of having her body polished, reshaped, unscarred, remade, Katniss returns home to ravaged District 12, only to sink into a deep depression. Rather than a happy ending, in which the monsters are banished and the heroine is restored to health and happiness, the last novel of *The Hunger Games* series ends with a heroine who lives with pain. Deeply aware of the imperfect world she has inherited, and will in turn pass on to her own cherubic children, Katniss struggles with physical and mental impairments that are never going to be polished away. She is able to survive in the world, not by denying the impact pain and stress have had on her, but by coping with them.

The trilogy’s final image of a deeply scarred heroine offers one means of reworking the fantasy that bodies can and should be endlessly renewed. To subscribe to the belief that all forms of illness and disability can and should be fixed, no matter what the cost, is to further disable both the donor and the recipients. For Ivan Illich, long concerned with what he considers medicine’s narcissistic insistence on perfection, the notion that bodies can be repaired like faulty machines, with spare parts obtained from often-mysterious sources, is a deeply disabling philosophy. The ability to cope with illness – an inevitable part of life – can be “enhanced but never replaced by medical intervention in the lives of people or the hygienic characteristics of the environment” (Illich 2003, 922). Rather than finding ways of dealing with the discomfort disabled bodies can cause, our current system turns suffering into “an expression of consumer demand for increased medical outputs” (ibid., 920).

With this attitude, it now seems rational to continually flee pain, rather than to face it, even at the cost of addiction (920). Rosemarie Garland-Thomson’s work goes further still, to argue that it now seems reasonable to eliminate imperfection even at the cost of life itself. According to this logic, “disability makes living untenable” and thus death is preferable to incurable imperfection (2004, 778). Such

thinking, Garland-Thomson argues, “draws a sharp distinction between disabled bodies imagined as redeemable and others considered disposable” (2004, 779). It is precisely these divisions between bodies worthy of rescue and bodies ripe for a grim harvest that animate human rights violations as they emerge in global organ trafficking. As disability theorists, we need to attend to how both global economics and long-established disability narratives are helping to draw the lines of this “sharp distinction.” For the overdeveloped world, medical miracles must continually be produced, repairing valuable bodies through organ transplants, even at the expense of others. Disability theory’s skepticism of perfectible bodies allows us to see how the “need” for such endless renewal is, in Scheper-Hughes’s words, “an artificial need, one that can never be satisfied, for underlying it is the unprecedented possibility of extending life indefinitely with the organs of others” (2000, 13). Our continued fascination with individual bodies – whether those of endearing disabled children, or of our own in illness or old age – dismantles the universal registers in which we need to administer human rights and the humanitarianism that proposes to further them.<sup>6</sup> Rather than indulging the fantasy of transcending the individual body’s limitations we would be better suited, if we, like Katniss, could somehow make peace with them. As the trilogy comes to a close, she dreads having to explain to her own children that “they play on a graveyard” (2010b, 390). So, the trilogy suggests, do we all. By denying that knowledge of our own mortality, by insisting on a fantasy that suffering can be eradicated, that bodies must be kept in perfect order by a constant supply of spare parts, the global hunger games will continue to consume those who believe they choose to play.

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## Chapter 5

# Structural and Cultural Rights in Australian Disability Employment Policy

Sarah Parker Harris, Randall Owen and Karen R. Fisher

Australia has a strong rights-oriented approach to disability policy, including ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). However, recent policy changes have constrained those rights through a series of welfare reforms, most clearly evident in contemporary welfare reforms in the key domain of open labor market employment. In response to the dual goals of reducing social security expenditure and increasing employment, Australian governments over the past three decades have made significant changes in welfare to work arrangements for people with disabilities. These reforms have failed to address the range of structural and cultural policy conditions needed to ensure equal participation in the labor market for people with disabilities. This failure was particularly evident under the Howard government (1996–2007), where widespread reform included new stringent eligibility assessments for the Disability Support Pension. This shift was influenced by neoliberalism and the hope of encouraging people with disabilities to take responsibility for their income needs by moving into the open labor market.

However, similar to other OECD nations, the shift to neoliberal active workfare strategies enacted during this decade has had a limited impact on the labor market participation of people with disabilities (OECD 2009). The latest Australian Bureau of Statistics report shows that the labor market participation rate of people with disabilities was 54.3 percent in 2009, and has remained constant since 1993 (Australia Bureau of Statistics 2012). The reasons most often cited for this low rate include both structural and cultural barriers that people with disabilities face, such as: inadequate information and advice about moving into employment (Human Rights and Equal Opportunity Commission [HREOC] 2005b); additional costs for transportation and other supports (Clayton and Honeycutt 2005); lack of flexibility in the working environment (Butterworth 2004); limited employment opportunities including low-paying jobs and fewer possibilities for promotion (Bill et al. 2004; Mavromaras et al. 2007); and stigma, poverty and discrimination (Goggin and Newell 2005; Saunders 2007). For many people with disabilities there remain significant disincentives to moving from welfare to work, including loss of benefits and other entitlements which are available for people in receipt of disability benefits (Whitehead 2010).

This chapter uses empirical data to identify barriers to employment following welfare reform in Australia and to explore how the employment experiences of people with disabilities after welfare to work reform are consistent with human rights principles. The research methods combine a critical policy literature review with focus groups with working age people with disabilities (n=24) and interviews with government officials (n=3), employment service providers (n=2), a manager from a peak body representing a group of employment service providers (n=1), representatives of a peak body that handles complaints from employment service users (n=3), and an employment recruiter in the human resources office of a large law firm (n=1). Tables 5.1 and 5.2 at the end of this chapter summarize these participants' details and pseudonyms are used in the text. This methodology allows the voices and experiences of people involved in all aspects of welfare reform to highlight key aspects of policy as they are experienced and administered by key informants.

The research was conducted in and around Sydney in July and August 2010. The participants were recruited through existing research contacts and the assistance of employment service providers in the city. The people with disabilities who participated were currently participating or had recently participated in employment services and were receiving benefits, and the stakeholders who participated in interviews were either directly involved with service provision or staff at key agencies that had a role in welfare reform. Because of this limited sample, the qualitative data may not be representative of Australia as a whole, or other urban areas in the country. Rather, the research is best considered a case study of Sydney that helps to shed light on national policies and existing policy gaps. Using the CRPD, we frame our analysis through an exploration of the structural and cultural barriers facing people with disabilities seeking to move from welfare to work, and argue why both should be addressed to facilitate equal participation.

### **A Rights-Based Approach to Employment**

In 2008 Australia formally ratified the CRPD legally binding itself to the provisions and spirit of the Convention. The CRPD was developed in response to the continued marginalization of people with disabilities in international human rights treaties. Although the CRPD does not specify new rights, it affirms that people with disabilities have and deserve rights on an equal basis with others. The CRPD is rooted in the social model of disability and recognizes that societal barriers prevent participation: "disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers" (United Nations 2006). These include both structural and cultural barriers as noted throughout the text of the Convention. Article 27 is of particular relevance to welfare reform because it refers to "work and employment." Provisions in Article 27 of the CRPD specify that people with disabilities should have access to employment in the same manner as the rest of population, which

includes equality in access to training programs and employment services, opportunities for entrepreneurship and making self-determined employment decisions. The government has a responsibility to promote opportunities for people with disabilities and ensure they have access to the accommodations they need. Employment in the private sector/mainstream settings is the ultimate goal, and people with disabilities should be free from harassment and discrimination, earn the same wages and benefits as other workers, and enjoy safe working conditions in these settings. While antidiscrimination is one of central principles of the CRPD, the Convention goes beyond prohibiting discrimination, implying that governments have an active role in promoting the rights of people with disabilities. The CRPD demands that states take actions to protect rights and go beyond antidiscrimination. One of the strongest contributions of the CRPD is that it raises awareness of people with disabilities as deserving of rights, and it asks national governments to recognize this in policy and law.

The CRPD is particularly relevant to an analysis of contemporary political discourse, and can be applied to new disability policy directions, such as those highlighted in the OECD policy forum, *Sickness, Disability and Work*, which explored welfare to work transitions for people with disabilities (OECD 2009). The policy message for participating countries involved the need for a culture of inclusion, with a dual focus on short-term active policy interventions and long-term structural reform. This represents a shift from earlier international and comparative disability reform analysis, where the focus was on individual responsibility and change, rather than broader structural and cultural reforms (OECD 2003, 2009). The recommendations for reform outlined by the OECD included both short-term strategies that seek to retain, recruit, and/or reintegrate workers with disabilities; simultaneously with wider reforms that promote capacity rather than incapacity (OECD 2009). Therefore, the OECD privileged and promoted workfare reforms that moved people from disability benefits into the labor market. Nevertheless, in order for such measures to promote rights, the reforms need to include both structural and cultural components. Accordingly, programs for skills development and training, employment services providers, and antidiscrimination legislation should occur alongside initiatives aimed at promoting capabilities, changing perceptions, and enabling autonomy for people with disabilities in the labor market.

This research applies the CRPD framework to Australian employment policy to examine whether it is consistent with a rights based approach in the context of welfare to work reforms. It concomitantly explores the degree to which these policies include measures that address structural change to enable people with disabilities to enter or re-enter the labor market. Last, but certainly not least, at stake in this chapter is the implementation of programs that address cultural discrimination, such as stigma, ignorance and fear of employing people with disabilities. We identify three areas that frame discussions of human rights in contemporary debates about welfare reform: (1) the economy and employers; (2) employment services and skills; and (3) accommodation and support. These areas include both structural and cultural barriers and are discussed below.

## **The Economy and Employers**

The CRPD emphasizes that employment on the open labor market is the ultimate goal for most people with disabilities; it further maintains that this is a right. The Convention uses the phrase “on an equal basis with others” to situate people with disabilities alongside the rest of the population. The government is to take active steps to promote this right by introducing legislative measures, including incentives and affirmative action, if necessary, to combat structural barriers to the labor market. Furthermore, national governments should promote the capabilities of people with disabilities within the labor market, through measures including employing them within the public sector and various awareness-raising campaigns. Concerns over a slow economy and employer fears should be addressed so that people with disabilities have equal access to the labor market.

Initially, welfare reform in Australia focused on long-term unemployed people characterized as dependent on welfare. Reforms attempted to reduce this dependency, which was defined as rooted in the individual; because they did not try to work and often lacked the skills to find employment (Chenoweth 2008). People with disabilities were included as a target of the reforms following the Welfare to Work amendments of 2005, which restricted eligibility for Disability Support Pension (DSP) to people who are assessed as able to work 15 hours per week or less. People with disabilities assessed as able to work between 16 and 29 hours per week are no longer eligible for DSP; rather, they receive Newstart Allowance (general unemployment benefits) and have mutual obligation to enter the labor market. Thus, many people with disabilities are now treated as unemployed, along with other groups such as sole parents. The public and employer are encouraged to regard people with disabilities as “potential workers” for these reforms to be effective (Alston 2010). This new policy approach embodies the neoliberal principles of individual responsibility and minimal government intervention, creating in the process policy contradictions. On the one hand a universal structural approach to unemployment mediates disability equality, as it treats all people in the welfare system the same. On the other hand, removing notions of difference ignores wider structural and cultural barriers that prevent people with disabilities from entering or re-entering the labor market.

When employed, people with disabilities are likely to be in part-time positions, have low relative income levels (except for people with disabilities with higher levels of education), and live in or near poverty (OECD 2009). People with disabilities experience additional structural barriers in a precarious employment market, which means that active workfare programs (especially policies that mandate mutual obligation to receive benefits) need to have flexible application policies to enable marginalized groups to move in and out of the labor market without fear of loss of benefit or other services. While there are some demand-side policies available (i.e. subsidies for employers), such policies are not emphasized by the government or businesses, and reforms do not pay enough attention to areas such as education and skills development programs to encourage employers to

focus on the skills of people with disabilities (Carney 2007). Current welfare to work policies and programs have placed too much emphasis on individual factors and supply-side policies, with little regard for demand-side policies or changing the broader labor market (Horn 2010).

Many of the participants in this research expressed confusion and frustration with the direction of government policies. These disadvantages have been exacerbated with the recent economic decline, which, as one person with a disability in this research noted, increased the barriers:

I think the difficulties we're up against in finding work is the state of the economy with the times being so bad and there's so many people losing their jobs, you're competing with so many people, many more people, also a lot of them are very qualified and just lost their jobs due to the economic state, so I think that's one reasons – being up against so many qualified people. (Leo, male, age 42)

One policy measure to address access to the labor market and negate some of the broader structural conditions that negatively impact marginalized populations is to increase private–public partnerships between government and business. Even in a weak economic climate, employers can assist people with disabilities by maintaining their commitment to hiring people with disabilities and continuing to work with employment providers. For example, the employer (Andy, Employer) interviewed in this research pointed out that his firm was not having any difficulty finding suitable applicants and therefore were not using employment services to advertise open positions. Additional policy measures by the government to work with businesses could promote opportunities for people with disabilities. Otherwise, the poor economy, coupled with lack of opportunities for employment experience often results in a major structural barrier for people with disabilities to find an entry-level position, let alone obtain a better job. Under such policy conditions, equal opportunities for participation may be very difficult for people with disabilities to attain.

In addition to structural barriers that, in a weak economy, limit access to the labor market, there are cultural issues that need to be addressed, particularly in relation to employers' perspectives of people with disabilities. From the employer's perspective, one of the reasons for not hiring more people with disabilities is that they have inadequate information regarding what hiring them entails. Employers also believe they face additional costs and may have concerns about additional risks they may face (HREOC 2005). From the perspective of people with disabilities, there was consensus among participants in this research that they just needed the chance to demonstrate their employability and capabilities to employer: "I think we're all capable of contributing to making money, but I think it's the whole – the employer giving us a chance and seeing what we're capable of doing. To a point the employers won't know or understand because they're not in our shoes" (Sue, female, age 19).

Peter Waterhouse et al. conducted focus groups with employers from small and midsize companies and found that employers are willing to hire people with disabilities but are not sure that they have the knowledge and capability to do so (Waterhouse et al. 2010). Additionally, employers were more concerned that they did not have the capacity to provide support to employees with disabilities than their capacity to provide formal training in disability employment services. It is evident employers need further training and education about disability. The participants in this research noted that such efforts need to come from government: "Business have an attitude that they don't want people with disabilities but if government worked with [employers] to change those attitudes then there would be more opportunity for people with disabilities to be in the workforce" (Gus, male, age 26).

Moreover, the majority of participants thought employers did not want to hire people with disabilities: "It's almost like employers are slightly biased in that category, they want someone who can work longer and not take breaks all the time" (Quinn, female, age 20). They thought that employers were concerned about accountability if a person with a disability was injured on the job: "Employers freak out, especially with people with visual impairment, that if something happens they will be accountable and so they don't want to employ you" (Barb, female, age 60). Such views have been supported elsewhere in the literature. One of the major barriers to meaningful employment is employers' perceived misconceptions about employing people with disabilities, which limits the demand for people with disabilities as employees and acts as a disincentive for people who have previously experienced discrimination in their job-seeking activities (Barnes and Mercer 2005). This demonstrates the relevance of and need for measures to address employers' needs and concerns, coupled with policies to raise awareness of the benefits of employing staff with disabilities (Department of Employment and Workplace Relations 2004; Disability Investment Group 2009).

These discussions reflect the structural and cultural barriers to participation that people with disabilities face within the Australian labor market, especially now. All of the stakeholders that participated in this research agreed that people with disabilities and their differences were not valued within employment; rather, employers (and the public) held fears and negative perceptions about employing people with disabilities. Employment disadvantages are constructed not only by the individual's impairment, but also by structural and attitudinal barriers pertaining to workplaces and employment practices (Morris 2006). That is, disability/impairment can lead to unemployment, but the attitudes and cultural expectations of people with disabilities as unable to work is also a leading factor in unemployment. If the employers recognized people with disabilities as members of a diverse workforce with their own skills, employment participation could improve.

## **Employment Services and Skills**

The CRPD promotes respect for difference and the acceptance of people with disabilities as part of diversity as a key principle in Article 3. Within this principle it is understood that disability does not mean that people have no skills. Recognition of the capabilities of people with disabilities is inherent throughout Article 27 (work and employment), and section 1(d) states the importance of “access to general technical and vocational guidance programs, placement services and vocational and continuing training” to further develop those skills and find opportunities to put them into practice (United Nations 2006).

The Australian Human Rights Commission suggests the needs of people with disabilities are not well understood within mainstream employment services, and even disability employment services have trouble supporting some people with disabilities, notably people who are deaf and hard of hearing or blind and visually impaired (HREOC 2005). When asked about how well general employment programs know how to work with people with disabilities, one of the policymakers responded: “On the whole, not very well,” (Emily, Policymaker). A focus group participant who had used mainstream services agreed: “They are good at what they do, I suppose, but not especially for people with disabilities” (Gus, male, age 26). The participants felt that mainstream service providers could help them find a job if there were some additional supports, including transportation, guidance about disclosing a disability, and discussions about various employment programs and benefits with employers. They also noted that their support workers could play an important role in discussing accommodations and that support in the employment process was critical. However, reforms have removed notions of difference from employment services, which means that people with disabilities are less likely to receive the disability-specific supports to which they are entitled. Under neoliberalism, people with disabilities are encouraged to be like other workers and not to need “special” services or supports. This is part of a broader discourse of neoliberalism, where welfare reform has rejected the original protective-social rights approach in favor of economic models of individual contracts and stripped-back awards (Carney 2006). Such approaches to disability policy are counter to the principles contained within the CRPD and further constrain the rights of people with disabilities to access employment services.

Alongside notions of difference, the role of choice and autonomy figures keenly in employment services, and the degree to which people thought they were able to exercise choice in guiding their employment goals varied. One focus group (comprised of people from different employment services, the majority of whom had visual impairments) felt strongly that many providers were interested only in finding them a job, even if it was unskilled. For people with visual impairments, the participants mentioned telemarketing and transcription as areas they were encouraged to consider. Employment service providers are encouraged to get any job outcome as quickly as possible under reforms that have moved the system to case-based funding. Although transitioning to case-based funding places

more focus on individual circumstance, for some people, notably people with intellectual and psychiatric disabilities, even the highest level of funding might not be enough (Human Rights and Equal Opportunity Commission 2005). The focus on employment outcomes was the key feature favored by the Howard Government, but the use of outcomes is questionable because this does not necessarily mean a job that allows people to meet their needs or realize their full potential (Carney and Ramia 2002; Chenoweth 2008). Allowing individual participants in employment service programs to have more choices and autonomy regarding their labor market participation can ensure that they are able to obtain the services and employment outcomes they need and shift cultural understandings of outcomes.

One of the roles of service providers is to help people with disabilities find open employment positions. Most of the people with disabilities who participated in these programs said that they have access to a case manager for one hour every fortnight, which was intended as time to identify and locate open employment opportunities. Many employment advisers would contact companies and inquire about employment positions. Sometimes an adviser would work with an employer to create a job for someone. However, people with disabilities in this research expressed frustration with this process because their case managers were frequently interrupted and not able to focus on them or give them a full hour of assistance. In addition, many employment services offered job clubs, and the participants said that these clubs helped to improve confidence because everybody worked together to find open opportunities, and they helped each other write letters and prepare for employment. After a few weeks, the benefits of the job club reduced because the same limited job opportunities remained available. Thus, services to help locate employment opportunities were not sufficient in practice. The employment service providers also noted frustration with current procedures they had to follow. One explained that the government had recently mandated that providers use a new IT form. The form was inflexible, “incredibly complex ... and [has] pushed administrative time up to 40 percent of a provider’s time.” She continued: “The IT system is determining service delivery, not collecting the data behind it” (Carly, Service Provider). People with disabilities bear the brunt of the impact of these changes, and the structure prevents service providers from having adequate time to work effectively with people with disabilities.

International directions of active labor market programs have likewise focused on supply-side measures designed to increase skills of people with disabilities, and many of those programs target assistance to socially excluded groups to deliver “soft” or foundational skills through personal support and job search assistance (Horn 2010). Job Services Australia performs this function by offering various levels of training and skills development to groups depending on an assessment of their labor market exclusion and social exclusion. Therefore, the skills training offered through Job Services Australia facilitates rights for people with disabilities as it redresses structural inequalities in skill and education levels pertaining to social exclusion from society. In theory, such policies increase opportunities for people with disabilities to participate in the labor market. Nonetheless, addressing

structural barriers is insufficient for creating equal participation opportunities without simultaneously addressing the cultural barriers surrounding people with disabilities and employment and their perceived capabilities.

As discussed elsewhere in the literature and supported by this research, people typically had very low expectations about the abilities of people with disabilities, and even though many of them are skilled, those skills are not typically pursued (Kearns 2008). This study found that employment service providers often showed little understanding of the capabilities and appropriate job outcomes for people with disabilities. Participants discussed how people with disabilities were often the first to be dismissed, particularly during the interview process and especially in a tough economic climate, because of misperceptions about their suitability for the job. One said:

If ten people apply for a job, one is disabled, they will consider them last and flick them off the list because the other nine are better at doing the job, like it could be computing, and the nine are fast speed typing – well, faster than the disabled person, and they can multi task better, so they can file better and photocopy better, so [the disabled] guy doesn't get considered. (Pete, male, age 40)

For people with disabilities to have the necessary training and skills to enter the labor market, perceptions towards capability must shift. The participants believed that the negative perceptions of disability directly affected people with disabilities' self-confidence related to competition with non-disabled people. One participant noted: "The competition with people who are completely able-bodied, the chances of me being picked are ... you know, it's a confidence thing, which is very hard" (Sue, female, age 19). The participants turned negative perceptions into barriers to labor market participation: "Having a disability is a big barrier, because people don't want to employ you, they think you can't do a job. A lot of employers look at disabilities and go 'we don't want you'" (Jess, female age 46). Participants wanted to be accepted for having a disability, without having to hide or avoid discussing it with potential employers: "They need to recognize our disabilities, accept it first before they move on to the next step of finding us a job. Most of the time we're advised not to say anything if we can get away with it" (Chris, male, age withheld). This "shaming" of disability only further perpetuates the stigmatized view of disability.

Welfare to work programs that address structural barriers by provision of training and/or re-skilling specific to addressing individual "deficiencies" remove notions of rights and overlook the interrelated cultural training that is necessary for employers (i.e. through cultural competency training in disability), and for individuals (i.e. self-advocacy training to develop effective strategies to address negative perceptions and stigma). To ensure that active workfare programs redress injustices at structural and cultural levels for people with disabilities, a training and skills component could be developed and delivered by people with disabilities in conjunction with businesses who are currently employing people with disabilities.

This partnership approach offers the possibility for equal participation rights of people with disabilities in employment.

## **Accommodation and Support**

Many people with disabilities need accommodations and supports to be successful in employment, for reasons related to their disability and the interaction of their disability with the work environment. CRPD Article 27, section 1(i) makes explicit mention that people with disabilities have the right to reasonable accommodations. This is enforced at the national level through anti-discrimination legislation. However there is confusion surrounding what “reasonable accommodations” entail, the associated costs, and the accommodation process. Additionally, there is both perceived and real stigma attached to workplace accommodation and supports, which may create additional barriers to equal participation in the labor market.

When attempting to transition to employment, people with disabilities often lack the support necessary to enable access the labor market (Knapp et al. 2008). A contributing factor is cost of accommodations, which was an issue for many of the participants. There were reports by the participants of spending \$1600 on software and the cost of a wheelchair being upwards of \$3,000. These costs are a personal barrier to employment when individuals have to bear the burden without assistance (Heron and Murray 2003). The participants in this study shared concerns that the government did not help out more with such costs; particularly, if they were encouraged to work by the government, they thought there should be provisions for equipment and software as it was impossible on the pension to purchase. This represents a system of structural injustice and a barrier to participation rights. Systems of redistribution and financing of additional costs need to be a stronger part of national policy and put into practice in order for people with disabilities to increase their rates of labor market participation.

People with disabilities require additional supports for full and equal opportunities; when such measures are in place, individual differences can be respected. Governments cannot expect all people with disabilities to be held to the same standard without accounting for their individual needs for accommodations and support. In Australia, under the Disability Discrimination Act (DDA), the federal government requires accommodations, but does not provide them. While policy and legislation around discrimination, accessibility, and accommodations might initially help in entering the labor market, many of the individuals in this research believed that it was not a positive approach or a long term solution. Some spoke about feeling angry or insulted by any legislation that was perceived to “force employers to do the right thing,” with all of the participants noting that they just wanted to be seen for their own capabilities, rather than the perception they “had” to be given the job, or “had” to be provided with costly supports and accommodations. Others discussed their uncertainty and fear about how to raise questions about accommodations on the job:

I think everyone kind of assumes we know what changes need to be made and that the boss will make those changes and we know what we're meant to do, but we don't really and it's kind of not knowing and being unconfident makes you nervous to even apply. (Sue, female, age 19)

The interviewees were aware that accommodations and accessibility requires more than just workplace modifications and legislation, with one policymaker noting that: "Our best providers do a lot of training around social inclusion making sure that not only the workplaces are inclusive but that people have the possibility to be involved in the broader community" (Bob, Policymaker). Another spoke about the need for increased involvement of employers in the process of hiring and providing accommodations: "It's still about changing attitudes and finding ways to employers to contact people with disabilities about job openings and teaching [the employers] about how to manage the accommodations and workplace modifications" (Carly, Policymaker).

Furthermore, policy officials thought that a positive recruitment campaign was needed for employers to hire people with disabilities. Social justice will not be realized without greater recognition of the abilities and skills that people with disabilities bring to the workforce. As Peter Bailey states, "[i]f the disadvantaged group is very much below the general norm of equality, mere elimination of discrimination may not enable its members to attain equality" (Bailey 1990). Expressly, employers could help address cultural barriers by further recognizing and appreciating those skills and value people with disabilities as an important contributor to their workforce. Service providers noted that government still had a long way to go: "Certainly there's a greater awareness of disability, but I don't think the government leads by example. It cuts many of its disability positions out ... deaf people still can't get captioning for movies, accessible transportation sucks" (Irene, Service Provider). This view was supported by a focus group participant, who recounted an experience of discrimination by a potential employer:

[Once] the person that organized the interview told them I was visually impaired I got a call saying, "sorry, he doesn't want to have an interview with you." I could get the job if they [disability employment service] pushed it, but do I want to work with a[n employer] that has this attitude? No. So he didn't even see me [for an interview]. It was pure discrimination ... it was terrible. (Barb, female, age 60)

When asked about the role of anti-discrimination legislation in welfare to work reforms, employment service providers and policymakers spoke about the day-to-day use of this legislation to reinforce legal structures as well as promote cultural change. Employment service providers found the DDA to be particularly useful as an educational tool for both their staff and people with disabilities: "We go over disclosing your disability, an employers' reaction to that, and whether that is discrimination or not. We also check up on clients in the workforce to make sure they're not being discriminated against" (Jen, Service Provider). Policymakers

discussed how the DDA is a useful “checking document” to ensure that when new policies and accommodation services are developed, they meet the requirements of the legislation: “It was one of the core pieces of information that helped develop the disability accommodation services, and it was a key document for us to make sure that we were doing what we needed” (Carly, Policymaker).

The research reinforced that in practice, a government’s commitment to providing accommodation and support as a right under both national and international legislation is useful only to the extent that it effects change at the local implementation level. There are both structural and cultural components that must be addressed by government, employers and service providers. Workplace modifications need to be accompanied by an emphasis on the benefits of hiring people with disabilities. In particular, this study reinforced the common misperception about the costs of accommodations to employers, and the real additional cost of disability. Welfare to work programs that solely emphasis moving into a job, without also accounting for the additional costs of employment support, are creating tensions between neoliberal-driven reforms and human rights based policy practices. Employment policy for people with disabilities needs to be implemented appropriately in a way that encourages a person’s holistic needs.

## **Conclusion**

The Australian government is facing the complex challenge of balancing free market economies with state regulated policies. There are a number of interrelated institutionally-situated and culturally sensitive issues for ensuring equal participation for people with disabilities that go beyond the scope and reach of active workfare legislation and policy. To support and facilitate workforce transitions over a significant time period, further understanding by policymakers, employment service providers and employers is required in order to help ameliorate the full extent of the socio-cultural and political-economic barriers that people with disabilities face. In following the United Nations CRPD approach to rights, disability policy requires the principles and practices of structural and cultural change simultaneously. Factors such as employer’s attitudes, economic conditions, availability of workplace accommodations, and opportunities for prior employment and training are all part of the broader content that must be accounted for when reforming disability policies. Although welfare reform legislation has put some programs into place to address the structural disadvantage people with disabilities face, until there is a greater acceptance of and desire for disability to be represented in the workforce, those policies will have little effect. Cultural considerations need to supplement these structural reforms. As the OECD argues in the *Sickness, Disability and Work* policy forum, moving people with disabilities from income support and into employment necessitates a culture of inclusion, with a dual focus on short-term active policy interventions and long-term structural reform (OECD 2009). Equal participation will be difficult to achieve for people

with disabilities to obtain without a simultaneous focus on both cultural and structural factors in the Australian labor market.

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**Table 5.1 Characteristics of Focus Group Participants**

<b>Pseudo</b>	<b>Gender</b>	<b>Age</b>	<b>Race/ethnicity</b>	<b>Education</b>	<b>Disability type</b>	<b>Benefit program</b>	<b>Employment program</b>	<b>Ever worked?</b>
Anne	Female	26	Indian	University Degree	Physical and Visual	DSP, Wage subsidies	Disability-specific provider	Yes
Barb	Female	60	Bulgarian	Tertiary	Visual	DSP		Yes
Chris	Male			University Degree	Visual	DSP, Mobility Allowance	Provider specific to clients with visual impairments	Yes
Deb	Female	48	Anglo Australian	BA Degree	Visual	DSP	General Employment Program	Yes
Erin	Female	28	Anglo Australian	BA Degree	Visual	DSP, Mobility Allowance	Provider specific to clients with visual impairments	Only as a volunteer
Frank	Male	48	Anglo Australian	Tertiary	Physical			Yes
Gus	Male	26	Anglo Australian	High School Certificate in IT	Mental Illness (Schizophrenia)	DSP	Disability-specific provider <sup>1</sup>	Yes
Hank	Male	35	Anglo Australian	High School Certificate	Visual		Disability-specific provider <sup>1</sup>	Yes
Ida	Female	53	Anglo Australian	School Certificate (Year 10)	Cardiac Patient		Disability-specific provider <sup>1</sup>	Yes
Jess	Female	46	Anglo Australian	School Certificate (Year 10)	Physical		Disability-specific provider <sup>1</sup>	Yes

Pseudo	Gender	Age	Race/ethnicity	Education	Disability type	Benefit program	Employment program	Ever worked?
Kurt	Male	49	Anglo Australian	School Certificate (Year 10)	Physical		Disability-specific provider <sup>1</sup>	Yes
Leo	Male	42	Anglo Australian	High School Certificate	Mental Illness (OCD)		Disability-specific provider <sup>1</sup>	Yes
Mark	Male	20	Anglo Australian	High School Certificate	Physical		Disability-specific provider <sup>1</sup>	Yes
Nick	Male	28	Anglo Australian		Physical		Disability-specific provider <sup>1</sup>	Yes
Omar	Male	21	Anglo Australian	High School Certificate	Epilepsy		Disability-specific provider <sup>1</sup>	No
Pete	Male	40	Anglo Australian	High School Certificate	Acquired Brain Injury		Disability-specific provider <sup>1</sup>	Yes
Quinn	Female	20	Anglo Australian	High School Certificate	Physical		Disability-specific TTW provider <sup>2</sup>	Yes
Rick	Male	19	Indian	High School Certificate	Visual	DSP	Disability-specific TTW provider <sup>2</sup>	No
Sue	Female	19	Anglo Australian	High School Certificate	Physical		Disability-specific TTW provider <sup>2</sup>	No
Tina	Female	19	Anglo Australian	High School Certificate	Hard of Hearing and Visual		Disability-specific TTW provider <sup>2</sup>	No
Vince	Male	19	Vietnamese	High School Certificate	Asperger's		Disability-specific TTW provider <sup>2</sup>	No
Wes	Male	19	Anglo Australian	High School Certificate	Physical	DSP, Mobility Allowance	Disability-specific TTW provider <sup>2</sup>	No

Yuri	Male	20	Anglo Australian	High School Certificate	Asperger's		Disability-specific TTW provider <sup>2</sup>	No
Zack	Male	21	Chinese	High School Certificate	Visual	DSP	Disability-specific TTW provider <sup>2</sup>	No
AVG		31.57						

\* Could not attend a focus group, so participated in a one-to-one interview by phone

<sup>1</sup> Employment services (including open, transition to work, and supported employment services) were offered by one program in an organization for people with a specific disability type; organization hosted a focus group for participants in the program

<sup>2</sup> Employment services (emphasizing transition to work) were offered by one program in an organization for people with disabilities; organization hosted a focus group for participants in the program

*Note* Blank cells were either withheld or unknown

**Table 5.2 Characteristics of Stakeholder Interviews**

<b>Pseudo</b>	<b>Title / role</b>	<b>Organization</b>	<b>Stakeholder type</b>	<b>Interview format</b>
Andy	National Recruitment Manager, Human Resources	Large national and international law firm	Employer	Phone Interview
Bob	Section Manager, Disability and Carers Programs Branch	National Department focusing on families and community services	Policymaker	Face-to-face Interview
Carly	Branch Manager	National Department responsible for employment services	Policymaker	Phone Interview
Dana	Senior Policy Officer	State-level Social Services Office	Policymaker	Phone Interview
Emily	Senior Policy Officer; facilitator of a group of service providers who recommend policy changes	National peak body for non-government disability services	Peak Body Representative	Face-to-face Interview <sup>3</sup>
Fred	Executive Director	National peak body for disability rights and advocacy	Peak Body Representative	Face-to-face Interview <sup>3</sup>
Greg	Manager, Resolution and Investigation	National peak body for disability rights and advocacy	Peak Body Representative	Face-to-face Interview <sup>3</sup>
Heidi	Manager, Resolution and Referral	National peak body for disability rights and advocacy	Peak Body Representative	Face-to-face Interview
Irene	Coordinator	Disability-specific provider <sup>1</sup>	Service Provider	Face-to-face Interview
Jen	Transition to Work Coordinator	Disability-specific TTW provider <sup>2</sup>	Service Provider	Face-to-face Interview

*Notes to Table:* <sup>1</sup> Same organization as 1 in Table 5.1 <sup>2</sup> Same organization as 2 in Table 5.1

<sup>3</sup> Participated as a group interview

## Chapter 6

# Disability in Humanitarian Emergencies in India: Towards an Inclusive Approach

Vanmala Hiranandani

The recent United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) ratified by India in 2007 mandates that all policies and laws in the country must be revamped to be in consonance with the rights-based approach enshrined in the CRPD. Article 11 of the CRPD on Situations of Risk and Humanitarian Emergencies accentuates the obligation of States Parties to undertake ‘all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters’ (UN Enable 2012). As India prepares to table its new Rights of Persons with Disabilities Bill in line with the CRPD, this is an opportune moment to take stock of existing disaster management policies and practices to assess to what extent are they truly inclusive of disability issues. Indeed, India is one of the worst affected countries with 64,478 disaster-related deaths and 659,134,721 people reported to be affected in 2000–2009 (IFRC 2010). A nation with diverse terrain and climatological conditions, 85 per cent of India’s land is prone to natural hazards, including earthquakes, cyclones, droughts, and floods (UNCRD & SEEDS India 2008). In addition, long-standing conflicts and civic strife constitute man-made disasters which have further eroded the country’s developmental gains over the last 60 years.

As a case study, India proves – by way of environmental, social, and political factors – an ideal site upon which to consider the shifting terrain of human rights, humanitarianism, and disability. Integral to this chapter is a multipart evaluation of how natural disasters bring to light the possibilities and limitations of human rights and humanitarian aid. Though there is limited data, evidence suggests that disabled people are among the most excluded and marginalized from both immediate interventions and longer-term recovery and rehabilitation programs. Anecdotal evidence reveals that at the onset of a disaster, emergency, or conflict situation, people with disabilities are more likely to face abandonment during evacuation (IFRC 2007). People with mobility impairments able to flee subsequently become more dependent because wheelchairs and other aids were necessarily left behind (Oosters 2005). Individuals with disabilities are at particular risk of being separated from family members and usual caregivers in a disaster (GoI & UNDP India 2008). Correspondingly, rates of morbidity and mortality are much higher among people with disabilities than the rest of the population

(Rajendra and Mitra 2008). This chapter draws from a larger study that reviewed existing research, policy and practice documents of government and non-government organizations in Canada, India and the United States to understand the ways in which disability has been addressed or overlooked in crisis situations in the three countries. Focusing on India, the chapter first provides a brief background by mapping the disaster management mechanisms in the country. The subsequent section presents findings pertaining to the following research questions:

- Is disability included in disaster management policy and practice, and in what ways?
- Is disability included in the training and education on disaster management?
- What gaps need to be addressed to ensure that disaster management is disability-inclusive?

The methodology adopted is a review of secondary data, including research literature, government documents, manuals and training modules, publications and reports of domestic and international organizations, disaster management curriculum of reputed institutions, and media reports of major humanitarian emergencies that have occurred in the country between 2000 and 2010. Persisting gaps are highlighted, and attention is drawn to re-think the concept of ‘vulnerability’ as it relates to humanitarian emergencies.

## **Disaster Management in India**

Until recently, the basic responsibility for response to humanitarian emergencies in India lay with state governments, with the Central Government providing supplementary financial and logistical support.<sup>1</sup> At the national level, the Ministry of Home Affairs was (and remains) the nodal ministry for all matters relating to disaster management. Historically, various phases of disaster-related work – response, relief, rehabilitation and reconstruction – were managed and implemented by untrained governmental and non-governmental personnel. The focus was primarily on response, rescue and immediate relief, while rehabilitation, preparedness and prevention were relegated to the background. Rescue efforts were characterized by little coordination and collective action among and between relevant agencies.

The Gujarat (western India) earthquake of 2001 and the tsunami of 2004 propelled the government to take several measures to strengthen preparedness, mitigation and response mechanisms in the country. In 2005, the Disaster Management Act created a 3-tier structure – a National Disaster Management Authority (NDMA) headed by the Prime Minister in New Delhi, and state and district disaster management bodies under chief ministers of states and district magistrates respectively (GoI 2011).

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<sup>1</sup> Disaster management does not find mention in the seventh schedule of the Constitution, where subjects in the Central, State and Concurrent lists are specified.

Such disaster management authorities are statutorily required to formulate 'disaster management plans' that include measures for prevention of disasters and the mitigation of their effects; integration of mitigation measures in development plans; preparedness and capacity building measures to effectively respond to disasters; and vulnerability mapping of different parts of the states to different types of disasters (GoI 2005). Further, the NDMA and the state district management authorities are required to establish minimum standards of relief pertaining to food, drinking water, sanitation, shelter, medical services, special provisions for widows and orphans, *ex gratia* assistance for loss of life, damage to houses and restoration of livelihood means. The National Institute for Disaster Management (NIDM) was established for human resource development through training and capacity building, research, documentation and policy advocacy (GoI 2011). Finally, the Act mandated the institutionalization of the National Disaster Response Fund and the State Disaster Response Fund to finance disaster preparedness and management activities.

In sum, the current policy framework has undergone a paradigm shift from a relief-centric, reactive strategy to a holistic, multi-dimensional and multi-disciplinary approach incorporating pre-disaster, prevention, risk reduction, and preparedness aspects to mitigate the impact of disasters (GoI 2011). This new approach draws from the conviction, at least on paper, that given the susceptibility of the country to natural disasters, development is unsustainable unless disaster mitigation and response is mainstreamed and built into the development process. Therefore, disaster management has come to occupy an important place in the country's policy framework. With increased funding to disaster management, training of first responders, development of school safety plans, integration of disaster management in school curricula, and various short-term and degree programs to enhance awareness and professional skills in on disaster management have been implemented (ex. NIDM 2013a; Thiruppugazh 2003; UNCRD & SEEDS India 2008).

However, the concepts, theories, and practices of disaster studies are based on research largely undertaken during the past 30 years, and are still in a nascent state of development, collection and synthesis. This is evident given that there are very few comprehensive disaster studies academic programs in India and, also, given that any professional association of disaster and conflict researchers has yet to be formed.<sup>2</sup> There is dearth of trained professionals equipped to deal with a variety of hazards in various stages; such paucity extends to those who can plan and implement a holistic and complete disaster response program. Moreover, disaster response in India has been marked by mismanagement, duplication, and exclusion of affected communities. There is still much scope for institutional learning from prior experiences (ex. Özerdem and Jacoby 2006; Ray 2005).

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2 Despite claims of disaster management as an interdisciplinary field, from the author's own experiences of teaching in disaster management in a reputed university in India, the divergence between natural and social sciences backgrounds of those engaged in disaster and conflict arenas has hitherto inhibited true inter-disciplinarity.

## **Disability and Disaster Management in India**

Within this evolving arena of disaster management, the concerns of people with disabilities have historically been non-existent or, at best, relegated to the periphery. Estimated to be nearly 15 per cent of the world's population (WHO 2011), counts of persons with disabilities in India are both ambiguous and much lower than global estimates. For example, the NSSO (2003) reported a total of 18.5 million persons with disabilities in India, while the 2001 Census identified 21.9 million persons with disabilities (Registrar General of India 2001), constituting a 20 per cent difference in government estimates. Estimating the prevalence of disability in India has been hampered by complex and multitudinous factors. Deep-seated social stigma results in the exclusion and invisibility of individuals with disabilities. The lack of adequate definitions of disability further compounds the task of accurately assessing the prevalence of disability in the country. People with disabilities in India have historically constituted a significant proportion of the poorest of the poor and continue to face inequalities with regard to education, health care, employment, and opportunities for social and community participation (ex. see Hiranandani and Sonpal 2010; National Disability Network 2012). Although the effect of natural disasters and conflicts is felt even stronger by disabled people and their relatives, the exclusion of persons with disabilities in humanitarian emergencies is even greater than in everyday situations.

Despite India's ratification of the CRPD in 2007, neither the National Disaster Management Act nor the state and district disaster management plans have been revised to include disability. Consequently, the disruption to physical, social, economic and environmental networks and support systems during crisis situations continue to disproportionately affect people with disabilities. When resources are scarce in the immediate response and long-term recovery period, discrimination on the basis of disability has often been noted (GPDD & WB 2009). Early warning, evacuation, relief and assistance, protection and rehabilitation measures designed for the majority very rarely meet the specific requirements of those with disabilities. Information regarding timings and venues of aid distribution are often inaccessible for persons with visual and hearing impairments, which consequently increases their exclusion.

Illustratively, during the tsunami relief efforts, food was distributed on a first-in-line basis, making it difficult for persons with disabilities (who were competing with non-disabled persons) to access food and water. Likewise, toilets in relief camps in Tamil Nadu state (southern India) were located too far from the shelters for persons with disabilities to use them (IDRM 2005). Indiscriminate and hasty amputations often by inexperienced doctors, made the fitting of prosthetic limbs problematic, thereby hindering rehabilitation (Rajendra and Mitra 2008). These problems are by no means limited to the tsunami; they remain consistent challenges in other large-scale natural and man-made disasters. Due to lack of identification and referral procedures, poorly adapted services, and limited access, hundreds of thousands of people with disabilities are effectively deprived of the humanitarian aid to which

they are entitled. The tardy rehabilitation after the Latur (Maharashtra, western India) earthquake in 1993 resulted in a manifold increase in stress and trauma: many individuals who became paraplegic awaited a humane response for several years. The devastating Gujarat earthquake of 2001 resulted in thousands of cases of amputations, paraplegia and other impairments, with no proper plans for their short and long-term rehabilitation (IDRM 2005).

However, after the 2004 tsunami, the Indian government has taken several measures such as the Disaster Preparedness Training for People with Disabilities, where 'disaster task forces' are trained in villages to help disabled people during natural disasters. Such task forces are also charged with equipping disabled persons with skills to cope, such as reaching a place of safety until the arrival of rescue teams (GPDD & WB 2009). Training of disaster relief personnel in accessible formats such as Braille, special computer software, audio versions, large print, use of sign language interpreters and production and use of communication tools is likewise planned (GoI 2012). Moreover, to ensure accessibility of amenities in relief camps, the government plans to undertake training of local builders and architects in universal design (GoI & UNDP India 2008). In the cyclone-prone state of Orissa (eastern India), the state disaster management authority (OSDMA) embarked on a project titled 'Integrating Disability in Community Based Disaster Risk Reduction and Response'<sup>3</sup> that addresses the key issues and challenges faced by persons with disabilities.<sup>3</sup> The project currently covers eight cyclone shelters, including six shelters of OSDMA and two of the Red Cross (GoI 2012). The central government recently partnered with the UNDP to formulate a toolkit to promote an understanding of the needs of persons with disabilities and thereby assist in mainstreaming disability in disaster management (GoI & UNDP India 2008). However, to date there is no assessment about the utilization and implementation of the toolkit by different stakeholders.

A Disaster Risk Management Program covering 17 states has been developed to address the concerns of disabled people in the planning process for preparedness and response by ensuring that segregated data is available to the evacuation, search & rescue, and first aid teams for effective response (GPDD & WB 2009). This disaster preparedness plan involves data collection on the location of persons with disabilities in towns and villages at risk of natural disasters (GoI 2012). Nonetheless, such efforts at collecting data, just as in the census count of disabled persons, often get mixed responses from the disabled community due to the fear that registration mechanisms would entail privacy violations and intrusion by the government that can easily use the data for other purposes (GPDD & WB 2009). Moreover, research has found that the government's disaster management information system is ineffective at establishing coping mechanisms, and does not promote the inclusion of people with disabilities in these operations, since inclusion has been limited to

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3 Orissa was renamed Odisha in 2011, and is one in a series of name changes that are perceived as a process of decolonization because the British colonizers had changed the names of several Indian cities and states during their regime.

surveying, relief and rehabilitation programs, without any involvement in planning or decision-making processes (Kett, Stubbs and Yeo 2005).

Although after most natural disasters the government provides a sum of money to the family of the deceased and injured individuals, several instances of discrimination have been noted. For instance, after the 2004 tsunami, in Tamil Nadu, persons with spinal injuries were paid Rs. 5,000 (approximately 82 USD) in compensation. Those who lost their limbs or eyesight received Rs. 25,000 (about 409 USD) (IDRM 2005). These paltry sums of money merely serve as a token of government benevolence, and are highly inadequate to compensate for lost livelihoods or ensure the financial inclusion of persons who acquire disabilities in humanitarian emergencies.

It is telling that disability is still overlooked in official documents on disaster management such as State Level Programs for Strengthening Disaster Management in India (GoI 2011), National Disaster Management Guidelines-Preparation of State Disaster Management Plans (GoI 2007), and Standard Operating Procedure for Responding to Natural Disasters (GoI 2010). While children, women with infants and pregnant women are included in the Standard Operating Procedures, persons with disabilities are not. Likewise, the government's guidelines on management of earthquakes, floods, biological, chemical and industrial disasters, cyclones and droughts, nuclear and radiological emergencies, and tsunamis (NIDM 2013b) are completely lacking in disability sensitivity. Despite the pivotal importance of accessible early warning and communication mechanisms for persons with disabilities, national guidelines on disaster management information and communication systems still fail to take into consideration accessibility concerns of the disability community.

The national guidelines on minimum standards of relief recently developed by the National Disaster Management Authority (NDMA) in consultation with various stakeholders mention disabled people as a 'vulnerable group' on par with other at-risk groups such as women, children, widows, orphans, older people, and people living with HIV/AIDS (GoI 2012). Disability is claimed to have been 'mainstreamed' since the minimum standards mention people with disabilities. While the 'special needs' of persons with disabilities (ex. separate food distribution points for easy access, construction of accessible toilets) is recognized as an important feature in the guidelines on some minimum standards of relief, disability is still dealt with separately rather than inclusively.

The absence of professionals in inclusive disaster preparedness, especially at the policy and planning levels, is another challenge, although disaster management as a discipline has received increased government attention and funding. Concomitant with the shift in disaster management from rescue and relief to a multi-sectoral approach, the Ministry of Human Resource Development focused on the need for integrating disaster management in the existing education system, since schools are potent avenues for forging durable collective values and building a culture of prevention and disaster resilience (UNCRD & SEEDS India 2008). There are various types of school systems in India – the Central Board of Secondary Education (CBSE), State Education Boards, Council for Indian School Certificate Examinations,

National Open School and International Schools. Of these, the CBSE has pioneered the integration of a short course on disaster management in the school curriculum.

From the data available, about 7,300 schools in the country follow CBSE curriculum with an enrolment of more than 900,000 children (UNCRD & SEEDS India 2008). The CBSE disaster management curriculum is focused on various natural and man-made disasters; it emphasizes preventive and precautionary measures to minimize risk during these disasters (CBSE 2005). Furthermore, CBSE has taken up extensive teacher training programs in a phased manner across the country. The National Council for Educational Research and Training (NCERT) has simultaneously developed resource books for training teachers in topics such as disaster management, community mobilization, inclusive education, learning disabilities, etc. (Yadav 2012). Nevertheless, a segregated approach persists, which treats these topics as stand-alone modules, thereby overlooking cross-cutting themes, such as experiences of persons with disabilities in disaster situations or safety drills in inclusive schools.

Similarly, various state governments are in the process of introducing disaster management subjects in the school curriculum. For instance, the state government of Andhra Pradesh incorporated disaster management in the social sciences curriculum of junior college and intermediate courses (Education Andhra 2010). The state government of Orissa in 2005 directed the state education authorities to make disaster management a part of the educational system and curricula (Rouhban 2010 cited in Deshpande 2011). Additionally, disaster management has been incorporated in defence training of student cadets in various programs such as the National Cadet Corps, National Service Scheme Scouts and Guides, Civil Defence etc. (UNCRD & SEEDS India 2008). While disaster education has made rapid strides in India, disability perspectives are absent in these curricula, contradicting the government's stated claim of mainstreaming disability in disaster management. Indeed, disability and inclusive disaster management is mentioned in only one publication titled '*Let's Make Schools Safer*', prepared by SEEDS, a non-governmental disaster-response organization (SEEDS India 2011). However, to what extent this book is used in government and NGO training programs remains to be ascertained.

In a more positive vein, the National Institute of Disaster Management acknowledges on its website that 'disaster is a key development issue and an inclusive disaster risk reduction framework is being advocated by all disaster management and disability management stakeholders through the world' (NIDM 2011, para 7). The site also stresses that it 'supports a robust inclusive disaster management framework and would like to contribute in this regard' (para 7). Accordingly, NIDM has conducted several activities such as a five-day training program on disability in disasters for government stakeholders. On Disaster Risk Reduction Day it organized painting, poster and slogan competitions for schools for children with disabilities. On International Day of Persons with Disabilities, NIDM organized two thematic lectures to promote awareness of disability in disaster contexts, etc. (NIDM 2011).

While these activities are well-intentioned, a review of NIDM-designed modules for the training of disaster management personnel across the country reveals a

complete oversight with regard to disability. For instance, there is no mention of disability in the modules on school safety, urban risk mitigation, flood risk mitigation and management, or district disaster management plan (see NIDM 2013a for various modules). In a training module on psychosocial care in disaster management, disability is cursorily covered in a 2-page unit titled ‘Working with People with Disabilities’ within the broader category of ‘Working with More Vulnerable Groups’ (NIDM 2009). Thus, despite the rhetoric of mainstreaming, disability is either non-existent within the training curricula of this apex national training institute, or, at best, disability constitutes an add-on component wherein people with disabilities are still perceived as a ‘vulnerable group’ in need of ‘special services’. Instead of mainstreaming disability as a cross-cutting issue, the government’s own training modules reinforce disability segregation.

University level courses and programs in disaster management have been growing across the country, with improved employment opportunities in this arena and increased government and private funding to relief, rehabilitation and preparedness activities. Most universities in disaster-prone states have policies for incorporating disaster management topics in the existing curriculum, but palpable results in terms of preparedness, mitigation and risk reduction remain to be assessed (Deshpande 2011). Certificate, diploma, Bachelor’s and Master’s degree programs in disaster management have also mushroomed. Even so, a review of several disaster management programs across India showed that disability is either completely missing from the curriculum; alternatively, people with disabilities are, as previously discussed, mentioned as a ‘vulnerable group’ along with women, children and the elderly, reflective of government documents.<sup>4</sup> Furthermore, although several of these institutions have established disability studies programs (e.g. National Centre for Disability Studies at IGNOU; Centre for Disability Studies and Action at TISS), interaction between disability and disaster management arenas is lacking.<sup>5</sup> The

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4 For the purpose of the present research, the author reviewed disaster management curricula of five universities across India – these include Certificate and Postgraduate Diploma in Disaster Management offered by distance education by Indira Gandhi Open National University (IGNOU), New Delhi; Masters in Disaster Management of Panjab University (north India); MA/MSc in Disaster Management of the Tata Institute of Social Sciences (TISS), Mumbai (western India); BA and M.Sc in Disaster Mitigation (distance education) offered by The Global Open University, Kohima, Nagaland (north east India), and MA in Disaster Management (distance education) of Annamalai University, Tamil Nadu (south India).

5 From the author’s own experiences of teaching in a multi-disciplinary Master’s program in disaster management in a reputed university in India, disability was non-existent in the curriculum. The author’s attempts to bring disability concerns within the ambit of the curriculum were, at best, met with sympathetic ears, or worse, resisted since the disability community was conjectured to be requiring ‘special assistance’. Most students, however, showed interest, openness, enthusiasm, and increased sensitivity towards inclusive disaster management when the oversight of disability issues was pointed out.

absence of interface is mirrored in the dearth of coordination between disability law and disaster management regulations.

### **The Role of NGOs: Public–Private Partnerships in Disaster Governance**

Although the National Disaster Management Act 2005 vests the responsibility for coordinated implementation with disaster management authorities at the state, district and sub district levels, in reality the policy implementation strategy has been to partner with non-governmental organizations through public-private partnerships. As such, Guidelines on the Role of NGOs in Disaster Management were formulated in 2010 to streamline the contribution of NGOs. Significantly, the Guidelines require NGOs to undertake risk-mapping, taking into account three areas of disability: physical, sensory (hearing, speech, vision) and intellectual (NDMA 2010). Further, the Guidelines require ‘Disabled-Friendly Relief Camps’, mandating all locations, such as school, large halls, community centres and stadiums used as shelter sites, be made accessible by adopting universal design standards. The Guidelines require persons with disabilities to be included in participatory consultative processes. Likewise, during rehabilitation and reconstruction phases, the Guidelines expect NGOs to ascertain whether houses, toilets and water sources are easily accessible.

To date, there is no comprehensive research in the country that investigates to what extent humanitarian organizations and NGOs are aware of these Guidelines or in what ways they adhere to disability-related requirements. Undoubtedly, there are several noteworthy NGO initiatives that pre-date the government’s Guidelines. For instance, the NGO UNNATI Organization for Development Education has worked on disability-inclusive design, disaster response, preparedness and risk reduction, and developed projects and materials in direct response to the Gujarat earthquake, the drought in Rajasthan, the tsunami, floods in Uttar Pradesh (North India), and the conflict in Assam (north east India) (UNNATI 2013). As part of relief operations in the aftermath of the Gujarat earthquake of 2001, the Blind Person’s Association provided prosthetic devices and rehabilitation aids, physiotherapy services, psychosocial support, vocational training, and micro credit programs for disabled persons (GoI 2012).

The Shanta Memorial Rehabilitation Centre (SMRC), a long-standing DPO, campaigned vigorously for Article 11 (Humanitarian Emergencies) of the UNCRPD. Based in cyclone-prone state of Orissa, SMRC has experience in relief programs during floods and cyclones since 1999. After the 2004 tsunami, SMRC joined a global campaign for the inclusion of disability in disasters and climate change discourse (GoI & UNDP India 2008; SMRC 2013). Analogously, Sarista Foundation organized several workshops and preparedness modules to train more than 7000 persons with disabilities in disaster prone states in India. After the 2004 tsunami, several NGOs were engaged in capacity building of local development agencies on disability inclusion; providing assistive devices, relief and rehabilitation; promoting self-help groups, access to compensation, psychosocial services to

persons with disabilities (Rajendra and Mitra 2008). Even with the government's emphasis on NGO involvement, few of these NGO efforts have been government funded – most have been in collaboration with international NGOs and donors.

To be sure, some international NGO programs on inclusive disaster management are notable. In 2008, Handicap International launched a program called '*Capacity Building of Disaster Risk Reduction Actors in Mainstreaming Disability Issues in India*' in collaboration with International Federation of Red Cross funded by European Commission Directorate General for Humanitarian Aid (ECHO). The project's overall objective is to improve the opportunities of persons with disabilities to participate in disaster risk reduction (DRR) initiatives. The project also seeks to build capacity, improve the knowledge and skills of other stakeholders, and disseminate lessons learnt in mainstreaming disability in DRR projects (HI 2012). The South Asia Regional Office of Leonard Cheshire Disability has initiated research and long term rehabilitation work during both the tsunami and Indo-Pak earthquake by creating Disability Resource Centres (DRCs) in seven locations in India, Sri Lanka and Pakistan. DRCs provide advocacy, information services on programs and services for persons with disabilities, mobility and assistive devices, community-based rehabilitation services, and promotion of inclusive education and economic empowerment (Rajendra and Mitra 2008). Similarly, after the initial emergency response in several disasters, Christopher Blendon Mission remains in the affected areas to support, plan and develop long-term programs that promote the inclusion of persons with disabilities into all aspects of community life, such as access to health care, rehabilitative services, livelihood programs, education, vocational training, and advocacy.

Although these domestic and international NGO efforts are laudable, their coverage and influence is limited. While, by now, most disaster relief and rehabilitation organizations explicitly state their commitment to disability inclusion, in practice this is limited to surveys, provision of aids and appliances and referrals. Development agencies dedicated to building houses, toilets and schools have often overlooked accessibility of these structures, citing the most common reason of pre-approved budget and plans that are unalterable (Rajendra and Mitra 2008). Efforts to train field level workers to adopt disability-inclusive practices are negligible (Rajendra and Mitra 2008). In an online consultation on disability in disasters conducted by the World Bank, many NGOs emphasized that 'red-tape', politics and discrimination in working with the state produced delays in providing much required services to disabled persons (GPDD & WB 2009). Moreover, most NGOs exist in urban areas; the vast rural areas, where disasters wreak most havoc, are still highly inaccessible and under-serviced.

### **Persistent Gaps, Neglected Areas, and Future Directions**

One of the main factors in the exclusion of persons with disabilities from many humanitarian responses is the dearth of data. As previously mentioned, disabled

adults and children are often stigmatized by families and communities. Often hidden from view, literally and politically, they are demographically non-existent and thus excluded from humanitarian interventions. For instance, after the 2004 tsunami in Prakasam District (Andhra Pradesh), people with disabilities did not have basic documents such as identity cards and disability certificates. Moreover, the district did not have any facilities to provide support services or aids and appliances such as prosthetics or hearing aids that can facilitate inclusion. In Chennai, the state capital of Tamil Nadu, persons with disabilities registered with local government agencies did receive some relief following the tsunami, primarily food, clothing and medical support. However, those who were not registered and those without a fixed address, such as migrant workers, did not receive any state support (IFRC 2007).

Oxfam, Handicap International, and several other organizations have compiled registers of disabled people since the tsunami. However, the issue of registration, like disability definitions, is problematic. Many persons with disabilities are not willing to identify themselves as disabled for fear of becoming labelled and marginalized. Statistics based only on visible impairments can, thus, be inaccurate and reinforce perceptions that disabled people are few and access issues are therefore unimportant (Kett, Stubbs and Yeo 2005).

Since the 1970s researchers have argued that the impact of a natural hazard depends not only on the physical resistance of a structure, but on the capacity of people to absorb the impact and recover from the loss. The focus has moved to social and economic vulnerability, with evidence that the impacts of natural hazards vary for different social groups and countries. The understanding of causal factors of disasters has, thus, shifted from natural hazards towards development processes that engender different levels of vulnerability (ISDR 2004). However, persons with disabilities are still constructed as a particularly 'vulnerable group' based on traditional assumptions that their vulnerability arises from their physical, sensory or cognitive limitations that are tragic but unavoidable (Hemingway and Priestley 2006). Even India's new Rights of Persons with Disabilities (RPD) Bill, currently in its draft stage, is limited insofar as it alludes to disaster preparedness cursorily, and makes no specific mention of accessibility in early warning systems, although it states the needs of people with disabilities must be considered in relief, rehabilitation and recovery. The underlying ethos of the RPD Bill is that people with disabilities in disaster situations constitute a 'special' and 'vulnerable population' whose safety and protection must be ensured.

The field of disability studies and the social model of disability have made it amply clear that disability is not simply a natural consequence of impairment. Limitations seen as arising from physical, sensory or cognitive impairments of the individual result from socially created disadvantages and exclusions. As reports from the tsunami and the Gujarat earthquake demonstrate, disabled people's lives were put at risk, not simply due to their limitations but by social and environmental factors, such as inaccessible buildings and facilities, the absence of specific evacuation plans, inaccessible warning information, the lack of accessible evacuation transport, and in some cases, the attitudes and actions of neighbours, staff and rescue workers

(Hemingway and Priestley 2006; IFRC 2007). Despite references to ‘inclusive disaster management’ in several national and international documents, the needs of persons with disabilities are still often overlooked by disaster planners, and the disability community has little or no input into disaster risk reduction and planning. Conflict- or disaster-related injuries put additional strain on the minimal public health care resources in the country. Consequently, persons with disabilities remain low priority in service provision, thereby worsening their isolation, social exclusion and marginalization.

Examining vulnerability from structural and socio-economic dimensions reveals how social disadvantage, poverty, structural exclusion and inequalities make disabled people disproportionately more vulnerable to natural hazards. In a disaster, the needs of persons with disabilities often correspond to those in the general population (e.g. water, sanitation, shelter, food). Nevertheless, at stake is how such services are provided and how goods are distributed. This is not to deny that people with disabilities have particular needs. However, to consider them only as requiring special attention is disempowering and disenfranchising.

Accordingly, in the aftermath of the tsunami, limited participation and input of persons with disabilities in decision-making processes and plans was a key finding (GPDD & WB 2009). In instances where participation was elicited, it has been mainly to obtain consent for predetermined plans rather than decision-making about the nature of interventions. International and mainstream organizations also claim that although they want to include the needs of people with disabilities in their disaster risk reduction activities, they do not have the necessary expertise and capacity to translate policy into effective practice (Rajendra and Mitra 2008).

Compared to the efforts of government and mainstream development agencies, there has been considerable evidence of the readiness and capacity for disaster response among disabled people’s organizations (DPOs) and community-based advocacy organizations. This is reflected in informal networks of support and communication and in specific forms of disability expertise that are not readily available within the mainstream disaster response systems. As Hemingway and Priestley (2006) contend, disability organizations have been quick to fill the gaps by mobilizing limited resources and peer-to-peer requests for support. Within hours of the 2004 tsunami, for instance, disability activists and their allies with internet access generated global support through websites and global email networks. In contrast to mainstream relief efforts, these grassroots initiatives were different in that they adopted an inclusive, rights-based approach, addressing structural and social barriers faced by disabled people.

Thus, experiences of the tsunami suggest that DPOs and informal networks have the expertise and capacity to respond in disaster situations, which must be strengthened and included at all levels of planning, prevention and disaster risk reduction. Persons with disabilities are best placed to inform policy and practice for their rehabilitation and removal of existing barriers to inclusion. Discussions with disabled people can improve the layout, facilities and organization of emergency shelters. The disability community can train disaster management staff in planning

and preparation, including drills and exercises. For instance, after the 1999 earthquake in Turkey, a program to support deaf people was initiated by an NGO. A core group of deaf people were trained as disaster awareness instructors, who then travelled the country training others (IFRC 2007). IFRC also cites a research study after the 1989 California earthquake, which found that persons with disabilities had a psychological advantage which made them less likely to become injured or to panic during and after the earthquake because they negotiate with difficult physical and environmental barriers on a daily basis. Their experience of constantly overcoming barriers is a unique source of knowledge that can inform policy and practices to make disaster management more inclusive. In sum, disaster, risk reduction programs must be developed in partnership with persons with disabilities, their support networks and organizations.

Furthermore, designating disability as a 'cross-cutting' issue' or disabled people as a 'vulnerable group', that has been the emerging trend in disaster management, may obscure the diversity within the population in disaster-affected areas. People with disabilities who belong to other minority groups based on gender, race, or ethnicity may face added disadvantages in having their needs met in a disaster situation. Displaced people, female-headed households, youth in conflict-affected areas and informal workers and small entrepreneurs with disabilities in disaster-prone regions also face multiple disadvantages. Most significantly, gender is often overlooked in humanitarian emergencies. For example, women with disabilities, presumed incapable of fulfilling traditional roles, face even greater stigma and discrimination in societies where they are viewed as subordinate to men. Women living with disabilities are at increased risk of poverty, domestic violence and sexual assault, and this has implications for their recovery in the aftermath of disasters (GPDD & WB 2009). Thus, there cannot be a 'one size fits all' approach in disaster management.

## **Conclusion**

Systematic research on disability in humanitarian situations in India is almost non-existent. Available documents suggest large-scale neglect, lack of accessible evacuation, relief and response systems, and the denial of the right to life and dignity of persons with disabilities. Where disability is at all mentioned in government documents, it is addressed from an individual model perspective, viewing persons with disabilities as a 'vulnerable group' or 'special population' with 'special needs'. While India's Disaster Management Act 2005 makes no mention of disability, the country has ratified the CRPD in 2007 and it has a long way to go in aligning its laws to CRPD principles. Only in recent years, few international non-governmental organizations operating in India and elsewhere have drawn attention to disability issues in humanitarian work, disseminating fact sheets, manuals and training materials. The curricula of major academic courses and government training

programs in disaster management and preparedness still have an alarming lack of disability component.

This chapter has emphasized that the ‘vulnerability’ of persons with disabilities is a function of social, institutional and environmental barriers that they face, rather than their impairments. Unless socio-economic exclusion and structural inequalities are addressed and rectified, persons with disabilities will continue to be disproportionately affected in situations of risk and humanitarian emergencies. While disaster management research, policy and practice no longer view disasters as natural consequences of environmental hazards but as consequences of human actions, the conceptualization of disability in social model terms has not entered this most important arena that affects the lives of disabled people in poorer communities living in situations of risk. Thus, it is imperative for disability studies to interface with disaster management to ensure the safety of and equity for disabled people in all stages of disaster response, rehabilitation and recovery.

Moreover, while economic growth in India in recent years has been impressive, the development paradigm has been unsustainable, resulting in unprecedented environmental degradation and widening socio-economic inequalities. It will take long years of people-centred development and social inclusion to address the complex and multiple root-causes and drivers of conflict. Disability has been overlooked in debates on sustainability, so too, research and policies pertaining to the two most salient results of unsustainable development – climate change and conflicts – have reinforced disability exclusion. Due to existing inequities and disparities, people with disabilities will likely face disproportionate impacts due to climate change. Disabled people and their families need adaptation and coping strategies, robust systems and mechanisms, and a social movement of disability understanding and action to mitigate and minimize the harmful effects of climate change, and promote sustainable access to basic necessities, livelihoods, health care, and community participation (Wolbring 2009). This arena requires further exploration in India.

The policy environment at national, regional and international levels must be influenced to include people with disabilities at all level of dialogues. Unless disability finds a place in policy dialogue, securing sufficient funding will remain a challenge. However, there is adequate evidence that funding is a necessary but insufficient condition to guarantee inclusive disaster management (Hans 2006). The most effective way to view emergencies through the eyes of people with disabilities is to actually involve them in all levels of planning, preparedness and reconstruction – both in letter and spirit. Disaster preparedness, recovery and mitigation are opportunities for societal transformation. The post-disaster and post-conflict recovery phases, particularly, can provide opportune moments to bring about a shift in societal attitudes towards disability by addressing socio-economic and structural inequities and improving opportunities for inclusion. By incorporating universal design features to make communities accessible for everyone, the rebuilding of a community after humanitarian emergencies can be a collective and transformative experience. It is no less imperative to include disabled persons’ organizations in sustainable development policy and practice: perhaps the

disability community can enlighten disaster and development professionals about human interdependence with the environment and with one another.

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## Chapter 7

# Monitoring Disability: The Question of the 'Human' in Human Rights Projects

Tanya Titchkosky

The sons of Adam are like the limbs of the same body. /For they share the same essence in creation. /When one limb is put to pain /The other limbs cannot remain at rest /O thou who do not feel the sufferings of mankind /Thou deservest not to be called a human being.

Gulistan of Sa'di, *The Rose Garden*, 1259.

Life is to be lived, not controlled; and humanity is won by continuing to play in face of certain defeat. Our fate is to become one, and yet many – This is not prophecy, but description ... but too much of your life will be lost, its meaning lost, unless you approach it as much through love as through hate. So I approach it through division. So I denounce and I defend and I hate and I love.

Ralph Ellison, *Invisible Man*, 1952.

the task, I believe, explicitly to universalize the crisis, to give greater human scope to what a particular race or nation suffered, to associate that experience with the sufferings of others.

Edward Said, *Representations of the Intellectual*, 1994.

This chapter examines the divisions and distinctions human rights discourse makes between person, disability and impairment as a way to explore the (dis) associations that still happen today between people and the category 'human'. I conduct my analysis by attending to discussions about projects that monitor human rights for persons with disabilities, especially those for developing nations. I treat these enunciations of human rights as an opportunity to uncover the meaning of taken-for-granted divisions as well as associations between what is loved and what is hated, what is human and what stands as other. By attending to those enunciations that point out that disability is 'natural but also social' as they monitor and highlight human rights infractions around the globe, this chapter pursues an analysis that reveals the meaning made of *human* and *disability*. I am most concerned with how human rights monitoring programs articulate divisions between impairment-effects and human rights infractions as well as distinctions between those who need human rights and those who can provide them. How are such divisions foundational to shared distinctions between nature and society and

between human and its outsiders? My aim is to reveal that what otherwise appear as oppositional sides are actually a part of a shared story of the category *human*.

My method of proceeding, which elsewhere I call a *politics of wonder*, is informed by postcolonial theory's insistence that any division established between an 'us and them' rubric is a key site of reflection. Such reflection militates against a progressive sense of 'marching forward' and is instead predicated upon 'approach[ing] it through division', as the opening epigraph by Ralph Ellison suggests. Those articulations that aim to train people to chart divisions between human, its rights, and its nature become an occasion to pause, turn back, re-inhabit – as Edward Said suggests – the divisions and wonder about how we *are* making history by explicitly universalizing the crisis of what people are assumed to suffer. Our task is to affirm, in the words of Said, 'the interdependence of various histories *on* one another, and the necessary interactions of contemporary societies *with* one another [since] the rhetorical separation of cultures assure[s] a murderous imperial contest between them – the sorry tale is repeated again and again' (1993, 38).

Continuing with Said, I use a 'contrapuntal perspective' since it requires the theorist to consider how discordant and discrepant experiences are related (1993, 32; 2003, 562). In disability studies, this contrapuntal perspective is exemplified by Rod Michalko, who theorizes oppressive divisions between sightedness and blindness. Michalko evocatively suggests that there is no 'sighted world'. Instead, there is a hegemonic world with blind and sighted people that is metaphorically understood as 'sighted'. The notion of a 'sighted world', which offers an unadulterated 'descriptive fidelity', enforces no life for blindness other than 'fitting in' (Michalko 1998, 140). The theorist's task is to figure out why this world requires the degradation of blindness or how the discordant experience of blindness is necessitated by worldly relations. The divisions between blind/sighted are analogous to those between colonized/colonizer in that they obscure divides and histories yet to be revealed. These divisions between disability and human rights are exemplified by the United Nations (UN), particularly in projects oriented to implement the Convention on the Rights of Persons with Disabilities (UN, CRPD 2008).

In recounting solutions for improving human rights for 'persons with disabilities', I do not recommend whether the solutions should be supported or eschewed, loved or hated. Instead, like Ellison, I approach the space that divides the problem from its solution *in itself*. Such a site proves an ideal place to reconceive how a greater humanity is to be 'won'. The following questions serve as guiding ones for this essay: how can we make the version of human produced by the noticing of the problem of disability and the development of human rights solutions far more humane? How does this intersect with the question of living life in distinction to its controlled management or, worse, the reproduction of disability as not-quite-human?

## The Problem

With regard to the Convention on the Rights of Persons with Disabilities, it is easy to notice that disabled people's human rights are often made uncertain. In fact, saying 'disabled people', is sometimes regarded as one such dehumanizing act since it makes disability a qualifier of personhood and personhood is often understood as a state without need of qualification; a stable state from which one secures their rights. The 30 Articles of the Universal Declaration of Human Rights (UN, UDHR1948) proclaim such an understanding at the start:

### Article 1.

All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

### Article 2.

Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status ...<sup>1</sup>

'All human beings', that is, 'personhood' in human rights discourse, is meant to serve as a universal category that can transcend 'distinction of any kind'. This includes that of the body, especially the disabled one. Personhood thus becomes a term that thwarts unjust societal responses to such bodies. This reading is made explicit in Article 25 of the Declaration, which states 'the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control'. Hence, the phrase '*disabled people*' makes what is supposed to be an *event* beyond human control into a distinct *qualifier* of personhood and an affront to personhood itself. The term 'disabled people' may risk the security of being understood as participating in the universal category; consequently, some people reason it is not a proper way to designate a group united under and against oppression.

The recommended alternative is to transcend embodiment. This is represented by the popular Western admonition, 'See the person, not the disability'. The solution, or so the argument goes, is to put 'people' before, or even over and against, the 'event' of disability, asserting in the process a human unity in the face of ongoing practices of dehumanization (e.g., disability distinctions). The persistence of the political

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1 Consider, also, the Cairo Declaration on Human Rights in Islam (1990), Article 1: 'All human beings form one family whose members are united by submission to God and descent from Adam. All men are equal in terms of basic human dignity and basic obligations and responsibilities, without any discrimination on the grounds of race, colour, language, sex, religious belief, political affiliation, social status or other considerations ...'

demand to privilege personhood over disability remains a common social activity in Western countries (regardless of efficacy). People-first linguistic expressions enact a separation between people and disability by establishing clear barriers between the two. The idea is that by widening this distinction, the better one's chances for participating in personhood and appearing to others as human. This 'human-appearance', however, is achieved only insofar as the distinctive gap itself is ignored. In other words, this human status is achieved so long as the division between personhood and disability is enforced but not contemplated (Titchkosky 2001b).

Despite all attempts at transcendence, embodiment remains a universal condition of humanity. *We*, in the most inclusive sense of that word, *all have bodies* insofar as we appear as some-body who is imbricated by meanings between self and other through these bodies. It remains the case today that despite the universal human condition of embodiment, and even with efforts to establish a universal and transcendent sense of human, not all bodies are granted the status of persons (let alone of human). For example, we witness daily in the media parental, law enforcement, and state killings of disabled people alongside reports of the systematic and global degradation, exclusion and confinement of disabled people (Sherry 2010; McGuire 2011).

There are various ways that the issue of disability is articulated. The social model of disability (Oliver 1996; Barnes et al. 2002) envisions a separation between impairment and disability as a way to address injustice. Disability is produced by disabling environments; disability is not the result of impairment but is rather understood as the result of inappropriate societal responses to embodied difference. In this sense, the social model has created a separation, one between impairment-effects comprehended as distinct from the life socially constituted as disabled. From a strict social model perspective, people are imagined as united via social oppression. They are likewise joined *as* disabled people *vis-à-vis* their division from impairment, which is taken as a brut medical reality. Again, this solution enacts a distinction between the 'Real' of impairment and social responses to embodied beings. At the same time, such a solution dis-attends to the making of this particular distinctive gap. It therefore remains easy enough to notice, and for some to hate and others to love, the ongoing attempts to separate *impairment from disability* as a solution to the problem of disabled people's uncertain statuses, especially that of human with rights.

In sum, we find ourselves in daily life dividing people from impairments, impairments from other impairments, or impairments from disability and anyone of these categories from 'human' or from 'the social'. The need to divide while taking this activity for granted is apparent in expressions such as the following: 'I may be impaired, but I still tie my own shoes'. 'Whatever our impairment experiences we still put our pants on one leg at a time'. 'I am disabled not stupid, stupid!' 'What are you crazy, I am blind not deaf?!' Tying shoes, putting on pants, disclaiming mobility, sensory, intellectual or mental differences metaphorically configure participation in personhood while degrading other differences as not-

quite-human.<sup>2</sup> But what are we to make of all these different dividing practices that surround our embodied existence and serve as solutions to the precarious, yet exclusive, category ‘human’?

### Approaching the Problem

To reflect upon the social meaning of acts of division, I proceed, albeit hesitantly, with an assumption. Assume that disability’s uncertain status in the realm of the human is not the result of a collective failure. That is, assume that we have not failed to conform to the worldwide effort by the UN, World Health Organization (WHO), World Bank, and most nation-states to govern how we delineate, and thus how we live, disability. Rather, assume that the united global move conforms to the demand to separate embodied reality from personhood. Assume too that the demand to separate the social from the biological is connected to the governmental desire to separate what is loved and what is not, and delimit what is to be defended and what is to be denounced (or at least diminished). These assumptions underscore the extent to which disability has become a global hegemonic ‘silent crisis’ (UN 1996).<sup>3</sup>

Suppose we assume, then, that we have conformed too well to that which grounds not only person-first language governance of disability but also confirms understanding *disability as a problem in general*. It is our collective conformity with regard to a polemical understanding of disability that functions as the orienting supposition. This problem, whether it be understood as medical or social in character, makes the phenomenon of disability become almost fully disassociated from ‘life’ (Michalko 2002; Goodley 2011; Overboe 2012). Notwithstanding the many common dividing practices that teach us that disability is not life (and thus is outside the realm of discrimination), the issue becomes identifying where to locate this problem by way of establishing what to hate, diminish, or at least what to control. *Segregated from life, disability appears as though it is detached from the wider question of what it means to be human.*

Insofar as an aspect of life dis-associated from life orders contemporary meanings of disability, a pressing question arises. What limits and what possibilities lie in emerging projects that aim to implement human rights by enlisting persons with disabilities into monitoring projects focused on disaggregating impairment conditions from human rights discourses? Not taking for granted the sense of the

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2 ‘The right to be human carries the violence of the past’, says Katherine McKittrick who, along with Dan Goodley, Rebecca Lawthom, Rod Michalko, and Rinaldo Walcott are nurturing the question of the human – thank you. Thanks to Christopher Smith and Laura Thrasher for engaging this paper by emphasizing the question of how disability is ‘associated’ with human. Thanks to Tara Milbrandt and Frank Pearce for helping me question the meaning of ‘rights’ which also has a long history beyond the scope of this paper but see Hofeld (1913).

3 As cited in Titchkosky, 2003: 247.

problem nor its division from the solution we can now ask the following: Beyond expanding the human rights agenda, what else might be happening with regard to disability as made manifest through human rights monitoring projects?

### **The Impairment-Problem within Disability**

In the *World Report on Disability*, it is estimated that one billion people ‘live with some form of disability, or about 15% of the world’s population’ (WHO 2011, 7). The *Report* further recognizes that people who live with disabilities face significant daily difficulties, which include high rates of poverty, violence, and early death and low rates of inclusion in education, healthcare, housing, and transportation (WHO, *World Report* 2011; UN, CRPD 2008; Shakespeare 2012). These difficulties grow in strength and prevalence within developing or war torn nations, and among First Nations and Aboriginal peoples.

Faced with a global problem of disability, governing powers such as the UN and the WHO differentially locate the genesis of experiential difficulty. At times, challenges in daily living are regarded as though they are caused strictly by impairment alone; at other times, these difficulties are depicted as caused by the interaction between an impairment condition and the environment. Alternatively, such tribulations are also sometimes framed as human rights issues, as discrimination resulting in unjustifiable exclusions and disadvantages. The Convention on the Rights of Persons with Disabilities (UN, CRPD 2008: Preamble e) recognizes that *disability* is ‘an evolving concept ... [that] results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others’. Nevertheless, the meaning of a restriction in aspects of daily living, remains steeped in ambiguity. This ambiguity is tied to questions that arise easily and often: Is a restriction in daily living the result of a biological version of impairment or is it the result of unjust social restriction? How does one tell the difference between impairment effects and disability discrimination? Thus, the logic of understanding is as follows: impairment within a disabled person’s life may or may not be connected to the attitudinal and environmental barriers that result in a collective’s interest to understand disability as a human rights issue.

Raising the question of whether biology or society is responsible for organizing a person’s life chances relies on the assumption that a person can be split from its embodiment. Such questioning assumes that biological life can be understood as separate and distinct from social life. Different cultures, at different times, and in different ways do indeed come to make these splits and distinctions between biology and society, as well as between body and self. For example, the *World Report on Disability* contains a preface authored by Steven Hawking, who opens with the statement that ‘Disability need not be an obstacle to success’ (WHO 2011, 3). Presumably, this represents a more ‘evolved’ concept of disability wherein we witness interaction between ‘persons with impairments’ and

attitudinal and environmental barriers. We are thus invited to imagine disability as a *potential* but not *de facto* obstacle to success. In de-naturalizing at least some part of disability-as-problem and by contradicting disability and success, we are also led to question whether it is, perhaps, society that is an obstacle to success for people with disabilities. Either way, disability becomes a unique problem that marks an occasion for a collective to make distinctions between nature and society.

Whether or not we maintain a correlation between forms of disability and levels or kinds of participation, it remains true that the act of making and noting such distinctions is neither biological nor natural. Nature does not determine how lines of distinction are drawn; thus impairment conditions do not ‘naturally’ preclude one from personhood. For instance, while it may be that blind people do not participate in seeing (although I do not think this is true), it is a further leap to assert a natural correlation between not participating in seeing and not attending school, or not having access to educational materials. We learn from this example that correlative articulations between types of bodies and forms of participation, whether treated as true or not, loved or hated, have real social and political consequences, especially in terms of how belonging and rights are imagined. The act of drawing lines, that is, our accounting procedures, could themselves be explored so as to reveal the construction of disability as problem. Simply put, this problem organizes distinct ‘disabled’ binaries: something social/not social, something natural/not-natural. Current human rights monitoring programs not only believe that this ‘split’ exists (naturally); they also use it as a first method to identify the problem of disability and human rights.

### **The Solution: Producing Discerning Humans**

It is commonly claimed that, with the advent of the Convention on the Rights of Persons with Disabilities, we are witnessing a ‘paradigm shift’ in the definition of disability. There seems to be a subsequent move away from a functional articulation of disability as ‘a restriction or inability to perform an activity in the manner or within the range considered normal for a human being’ (WHO 1980). Within internationalist imaginaries, it is furthered asserted that disability encompasses ‘the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others’ (UN, CRDP: *Key Legislative Measures for its Effective Implementation* 2011, 5–6).

The shift from discerning what is considered normal for a human being toward ascertaining how disability appears as an impairment embedded in complex interactional scenes is reflected in government literature. Consider one such typical example of discernment:

The Government of Canada’s efforts at integrating services for people with disabilities have, for a number of years, been guided by the understanding that

disability is not defined merely as being the direct result of a health problem or any physical or mental limitation. Instead, it is seen as the result of complex interactions between a health problem or functional limitation and the social, political, cultural, economic, and physical environment. These, in combination with personal factors such as age, gender, and level of education, can result in a disadvantage – that is, a disability. This link between a functional limitation and the disadvantage is what courts try to determine in investigating disability-based human rights complaints. (*Advancing the Inclusion for Persons with Disabilities* 2006, 6)

This understanding of disability shows that governments ‘for a number of years’, have known what most disability studies scholars acknowledge: namely, that disability is made, not born (Scott 1981; Oliver 1996). At the very least, disability is other than a direct result of a ‘health problem or any physical or mental limitation’ (*Advancing the Inclusion* 2006, 6). Thus, at the state level, efforts to integrate, provide services, or otherwise respond more equitably to disability cannot be based solely on the presence of impairment defined as functional limitation. Moreover, some people some of the time know that impairment is not the sole conditioning factor of a person’s life. Functional and health limitations ostensibly reside somewhere in the midst of ‘social, political, cultural, economic, and physical environment’ and ‘personal factors, such as, age, gender, and level of education’. This means that a ‘health problem or any physical or mental limitation’ makes an appearance *in*, are seen as the result *of*, and can be addressed *as* a complex interaction among personal factors (age, gender), social factors (political, cultural, environment) and the fact of embodiment (functional limitations or health problems).

Displaced, downplayed, and even dismissed are articulations of disability as a straightforward departure from normalcy.<sup>4</sup> What remains is a growing need to discern links and distinctions regarding how disability is being made to matter within the activities of daily life and the courts.<sup>5</sup> Correspondingly, this ‘link between a functional limitation and the disadvantage is what courts try to determine in investigating disability-based human rights complaints’ (*Advancing the Inclusion for Persons with Disabilities* 2006, 6). Set in the welter of cultural life, we are introduced to an intricacy of and between ‘limitation’ and ‘disadvantage’. But, more than this, we are introduced to a need for people to comprehend that they *need to discern* such complexity when they perceive disability. Is the worker with a degenerative muscle disease, for example, not assigned a locker space because of disability discrimination? Or, does the difficulty of having a degenerative

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4 I use ‘displaced’ to indicate that functionality is not ‘gone and forgotten’. After all, the entire WHO classification system of disability (be it the 1981 ICIDH or the 2001 ICF version) is grounded on a body of functions, intricately mapped, but also ‘By including contextual factors, in which environmental factors are listed ICF allows to record the impact of the environment on the person’s functioning’. (<http://www.who.int/classifications/icf/en/>).

5 The need for discernment is made explicit in article 33 of the CRPD (but is implied throughout) and implementation of such rights has often taken the shape of monitoring.

muscle disease make the omission of such space a disadvantage? Or, is the lack of a locker merely a sign of economic rationality winning out over normative conventions? Can it no longer be assumed to be part of this work place, and, if so, does the worker know how to request a special accommodation? If not, is this due to 'personal factors' or 'environmental' ones? These questions invite critical acts of 'monitoring' how and why disability is rendered manifest via the divide between 'natural limitations' (e.g., biological impairments) and discriminatory societal responses.

This shift in textual accounts of disability by way of problem and solution, positions readers as individuals who *should* be animated by a need to perceive personal, social, physical, and economic divisions. This perspective is what urges us to be interested in disability as a complex matter of discernment: 'Include! But to what end? Difference or difficulty? Limitation or disadvantage?' We are coached to delineate between limitations and disadvantages where impairment functions as a natural limit and hardship signifies a socially imposed state of unwanted affairs. This need to discern complexity *as* a clear line between 'the given' and 'the made' is now what we, like the courts, are being asked to face with regard to cultural differences recognized as constituting the lives of people who live 'with disabilities'. We are trained to demarcate human rights issues (the made) from non-human rights ones (the given as if by nature alone). If disability is positioned as rooted in impairment, understood as biological, and sometimes read as social in character, then the question of disability as it is a lived part of daily life may also be tied to a state of nature, to a social contract, or some relation between the two.

Despite the powerfulness of science, medicine, and bureaucracy, drawing the lines between what will count as nature and what will count as society remains an interactional scene steeped in conflict and uncertainty. How the ambiguity between nature and society, between person and their difficulties, are noticed, documented, articulated, and addressed by governing bodies reveals much about what disability is already taken to be, namely, a problem in need of proper discernment. Discerning a conflict between disability and society is not new, but perhaps there is something original in discerning the exact relationship between functional limitation and sociopolitical disadvantage. What is heralded as an 'evolving conception' reflective of a 'major shift in global understanding and responses towards disability' fixes body and life chances with the 'clasp' of human rights (WHO 2011, 7; CRDP 2008, preamble e and following). Recalling Said, we can now ask, 'How does this associate us with conceptions of the human as a universal crisis of our collective understandings and with those made to suffer as and in its margins?' To give greater scope to what it means to *suffer biological conditions as though they are separate from their social location* requires that we attend to the actual activity of drawing lines of division between key categories of interpretation, especially with regard to human/not-human.

### **More than Merely Biological and Also Social**

To reiterate and expand, disability is today associated through common expressions that suggest that it is 'more than merely biological', and that it is 'also social'. Such expressions orient us toward the meaning of *human* as somehow outside its own embodiment and other to its biology. Through these common ways of articulating disability, the human is thus tacitly positioned as the one who can make and discern such distinctions, that is, draw (and believe in) a line between biology and the social. Within some forms of disability studies and activism, the ability to separate person from disability and to discern the difference between disability-as-impairment effects and disability-as-societal responses is essential, especially if a rights discourse is to take hold and hold sway (Pothier and Devlin 2006, 3). How might we best regard this way of making a conception of the human?

Recall the United Nations' 2008 *Convention on the Rights of Persons with Disabilities*, which frames people with disabilities as having the same rights as any other people: equality, dignity, autonomy, independence, accessibility and inclusion. According to the Convention, acknowledging these rights will be 'key to ensuring that people with disabilities are able to fully realize equal citizenship in the world' (2008, *ibid.*). The advent of UN ENABLE programs as well as the launching of the *World Report on Disability* can be read as engendering such acknowledgement by monitoring how disability is linked to or barred from the provision of rights. The movement toward understanding disability as a human rights issue can also be witnessed in the growing set of practices and protocols at all levels of government and international organizations to monitor disability as a human rights issue. Programs around the globe are oriented to teaching people to understand disability in human rights terms, offering protocols that regularize how people discern and launch human rights complaints, and to enable people to 'fully realize equal citizenship in the world' (*ibid.*).

To monitor, means to identify as a way to come to know; it is to come to take into consciousness those lines between human and its other as they are drawn in government and legal structures, by disability organizations, in the media, and in individual experience. This monitoring requires, first of all, the ability to discern lines of division and, second, discern where such lines should be drawn. Such discernment requires an ability to divide what a society prevents disabled people from doing from what a functional limitation prevents people from doing. In other words, more and more people are being trained to draw the line of division between the human and the biological, between the social and natural.

The human becomes those who not only interprets the edges of humanity but can also participate in drawing the line of division between human and non-human, etched through monitoring practices, policies and procedures. Understanding one's self as the effect of the practices that actualize a sense of human (or not), serves to empower people to write/right themselves into the human community. Convincing others that I am human too, 'just like you', and that I 'should enjoy the same rights –

civil, political, economic, social and cultural' – as do you, requires techniques for drawing lines, lines that may offer an ever expanding sense of inclusion into the human realm. And yet the category of human remains one that can account for itself *only* by positing something (or someone) outside its borders (Butler 1997). Thus to declare myself or you as human requires that I have an implicit sense of what or who is not human. The human rights monitoring industry is grounded on and provides for just such a sensibility. But, is this yet something to wonder about?

Training people to both monitor and use the human rights resources that their country provides, means engaging in mechanisms that can actively include a person into the human community (whether one's rights are actualized or not). In this sense, monitoring and seeking to secure human rights is not only a legal practice, it is also a practice identifying the practitioner as participant in drawing lines of division, an act vital to the establishment of a sense of the human community (as currently conceived). There is, then, a type of human for whom the ascription of human rights must be 'seen' to be achieved; there is the type of human who in getting married, going to school, securing employment, symbolizes the actualization of rights that further serves to inscribe their self and others into the category of human. This suggests that we have at least three ways of making the category human appear around the globe today. There are humans with rights actualized. There are humans who can achieve their rights by drawing themselves onto the correct side of the dividing line. And, finally, a shrinking sense of those who are 'naturally' without rights but who, nonetheless, exist on the margins of the category human.

Human beings have established a relation to the acquisition of rights that positions some people as needing to 'do' human rights monitoring as a way to participate in the community understood as human. *Some humans need to 'do' human if they are to be seen to 'be' human.* It remains true that if you cannot be seen to be able to draw the lines of division between human and non-human, or at least to have others draw you on the right side of those lines, then you, or some part of you, will not be regarded as the bearer of rights. Perhaps it is now necessary to reconcile ourselves to what it means to have sets of procedures, policies and programs that train people to be prepared to draw lines that demarcate the extent and even the possibility of inclusion as a practice whereby a version of the human becomes a set of doings.

Reporting on the work of a plethora of monitoring programs launched around the globe, Disabled Peoples International (DPI) observes:

In January 2010 over 100 people with disabilities from around the world came together in Geneva to discuss how to monitor the implementation of the Convention on the Rights of Persons with Disabilities (CRPD). The Convention requires that Disabled People's Organizations participate fully in the monitoring process of

this treaty. Disabled Peoples International (DPI) is deeply involved in the global process to make the CRPD work. (DPI, *Disability Dialogue*, 2010, 11–12)<sup>6</sup>

Much hope for the future is placed on these monitoring activities. While there is a brief concluding remark in the UN Thematic study by the Office of the High Commissioner for Human Rights (2009, 16 point 76) that the implementation of the CRDP is distinct from its protection, promotion and monitoring, it appears that most of the activities associated with ‘the first human rights treaty that comprehensively details all human rights of persons with disabilities’ is tied to monitoring practices. This focus on monitoring is made clear throughout the entirety of the High Commissioner Thematic study (2009, points 1–75). Recall that Article 28 of the Universal Declaration of Human Rights (UDHR, article 28) states that, ‘Everyone is entitled to a social and international order in which the rights and freedoms set forth in this Declaration can be fully realized’. Ironically, it seems that Article 28, as it relates to disability issues, has become *Everyone is entitled to monitor everything in order to discern whether the social and international order in which the rights and freedoms set forth in this Declaration are being realized* (consider, also, Articles 31–42 of the CRDP).

Many of the CRDP implementation programs express their commitment to monitoring. For example, Disability Rights Promotion International (DRPI), states that it is ‘Working to establish a monitoring system to address disability discrimination globally’ (<http://drpi.research.yorku.ca/resources>). DRPI describes its work with their partners as realizing ‘their belief in the need for real change’, while working with:

individuals, organizations and international bodies with established expertise around particular tasks [of monitoring]. DRPI (2008) has adopted three broad areas for monitoring based on recommendations by the participants at the Almâsa Seminar: monitoring systems, monitoring individual experiences and monitoring media. Human rights monitoring has been broken down into these areas to find the discrete pieces of knowledge in order to paint a picture of the current situation faced by individuals with disabilities. (ibid.)

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6 There are other rights monitoring projects e.g., International Disability Rights Monitor, ‘Providing the tools to fight disability-related discrimination’ <http://www.idrmnet.org/index.cfm?m=1>; the Australian Federation of Disability Organisations, ‘Human Rights Monitoring Project’ <http://www.afdo.org.au/>; the International Disability Alliance Secretariat, studying the Effective Use of International Human Rights Monitoring Mechanisms to Protect the Rights of Persons with Disabilities. <http://www.internationaldisabilityalliance.org/>; The Harvard Law School Project on Disability (HPOD) that works to promote the human rights of people with disabilities worldwide <http://www.hpod.org/convention/monitoring>.

These programs train people and governing bodies to view disability as a human rights issue. Such programs are guided by the impulse to ‘paint a picture of the current situation faced by individuals with disabilities’ (ibid.). The advent and growth of monitoring programs can be read as representing a shift from an individual or charitable use of human rights discourse to a much more highly regularized use of human rights protocols. To be sure, this monitoring is expansive, touching every continent and involves notable scholars, government officials, lawyers from many different countries, many of whom are disabled people.

My point here is not to measure the quantity nor evaluate the quality of these programs. My concern, instead, is how disability, as represented by monitoring programs, represents distinctions between the social and the biological and, thus, reflects a particular version of the human in human rights discourse. Such programs are oriented by a goal to ‘build towards a comprehensive understanding of the rights of people with disabilities and the discrimination they face, which involves extensive monitoring. Like all such human rights monitoring practices, this builds upon a conception of a type of human who is a bearer of rights. It is also reliant on training others to see this personhood as a means of rights protection:

The lives of people with disabilities are changing. Around the world, people are beginning to understand that disability is a human rights issue. People with disabilities and their families should enjoy the same rights – civil, political, economic, social and cultural – as everyone else. (DPRI, *Facilitators Version* 2008, 17)

Thus, to understand that disability is a human rights issue is to understand that people with disabilities are fixed to the political, social and economic lives of a country and therefore should enjoy the same rights as everyone else. But, it also means establishing more ways to discern distinctions between functional limitation and life chances, biology and society, and thereby to naturalize disability as an occasion to enact such discernment. Indeed, disability may even seem to be that which should stimulate a continual need to discern such borders.

## Conclusion

Undoubtedly, the number and types of people who are locatable within the confines of the human are changing. However, the confines of what it means to be *human* might not be. I am not suggesting that it is not ‘reasonable’, especially under bureaucratic rule, to ensure there are distinctions made between a functional or health limitation, and societal forms of discrimination. I am, however, suggesting that through this highly accepted and expected advancement of human rights monitoring, people are being trained to draw the human/non-human divide as a regularized practice that serves to make the monitor perceive, and even appear as, the category human. *Human will do in order to be*. In the case of disability, this

version of human requires holding on to the possibility that there is some kernel of non-human, some functional limitation or health condition that is not social; some part of an individual's life that is not more than merely biological; some problem-thing that 'we' who belong to the human community need to be seen as able to recognize and cordon off. Disability becomes the limit case *par excellence* and is made to signify (yet, again) not-life, not-human. This is the individual that bares a 'useless difference' and is regarded by individuals, and even by the courts, as 'already dead' (Michalko 2002; Razack 2011).

Returning to Ellison's opening statement, the problem is not 'prophecy' – the problem is not how better to draw the dividing lines between body and society, biology and culture, disability and person, natural exclusion and injustice. The problem is not the need for better definitions, systems, and technologies for deciphering the kernel of non-human hidden within humanity. The problem is not even that we feel so compelled to continue to draw and monitor such lines or that we have taken this as the only hope, within the current system, for the protection of persons with disabilities. The problem is this: we have an unexamined conception of human to which instances of disability are subject and against which disability is judged that is not under the same systems of discernment as are the actual people perceived as disabled.

There is still a version of the human-being that needs human-doing and this may be inescapable. After all, how can we extract ourselves from the fact that 'human' is not a product of nature? It is likely that the category of human has always needed its imagined limit in the face of which it can achieve its own self-recognition (Butler 1997, 15). But this does not mean that the very thing so essential to the system of human rights – namely, human(e) discernment – cannot be turned to face the monitoring systems themselves as an imaginative way to remake this essentially functionalist version of the human-being as always a human-doing. The ultimate horror may be that the human category is human made and yet it is so difficult to forge any associations with a need to remake it otherwise than the same.

If there is any truth in the above analysis, it might suggest that there is a further inequality of concern: Is it humane to ask those least likely to be included into the human community to perform the task of drawing the lines of inclusion, thus doing-being-human in the face of all those who already count as human beings? Is it time to expand this task and even the scope of a collective interest in it? A radical humanism might seek to show how all people are affiliated with the horror of a taken-for-granted version of human and thus are also affiliated with the suffering of needing to re-make a focus on inclusion mechanisms into a focus on the question of the category of the human itself. Is it time, as Said suggests, to embark on the universal task of remaking the human?

The human rights monitoring programs are certainly committed to including the historically excluded into the category of the human. But, can this commitment also include the task of re-making the category human itself, thus making for a more humane humanity? Perhaps a more humane humanity can be won if we

expand our sense not only of who should be included into the category human while monitoring infractions; but also address the place of monitoring humans in our human made world. Wondering about human in and through ‘rights boundary work’ might allow us to approach the divisive category of human and reconsider the confines of the human we have already made ourselves to be.

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## Chapter 8

# The Specter of Vulnerability and Disabled Bodies in Protest

Eunjung Kim

The film *Kandahar* (2001, dir. Mohsen Makhmalbaf) features a scene in which a group of survivors of land mine explosions vigorously hop on their crutches with their eyes fixed on something up above. Following their gaze, the camera shows a pair of plastic legs falling down, dangling from a parachute, and then shifts to a shot of the men's lower bodies with their stumps. This spectacle of disabled bodies and humanitarian aid registers with Western viewers as "the most powerful scene in the movie," because it is "grounded in the realities of Afghanistan's long cycle of occupation and sectarian warfare that continues today" (Davidson 2008, 188). The ensemble movement of disabled men captures the intensity of desire and competition for scarce resources in a barren landscape. A connected pair of plastic legs resembles the limbs of a posed mannequin rather than a functional prosthesis, yet it is pursued randomly by unilateral amputees – not for their own use but rather for its exchange value. Later a hand amputee, who sells a prosthetic leg acquired in a Red Cross camp, says, "These fields are full of land mines. It's good to have replacements," an observation that underscores the market-based approach to humanitarian aid. The scene – which does not show suffering strangers waiting to be helped or grateful recipients who directly benefit from prostheses – shatters the fantasy that humanitarian aid alleviates suffering.

The active pursuit undertaken by amputees who have needs, desires, and strategies for survival is contrasted with the failure of humanitarian work, displaying a surreal realism (see Mirza 2009). The scene's critique of humanitarianism is reversed via the film's representation of vulnerability in a way that highlights the need for humanitarian help. Specifically, the film centers on an Afghan-born woman named Nafas, who hurries from Canada to Kandahar to meet her sister whose legs were blown off by a land mine. Nafas's sister has written that she plans to commit suicide at the next solar eclipse. However, Nafas's journey is impeded by the complications of war-torn Afghan life and gendered restrictions. Her disabled sister never appears in the film, for in the end Nafas fails to reach Kandahar in time. Evoking compassion and the desire to rescue, the looming presence of her sister affectively emphasizes her vulnerability by making visible wounded bodies and the ever-present threat of harm.

Another example of vulnerability evoking the desire to rescue occurs at the Iran–Afghanistan border, where a teacher trains hundreds of young girls who are

about to return to Afghanistan about the danger of booby-trapped dolls. At the training site, Nafas records a letter to her sister:

[The young girls] are being told not to approach those dolls that you once stashed and which blew off your legs when you were escaping, so they won't lose their legs like you did. I am glad you don't know the truth that in Afghanistan these past twenty years, one human being has died every five minutes from mines, from war, famine, or drought. If you knew that, you would have lost hope every five minutes and with that you would have wanted to kill yourself.

While making clear to viewers the severity of the violence, Nafas gives the statistics a temporal dimension: setting the exact intervals at which harm occurs in effect rationalizes and naturalizes the existence of violence. Nafas informs the audience of the assumed truth, which the disabled sister is cast as too emotionally vulnerable to handle. Both the absent disabled sister on the verge of committing suicide and the people who are getting killed or injured every five minutes are summoned as the specters of vulnerability.

The ominous threat is given form in a telling scene. The teacher tells her students if they step on a doll on the ground and hear a sound, they will die. With eyes closed, she randomly throws several dolls. The camera shifts to the legs of five girls, lined up against a stone wall; the shot is focused on a doll that falls right in front of them. One girl, who appears to be blind, squats down. While the other girls' legs move away from her and out of the frame, the blind girl begins to sing and playfully flap her hands in the air with a hint of smile. The camera then cuts to a nearby girl who stares at the doll on the ground, juxtaposing her apprehension and the blind girl's seeming unawareness. In contrast to the spectacle of male amputees pursuing parachuted aid supplies and the sighted girls' ability to detect and avoid harm, the blind girl embodies a disabled and gendered vulnerability.

The viewer's gaze on the blind girl in *Kandahar* leads to what Sherene Razack (1998) calls the privatization of the social construction of disability, which happens "when we focus on the vulnerability and incapacity of individual women and not on the social relations that transform a physical or mental condition into a condition of great vulnerability" (139). Disability is perceived as an anomalous incapacity, inviting harm or providing causes of harm, and as located within an individual body isolated from the social contexts that facilitate violence. Such privatization emerges in the images of the vulnerability and incapacity of individual women in the non-Western world, which obfuscate the social relations that transform a physical or mental condition into vulnerability: "Pity is the emotional response to vulnerability," according to Razack, a response that "does not necessarily lead to respect, to a willingness to change the condition that hurt people with disabilities" (138). As the camera shows Nafas calmly walking and talking into a recorder about women's *burqa*; anxiety over immediate danger that was created by the shot and reverse shot of the blind and the sighted girl is replaced with pity and a sense of doom associated with the imagined future harm. In this way, the gaze of pity is

based on a construction of disability and of a position of complacency that fails to account for how the viewers were historically and materially connected to and implicated in the plight of those in the images even before the US-led invasion of Afghanistan.

This training site introduced by Nafas on her journey to save her disabled sister makes visible the risk of injury and casualty as well as the attempt to minimize them by educating the potential victims. Benjamin Reiss (2010) reminds us that François Ewald explained risk as “a statistical category invented by the insurance industry and adopted by institutions as a mechanism for self-preservation” (39). To be sure, those at the border training site are not concerned about liability or financial compensation in case of injury; however, the emphasis on educating potential victims to protect themselves before they return to Afghanistan and the scene of the blind girl being abandoned, as all the others quietly move away without assisting her, certainly display a privatized form of risk management based on individual capabilities. “Whereas ‘risk’ rationalizes and objectifies problems,” Reiss argues, “the concept of vulnerability is relational and flexible” (39). Managing risks by teaching girls to individually avoid harms underscores the blind girl’s vulnerability, thereby shifting a vulnerability that is “not necessarily assessed or managed from the top down” (Reiss 2010, 39) to a condition that is rigidly specific to othered bodies. As Tim Brown (2011) observes, the invocation of vulnerability in global health discourses is “oriented towards the fears of the rich rather than the needs of the poor” (324). Brown further argues that the attempts to protect global populations against diseases “still appear to prioritize the national security demands of the global North” (324). In this framework, vulnerability is no longer an ontological and relational state that all human beings share. Rather, it is visually and psychically contained in the body of an Other – here, a girl child with a disability.

Because vulnerability works as a temporal projection toward the future, capturing it in the present seems impossible. Even in the moment of experiencing pain, suffering, and death, vulnerability escapes to another future in which living bodies will be further wounded and dead bodies will be violated and witnessed: the transmission of harm has no end. To visualize vulnerability and make it manifest in the present one thus must manage this futurity by presenting bodies with asymmetrical power and by coding certain embodiments as evidence or causes of harm. Doing so roots visualized vulnerability deeply in historical events and in the knowledge of what has happened in the past to people who share specific characteristics and space. Therefore, vulnerability operates via hierarchical constructions of differences. Privatized vulnerability is the key in constructing power and difference, as the determination of subjects as vulnerable can make them vulnerable.

In this temporal management of visualizing vulnerability, two different affects might emerge. On the one side, observers may experience empathy toward the vulnerable subject while desiring their own security of oneself and glossing over the wounding power. On the other side, the vulnerable subject’s capacity or willingness to be wounded may be so great that it blocks empathy; instead, it may reveal the complicity of the viewers in constituting the wounding power. In the former process,

spectral vulnerability is created by invoking an absent referent of identification that enables viewers to calculate the chances of future harm and thus to determine what actions are acceptable. In the latter, vulnerability as a collective capacity to be wounded and as a resistant passivity, can be deployed to accompany a claim for social justice and human rights. The vulnerability of the girl registers dramatically differently when, rather than seeing blindness as automatically increasing risk, one perceives her action of sitting down as a refusal to play along that illustrates her resistant passivity. The blind girl in *Kandahar* may be singing playfully, knowing that she is facing no actual harm or knowing that sitting down will prevent her from inadvertently stepping on any dolls. The emotional reaction to seeing an image evolves an interpretive process based on the viewer's attitude toward disability.

To be sure, international humanitarian communications have moved beyond simply the shock-generating images of suffering (which Plewes and Stuart [2007] call "the pornography of poverty"), in response to ongoing criticism about relying on the emotional effects of guilt and indignation (Chouliaraki 2010). "Positive image appeal" that emphasizes the sufferers' dignity and agency has likewise been faulted for its oversimplification which masks real issues and also produces suspicion about the actual needs (*ibid.*). Nevertheless, humanitarian medical fund-raising in the West relies mainly on disempowering images of racialized, gendered, and disabled non-Western bodies as needing help, an approach that feeds on the assumption that disability – particularly outside of a Western context – in and of itself is direct evidence of tragic harm, injustice, and deprivation (see Jarman 2005; Siebers 2008).

The multiple representations of disability – which make visible the failures of international aid, highlight the differentially experienced effects of wars, and constructs bodies as vulnerable and less vulnerable – serves as one of the primary foci of this essay, which in part considers the role of spectral vulnerability in humanitarian representations. To pay attention to global inequity of economy and power, according to Michael Davidson, is to think about "a kind of phantom limb phenomenon that registers a phantasmatic 'whole body' that can no longer be constituted or imagined" (2008, 180). Davidson emphasizes that while disability studies focusing on "first world" texts may have moved beyond the analogical interpretation of disability as loss and tragedy, the metaphor of disability in a "third world" context continues to expose "the conditions that create and sustain bodily difference" (170).

What would happen if one compares the view of disability as evidence of social injustice and global struggle and the view of disability as evidence of diversity and belonging? Are the two perspectives incompatible? How does looking at disability as representing broader social contexts limit the understanding of everyday lives of disabled people vis-à-vis nondisabled people in non-Western societies? Is the disabled body constructed as tragic consequence of injustice specific to the non-Western world and positioned in relation to disability constructed as diversity and culture in the Western world? When bodies are wounded by violence, at what point does this consequential body of harm become a being entitled to resources

and accommodation beyond the grief associated with loss of an able body? As Davidson points out, disabilities in the non-Western world often highlight the circumstances that produce impairments, such as material conditions, histories of colonialism and slavery, neoliberal capitalism, and wars. Moreover, the global economic systems of inequality, racial and gendered violence, warfare, and capitalism, and the histories of colonization that produce disability also affect the ways in which disabilities are experienced (Erevelles 2011). In addition, disablements occur both in and outside the West through accident, birth, personal will or no identifiable cause, while simultaneously they are produced by dangerous labor conditions, violence, poverty, environmental pollution, and limited access to health care. Yet whatever the conditions that bring about disability or impairment, those same bodies, constructed as harmed, are transgressive, resistant, and radically vulnerable in ways that challenge the existing hierarchy between disability and nondisability, far from being static as evidence of causes of their embodiments.

In what follows, I analyze vulnerability as an intercorporeal affect communicated through the display of the power to wound. I apply this affective frame to my reading of how woundable bodies move in and out of identities designated as vulnerable. Such an analysis involves aesthetics, ethics, and the politics of violence, which together create a circular logic that simultaneously responds to and produces the vulnerability of women with disabilities within a global humanitarian context. This logic instantiates the desire to protect women with disabilities by rendering them as needing protection. Thus Susanna Kaysen describes her experience at an American psychiatric hospital: “Naked, we needed protection, and the hospital protected us. Of course, the hospital had stripped us naked in the first place – but that just underscored its obligation to shelter us” (Kaysen 1993; in Reiss 2009, 23). Kaysen captures how the so-called protector fundamentally relies on the existence of protectable persons, whose vulnerability must be created by stripping them naked, both figuratively and literally. *Kandahar*’s image of a blind girl takes advantage of such dependence insofar as viewers become emotionally-driven surrogate protectors.

This essay also examines the identitarian imposition of vulnerability: that is, it explores how vulnerability is attached to certain medical and legal categories of identity. In turn, these characterizations authorize ethically problematic treatments based on the prediction of greater harm. To situate this argument, I first consider the use of vulnerability in discussions of identity politics and universality. I then shift to close readings of two works that sometimes challenge and at other times confirm these categorizations. The Girl Store, a New York City-based online donation site launched in 2011, pleads with consumers to pretend to “buy a girl” (from India) before traffickers do, bringing to mind the 2005 article about purchasing two trafficked Cambodian girls by the *New York Times* columnist Nicholas Kristof. The South Korean short film “Believe It Or Not: Chandra’s Case” (included in the 2003 anthology *If You Were Me*) presents the real-life story of a “nondisabled” migrant woman from Nepal whose inability to speak Korean leads the authorities to label her a mentally and intellectually disabled Korean

woman and institutionalize her for more than six years. Lastly, the essay considers how vulnerability is employed as a political tool – in a manner that challenges the identitarian appropriation of vulnerability – by introducing a 2006 crawling protest in Seoul undertaken by activists with physical disabilities and their allies to demand that the government provide in-home assistance. This protest radically rejected any form of humanitarianism; rather, it claimed that ensuring the rights to which people with disabilities are entitled is the state’s responsibility.

### Identifying Vulnerability

Who ultimately should be designated as belonging to vulnerable populations? The universal vulnerability of all embodied lives coexists with the fact that some groups are deemed far more vulnerable. One of the ethico-political determinations of vulnerability appears in the institutional guidelines for biomedical research. In the context of research ethics, vulnerability “involves a diminished ability to protect one’s own interests, typically manifested through an inability to give informed or voluntary consent” (Wendler and Grady, 2007). According to the *International Ethical Guidelines for Biomedical Research Involving Human Subjects*, the vulnerable groups are determined by age, disability, identity categories, economic status, and operational power relations. This publication lists children and persons who are incapable of giving informed consent because of mental or behavioral disorders; junior or subordinate members of a hierarchical group; elderly persons; residents of nursing homes; people receiving welfare benefits or social assistance, as well as other poor people and the unemployed; patients in emergency rooms; some ethnic and racial minority groups; homeless persons; nomads; refugees or displaced persons; prisoners; patients with incurable disease; individuals who are politically powerless; members of communities unfamiliar with modern medical concepts; and persons who have serious, potentially disabling or life-threatening diseases (CIOMS 2002).

Responding to such broad categorizations, the National Institutes of Health section on the Ethics of Human Subjects Research led by David Wendler and Christine Grady contends that current understandings of vulnerability include too many groups, “to the extent that it can be difficult to determine who is not vulnerable.” They further argue that current concepts of vulnerability are applied indiscriminately to whole groups of people without considering individual and personal differences, adding that viewing “all poor people, pregnant women, members of ethnic or racial minorities, and people with terminal illness as inherently vulnerable has been particularly controversial” (Wendler and Grady, 2007). They thus take the position that special protections for research participation must be based on specific factors beyond an individual’s membership in a “particular sociodemographic group,” thereby challenging the significance of group identity in determining vulnerability.

This skepticism regarding the group specific application of “vulnerability” provides an apt entry into the term’s multivalent reaches and resonances. Indeed the concept is applicable to individuals, minority identity groups, or all human beings. Visual representations of vulnerable bodies yet to be harmed often rely on preconceptions about so-called incapacities of certain identity groups that provoke an emotional engagement (as in *Kandahar*). If an identitarian visualization of the vulnerability of a disabled body exploits the presumptive powerlessness of minority groups and the independent management of harms, what could be gained or lost by considering vulnerability a universal condition that is shared by all? How do the structural and social forces that systematically expose certain groups to harms make the presumption of powerlessness a reality?

To answer these questions, it is helpful to consider the importance of understanding vulnerability as a condition specific to groups minoritized by identity or geography. Ulrich Beck (2009) emphasizes that differences in vulnerability and risks are rooted in history, noting that “social processes and relations lead to unequal exposure to risks and the resulting inequalities must be treated as largely an expression and product of power relations at the national and global levels” (178). Martha Fineman (2008), on the contrary, states that we have passed the era of identity politics and views vulnerability as a “post-identity” inquiry. Fineman moves away from considering vulnerability as victimhood, deprivation, dependency, or pathology; rather, she approaches it as a hermeneutic device that requires proper actions to be taken: “Vulnerability analysis demands that the state give equal regard to the shared vulnerability of all individuals, transcending the old identity categories as a limitation on the recognition that the state has a vital role to play in protecting against discrimination” (20). It thus entails a universal and constant condition: “Understanding the significance, universality, and constancy of vulnerability mandates that politics, ethics, and law be fashioned around a complete, comprehensive vision of the human experience if they are to meet the needs of real-life subjects” (5).

Beck and Fineman present two contrasting perspectives on identity and vulnerability. Beck may consider “vulnerable people” to be members of distinct groups who are living in realities that disproportionately expose them to harm; therefore, identity plays a central role in constructing agents that produce knowledge of such realities. Fineman presents vulnerability as the universal human condition; thus policies and special measures to prevent discrimination based on minority identity become undesirable, producing only division and harmful competition. Given these declarations that the state has responsibilities to adequately provide for its inhabitants, both citizen and noncitizen, how does one begin conversations about disability? I pose this question because the existing lexicon of identity politics continues to fail to acknowledge disabilities and indigenous status that produce systems of privilege and segregation. Statements such as “the vulnerable are the hardest hit” and “we are all vulnerable” are rarely made by those who typically are labeled vulnerable, and thus they tend to mask embodied disparities and geographical specificities as they are used to forge alliances.

A point made by Judith Butler (2006) is useful in resolving the logical incompatibility of the universal and identitarian perspectives on vulnerability without resorting to the differential degree of vulnerability. The primary vulnerability at the core of all human lives, as exemplified by the infant state, needs to be distinguished from the vulnerability that is constructed differentially by social responses to this primary vulnerability: “Although I am insisting on referring to a common human vulnerability, one that emerges with life itself, I also insist that we cannot recover the source of this vulnerability: it precedes the formation of ‘I’” (31). For the groups whose needs are thwarted, Butler states, vulnerability is a sign of deprivation: “Lives are supported and maintained differently, and there are radically different ways in which human physical vulnerability is distributed across the globe” (31–2). In a more recent virtual roundtable discussion, Butler addressed two different dimensions, one existential and the other contingent:

We can make the broad existential claim, namely, that everyone is precarious, and this follows from our social existence as bodily beings who depend upon one another for shelter and sustenance and who, therefore, are at risk of statelessness, homelessness, and destitution under unjust and unequal political conditions. As much as I am making such a claim, I am also making another, namely, that our precarity is to a large extent dependent upon the organization of economic and social relationships, the presence or absence of sustaining infrastructures and social and political institutions. (In Puar 2012, 170)

On this view, rather than a particular group with difference being essentially a locus of vulnerability, the vulnerability corresponding to a particular group is produced by social and economic relations and institutions. These discussions about vulnerability and precarity are largely motivated by global economic measures, including austerity, and the securitization of nation-states, as well as large-scale environmental disasters. They focus on the broader “precaritization” of the public, the 99 percent identified in the slogan of the Occupy movement. At the same roundtable, Isabelle Lorey emphasized that the democratization of precariousness “doesn’t at all mean equality in insecurity; inequalities are not abolished” (in Puar 2012, 172). She pointed out the limits of universalizing vulnerability and precariousness: “If we say, ‘we are all precarious,’ then the precariousness that is shared with others is always something that separates us from others, and at the same time it is something we have in common with them” (172). But the question still remains: How do the designations of the most vulnerable interact with group designations, such as people with disabilities?

Making a point similar to Razack’s on the privatization of the construction of disability, Tanya Titchkosky (2007) warns that the notion of “the vulnerable” has the effect of concealing social relations and turning differences in capacities and degrees of vulnerability into individual fates, divorced from social context. As she focuses on who is considered invulnerable when “the vulnerable” is uttered, she makes clear that the category of the vulnerable does not transcend the boundaries

of marginalized identities; instead it blurs them as all become “the powerless,” inherently predisposed to harm. And this is what happens in *Kandahar*’s representations of disabled women. Titchkosky challenges the understanding of vulnerability as personal attributes associated with the perceived weakness of individuals, and she redirects our attention to governing social conditions and the ways in which embodiment is interpreted.

As disability is mapped onto the geography of vulnerability, Michelle Jarman and Chandra Mohanty both suggest that identities must be transgressively reformulated in a way that does not neatly overlap with conventional minority identities. Jarman (2005) argues that disability, when constructed as an essentialized vulnerability, falsely draws a sharp contrast between “the limitless potentialities” of the first world and “the inevitable suffering and limited existence” in the third world (108). She criticizes the “western dependency upon this discursive deployment of disability,” which effects both non-Western others and US national identity, for the latter is constructed through “the purifying eradication of physiological and aesthetic difference” (108). She offers instead a reading of disability as radical vulnerability, able to forge cross-identity, cross-cultural alliances that refuse the inscription of Western values upon third world bodies. Jarman declares, “If we think of disability in terms of radical vulnerability, we insist not only upon a critical reading of the figure presented as innately vulnerable, but more importantly, upon exposing the concealed fears and desires mirrored by the discursive drive to exclude, efface, or eradicate” (109). Radical vulnerability is a transgressive point of departure for exposing the divides mapped onto an uneven geography and the privilege hidden beneath the claim of universal vulnerability. Mohanty (2003) argues that by understanding the particularities of groups and their micro-identities, we can better grasp “the connections and commonalities because no border or boundary is ever complete or rigidly determining. The challenge is to see how differences allow us to explain the connections and border crossings better and more accurately, how specifying difference allows us to theorize universal concerns more fully” (226).

By failing to pay attention to numerous accounts of specific contexts and external factors that are integral to but not inherent in the human condition, by ignoring the connections between them while recognizing how vulnerability is seemingly privatized within “abject” bodies, the universal understanding of vulnerability is in danger of projecting the fear of disability onto another. This danger speaks to the fact that the presence of others may impel the consciousness of one’s own vulnerability. Margrit Shildrick (2002) poignantly describes this dynamic: “Regardless of ethical intent, those on the receiving end of (limited) beneficence are never able to claim equal agency while their vulnerability remains. Vulnerability is positioned, then, as that which impairs agency in the ‘damaged’ other while inspiring moral action on the part of the secure self to make good the perceived lack” (77). She defines vulnerability as “an existential state that may belong to any one of us, but which is characterized nonetheless as a negative attribute, a failure of self-protection, that opens the self to the potential of harm” (1). The contradiction between universality and negativity

comes from “the psychic evocation of a primal lack of unity as the condition of all,” which leads us to avoid the disabled or damaged body (Shildrick 2000, 224). Whereas Fineman sees the universal understanding as precisely what may free vulnerability from negative associations, Shildrick views universality as the origin of its negative perceptions. However, both find great potential in vulnerability: when reconsidered, it can be a valuable device for us to reassess hidden assumptions and its “radical undecidability” challenges the seemingly secure categories of the self and non-self and makes us rethink the nature of embodiment itself (Fineman 2008; Shildrick 2002, 2).

To speak of the vulnerability of an individual, of a group, or of all human beings is thus to make specific claims about differential power, as well as to acknowledge the speaker’s own feelings of the capacity to be wounded by others and to wound other bodies. This capacity to be wounded may generate power to make claims for justice and reveal violence. Making visible the vulnerability of others in a particular space and time is not the same as knowing that every single one of us is existentially and always vulnerable to loss, death, deprivation, violence, and unintended changes. Images that deliver a sense of vulnerability are rarely designed to capture its universality shared by the viewer and the viewed. Encountering the display of potential harm at a distance, the able-bodied viewer may experience a certain affect – pity, empathy, compassion, fear, outrage, disgust, a sense of relief, a desire to save or run away, or an urge to obliterate. Quickly the viewer assesses the vulnerable body by referring to a larger social group to which the body seems to belong and then predicts what may happen to it. It is this presence of impending futurity that distinguishes a scene of vulnerability from a scene of suffering grounded in what is happening in the present. The vulnerable body in front of the viewer defies the universality of vulnerability.

### **Prognosis of Harm**

How does vulnerability become a prediction of imagined harm invoking actions of “rescue” before the harm occurs? In other words, can the projection of future harm be taken as meaning that harm is already done or that it will certainly be done? In an identitarian attempt to manage vulnerability’s futuristic aspect, the vulnerable subject’s body is overlaid with statistics of past occurrences of harm that are based on identity group membership. An online donation site, the Girl Store, provides one striking example of such a conflation of time. On its opening page, a video of animated texts plays. After the words “100% GENUINE GIRLS,” “YOUNG,” “INNOCENT,” and “AND AVAILABLE” are floated over the image of a young girl, “EXPERIENCE THE SENSATION OF BUYING A GIRL” appears, accompanied by a dramatic drumbeat. A moment later, the sentence fades out, replaced by the phrase “HER LIFE BACK.” At the end of the brief video, the viewer sees the message “BUY A GIRL BEFORE SOMEBODY ELSE DOES.” Calling itself “the first e-commerce site where purchasing school supplies helps girls avoid being sold into marriage or sex

slavery,” the campaign casts the Indian girls on display as already trafficked and presents alluring images of them as waiting for visitors to buy them back.

When I visited the website in May 2012, on its “shop” page I saw three girls depicted against a white background: Panna, Vinita, and Leena, ages four, five, and five, respectively. In full-body shots, their movements are captured in a video loop, which gives them the appearance of live images in a cyber-world store window awaiting purchase. For Panna, Vinita, and Leena, the vulnerability of being an Indian girl changes into that of being trafficked, which the site insinuates has already happened. But the names and ages associated with the photos change randomly over time. In fact, the same photo earlier identified as Panna was in December 2012 named Aarti, age six. In a sense, the realness of these girls is irrelevant for this website’s promotion; its representational strategy depends instead on deploying iconography to generate consumption for emotional rewards. Next to each girl are items such as books, shoes, and bags, all with price tags. Some are stamped with the label “PURCHASED.” When all the items have been purchased for one girl, her body is itself stamped with a label: “OFF TO SCHOOL.” The entreaty to donate creates an illusion that merely purchasing school supplies will guarantee an education and that this education, whatever the specific details and regional contexts, will solve the structural, economic, and cultural problems assumed to exist in India.

The campaign relies on the impulse to control another’s future through individual spending, an operating principle of the trafficking industry. Furthermore, it creates the character of the virtual time traveler, who can prevent trafficking by using the same methods as the perpetrator. The site avoids engaging with the complex economic considerations that undergird voluntary and involuntary participations in the sex industry and other labors. Consequently, visitors engage in another kind of trafficking – what Michele Friedner calls “humanitarian trafficking” – by participating in this rhetoric of rescue (personal communication). The girls in India are cast as among the most vulnerable populations in the world as economic deprivation increases, a vulnerability that can presumably be easily rectified by those in the United States by their attention and purchasing power. This visualization of vulnerability, created by comparisons between the girls’ bodies and by the website visitors’ “sensation of buying a girl,” aggravates inequity caused by political and geographical differences. Although the site is simply requesting donations of money to purchase school supplies, its methods exacerbate a mode of economic asymmetry and simulate the ownership of another’s life.

This latter point – which involves hierarchical systems of power and exchange – sharply delineates a primary difference between humanitarianism and human rights. Humanitarianism, motivated by morality, aims to promote human welfare by assisting people in need and alleviating suffering. However, such a project does not necessarily address the injustice of the violation of the rights to which individuals are entitled by law (Wilson and Brown 2009). Assistance under humanitarianism is provided out of good will, not on the assumption that recipients are entitled to such social provision. In their discussion of Margaret

Kellow's work on the historical and contemporary redemption of slaves, a method of freeing them that in effect supports slavery, Richard A. Wilson and Richard D. Brown note: "Because a commitment to humanitarianism can frequently be fulfilled and rewarded more promptly in the here and now than can a commitment to human rights, humanitarianism more reliably delivers emotional rewards" (11–12). The rhetoric and aesthetics of vulnerability in the *Girl Store*, much like the representations of disabled women from *Kandahar*, do not address the structural issues at stake and their geopolitics; rather, vulnerability is shown as fated, in the disempowered bodies of the girls. This presentation intensifies the power to harm and activates the power to rescue.

According to Jasbir Puar (2009), identity is understood as "risk coding" in the "formulation of risk, calculation, prognosis, statistical probability" (165). Each body is coded with a legible level of risk that determines vulnerability. At any moment it can be assumed to be an already-damaged body to justify a certain treatment and to erase its present embodiment. Beyond acknowledging the body's inherent frailty and mortality, these visualizations of vulnerability introduce an ability to be wounded and generate affects and political relations. At the same time, such spectacles exaggerate power differences by binding vulnerability to the bodies of others. In other words, these strategies problematically make vulnerability the exclusive domain of marginalized (e.g., racialized, gendered, and disabled) identities and subjects. In that regard, vulnerability cannot be visualized as universal. Instead, it is manifest in relational and relative formulations about the space and the bodies that are wounded, disabled, and coded with risks.

### **The Limits of Empathy and Traveling through the Circuits of Identities**

How one understands vulnerability is fundamentally shaped by the construction of identity; it is also linked to the boundaries that people create for the representational and affective realms. A South Korean anthology film on human rights, funded by the National Human Rights Council, illustrates these vexed politics of identity, vulnerability, and empathy. Its English title, *If You Were Me* (2003), asks the viewers to empathize with the sufferings depicted in the film. In contrast, the Korean title translates as *Six Gazes* (*Yösöt kae ū sisŏn*), which highlights distinct and diverse perspectives and stories, thereby hindering an immediate interpersonal connection. One of its six short films, *Believe It Or Not: Chandra's Case* (2003, dir. Park Chan Wook), illustrates how the empathetic understanding of what it would be like "if I were you" becomes significantly limited within a framework based on single identities and focused on the *differences* of each group rather than on shared vulnerability; it thus reveals the limits of what Saidiya Hartman calls "disembodied universality" (1997, 21; in Razack 2007, 378). The film restages the actual experiences of Chandra Kumari Gurung, a Nepalese migrant worker who becomes lost after leaving her factory alone. She eats in a restaurant but discovers that she cannot pay – the money she thought was in her pocket is gone.

Not realizing that she cannot speak or understand Korean, as her foreignness is not readily apparent to Koreans, the owner mistakes her mother tongue for Korean gibberish; he calls the police, who then take her to a psychiatric hospital as an “unidentified” person. Ethnic and linguistic similarities between Nepalese and Korean, rather than differences, enable this misidentification and the construction of her disability. While in medical custody, she is diagnosed as “feeble-minded” and transferred to another facility. There, she is diagnosed with “mental retardation,” “depression,” and “schizophrenia.” Adding to the confusion, Gurung is at one point sent to the municipal “reformatory” for sex workers; she soon returns to the psychiatric hospital. These inappropriate identities, which are produced by representatives of the state and medical professionals, warrant a series of forcible institutionalizations lasting six years and four months.

The film starts and ends in her village in Nepal, with a lengthy identification sequence. One woman at a time is shown in an upper body shot mimicking an ID photo and answers “no” to the question “Are you Chandra?” When one woman finally replies “yes,” the film proceeds with her story from her point of view as she moves through the streets of urban South Korea. She is visible to viewers only in Nepal: her face never appears in South Korean scenes. A sustained shot from her eye level makes explicit that the viewers are to assume her viewpoint and her situation. At the same time, the film tacitly encourages viewers to put themselves in the position of those who contributed to her misidentification and the subsequent denial of her rights. Despite their negative depiction, the police officers, doctors, nurses, and staff working in the institutions talk to the camera without restraint, “innocently” rationalizing their actions.

The film generated a strong response from audience and critics, who commented on the reality of human rights abuses and the vulnerability of migrant workers in South Korea, as well as the horror of involuntary institutionalization based on misidentification. These reactions, triggered by the thought of being identified in a foreign country as disabled when one is not, are linked to an embodied horror, but they do not address the entirety of involuntary institutionalization. What does this say about the human rights of those who are “correctly” diagnosed with a mental illness, or those who are sex workers? Indeed, in order to criticize the convergence of foreignness and disability as a human rights violation, the film carefully establishes Gurung’s “true” identity as a nondisabled Nepalese woman. Her factory manager asserts, “She was perfectly fine. She was a great worker, very docile. Why would I hire her if she looked like a mental patient? There are plenty of foreign workers for hire everywhere.” This testimony reveals another hierarchy among immigrants, as their disability status and appearance are used as criteria for employability.

The film’s invitation to empathize with Gurung shows the limitation of affective responses, because it does not question the systems of institutionalization or how individuals and authorities deal with those who are lost and have difficulty communicating. Nor does it challenge the supposition that disabled persons are inferior. Seemingly distinct groups – disabled women, sex workers, and Nepalese migrant workers in South Korea – are connected in the systems of

institutionalization. Audiences understand the human rights abuse in Gurung's experiences precisely because she is not disabled. Her vulnerability is created not only by her status as a migrant worker but also by the existing systems that institutionalize disabled individuals and sex workers. She is "rescued" with the help of a translator brought in because of her persistent efforts to communicate that she is a Nepalese, while the other women in the institution are ignored and not seen as needing rescue. The mistake about Gurung's identity in fact shows that human rights for one group cannot be separated from those for another, while her rescue confirms that the treatment of people who are "correctly" identified is problematic. The film also shows that identity categories are arbitrary and precarious in a context in which the label "disability" authorizes involuntary institutionalization. If disabled people had been living in a supported community, then Gurung might have been able to get in touch with her coworkers after she was misidentified as disabled, as they actively searched for her and posted flyers with her photo throughout the neighborhood.

Lauren Berlant (2004) argues, "The aesthetic and political spectacle of suffering vulnerability seems to bring out something terrible, a drive not to feel compassion or sympathy, an aversion to a moral claim on the spectator to engage, when all the spectator wants to do is to turn away quickly and harshly" (9–10). Nor should eliciting compassion or assuming empathy be a goal; as Amy Shuman provocatively observes, "Empathy is almost always open to critique as serving the interests of the empathizer rather than the empathized" (2007, 180). What justifies this institutionalization of problematized bodies and how does it relate to vulnerability? The universality of vulnerability presupposes empathy and the ability to realize that one's vulnerability is tied to that of others. The attempt to create barriers to protect oneself from others is rooted in an understanding that vulnerability justifies the separation of others from the self. Here vulnerability as a category of difference operates in not an ethical but a political realm, as protective power is involved in the constitution of harms and violence.

### **Collectivity and Performing Vulnerability**

While *Kandahar*, the Girl Store, and "Believe It Or Not" highlight problematic uses of vulnerability to spur humanitarian impulses, it is also important to recognize that minoritized people deploy visual and corporeal expressions of radical vulnerability as a way to protest society's systemic failures. In my concluding analysis, I examine a public protest that performed vulnerability to upset the asymmetry of power, dispelling spectral vulnerability through political deployment. On 27 April 2006, a group of South Korean activists with physical disabilities abandoned their wheelchairs, got on the ground, and began to crawl on a busy bridge over the Han River, moving toward Nodoul Island. Others followed in their wheelchairs, while some pushed empty wheelchairs; more than 80 individuals took part in the protest. In the black-and-white photograph of the action taken by Kwōn Hūi

Süng, the camera maintains some distance from the crawlers, while raising their bodies above the viewer's eye level.<sup>1</sup> The asphalt ground of the bridge occupies the bottom half of the photo. The shadows of figures standing beyond the left margin of the image underscore the limited space that the crawlers, taking very different positions, can claim with their bodies. In the background are high-rise buildings and a billboard, which serve as shorthand for an urban landscape. On the right side, several men wearing uniforms and caps look back into the distance, indicating that more protesters are approaching. Those in the front line are sitting down on the ground, hunching over to crawl or leaning back to slide. One person stares at the camera while others are indifferent to its presence. They are wearing vests printed with the words "Legislate personal assistant service!"

This protest was a direct response to the plan by the then mayor, Lee Myung Bak, to build an opera house on the island at the cost of \$700 million. The struggle had started several months earlier, when Cho T'ae Kwang, a physically disabled man who lived alone, was found frozen to death in his room: water had leaked through a broken pipe under the floor on which he slept. Disabled activists declared that the state's neglect and the lack of state-funded services had directly caused his death. Correspondingly, they demanded governmental policies that would provide personal assistants to disabled people to ensure their right to life. Many protesters had already spent more than 40 days in tents in front of city hall before this crawling protest. Becoming vulnerable by stripping away all prostheses was their primary method of advocating for their legal entitlement to human rights. Their willingness to remove supportive technology was an act of deprivatizing disability and de-emphasizing capacity and independence, intended to remind the state of its duty to provide the means for basic human survival.

The gender of the people on the ground in the photo cannot be determined with certainty: two weeks before the crawl, the activists chose to shave their heads in front of city hall to publicly demonstrate their collective will. By uniting to remove parts of their bodies and to depersonalize themselves, the activists declared that they would suspend their daily lives and identities and become only protesters. One of the leaders, Park Kyoung Suk, solemnly announced, "Personal assistant service is the right of disabled people, the state's obligation, and a human right. We want to live like other human beings and live as human beings." The vulnerable bodies in the neoliberal modern landscape provide a visual contrast to the asphalt road: they refuse to appeal to the humanitarian impulse to reduce suffering, choosing instead political confrontation by positioning disabled embodiment in the most intimate contact with the hostile environment. By claiming vulnerability as their protest's theatrical, political, and authentic tool, they demonstrate that being alive is a fundamental human right and the major part of their everyday labor that is not valued by society. Their collective vulnerability on the ground invites neither pity nor the ableist gaze; rather, it generates a sense of their endurance and the irrelevance of any other qualities. This public display of temporary suffering rejects compassion

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1 <http://lovehm.tistory.com/519> (accessed on June 10, 2013).

or any affective response as it seeks systemic changes through what Lorey calls “self-precarization” or “protests of the precarious” (in Puar 2012, 164, 165).

It is the collectivity of their action that differentiates these activists from the popular image of the all-overcoming “supercrip” who strives to be independent without state assistance and displays the ability to complete extraordinary tasks. The group of activists and the photographer seek to make visible the opposite, the vulnerable life. Embodying vulnerability in the present inevitably involves the wounding of oneself. Three activists were hospitalized; and one of the crawlers, Park Young-Hee, told me that although men urinated publicly along the way, she hadn’t been able to urinate for more than seven hours. There was no restroom she could access when she finally arrived on Nodeul Island. As a result, police officers had to lift her and carry her back to the demonstration’s starting point, and she had to endure pain afterward. Because she and other women with disabilities often regulate their liquid intake as they plan a day out in a world with few or no accessible restrooms, Park claims that her action was not one of overcoming disability but merely of performing out in the open a hardship with which many people with disabilities must struggle daily in isolation. This is the reason that Cho T’ae Kwang, who died on his icy floor, is not summoned as a specter of vulnerability displaying the prognosis of disabled people. Rather, the more than eighty people who crawled on the bridge embody his death. As a result, the spectators who were angered by the visibility and presence of the vulnerable bodies on the ground, claiming equal rights to occupy the space, were not inspired to compassion or enabled to rescue the vulnerable. In their willingness to perform crawling and to make visible the hidden daily struggles and the deaths, the activists defy the privatization and futurity of vulnerability. By radically embodying vulnerability here and now, the crawlers ironically become no longer pitiable but instead evidence against the premise of self-sufficiency and self-care.

It took more than seven hours for protestors to crawl just over one kilometer to reach the island, successfully garnering both media attention and a police presence to guard them from the angry public caught in the traffic jam. The drivers’ rage at the presence of the bodies on the ground is an important affect that contrasts with the compassion and empathy of the distant viewers in the three previous examples. The inconvenience caused by the unexpected presence of bodies moving slowly on the space exclusively reserved for high-speed vehicles reveals the system of entitlement and mobility that governs the space. People on the bridge in the cars were implicated in this struggle and became powerless – able to help neither the vulnerable people on the ground nor themselves. The frustration at the impossibility of remedying or escaping the situation was redirected toward the authorities’ neglect. The next day, city officials requested a meeting with the activists. A few days later, local lawmakers promised to pass a bill ensuring disabled people’s right to personal assistant service. The protest ignited nationwide protests by disabled people demanding that their local governments similarly provide care assistance.

Without the transgressive performance of the embodiment of disability, vulnerability itself is entrenched within the liberal subject and the neoliberal state.

The “disembodied universality” of vulnerability conceals the systems of privilege based on protective power and protected status in order to isolate each individual’s vulnerability (Hartman 1997, 21). The protesters in many ways embody the specificity of vulnerability with regard to disability – a vulnerability that demands social accommodation, which is integral to enacting systemic change.

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# Chapter 9

## Persons with Disabilities in International Humanitarian Law – Paternalism, Protectionism or Rights?

Janet E. Lord

### Introduction

The adoption of the Convention on the Rights of Persons with Disabilities (CRPD 2006) represents an important and (potentially) progressive development in the protection framework accorded to persons with disabilities under international humanitarian law (IHL).<sup>1</sup> Article 11 of the CRPD obliges States to protect persons with disabilities from harm in situations of risk, consistent with IHL and human rights law. The provision plays a unifying role in drawing together obligations to safeguard protection to persons with disabilities in both peace and conflict situations.<sup>2</sup> It contributes to the overall protection framework in human rights and IHL by introducing, explicitly for the first time in an international human rights treaty, the requirement that reasonable accommodation be provided to ensure non-discrimination and that the failure to do so results in a finding of discrimination. This duty to accommodate, forming part of the CRPD's (and by extension human rights law more generally) non-discrimination and equality framework, has important implications for the specific application of IHL to the situation of persons with disabilities, an issue that is both under theorized and wholly without

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1 International humanitarian law as discussed here refers to international rules as set forth in treaties or as established by custom, which address humanitarian concerns arising from international or non-international armed conflicts directed at the protection of persons and property that are, or may be, affected by an armed conflict and places limitations on the methods and means of warfare. See International Committee of the Red Cross, Advisory Service on International Humanitarian Law, *International Humanitarian Law and International Human Rights Law: Differences and Similarities* (2003), [http://www.ehl.icrc.org/images/resources/pdf/ihl\\_and\\_ihrl.pdf](http://www.ehl.icrc.org/images/resources/pdf/ihl_and_ihrl.pdf).

2 On the interrelationship between human rights and IHL, see International Committee of the Red Cross, IHL and Human Rights, <http://www.icrc.org/eng/war-and-law/ihl-other-legal-regimes/ihl-human-rights/index.jsp> (“International humanitarian law and international human rights law are two distinct but complementary bodies of law. They are both concerned with the protection of the life, health and dignity of individuals. IHL applies in armed conflict while human rights law applies at all times, in peace and in war.”). *Ibid.*

operational interrogation or guidance for duty bearers or humanitarian assistance organizations working in conflict-affected areas.<sup>3</sup>

Armed conflict is both a cause of disability and a complicating factor for persons living with disability (World Bank and WHO 2011). Violations of human rights and humanitarian law result in trauma and impairment that lead to disability. Persons with disabilities who are living in or fleeing from conflict zones face numerous threats to their physical and mental health and well-being, further aggravating pre-existing disability or leading to secondary disability (United Nations 1983). Armed conflict and the violence it produces creates a multitude of risks, whether from attacks directed at individuals, the presence of landmines and other unexploded ordinance, exposure to the elements for civilians or combatants who have little protection, and risks of other trauma that can create or exacerbate psychosocial conditions (Baingana, Bannon and Thomas 2005).

The pervasive exposure of persons with disabilities to discrimination in peacetime is exacerbated during armed conflict. More often than not, persons with disabilities experience multidimensional disadvantage in conflict on account of disability, in combination with other vulnerable status based on gender, poverty, ethnicity and the like. The barriers that persons with disabilities experience during peacetime in accessing education, employment, health and rehabilitation, and an adequate standard of living are intensified in times of conflict (Lord and Stein 2006). Persons with disabilities are often more restricted in their mobility in times of conflict. As such, they may not be able to call attention to their specific needs in situations of risk. They may also face physical and communication barriers in accessing emergency information in conflict. Women with disabilities, already at disproportionate risk for sexual violence during peace, are at greater risk of violence due to the insecurity of wartime (Human Rights Watch, 2010). Understanding IHL through a disability lens enables the identification of mistreatment rooted in the disability experience, such as physical and sexual abuse, inhumane living conditions, isolation and neglect, beatings, forced sterilization, medical experimentation and forced treatment without consent, involuntary confinement, and the like.

This chapter employs a disability rights perspective as its analytical framework to examine the implications of IHL for persons with disabilities. Its focus is on the protection accorded to persons with disabilities in their various roles in armed conflict as well as the disabling impact of armed conflict that has given rise to a number of IHL rules. It works within – though does not proclaim to resolve – a clear tension in IHL and international disability rights: IHL positions certain groups, persons with disabilities among them, as highly vulnerable and thus in need of special protection and, appropriately, seeks to cast a protective veil around

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3 What little there is concentrates on humanitarian protection only in the context of refugees and IDPs. See, e.g., Janet E. Lord and Michael A. Stein, “Implications of the UN Disability Convention for Refugees and Internally Displaced Persons with Disabilities,” *Arizona Journal of International and Comparative Law* 27: 401 (2012).

them. The disability rights paradigm extant in the CRPD, by contrast, breaks free from paternalistic models of protection evident in IHL instruments and requires law and policy to be animated by a social model understanding of disability, as opposed to medicalized conception, and informed by principles of autonomy, non-discrimination, independence, inclusion and equality of opportunity (Kayess and French 2008). This perspective, therefore, is critical of approaches that are centered on individual deficit and insensate to social and institutional structures that oppress, isolate and reinforce vulnerability. Given that the bulk of IHL instruments according protection to vulnerable populations were written well before the emergence of a disability rights narrative in domestic or international law, the potential of disability rights standards to inform IHL – and the challenge to translate its framework into meaningful action – is considerable.

The chapter proceeds in three sections. The first section examines the conceptualization of disability within the general and specific protection framework of IHL. The second section analyzes disability in relation to prohibitions and restrictions on the means and methods of warfare. And the third section addresses the tension inherent in protective models of IHL and international disability rights and considers whether and how the CRPD offers a palliative response. It concludes by considering whether and how the further development and understanding of an IHL disability perspective will contribute to the resilience and overall effectiveness of IHL and strengthen the protection of persons with disabilities through addressing their specific needs in – and in the aftermath of – armed conflict.

International humanitarian law standards – both obligations set forth in international treaties as well as customary international law – underscore the obligation to provide protection and assistance to affected populations in time of humanitarian crisis, including persons with disabilities (Geneva Conventions of 1949; Henckaerts and Doswald-Beck 2005). It is a framework designed to safeguard victims of armed conflict, together with limitations on the effects of armed conflict, in recognition of the principle that the means and methods of warfare are not unrestricted (Pictet 1985).

The basis for establishing treaty-based protections is well known and arose out of a concern for seriously wounded soldiers left to die and on the battlefield and war veterans experiencing traumatic injury. Thus, the first hand observations of Henry Dunant on the Battle of Solferino who witnessed soldiers left unattended and unassisted on the battlefield provided the impetus for the establishment of what ultimately became the International Committee of the Red Cross (Dunant 1862). His account also led to the convening of a diplomatic conference at which states adopted the Convention for the Amelioration of the Condition of the Wounded in the Field (Geneva Convention, 22 August 1864).

At its core, the IHL is focused on ensuring humane protection to persons rendered disabled – or otherwise *hors de combat* – as the result of combat and, second, on the prevention of unnecessary suffering (Sassoli and Bouvier 2006, 219). There is thus recognition in the earliest international humanitarian law instruments that protection must be accorded to persons affected by the disabling impact of armed

conflict, first on wounded or sick combatants and, later with increased emphasis, on civilians (Geneva Convention of 1864).

Persons with disabilities are protected in general terms under the principles of IHL that aim to shield all persons not actively engaged in hostilities from harm *and* under specific rules specifying protection on account of disability (Grieg 1985; Pictet 1985). Adverse distinction, referring to differential treatment in the application of IHL on account of “race, colour, sex, language, religion or belief, political or other opinion, national or social origin, wealth, birth or other status,” is prohibited (Rosenblad 1979). While disability is not specifically mentioned as a prohibited ground of adverse distinction, it would be covered under “other status” and in the light of developments in international law that amplify disability status as worthy of protection against discrimination (ICCPR 1966, art. 7; CRPD 2006, arts. 5, 2).

The prohibition against adverse distinction in the treatment of civilians and persons rendered *hors de combat* is set forth in common Article 3 of the Geneva Conventions (Geneva Conventions of 1949). It is also recognized in the Third and Fourth Geneva Conventions and as a fundamental guarantee by Additional Protocols I and II (Third and Fourth Conventions of 1949, arts. 16, 30, 44–5, 49, 110 and 16–17, 21–2, 27, 85, 119 and 127 respectively; Additional Protocols of 1977, arts. 9, 75 and 2, 4 respectively). Thus, persons with disabilities are entitled to the same protection afforded to all persons under both the rules pertaining to treatment and protection as well as the rules relating to the means and methods of warfare. Further, adverse distinction in IHL implies that while discrimination between persons is prohibited, a distinction is permissible to give priority to those in most urgent need of care. As an application of this principle in IHL, no distinction may be made among the wounded, sick and shipwrecked on any grounds other than medical (First Geneva Convention 1949, art. 12; Second Geneva Convention 1949, art. 12). Another illustration is provided in the Third Geneva Convention: Article 16 of that treaty holds that all prisoners of war must be treated alike, however, it allows for the possibility of preferential treatment to be accorded to them by reason of their state of health, age or professional qualifications (Third Geneva Convention 1949, art. 16). Positive duties to distinguish amongst individuals who are *hors de combat* include the right of seriously wounded prisoners of war to be repatriated during hostilities (Third Geneva Convention 1949, art. 109(3)). This duty ought to apply in respect of prisoners of war who, though perhaps not requiring the kind of urgent medical assistance of seriously wounded prisoners, have disability accommodation needs warranting prioritization for repatriation.

The idea of adverse distinction tracks with the notion of positive discrimination in contemporary human rights law (CRPD 2006, art. 5; CEDAW 1979, art. 2). Positive discrimination holds that specific measures necessary to advance or achieve de facto equality of historically marginalized groups, such as persons with disabilities, women or racial minorities, shall not be considered discrimination (CRPD 2006, art. 5(4)). Obligations in respect of disability accommodations and accessibility measures fall within this category of

permissible distinction and are elaborated in the CRPD, providing the opportunity to add texture to IHL rules and operational guidance consistent with the needs of persons with disabilities.

The principle of humanity in IHL animates the formulation of a wide range of both general and particular rules (Coupland 2001; Slim, 1998; Meron 2000). Rules relating to the humane treatment of civilians and those who have laid down their arms derive from this principle and find expression in a number of IHL provisions applicable in both international and non-international conflicts. Common Article 3 of the Geneva Conventions, for example, is rooted in the principle of humanity and gives rise to specific applications of the notion in its articulation of rules proscribing violence to life and person, including murder, cruel treatment and torture as well as outrages upon personal dignity, in particular, humiliating and degrading treatment, among other acts (Geneva Conventions 1949, art. 3). The general protections of IHL reflecting the principle of humanity apply equally to persons with disabilities and, in addition, IHL specifies rules of special protection for persons with disabilities, as considered in more detail below. In addition, notions of humanity and humane treatment prescribe protection in the form of judicial guarantees, including rights of due process, for individuals put on trial for violations of IHL. In keeping with non-discrimination norms, the trial of persons with disabilities must be accessible and, where needed, reasonable accommodations provided. The human rights analogue is the prohibition against torture and other forms of abuse (UDHR 1948, art. 5; ICCPR 1966, art. 7).

General protection against the effects of armed conflict is recognized as a fundamental axiom of IHL. The principle of distinction is paramount and holds that parties to an armed conflict are required to distinguish between civilians and combatants and must not direct attacks against civilians and the civilian population (Sassoli and Bouvier 2006; Rosenblad 1979). Notably, such protection also applies to attacks, though not directed or targeted at civilians, of a nature to strike military objectives and civilians (or civilian objects) without distinction (Conventional Weapons Convention, IV). The principle of distinction thus requires differentiation and protection in respect of civilians who do not take part in hostilities and in respect of combatants who no longer take part in hostilities on account of falling into the power of the enemy, if wounded, sick or shipwrecked, or if parachuting out of an aircraft. Persons with disabilities enjoy this general protection either on account of their civilian, non-combatant status or because they fall within the category of a combatant rendered *hors de combat*.

### *Persons with Disabilities as a Specifically Protected Group in IHL*

IHL recognizes that persons with disabilities have specific needs and are thus entitled to special protection for their benefit in the context of armed conflict. The nature and precise scope of this protection is less developed than under international human rights law. Thus, a number of IHL instruments recognize that special respect and protection are to be accorded to persons with disabilities

and others whose status may render them vulnerable or disadvantaged without, however articulating the parameters of such protection. In addition, the language used to describe disadvantage on the basis of disability is not uniform and, not surprisingly given the era in which many IHL instruments were drafted, generally departs from modern conceptualizations of disability under human rights law.

Persons with disabilities may fall into one or more categories of groups recognized as entitled to special protection on account of civilian or ex-combatant status. The term “disabled” while appearing in the Geneva Conventions, is not used with consistency in IHL instruments or in national military manuals. Persons with disabilities are variously captured in provisions referencing the “infirm,” “wounded,” “sick,” and “disabled.” Moreover, certain groups within the disability community are sometimes specifically referenced, in particular persons with “mental disease” or individuals who are “blind,” “maimed,” or “disfigured.” These terms are an indicator of disability, although they do not track with contemporary terminology as exemplified in the CRPD (CRPD, 2006, art. 1). Additional Protocol 1 supports a broad-based approach and lends some definition to these various terms associated with disability. Thus, Article 8(a) provides that the terms “wounded” and “sick” mean persons ... who, because of ... physical or mental disability, are in need of medical assistance or care ... and other persons who may be in need of immediate medical assistance or care, such as the infirm” (Additional Protocol 1, 1979, art. 8(a)).

The terminology reflects a medicalized approach to disability and clearly not disability as understood in disability rights terms (Shakespeare 2013). However, when filtered through a disability rights lens, IHL terminology may be reinterpreted to cover both the sense of disability covering wounded soldiers and civilians in need of medical attention, as well as persons who, on account of their disability, may require specific forms of assistance or protection, though not medical care (e.g. Deaf persons who are unable to access radio messaging; elderly civilians with mobility restrictions; persons with intellectual disabilities who are unable to read or follow complex instructions).

The concept of special protection for persons with disabilities derives from the principle of humanity and is of ancient origin, reflected, for example, in Islamic law according to which “non-combatants who did not take part in fighting such as women, children, monks and hermits, the aged, blind, and insane” were not to be molested (Khadduri 2006, 103–4). This principle is supported in numerous provisions of the Geneva Conventions. For example, Article 30 of the Third Geneva Convention provides that “[s]pecial facilities shall be afforded for the care to be given to the disabled, in particular to the blind, and for their rehabilitation, pending repatriation” (Third Geneva Convention, 1949, art. 30). Article 17 of the Fourth Geneva Convention requires “[p]arties to the conflict shall endeavour to conclude local agreements for the removal from besieged or encircled areas of ... [the] infirm” (Fourth Geneva Convention 1949, art. 17). Provisions in both the Third and Fourth Geneva Conventions accord protection to the evacuation and the treatment of persons deprived of their liberty) Third and Fourth Geneva

Conventions of 1949, arts. 16, 30, 44–45, 49, 110 & 16–17, 21–22, 27, 85, 119, 127 respectively). Article 16 of the Fourth Geneva Convention provides that the infirm “shall be the object of particular protection and respect” (Fourth Geneva Convention 1949, art. 16). Relatedly, Articles 16, 44, 45 and 49 of the Third Geneva Convention provide in relation to the treatment of prisoners of war that their state of health should be taken into account (Third Geneva Convention 1949). The Fourth Geneva Convention makes similar provision in respect of the health of protected persons (Fourth Geneva Convention, 1949, arts. 27, 85, 119). The right of disabled persons to protection and care is also recognized in IHL instruments covering non-international armed conflicts.

Many military manuals and the legislation of many states require special respect and protection for persons with disabilities, reaffirming the protection granted under IHL instruments (Henckaerts and Doswald-Beck, 2005, Rule 138). The Colombian Constitutional Court recognized the principle in its 2007 decision:

Taking into account ... the development of customary international humanitarian law applicable in internal armed conflicts, the Constitutional Court notes that the fundamental guarantees stemming from the principle of humanity, some of which have attained *ius cogens* status, ... [include] the obligation to respect the special rights of ... the disabled affected by the armed conflict. (Colombian Constitutional Court, Case No. C-291/07, 2007)

Complementary provisions appear in other international documents, including, for example, the ICRC Plan of Action adopted by the 27th International Conference of the Red Cross and Red Crescent according to which all parties to an armed conflict must undertake measures to protect and respect civilians, including protective measures for disadvantaged groups such as persons with disabilities (ICRC 1999). Likewise, the Vienna Declaration and Programme of Action, adopted by the World Conference on Human Rights, calls upon States and parties to armed conflicts to observe IHL rules based on concern for violations impacting civilians, in particular persons with disabilities (Vienna Declaration, 1993, section 1, para. 3).

### **Disabled Prisoners of War**

Prisoners of war are a specifically protected group under IHL and, within that category prisoners with disabilities are entitled to special protection (Rodley 1987). Those holding prisoner-of-war-status under IHL rules are entitled to certain standards of treatment and, owing to the fact that prisoners of war may be held without specific individual basis or specific procedure so as to prevent them from further participation in hostilities, it follows that the central purpose of detention is not to punish. Rather, persons holding such status are to be prevented from direct engagement in hostilities and protected.

Protection in this context relates essentially to the provision of medical assistance and hygienic conditions of internment and prioritization of repatriation for prisoners requiring medical or, it is thought, rehabilitation services. Thus, the Third Geneva Convention provides that a Detaining Power must “take all sanitary measures necessary to ensure the cleanliness and healthfulness of camps and to prevent epidemics” (Third Geneva Convention, 1949, art. 29). Medical inspections are to be held “at least once a month” to assess “the general state of health, nutrition and cleanliness of prisoners and to detect contagious diseases, especially tuberculosis, malaria and venereal disease” (Third Geneva Convention, 1949, art. 31). Further, subjecting prisoners to medical procedures not justified by the state of health of the person concerned is prohibited. A Detaining Power is required to provide free of charge any medical attention required by the state of health of prisoners of war (or civilian internees) and prisoner-of-war camp must have an adequate infirmary (Third Geneva Convention, art. 30).

The Third Geneva Convention addresses termination of captivity, both in instances where hostilities have come to an end and, significantly for present purposes, where the prisoner’s mental or physical integrity is seriously compromised. While prisoners of war must be repatriated when hostilities conclude, seriously wounded soldiers have priority for repatriation. Parties to the conflict are required to send back to their own country, irrespective of number or rank, prisoners of war who are “seriously wounded and seriously sick” and “after having cared for them until they are fit to travel” (Third Geneva Convention, 1949, art. 31). Direct repatriation is required for those who are (1) “[i]ncurably wounded and sick whose mental or physical fitness seems to have been gravely diminished”; (2) “[w]ounded and sick who, according to medical opinion, are not likely to recover within one year, whose condition requires treatment and whose mental or physical fitness seems to have been gravely diminished”; and (3) “[w]ounded and sick who have recovered, but whose mental or physical fitness seems to have been gravely and permanently diminished” (Third Geneva Convention, 1949, art. 110). In addition, prisoners of war affected by serious diseases or who are in need of special treatment, surgical procedures or hospital care are required under IHL to be admitted to military or civilian hospitals where such treatment can be provided. Medical supplies are among the relief shipments that prisoners of war and interned civilians are allowed to receive, either individually or collectively (Third Geneva Convention, 1949, art. 110).

Beyond IHL treaties, the idea of special protection for disabled prisoners is expressed variously in military manuals of numerous states. Thus, for example, the US Army Field Manual (1956) provides: “Special facilities shall be afforded for the care to be given to the disabled [POWS], in particular to the blind, and for their rehabilitation, pending repatriation” (United States Army Field Manual 1956). This, read together and in the light of the CRPD, amounts to a duty to reasonably accommodate a prisoner with a disability (CRPD, 2006, arts. 5 and 2).

Human rights tribunal jurisprudence reveals that the conditions of one’s detention in prison is subject to review and justifies inquiry into the nature and

conditions of detention. In *Huseyin Yikdirim v. Turkey*, the ECHR held that a violation of Article 3 (prohibition against torture and inhuman and degrading treatment or punishment) had occurred in the case of a disabled prisoner who required extensive support (*Yikdirim v. Turkey*, Eur. Ct. H.R. (2007)). Left under the care of his cell mates in prison, and while in the prison hospital wing, his siblings, for three years he relied on them to feed, wash, dress, and perform other essential functions. The Court found that this amounted to “degrading treatment” within the meaning of Article 3. In *Keenan v. United Kingdom*, the ECHR found a violation of Article 3 for a prisoner with a psycho-social disability who was confined to seven days isolation without effective monitoring or psychiatric evaluation during which he killed himself (*Keenan v. the United Kingdom*, 2001, para. 116). The Court held that punishment under these circumstances, which may have threatened the physical and moral resistance of the prisoner, was “not compatible with the standard of treatment required in respect of a mentally ill person.” (Id.) The failure to provide reasonable accommodation to a prisoner with a disability will run afoul of the principle of non-discrimination and, depending on the circumstances, may well constitute a violation of the prohibition against torture and other cruel, inhuman or degrading punishment.

Not all IHL provisions correspond to the emerging human rights jurisprudence concerning the protection of persons with disability held in detention. In fact, IHL contains provisions rendering protections apparently contingent for certain types of disability. Thus, for example, the rule in the Third Geneva Convention that isolation wards must be set aside not only for prisoners with contagious diseases as a method of quarantine, but likewise for persons with “mental diseases,” is antiquated as well as discriminatory under human rights and one would think, IHL principles (Third Geneva Convention, 1949, art. 30). Such treatment could, under the terms of IHL, be justified if one accepts the IHL principle allowing differential treatment on the basis of medical status, but surely the intent of that rule is to draw a distinction that works in favor of and not against the prisoner. Absent guidelines, such provision could work to disadvantage rather than accommodate a prisoner with a mental disability and is discriminatory on its face.

### **Access to Humanitarian Assistance**

IHL requires that assistance and protection be afforded to the civilian population during armed conflict. When the population in territory under the control of a party to the conflict cannot be adequately provided with food, water and medical supplies, humanitarian relief access must be facilitated. Relief consignments must be allowed rapid, safe and unimpeded access (UN Security Council Res. 1265 (1999); 1296 (2000); 1314 (2000)). This is irrespective of the destination of the supplies, for instance to support the needs of civilians belonging to the adverse party to a conflict. In many instances, persons with disabilities in the civilian population are among the least accessible members of a community in need of assistance,

owing to factors such as isolation, restricted mobility, and communication or information barriers. For individuals detained in the context of armed conflict, the Fourth Geneva Convention requires access to protected persons by the ICRC (as well as other humanitarian organizations) for the purposes of providing assistance, such as the distribution of relief supplies (Fourth Geneva Convention, 1949, art. 149). Human rights law amplifies these protections for persons with disabilities by setting out specific state obligations in respect of, for example, rehabilitation and the provision of assistance devices, access to information and so on. These principles help to clarify the specific content of humanitarian assistance access.

It is axiomatic that persons with disabilities are not only victims of armed conflict but they also participate in armed conflict. A number of issues arise with respect to this recognition. First, the reintegration of ex-combatants with disabilities – those who have directly participated in hostilities – can be particularly difficult due to historic disadvantage and discrimination against persons with disabilities in society generally. This issue was addressed in the Mine Ban Treaty that contains obligations for States Parties to provide assistance to victims – whether ex-combatant or civilian – by providing medical care and rehabilitation, as well as ensuring the social and economic reintegration of landmine survivors (Mine Ban Treaty, 1997, art. 6(3)). More expansively, the Cluster Munitions Convention obliges States to provide for the medical care, rehabilitation, psychological support, and social and economic inclusion of cluster munitions victims in areas under its jurisdiction or control (Cluster Munitions Convention, 2008, art. 5). Such provisions are complemented and reinforced by human rights treaties that recognize the rights of trauma survivors and survivors of various human rights abuses to certain protections. Thus, for example, the Rights of the Child Convention recognizes the right of children to receive treatment if they have been subjected to maltreatment and to seek judicial intervention where necessary, a provision of relevance to child soldiers (CRC, 1989, art. 16).

### **Conceptualizing Disability within the IHL Protection Framework**

Protection within IHL requires some mechanism by which individuals with specific needs and subject to particular harm during armed conflict may be identified. Here, a superficial social model of disability, according to which disempowering and inaccessible social structures and institutions are the sole locus of analysis, is not particularly helpful or illuminating. As commentators have suggested, where, under rigid accounts of the social model of disability, impairment is rendered invisible, regimes that have protection as their primary purpose have no effect. That said, applying the insights of the social model to the vulnerability framework utilized by groups such as the ICRC may help to expose the unique disadvantages that the diversity of the disability community possesses in situations of risk. As an illustration, a Deaf person's deafness does not render her/him medically infirm or sick in the sense of the traditional IHL disability lexicon. He or she is, however,

uniquely vulnerable during armed conflict where, for example, he/she cannot access critical emergency information. Greater attention within IHL to the diversity of disability and, consequently, the range of protection needs, would be helpful.

IHL imposes specific rules relating to weapons which abolish altogether, restrict or regulate weapons or the use of weapons in war. Early IHL instruments regulating weapons of war have, as their principal animus, the prohibition of weaponry that cause either superfluous injury or unnecessary suffering, or are proscribed on account of their indiscriminate effects, that is, the inability of the weaponry to differentiate between combatant and non-combatant (German Military Manual 1992, sec. 406). As such, the characterization of disability in this specific IHL context is preventive in character, not protective of individuals falling within the disability category. Unnecessary suffering is vague and difficult to define, although the International Court of Justice attempted a definition in its advisory opinion in the *Nuclear Weapons case*, where the concept was deemed “a harm greater than that unavoidable to achieve legitimate military objectives” (International Court of Justice, *Nuclear Weapons Case*, para. 238). Other attempts at definition hinge on whether the weapon would lead inevitably to permanent disability, as in the US Air Force characterization of poison and its prohibition as rooted in the “inevitability of ... permanent disability” (United States Air Force 1998, A4.8.4).

A number of specific rules regulating the means and methods of warfare are premised on the prohibition against unnecessary suffering and are rooted not only in assaults on physical integrity beyond military reason, but also on highly visible manifestations of traumatic injury. Thus, the St Petersburg Declaration of 1868 forbids certain types of ammunition on this basis and was the first formal instrument prohibiting the use of certain weapons in war (St Petersburg Declaration 1868). Its preamble recognizes the principal objective of war (to weaken the military forces of the enemy); however, this objective “would be exceeded by the employment of arms which uselessly aggravate the sufferings of disabled men, or render their death inevitable” and, further, that “the employment of such arms would, therefore, be contrary to the laws of humanity” (St Petersburg Declaration, pream. paras. 4 and 5). The adoption of the Declaration of St Petersburg served as the impetus for other types of prohibitions at the two Hague Peace Conferences of 1899 and 1907. The Hague Declarations relating to the discharge of projectiles and explosives from balloons, the use of asphyxiating gases and the use of expanding bullets were inspired by the Declaration of St Petersburg and make reference to it in their respective preambles (Hague Declarations I, II and III of 1899; Declaration of St Petersburg 1868).

More recently, certain categories of weapons leading to permanent disability have been the subject of international regulation. Weapons causing blindness have long been viewed as particularly egregious owing to their disabling effect and, more recently, international attention has turned to the use of laser weapons (Human Rights Watch 1995). Lasers that are specifically designed to cause permanent blindness to unenhanced vision as the sole combat function or one of them are prohibited

under Protocol IV to the Convention on Certain Conventional Weapons governing the use of blinding laser weapons (CWC, Protocol 4, 1980, art. 1). Restrictions on the use of landmines rests primarily on the indiscriminate nature of the weapon and the likelihood that such weapons will continue to kill innocent civilians long after the conflict and also on the principle of unnecessary suffering (Lord 1995: 311). Amputation, branded under IHL as “mutilation and disfigurement” is one common consequence of landmine injury and, as one commentator notes, “States became ... concerned ... with the increasing number of mutilated civilians in the aftermath of wars and armed conflicts especially in the Third World” (Detter, 2000, p. 218). Media images of landmine survivors, many of them markedly disempowering from a disability rights perspective, created a surge in global attention on anti-personnel landmines. Protocol II to the 1980 Weapons Convention introduced some restrictions on the use of landmines but was ultimately determined to be ineffective as it failed to provide protection against the injury of civilians (CWC, Protocol II 1980). This agreement was followed by an outright ban on anti-personnel landmines in the Mine Ban Treaty (Mine Ban Treaty 1997).

### **Methods of Warfare Prohibited for Causing Unnecessary Suffering**

Related to the rules prohibiting the use of certain weapons are rules designed to limit the disabling impact of certain *methods* of warfare on those engaged in combat and to provide collateral protection for others. This category of rules is of ancient origin. The prohibition against the poisoning of wells might be regarded as a precursor to the modern rule proscribing certain disabling methods of warfare on the basis of unnecessary suffering, although it was likewise linked to the interests of occupying forces to access safe water supplies. Rules prohibiting methods of warfare, like the rules prohibiting the use of certain weapons, have disability related dimensions.

Chief among methods of warfare prohibited on the basis of their disabling effects is mutilation, prohibited early on in the Lieber Code and reaffirmed in Common Article 3 of the Geneva Conventions which denounces “mutilation” of civilians and persons hors de combat (Lieber Code 1863; Geneva Conventions of 1949). Mutilation is likewise prohibited by specific provisions of the Third and Fourth Geneva Conventions and is recognized for civilians and persons hors de combat in Additional Protocols I and II. Mutilation constitutes a war crime in both international and non-international armed conflicts under the Statute of the International Criminal Court (ICC) and is also recognized as a war crime in non-international armed conflicts under the Statute of the International Criminal Tribunal for Rwanda (ICTR) (ICC Statute, art. 8(e); ICTR, 1994, art. 4(a)). The modern exemplar of this prohibited practice is the widespread amputation of captured forces during the civil war in Sierra Leone (Human Rights Watch 1999). The practice of inscribing tattoos onto the bodies of captured combatants in the Sierra Leonean conflict would likewise fall afoul of this prohibition (Kamara 2007).

The Special Court for Sierra Leone likewise recognized the crime which it defined in *Prosecutor v. Brima, Kama & Kanu* as follows:

- a. The perpetrator intentionally subjected the victim to mutilation, in particular by permanently disfiguring the victim, or by permanent disability or removal of an organ or appendage of the victim;
- b. The perpetrator's conduct caused death or serious injury endangering the physical or mental health of the victim;
- c. The perpetrator's conduct was neither justified by the medical, dental or hospital treatment of the victim, nor carried out in the victim's interest;
- d. The victim was a person protected by one or more of the Geneva Conventions of 1949 or was not taking an active part in the hostilities at the time of the alleged violation;
- e. The violation took place in the context of and was associated with an armed conflict;
- f. The perpetrator was aware of the factual circumstances that established the protected status of the victim (Special Court for Sierra Leone, 2007, para. 172).

Proscriptions of the kind referenced in the previous paragraphs relate not only to the suffering caused as an immediate result of traumatic injury; they link to perceptions about certain types of disability as particularly horrific. Witness, for example, the ubiquitous image of the soldier blinded by mustard gas in World War I (Sargent 1919). The contemporary analogue is the ex-combatant or disabled civilian landmine survivor that has so captured the attention of the global media recoiled in horror at a life made miserable and not worth living, irrespective of the resilience of the survivor. Such characterizations render individuals affected as hapless victims worthy of our pity and charity. Moreover, they foreground highly visible medical aspects of trauma, while pushing to the periphery other disabling impacts of war, such as persistent sexual violence against women and girls, to which, it should be added, disabled women are disproportionately at risk (Ortoleva and Lewis 2012).

From a disability studies perspective, legislative stereotyping of disability such as that reflected in the IHL categories of "mutilation" and "disfigurement" serve to "inflict categories of deviance on unusual bodies thereby creating hierarchies between strictly defined "able" or "normal" bodies and the bodies of disabled individuals" (Silvers 2013). An illustration of a particularly egregious form of legislative stereotyping may be found in various municipal ordinances of the late nineteenth century according to which a Chicago law spoke of a person "who is diseased, maimed, mutilated or in any way deformed so as to be an unsightly or disgusting object, or an improper person to be allowed in or on the streets" and, accordingly, prohibited such individuals from public view (Schweik 2009). Related, perhaps, to the recognition that such characterizations are decidedly at odds with a disability studies and disability rights narrative, is the increased resistance to utilization of the term "female genital mutilation" to describe a specific human

rights violations against women and preference for a less judgmental and less victimizing term (female genital cutting) (United States DHSS, n.d.). The upshot of characterizations of human rights violations, whether grave breaches of IHL or particularly egregious human rights violations, is that certain labeling may have unintended consequences and serve to reinforce the very human rights principles at stake in such cases.

Disability within IHL connotes an essentialized state – deformity, disfigurement, mutilation – a medical condition that, first and foremost, warrants special restrictions often in the form of outright bans on the means and methods of warfare and, secondarily directs its attention is directed at cure and correction (Snyder and Mitchell, 2001; Longmore and Umanski 2001). Weapons or methods of warfare that produce traumatic injury, as in injurious wounding that is difficult to treat or amputation as a result of anti-personnel landmine use or wounding in the manner utilized in Sierra Leone, are highly visible and thus highly symbolic. The gradual, and decidedly belated attention to supporting the survivors of armed conflict, whether amputee ex-combatant, child soldier with psycho-social disability, or female civilian subjected to sexual violence, is welcome. This development is working to break down the traditional distinction between the Law of Geneva and the Law of the Hague which artificially separated IHL rules directed at protecting victims from IHL rules regulating the means and methods of warfare.

### **Applying the CRPD Framework to IHL**

IHL, like the general culture, associates disability with disease, defectiveness, deformity and “otherness” that is starkly contrasted with the battle-ready, hyper-masculinized combatant who is presumptively capable and not the focus of rules of special protection based on vulnerability. The convergence of IHL and international protection around a particular conceptualization of vulnerability, whether on account of disability, age, gender or some other marker, has not yielded progressive or contemporary accounts of disadvantaged groups in IHL law or its operationalization. This reflects the bias that disregards the experiences of women, persons with disabilities and other marginalized groups. While this has been identified as a shortcoming of IHL, it is an incident of its narrowly defined objectives and inherent limitations of IHL which are not pitched towards societal transformation. That said, the standard disability critique – that the medical model of disability supports medical intervention to “correct” disability in a way that is coercive and ultimately oppressive – sits uncomfortably alongside the limited objective of IHL to provide protection to the vulnerable, the victim, the helpless, irrespective of their disability status. In that sense, all of IHL evokes a certain paternalism that could arguably be regarded an acceptable trade-off for the application of minimum rules governing an area allegedly at the vanishing point of law (Lauterpacht 1952, 382).

Disability as historically reflected in IHL is centered on the concept of the wounded or broken body, first in relation to the soldier rendered inactive and *hors de combat* and in need of protection and later, more broadly to civilians and the concept of survivor assistance (Amundson 1992, 105). The medical model of disability as theorized in disability literature emphasizes an individualized understanding of disability and portrays disability narrowly as a medicalized phenomenon, to the exclusion of broader, socially contextualized aspects of the disability experience (Finkelstein 1980; Oliver 1983, Morris 2001). The conflation of disability with infirmity, disease, mutilation, and the dissembled body, more pronounced in the older IHL instruments, evokes a perception of disability as a unitary experience that is uniformly terrible. Witness, for example, the storyline in *Downton Abbey* that uncritically presented a soldier blinded by gas in World War I who, upon his return, could not imagine a life of meaning and who, therefore, took his own life (*Downton Abbey*, Season 2, Episode 2). More often than not, the experience of the disabled ex-combatant is made difficult by the failure to meet his/her needs in terms of post-conflict reintegration and access to the full array of medical and rehabilitation supports that make possible a life with disability that maintains dignity, autonomy and inclusion. This is particularly the case for ex-combatants experiencing psycho-social disability, such as post-traumatic stress disorder or, as recent studies indicate, female ex-combatants who have experienced sexual violence (MDRI 2002).

The standard approach privileges medical diagnosis and treatment and, as critics of the medical model of disability argue, relegates persons with disabilities to the role of the “sick” and inexorably tethered to illness (read helplessness) (Amundson 1992, 105, 109–11). It leaves out of the equation a more holistic understanding and approach beyond medical intervention that situates the disadvantages associated with disability as a social phenomenon. Understood in this way, IHL characterizations of disability reflect a legislative stereotyping that is, within a human rights frame, anathema to human rights realization by marginalized groups. Furthermore, the neutrality regarded as a fundamental tenet of IHL is brought into question in the stereotyped perception of persons with disabilities that leads invariably to the kind of differentiation that reinforces stigma and discrimination. The reference in the Third Geneva Convention for example, to the isolation of prisoners with “mental diseases” without any reference to appropriate support or treatment is antiquated and undermining of human rights protections, including the proscription against discrimination on the basis of disability (Third Geneva Convention, 1949, art. 30). Signs of more progressive orientations are in the making. Excessive attention in the early IHL instruments prohibiting certain weaponry on the basis of unnecessary suffering yet without attention to supporting survivors has, fortunately, given way to treaties that couple prohibitions with protections and support for survivors, along with access to information (e.g. mine risk education) that can prevent traumatic injury. The emergence of international disability rights, most notably as set forth in the CRPD, is contributing to a shift in the conceptualization of disability as a medical

issue or in IHL terms to beneficent ideas about caring for wounded and disabled soldiers, to a more broadly (and socially) constructed human rights issue that seeks to dismantle barriers for all persons with disabilities (National Council on Disability 2002). A socio-contextual understanding of disability as understood in disability studies and as reflected in the CRPD underscores the range of societal factors – separate and apart from individual limitation – as determinative of the ability to participate in society (Hahn 1994, 101; Stein 2004). In so doing, it reorients away from disability as individual deficit and toward the identification and removal of barriers that inhibit full realization of personhood. The CRPD thus recognizes that “disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (CRPD 2006). Elements of the social model are also reflected in Article 1 of the CRPD which provides that “[p]ersons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (CRPD 2006).

The adoption of the CRPD should serve to animate the protective framework accorded to persons with disabilities within IHL, much as instruments on child protection and the rights of women have so informed IHL protection for those groups (CEDAW 1979; CRC 1989). Article 11 of the CRPD requires positive measures of protection and safety by States Parties for people with disabilities affected by situations of humanitarian emergencies and risk, including efforts directed at assisting refugees and IDPs (CRPD 2006).<sup>4</sup> The necessity of such protection is recognized overtly in the CRPD’s preamble which affirms that “the observance of applicable human rights instruments are indispensable for the full protection of persons with disabilities, in particular during armed conflicts and foreign occupation” (CRPD 2006).

A core mandate of the CRPD is to clarify and make applicable existing general human rights obligations to the context of the lived experiences of persons with disabilities which, of course, includes the application of these principles in peace and in times of conflict (Lord and Stein 2008, 449, 456). Its specific obligations add disability-specific content to well-established human rights obligations (for example requiring non-discrimination in relation to health care access or mandating rehabilitation) and thereby contribute to the interpretation of other instruments. Indeed, its provisions speak also to important role of private actors, such as humanitarian organizations, in ensuring the implementation of the Convention (CRPD, 2006, art. 4). The progressive development of a disability

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4 The full language of the text of Article 11 reads: “States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.”

sensibility in domestic and international law and policy compels a reconsideration of the framing of disability across international law generally, including in IHL, and also requires IHL actors to consider and then respond to the requirements presented by human rights obligations.

The protection of the disabled soldier or civilian in IHL is contingent on a conceptualization of the disabled body as medical pathology. That protection thus comes heavy laden with assumptions of the disabled body as horrific form, dissembled, and “other” (Coco 2010). A disability rights narrative lays bare and challenges these assumptions in IHL (and indeed the conceptualizations of disability in other international instruments) about disability and about persons with disabilities. The CRPD presents a unique challenge for IHL, that is, how to incorporate the insights of social-contextual understandings of disability, whilst retaining the protective function of IHL and without asking more of IHL than it can possibly achieve (Durham 2005).<sup>5</sup>

## Conclusion

The shift in orientation from disability as medical pathology, deviant form or pitiable condition worthy of charitable concern to disability as a rights issue in the CRPD is significant for the purposes of IHL interpretation. It is likewise relevant for the creation of a disability inclusive mandate for all governments, UN agencies, the ICRC and other humanitarian assistance organizations. The CRPD modernizes human rights law in the context of disability and offers the opportunity for IHL to be clarified in keeping with its general principles and complementary protections. Moreover, in explicitly incorporating the protection of persons with disabilities in armed conflict and other situations of risk, the CRPD provides an opportunity to reassess framings of disability in IHL in the light of the CRPD and consistent with principles of dignity, non-discrimination, autonomy, inclusion and respect for difference (CRPD, 2006, art. 3).

That said, the CRPD, in order to give full effect to IHL, creates the need for a complex and nuanced application of CRPD principles and provisions. While the social construction of disability in the CRPD is a major advance in the rights-based conceptualization of disability, like gender, the full implications of social construction cannot be fully realized within the narrow parameters of IHL. Indeed,

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5 As Durham has noted in assessing the gender critiques of IHL: “Many of these criticisms highlight the tensions between the pragmatic and limited aims of IHL and the range of expectations placed upon this area of law ... IHL does not attempt to place any regulations upon the basis of social structure before, or after, the conflict ... its limited aim leaves no room ... for deeper social analysis of inherent inequalities required by feminist legal theory.” Helen Durham, “International Humanitarian Law and the Protection of Women,” in Helen Durham and Tracey Gurd (eds), *Listening to the Silences: Women and War* (Koninklijke Brill, Leiden, 2005, 97).

as some commentators as emphasized, the expectation that IHL accomplish the kind of restructuring of society contemplated by an in-depth gender analysis or, in the instant case, disability inclusion, is misplaced (Durham 2005). Inasmuch as the CRPD sets out to expand the protective scope of IHL and, specifically, contribute a progressive disability lens to that legal framework, it serves an important and clarifying function. Illustratively, such an analysis draws suggestive lines of inquiry requiring further work: What is the disparate impact of armed conflict on persons with disabilities? How can persons rendered disabled as a result of conflict be accommodated and integrated, for instance in post-conflict demobilization, disarmament and reintegration programming? What can IHL contribute to the accommodation of disabled persons held in detention? Whether and how can IHL avoid the kind of legislative and policy stereotyping that tends to reinforce stigma and discrimination? These and other questions require further examination.

Recognition of persons with disabilities in IHL allows for a consideration of the implications of the IHL protective framework holistically, within a rights-based, social model understanding of disability. Looking forward, the emergence of an international disability rights framework should form the foundation for more thoughtful, disability-specific planning in the operationalization of IHL and in the humanitarian assistance realm, both as a matter of policy as well as field implementation. While, following Andrew Byrnes, it is true that human rights treaties leave the precise contours of treaty obligations to evolve over time, the CRPD is suggestive of opportunities to bridge IHL, human rights and disability (Byrnes 2010). In that sense, the CRPD is a new normative landscape against which IHL obligations must be assessed and accordingly refreshed. The acknowledgement that persons with disabilities compel specific attention in IHL, coupled with a reappraisal humanitarian law that takes into account the actual ways in which disabled men, women and children experience armed conflict, is long overdue.

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# Chapter 10

## United Nations Policy and the Intersex Community

Ethan Levine

In December 2012, Organization Intersex International (OII) released an open letter to the United Nations High Commissioner for Human Rights (Viloria 2012). Delegates from six continents demanded an end to human rights abuses of intersex persons, including the subjection of intersex athletes to degrading “gender verification” tests, the continued use of harmful prenatal treatments to prevent intersex conditions, and the subjection of intersex infants and children to medically unnecessary surgeries in order to “avoid LGBTI outcomes” and render their bodies aesthetically normative. Of further concern was the American Psychiatric Association’s addition of Disorders of Sex Development to the DSM-V, a decision which “presumes that [intersex features] lead to psychological pathology, which has not been demonstrated, and is in fact contested by existing psychological research” (Viloria 2012). Delegates called for greater attention to such abuses and for the inclusion of intersex people in human rights rhetoric and antidiscrimination policy.

To be sure, these concerns are well-founded. In the majority of states worldwide individuals are designated a sex at birth and then socialized to perform a range of socially corresponding behaviors. This practice typically relies on a binary model of sex, wherein the medical constructs of maleness and femaleness are regarded as natural categories into which healthy human bodies should fit. Intersex individuals, whose bodies defy easy classification as male or female, pose a problem for states and medical providers who adhere to this binary. While some states and communities have responded through either rejecting or modifying the sex binary to accommodate sexual diversity, the majority conflates intersex features with deformity and disability (UN General Assembly, Human Rights Council 2011, 22–3).<sup>1</sup> This perspective justifies a “treatment” regimen of surgical and hormonal intervention, along with rigid gender socialization aimed at transforming the intersex person into a normative male-assigned man or female-assigned woman.

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1 The report specifically mentions Australia, India, Nepal, Pakistan, Portugal, the United Kingdom, and Uruguay as states that have “made it easier for transgender and intersex persons to obtain legal recognition” (24).

Set adjacent these bodily regulations and problematically embodied norms, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) provides a strong foundation from which to challenge these approaches to intersexuality. Convention authors recognized disability as a fluid concept with social and environmental dimensions (UN General Assembly 2006, 2). This principle is reinforced through consistent emphases on the interactions among disability, gender, and age as axes of oppression. The preamble recognizes women and girls' heightened risk of violence and exploitation, advocates a gendered perspective in human rights work, and draws attention to the needs of children with disabilities. Several articles of the CRPD offered safeguards in regards to the physical and mental well-being of disabled individuals, advocating for the prohibition of nonconsensual medical experimentation, torture, and abusive practices. State parties are obliged, "[t]o combat stereotypes, prejudices, and harmful practices relating to persons with disabilities, including those based on sex and age," and to incorporate "age-, gender-, and disability-sensitive" measures into violence prevention and response efforts (8, 12). Such tenets are not merely compatible with the movement for intersex rights and liberation; they are essential to it.

Unfortunately, uncritical adherence to the binary model of sex prevents the UN from effectively advocating on behalf of the intersex community. It is this binary, revealed in the notion that "male" and "female" encompass the full spectrum of human physical sex, that justifies that conflation of intersexuality with deformity and disability. In turn, such bifurcation reinforces the sort of abusive practices challenged by the CRPD. These limitations remain in spite of the groundbreaking 2011 report, "Discriminatory laws and practices and acts of violence against individuals based on their sexual orientation and gender identity," which explicitly acknowledged intersex individuals' comparatively high risk for violence and abuse, as well as the routine subjection of intersex youth to "discrimination and medically unnecessary surgery, performed without their informed consent, or that of their parents, in an attempt to fix their sex [sic]" (UN General Assembly 2011, 11 and 18). While this report recognized the limitations of binary sex, and documented several states' efforts to expand sex classification systems and/or allow intersex persons to change their designations in accordance with their identities, the UN's own approach to sex and gender was spared critical scrutiny.

The United Nations has, at its disposal, an array of means through which to better support the intersex community. Officials might explicitly incorporate intersex persons into the population covered by the CRPD; analogously, the international body could expand the provisions of the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) to include the intersex community (UN General Assembly 1979). Alternatively, the United Nations could publish a separate convention on the rights of lesbian, gay, bisexual, transgender, and intersex (LGBTI) persons. Each of these could conceivably be accomplished with or without modifying UN understandings of sex and gender to incorporate intersex identities. Following a review of medical responses to intersexuality, this

essay offers an assessment of the benefits and drawbacks of applying the CRPD to intersex human rights violations, and of framing intersex issues as disability issues. It concludes with a comparative consideration of disability, gender, and sexuality-based approaches to advancing intersex human rights.

## The Intersex Community

To reiterate and expand, sex assignment is the process through which individuals are classified as either male or female. While this rarely involves more than a quick inspection of external genitalia, medical professionals act under the assumption that a variety of other features will accompany those genitalia. A newborn with a medically sanctioned (i.e. sufficiently large) penis and descended testes will be presumed to have XY chromosomes; it will be assumed that this newborn will eventually develop male-typical secondary sex characteristics such as a deepened voice and increased body and facial hair. A newborn with a vagina and medically sanctioned (e.g. sufficiently small) clitoris will be presumed to have XX chromosomes, internal reproductive organs including two ovaries and a uterus, and to inevitably develop female-typical secondary sex characteristics such as breasts.

“Intersex” functions as an umbrella term for individuals whose bodies do not meet the medical criteria for maleness or femaleness. While there is some argument regarding which bodies qualify as intersex, and thus also disagreement regarding the prevalence of intersex conditions, it is not necessary to set precise boundaries here; any features that may complicate the process of sex assignment are relevant to the present discussion.<sup>2</sup> Some such features are visible at birth, and may consequentially be noted during the aforementioned inspection. Possibilities include the presence of both a penis and a vagina, as well as the presence of such medically unsanctioned structures as a micropenis or hypertrophied clitoris. Other features may go undiscovered for years. For example, a newborn with female-typical features may have undescended testes, and may experience a deepening voice and the “dropping” of said testes in puberty rather than the expected breast development and menstruation.

While intersex features are a universal reality, attitudes towards them are far from universal. Cultural notions of and about sex influence the categories with which we are comfortable. These dominant readings likewise shape the stigma, prestige, indifference, etc. awarded to those who fall outside of accepted categories.

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2 Arguments tend to center around the precise medical criteria. Some insist that genitalia must be difficult to classify as male or female, or must be phenotypically inconsistent with chromosomal sex, in order for an individual to qualify as intersex. Others offer a more broad interpretation that may include more “minor” variations in sex development, such as Klinefelter Syndrome, in which individuals have typical male genitalia, typical male secondary sex characteristics, and XXY sex chromosomes. See Preves 2003, 2–4; Sax 2002, 174–7; Fausto-Sterling 2000, 51–4.

These ideas are regarded as commonsensical, as demonstrably obvious truths regarding the human body (Geertz 1975, 13–17; Elliott 1998, 37). For example, if I have been raised to believe that there are only two sexes, I will probably perceive intersex individuals as unfit or malformed. Conversely, if I have been raised to believe that most people are either male or female, but that additional sexes can and do exist, I may perceive those same individuals as simply unique. Such divergent understandings of human biology profoundly impact the treatment of intersex persons.

Discursive practices in contemporary medicine tend to encourage a conflation of intersex features with malformation. The concept of “ambiguous genitalia,” often employed to describe infants who “fail” their initial inspection, is quite telling in this regard. Physicians rarely, if ever, seem unsure as to which structures comprise an infant’s genitalia. Medical literature on sex assignment is full of detailed descriptions and medical terminology for a wide range of intersex features. The genitalia, themselves, are not ambiguous. The real ambiguity concerns physicians’ difficulty in assigning intersex bodies to normative sex categories. Additionally, the term “intersex” has been increasingly abandoned in favor of the more overtly pathologizing “disorders of sex development.”<sup>3</sup> The presence of a disorder suggests that treatment is warranted. Furthermore, those who perform elective surgeries on intersex youth may justify such practices through this implied need for treatment, in spite of the fact that many intersex individuals are considered healthy with little to no medical intervention. Even those whose gonads pose a risk for malignancy may often postpone intervention until adolescence (Wisniewski, Chernausek, and Kropp 2012, 1–2 and 58–89; Accord Alliance 2008, 2–9 and 28–31; Diamond and Sigmundson 1997, 1049; Lee et al. 2006, 490–92).

Historically, medical treatment of intersex youth has drawn largely on the assumptions that (1) individuals are psychosexually neutral for the first two years of life, and might be successfully assigned to either normative sex during this time period, and (2) sexual development is tied to the physical appearance, expressly the appearance of external genitalia (Bostwick and Martin 2007, 1501–2; Diamond 1997, 199; Santos and Araujo 2008, 574; Liakopoulou et al. 2009, 61; Mazur 2005, 414–19). These assumptions, drawn largely from the work of John Money and his colleagues, pressure doctors and families to select a normative sex assignment for intersex infants as early as possible, and to modify their bodies accordingly for fear of psychological distress (Money, Hampson, and Hampson 1955, 288–90 and 295–6). These practices persist in spite of the fact that historical and contemporary research provide “no consistent evidence” that having atypical genitalia causes psychological distress, or that any such distress is greater than that caused by the reduced sexual function and pleasure often associated with such medical interventions (Santos and Araujo 2008, 574; see also

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3 For discussions regarding the political and social dimensions of this shift, including arguments for and against the retention of intersex as a medical term, see Lee et al. 2006, e488–e500; Diamond 2009, 172; Feder and Karzakis 2008, 33–5; Reis 2007, 536–41.

Diamond 1997, 207–9). This approach also supports conscientious socialization into the gender role normatively attached to a chosen sex-assignment. After all, the removal of a micropenis and construction of a vulva are meant to do more than transform an intersex-looking child into a female-looking child; such interventions aim to produce a little girl who shall eventually grow up to identify as and (inter) act like a woman.

Researchers have increasingly embraced a more comprehensive approach that takes characteristics such as brain masculinization, androgen levels, and sex chromosomes into account; and places considerably less emphasis on genital appearance.<sup>4</sup> This perspective tends toward a search to identify intersex patients' "true" – or "truer" – sex. Considerable effort has been directed towards identifying the biological factors at play in gender identification, so that doctors might make as informed a judgment as possible as to which medical interventions are warranted (Bostwick and Martin 2007, 1502–3; Meyer-Bahlburg et al. 2006, 681–2; Meyer-Bahlburg 2005, 423–4 and 432; Cohen-Kettenis 2005, 407–8). It is often recommended that these interventions be accompanied by social and psychological reinforcement of assigned gender roles, owing to the established influence of family and peer groups in shaping identifications and behaviors.

Nevertheless, early medical interventions have faced substantial criticism. In 1965, sexologist Milton Diamond challenged the theory of psychosexual neutrality at birth (Diamond 1965, 150–67). Drawing upon psychology, medicine, and evolutionary biology, he found that individuals are predisposed toward specific gender orientations. Significantly, he further argued against any sharp distinction between human biology and social learning in accounting for sexual behavior. More than three decades later, in the late 1990s, Diamond advocated a patient-centered approach to intersex conditions, advising against cosmetic surgeries and for full disclosure and consent in regards to diagnosis and treatment. While recognizing that parents might have strong feelings regarding the appearance of "normalness" in their children, Diamond nonetheless advised that, "the child remains the patient and should be the ultimate decision maker" (Diamond 1997, 206–9, quotation on 208; Diamond and Sigmundson 1997, 1047–9). This position diverged widely from dominant medical practices that tended to leave all decision-making to physicians and parents, and discouraged the disclosure of intersex conditions to patients for fear of causing distress and/or compromising gender socialization. Additionally, Diamond's emphasis on patients' consent suggested that physicians delay or forego medical intervention whenever it was medically safe to do so, considering that newborns are ill-equipped to weigh the consequences of elective genital surgeries.

Community activists with The Intersex Society of North America (ISNA, founded 1993 and closed 2008) and the Accord Alliance (formed in 2008), along with supportive researchers and medical providers, have worked tirelessly to raise

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4 See Fine 2010, 119–27 for an excellent critique of neuroscientists' efforts to "sex" the brain, particularly in regards to intersex persons with congenital adrenal hyperplasia.

awareness regarding the concerns and experiences of intersex individuals. Many have emphasized patients' (lack of) consent to treatment, as well as evidence of patients' psychological distress and decreased sexual and reproductive function (Accord Alliance 2008, 2–3, 16, 28–30, 34–5; Berenbaum 2006, 15–18; Preves 2003, 62–4, 73–81; Kessler 1998, 55–64, 68–70, 78–80; Haas 2004, 42, 62; Lee et al. 2006, e491–e496; Chase 1999, 452; Wisniewski et al. 2012, 63–8). Stigmatizing and misleading treatment by medical providers, including pressure for numerous medically unnecessary examinations and surgeries; and the failure of early medical interventions to demonstrably reduce distress among patients' parents, have drawn harsh criticism (Santos and Araujo 2008, 577–579; Jurgensen et al, 2006, 364–9; Accord Alliance 2008, 15–16, 31–2; Haas 2004, 62–4; Preves 2003, 63–73). This awareness-raising has led to a reevaluation of treatment protocols. An international consensus statement on intersex conditions, published in 2006, offered the following recommendations:

- (1) gender assignment must be avoided before expert evaluation in newborns;
- (2) evaluation and long-term management must be performed at a center with an experienced multidisciplinary team;
- (3) all individuals should receive a gender assignment;
- (4) open communication with patients and families is essential, and participation in decision-making is encouraged; and
- (5) patient and family concerns should be respected and addressed in strict confidence. (Lee et al. 2006, e490)

These principles are largely consistent with ISNA and Accord Alliance guidelines (see Accord Alliance 2008, 2–3). While they have yet to be implemented in full by any institution, their emphases on quality of life and consent represent a powerful effort to move towards patient-centered care (Accord Alliance 2012).

It is worth noting the persistence of binary approaches to sex, even among advocates of patient-centered care. Literature regarding the diagnosis and treatment of intersex conditions consistently acknowledges that some patients experience gender dysphoria and/or transition out of their initially assigned sex (Diamond 1997, 205–9; Meyer-Bahlburg et al. 2005, 682; Meyer-Bahlburg 2005, 423–4; Mazur 2005, 414–19; Liakopoulou et al. 2009, 616–17; Cohen-Kettenis 2005, 407–8; Dessens, Slijper, and Drop 2005, 393–5; Slijper et al. 1998, 137–43). Yet this is rarely taken as evidence that normative categories are inadequate. Researchers point to other factors such as misjudgments in sex assignment, gaps in knowledge regarding gender identification, or inconsistent gender socialization. Activists may appeal to the challenges inherent in classifying and raising non-normatively gendered children, without aggressively criticizing the structural forces responsible for those challenges (Intersex Society of North America n.d.). The critical differences among approaches to the treatment of intersex conditions concern communication practices among medical providers, patients, and families; and the perceived (lack of any) necessity to produce normative-looking bodies.

There are certainly exceptions. Since the emergence of the intersex movement, individuals have increasingly (re)claimed intersex identities. Some have used intersex as a qualifier for normative categories, as in “intersex man,” whereas others have conceived of and experienced intersexuality as a distinct from those categories (Preves 2003, 125–6 and 132–43; Kessler 1998, 83–90; Wiesemann 2010, 302). Some activists and scholars have advocated for an expansion, modification, or outright rejection of the sex binary (Preves 2003, 154–5; Valentine and Wilchins 1997, 220–21; Warnke 2001, 129–35; Elliott 1998, 36–9). There are also a number of societies and cultural groups that conceive of sex and gender as non-binary (Feinberg 1996, 21–31; Preves 2003, 39–43; Elliott 1998, 36–7). Some recognize three sexual and/or gender categories which may amount simply to regarding one intersex condition or transgender pathway as legitimate, others acknowledge more. While there is insufficient space here for a detailed review of historical and contemporary non-binary frameworks, this much is clear: the mere existence of diverse approaches indicates that the sex binary is socially, rather than biologically or “naturally,” imposed.

### **Intersexuality and Disability Policy**

Intersex features comprise a category of often pathologized difference. Communities that adhere to a strict male/female binary often regard such features as problematic, and respond with repeated medical and social intervention. These practices persist in spite of a growing body of evidence suggesting that intersex features do not, in and of themselves, cause psychological distress; whereas interventions to “fix” them risk considerable physical and psychological harm. Admittedly, the United Nations has been slow to recognize the existence of intersex people, and thus has made minimal progress in addressing the concerns of this community. The CRPD might prove useful here, although such an approach is not without drawbacks. Chief among them is a potentially problematic, seemingly unavoidable conflation of intersexuality with disability.

Yamuna Menon, LGBT activist and policy analyst, encountered similar issues in assessing the potential of the Americans with Disabilities Act (ADA, 1990) to improve the status of intersex persons in the United States (Menon 2011, 1243–51). She identified a series of drawbacks which chiefly emphasized the cumulative impact of social and medical marginalization. Specifically, disabled bodies are often regarded as abnormal, and classifying intersex bodies as disabled might intensify their pathologization (even for those whose conditions pose no medical threat) (1245–6). Additionally, non-disabled individuals sometimes feel discomfort in their interactions with disabled individuals; analogously, gender normative individuals sometimes feel uncomfortable in their interactions with gender non-normative individuals. A disability rights strategy might force intersex persons to grapple with both sorts of social discomfort (1232–44). However, given the normative tendency to “disable the intersexed and neuter the disabled,”

it may be unrealistic to regard these concerns as new or unique to a disability rights approach (Colligan 2004, 46). Indeed, it may be unrealistic to characterize intersex and disabled communities as wholly separate, in light of contemporary medical and social discourses concerning “normal” bodies.

Menon also addresses the possibility of community resistance. Disability rights activists might “find it an ‘intrusion’ for an intersex person, who may appear non-disabled, to use disability law to advance their rights,” and intersex rights activists might be reluctant to classify intersex conditions as disabilities (1245–6). Regarding the latter concern, activists have embraced divergent approaches. For example, OII Australia stands radically opposed to the conflation of intersexuality with disability, declaring that “intersex is not a medical condition or a disorder or a disability or a pathology [sic] (OII Australia 2010, 3).” On the other hand, Emi Koyama of the US-based Intersex Initiative engages actively with the social model of disability, situating intersex politics within and alongside radical disability politics (2006). Koyama points out that, like intersex people, those with disabilities have been subjected to unnecessary procedures to “normalize” their bodies. Children with disabilities, like intersex children, have been forced to pose nude before groups of curious medical students and providers. Koyama also draws upon the social dimensions of disability in framing responses to intersex features. Regarding intersex activist Esther Morris, Koyama notes that “not having a vagina was not a disability; the social expectation that she needed to get one in order to live a happy and productive life marked her body disabled” (2006).

Ultimately, Menon argues that the drawbacks of using disability policy are surpassed by the benefits (1247–51). The ADA offers legal protections and resources are presently inaccessible through other means. Indeed, “[f]or a community otherwise socially ostracized, grossly misunderstood, and socially shunned, the use of the ADA may actually elevate the status of intersex individuals into a more favorable category than its current social and legal status” (1248). Her argument is strengthened by an assessment of policy makers’ increasingly broad understanding of disability. The United States legal notion of “impairment” is quite expansive. Intersex individuals whose conditions require ongoing medical care, who experience difficulties with reproductive or sexual functioning, or who experience ongoing psychological distress (whether in relation to an intersex condition or its treatment) might all find protections through the ADA (1236–40). Additionally, legislation can and does acknowledge the significance of environmental and social factors in constructing categories and experience of disability (1247–9; see also Jeon and Haider-Markel 2001, 221–7). Intersex conditions that pose no threat to functioning in and of themselves, but are perceived or experienced as impairing due to societal adherence to the sex binary, might consequentially qualify for ADA protections.

Menon’s analyses apply readily to the CRPD. Activists working at the international level face similar concerns regarding stigma and pathologization, as well as a lack of alternative routes towards securing protections. The convention employs a social model of disability, emphasizing social and environmental barriers rather than individual differences or deficiencies (United Nations General

Assembly 2006, 1–3). In fact, the UN arguably takes a more sophisticated approach than the US, as illustrated in this passage from the preamble:

*Recognizing* that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others. (italics in original)

Whereas pursuing ADA protections might require permanently accepting the classification of intersex conditions as disabilities, utilizing the CRPD might not. Activists might treat CRPD gains as dependent upon the continued perception of intersex conditions as disabilities and/or the continued lack of preferable policy alternatives. If UN officials regard disability as “an evolving concept,” they should appreciate the possibility of populations acquiring and losing CRPD protections across time and space.

Several other tenets of the CRPD seem to align with those of the intersex movement. Activists who desire stricter regulation of medical practices might make use of provisions that mandate state involvement in the prevention of degrading and abusive treatment (12). Medically unnecessary surgeries and hormone regimens, particularly when paired with secrecy around diagnoses and the “reasons” for treatment, could conceivably be prohibited by the CRPD. Additionally, the aim of ensuring that disabled persons are free to make their own choices, including but not limited to those regarding medical care and family planning (2, 15–18), echoes intersex activists’ and allies’ demand for patients’ informed consent.

UN officials recognize the importance of community involvement, and advocate including disabled persons in decision-making processes regarding community policy and programming (2, 24–5). The CRPD further demands that state parties work to make public services and facilities accessible to persons with disabilities. These actions should be accompanied by efforts to reduce marginalization through such means as public awareness campaigns; non-stigmatizing media portrayals; and the promotion of respectful attitudes throughout primary, secondary, and advanced education (8–10). These aims complement intersex activists’ efforts to incorporate the views and lived experiences of intersex persons into social and medical policy design. CRPD provisions might enable activists to design and enforce protocols for accessibility that address such matters as gendered restrooms and gender categories in documentation. Additionally, intersex-inclusive school curricula and public awareness campaigns might go a long way toward reducing discrimination and isolation.

Finally, CRPD authors and intersex activists share an emphasis on intersectionality. The marginalization of intersex people is unavoidably multifaceted, encompassing societal conceptions of sex, gender, and age as well as disability and chronic illness. The language of the CRPD continually stresses the significance of considering the multiple, intersecting axes of stratification that impact disabled persons’ lives (2–3, 5, 7–8, 12, 15–16, 18, 21). UN officials

indicate that gender must be considered throughout the process of designing and implementing disability policy. They recognize that disabled women and girls face multiple forms of discrimination, and emphasize the significance of sexual and reproductive health. Respect for children with disabilities, both in terms of the development of personal identity and involvement in decision-making, is also a recurring theme.

There are limitations to this approach. Concerns regarding stigma and pathologization, along with possible tension among activist communities, seem unavoidable in spite of the UN's fluid understanding of disability. Those who desire to move beyond binary sex classifications might be dissuaded by language that treats the categories of man, woman, male, and female as exhaustive and unproblematic. The greatest drawback may lie in the UN's historical lack of engagement with intersex issues, and doubt as to whether UN officials would support the use of the CRPD as a means towards improving conditions for intersex people in member states. Even so, the tenets of the CRPD remain largely compatible with the aims of intersex rights and liberation. The UN has drawn attention to the mistreatment of intersex persons elsewhere, citing widespread "discrimination and medically unnecessary surgery" as well as hate violence against intersex rights activists (UN General Assembly, Human Rights Council, 2011, 18 and 11). Perhaps what remains is to bridge these ideas through the explicit application of the CRPD to intersex populations. UN officials could achieve this without modifying or amending the convention, as they would merely need to demonstrate its relevance. A report detailing the medical and social mistreatment of intersex persons, the specific provisions of the CRPD that offer protections, and recommendations for better practices (such as those outlined in the 2006 consensus statement), should suffice.

Of course, this approach would require the UN to confront the matter of whether intersexuality implies disability. Drawing on the language of the CRPD, a report might indicate that such protections apply only where social and environmental barriers hinder the full participation of intersex people in society, and/or where intersex diagnoses are regarded as physical or psychosocial impairments by medical and psychological professionals. This would spare the UN from engagement in disability classification, while providing space for intersex activists and community members to regard disability protections as temporary and/or contingent upon cultural and historical conditions.

## **Gender and Sexuality-Based Approaches**

Intersex issues might alternatively (or additionally) be framed as issues of sex and gender. This would render CEDAW more fitting than the CRPD. It is worth noting that CEDAW has already been used to argue against medically unnecessary genital surgeries. The UN General Assembly recently passed a resolution calling for an end to female genital mutilation, following a tireless effort by several African member states and the Inter-African Committee on Traditional Practices

(UN General Assembly 2012; UN General Assembly, Third Committee, 2012). This resolution cited CEDAW provisions as central to “breaking the cycle of discrimination and violence” against women and girls, and reaffirmed CEDAW emphases on education and healthcare reform (3–4). Such developments indicate that CEDAW might be well suited for arguing against the medically unnecessary surgeries performed on intersex infants.<sup>5</sup>

UN officials could support the intersex community through releasing a report that detailed the applications of CEDAW to intersex persons, or take a more active approach and transform the Convention on the Elimination of All Forms of Discrimination Against Women into a Convention on the Elimination of All Forms of Discrimination Against Women and Intersex Persons. The convention’s description of discrimination might be expanded as follows:

*Original:* “For the purposes of the present Convention, the term ‘discrimination against women’ shall mean any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, or any other fields” (Article 1).

*Addition:* The term “discrimination against intersex persons” shall mean any distinction, exclusion or restriction made on the basis of intersex status which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by intersex persons on a basis of equality with non-intersex persons, of human rights and fundamental freedoms in the political, economic, social, cultural, or any other fields.

Further modifications might be made throughout the articles of CEDAW to incorporate intersex persons. Consider the following:

*Original:* “State Parties shall take all appropriate measures:

(a) To modify the social and cultural patterns of conduct of men and women, with a view to achieving the elimination of prejudices and customary [sic] and all other practices which are based on the idea of the inferiority or the superiority of either of the sexes or on stereotyped roles for men and women” (Article 5).

*Modification:* State Parties shall take all appropriate measures:

(a) To modify the social and cultural patterns of conduct of men and women, including intersex men and women, with a view to achieving the elimination of prejudices and customs and all other practices which are based on the idea of

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<sup>5</sup> See Colligan 2004, 54–5, 57 for a brief review of some activists’ efforts to depict intersex surgeries as “IGM,” or intersex genital mutilation.

inferiority or superiority due to sex or intersex status, or on stereotyped roles for men and women.

*Alternative Modification:* State Parties shall take all appropriate measures:

(a) To modify the social and cultural patterns of gendered conduct, with a view to achieving the elimination of prejudices and customs and all other practices which are based on the idea of inferiority or superiority due to sex or intersex status, or on stereotyped gender roles.

If efforts to reduce discrimination against women are, in fact, efforts to reduce discrimination in regards to sex and gender, than intersex issues and women's issues should align easily. If this is not the case, the intersex applications of CEDAW may be limited to intersex persons who happen also to be women.

Those who are reluctant to conflate intersex issues with disability and/or women's issues might prefer the development of a new convention that, from the outset, would address intersex persons directly. UN officials have taken an interest in documenting discrimination and violence in regards to sexual orientation, gender identity, and intersex status. Unfortunately, their capacity to act on their observations is limited. The absence of a framework for LGBTI human rights will hinder any efforts to classify discrimination and violence towards LGBTI people as human rights abuses (i.e. as the domain of the UN). A Convention on the Rights of Lesbian, Gay, Bisexual, Transgender, and Intersex Persons; drawing on data from the 2011 report and modeled after existing conventions such as the CRPD, might help to resolve the present discrepancy between problem identification and problem intervention. It remains to be seen whether UN officials would prove amenable.

Regardless of the angle (i.e. disability, sex and gender, and/or LGBTI), any human rights approach would force UN officials to choose between two substantially different paths towards advocating for intersex persons: embracing a modified sex-gender binary that incorporates intersex women and intersex men (and perhaps also, but not necessarily, transsexual women and transsexual men), and rejecting binary frameworks altogether. This dilemma reflects a longstanding conflict among intersex activists and scholars. Binary frameworks invalidate people who identify outside of normative categories, including individuals who claim intersex as a sexual identity distinct from male and female, as well as those whose gender identity lies beyond the normative categories of man and woman (including, but not limited to, intersex persons who identify as genderqueer or gender-fluid). On the one hand, if we attempt to advance intersex rights without challenging sex and gender binaries, we risk further marginalizing those who are already among the most marginalized within the intersex community. On the other hand, there are considerable practical benefits to maintaining a binary framework. The UN could not credibly propose the adoption of additional sex or gender categories, or intersex-inclusive approaches to sex and gender neutrality, without drastically revising its own publications. Such neutrality has hitherto been realized

through the inclusion of males and females, and of men and women, rather than the abandonment of sex and gender specificity.

The struggles faced by ISNA activists indicate the considerable political risks of openly challenging normative categories. Although the ISNA did not advocate the use of intersex as a third sex category, false accusations to that effect played a role in the subsequent closing of the organization. “Widespread misinformation about ISNA’s positions” was among the reasons cited for members’ decision to close ISNA down and pass the community torch along to the Accord Alliance (ISNA 2012; see also Dreger and Herndon 2009, 216–18). While UN officials might prove up to these and other challenges, it seems more likely that they would opt for the less controversial tactic of incorporating intersex men and intersex women into the target populations of existing and forthcoming rights conventions. The history of international LGBT activism gives testament to this. Those LGBT activists who have proven the most inclined to adopt human rights frameworks, and who have tended to be the most successful in doing so, have been those who favor assimilation into mainstream culture and institutions. Those who favor oppositional strategies, advocating for more radical changes to social institutions and the development of alternative discourses, have chosen and fared differently (Mertus 2007, 1062–4). This is not to suggest that intersex status is comparable to queer and/or transgender identity, but rather to emphasize that the human rights arena has been most amenable to strategies that privilege compliance with normative categories. Individuals and activists who are not, or who lack interest in being, “just like everyone else” tend to be left behind.

Do the limitations of UN protections, existing and prospective, outweigh their potential to reduce the violence and discrimination directed towards intersex people? The answer remains unclear. Activists and community members who reject human rights approaches will have much to answer for. The potential benefits of CRPD protections are difficult to ignore, particularly in light of the fact that activists might regard disability status as contextual and temporary. Gender and/or LGBTI-based strategies might further resolve concerns regarding the conflation of intersexuality with disability. Yet those who support human rights approaches will also have much to answer for. Regardless of the specifics (i.e. the use of the CRPD, CEDAW, or an alternative/new convention), activists will be pressured to choose between pursuing protections that privilege those intersex individuals who happen also to be men and women, and pursuing a more inclusive strategy that would necessitate a fundamental reframing of sex and gender throughout UN policy.

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## Chapter 11

# HIV/AIDS, Disability and Socio-Economic Rights in South Africa

Lydia Apon Strehlau

AIDS remains one of the world's most serious health challenges, with 34 million people living with HIV globally. (UNAIDS Report on the Global AIDS Pandemic, 2012) The rapid expansion of antiretroviral therapy has played an integral role in the global response to the AIDS pandemic and has played a pivotal role in prolonging the lives of many People Living with HIV (PLHIV). From 2010–2012, access to HIV treatment grew by 63 percent; most who gained access included people in low- and middle- income countries that were eligible to receive HIV treatment, particularly antiretroviral therapy (UNAIDS World AIDS Day Report, 2012). Correspondingly, what has become increasingly apparent is a greater need for measures which address the disablement challenges that will arise, not only from the disease, but also from side effects of treatment of the disease. HIV/AIDS and disability intersect where people living with HIV may develop impairments and disabilities as a result of the disease, thus rendering them unable to carry on with their day to day functions, whether permanently or temporarily. In this regard, PLHIV may be identified as disabled vis-à-vis AIDS induced impairments. Appropriate interventions and coordinated responses must be devised to address these disablement challenges. We must also shift our focus towards how to improve the overall quality of life of PLHIV through the concomitant realization of socio-economic rights, in this way addressing their disablement challenges and promoting the realization of their human rights.

The end of the apartheid era in South Africa witnessed a shift towards human rights, with more emphasis placed on promoting and demonstrating the value of, and the need for, such protections. Valuable in-roads have been made towards the promotion of socio-economic rights, especially with regard to vulnerable people who are unable to take care of themselves. This has done by way of, inter alia, the provision of social assistance through grants, free primary health care as well as access to antiretroviral drugs (Department of Social Development). Whereas social security provisioning is high on the government's agenda, the result of the inherited skewed patchwork of a social security system has presented several challenges. On the one hand, synergy between policy direction and political will remains a concern. On the other hand, there is the question of implementation and adherence to norms and standards. (Olivier 2008, 185–6).

This becomes a greater issue when considered in the context of South Africa's unemployment rate of 25.5 percent with 4.7 million people unemployed in the third quarter of 2012, the prevalent structural inequality that is a legacy of apartheid, and the high HIV prevalence rate of 17.3 percent (South African Quarterly Labour Force Survey, 2012). Caught between the proverbial hard place of an ever increasing demand for support by way of inter alia disability grants and rehabilitative services (a push factor), the South African government must also contend with the pull factor of financial and human resource constraints. At stake is an effective, holistic and coherent response to HIV/AIDS vis-à-vis its disablement challenges, which necessitates a governmental balancing act between competing state priorities. The South African Constitutional Court has become the epicenter from which this delicate balance has found expression by interpreting the letter and the spirit of the law and government's mandate towards the fulfilment of its human rights obligations. Accordingly, one of the ways in which these challenges can be addressed is through appropriate and well-structured laws and policies, as underpinned by developed international frameworks.

This chapter explores the fulfilment of State's obligations in terms of adequately addressing the disablement challenges facing PLHIV through social security provisioning. This essay takes into account the disability framework outlined in the United Nations Declaration on the Rights of People with Disability (CRPD), as well as the International Covenant on Economic, Social and Cultural Rights (ICESCR). Towards this end, the South African constitutional court case of *Grootboom* is analyzed with a view to highlighting how it impacted on the South African socio-economic provisioning discourse as well as implications globally. Though the case of *Grootboom* was premised on the right of access to housing, it has particular relevance to the disability discourse in so far as the court decided more generally on the obligations of states vis-à-vis the provision of socio-economic rights towards the realization of basic human rights. This is of particular relevance to the disability discourse vis-à-vis an adequate response to HIV/AIDS. In conclusion, the paper considers global lessons for the intersection between the disablement challenges of PLHIV and the realization of socio-economic rights.

### **Contextual Framework for Disability and HIV/AIDS**

HIV/AIDS is not explicitly mentioned in the CRPD as a disability; however Article 25 (a) of the Convention may be interpreted to include HIV/AIDS as a disability (United Nations General Assembly). Article 25(a) provides that State Parties shall:

Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons,

including in the area of sexual and reproductive health and population-based public health programmes.

As per the Convention, disability is defined in relation to the individual's interaction with his environment and the limitations that inhibit full participation. People with disabilities are delineated as including those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others. This definition ascribes a social rather than medical model of disability. This context is distinct from the more traditional viewpoint of disability wherein the focus is on the physical or mental disability itself. In this regard, consideration is given to what disadvantages disabled people vis-à-vis a complex web of negative social attitudes and cultural assumptions as well as environmental barriers (policies, laws, structures and services) that result in economic marginalization and social exclusion. Lindquist Bengt correctly opines that a social model of disability defines difference and disadvantage thereby indicating what social change needs to take place to ensure equality and justice for those people with disabilities (Bengt 2000).

Adopting the social model approach of disability with regard to HIV/AIDS takes into consideration the nuances that are unique to the disease. In most instances, the disablement challenges suffered by PLHIV are brought about as a result of their interaction with the environment. For example, inadequate housing exacerbates the onset of tuberculosis whereas poor nutrition owing to inadequate financial means results in a lowered immune system; bring upon impairments. In this way, HIV/AIDS related disability is greatly influenced by the individual's interaction with his or her socio-economic environment; which ultimately, whether permanently or temporarily, affects the individuals' ability to function. Preventative measures in terms of access to adequate socio-economic conditions thus play an integral role in reducing the onset of disablement challenges faced by PLHIV.

Disability viewed as an interaction with one's environment is a progressive one that recognizes the multi-faceted issues affecting PLHIV. By adopting this viewpoint, a holistic approach encompassing multi-faceted support to address the disablement issues facing PLHIV range can be prioritized. This approach also underscores the need to promote the realization of socio-economic rights as an important intervention for addressing the disablement challenges facing PLHIV. The need to realize social security for all is also underpinned in Article 2(1) of the ICESCR which enjoins state parties to ensure that the right to social security is realized by all. State parties are encouraged to undertake to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to progressively realizing the socio-economic rights, including particularly the adoption of legislative measures.

## **Social Security Provisioning, HIV/AIDS, Disability, and *Grootboom* in South Africa**

Before the 1994 abolition of apartheid, the labor–welfare system had its roots in discrimination and disadvantage along racial lines. Education, health and housing benefits were biased towards whites, with labor market policies designed to protect the position of whites. Massive investments in public education for white children in the 1950s and 1960s resulted in white workers securing the skills that enabled them to succeed in the 1970s and 1980s, thus commanding high incomes in free labor markets. These interventions largely removed their dependence on direct state interventions. Essentially, the apartheid social welfare laws for whites was based on a combination of income measures through job reservation and other forms of assistance and in kind benefits through inter alia education, health and housing (Report of the Committee of Inquiry into a Comprehensive System of Social Security for South Africa, 21–22).

Black South Africans, in contrast, were on the receiving end of extensive labor-market discrimination and disadvantage, underpinned by inferior education, influx control, the Group Areas Act and other controls. These measures were designed to undermine black income and consequently inhibited their social development (Committee of Inquiry, 21–22). With the abolition of apartheid, labor market regulation was de-racialized with formal racial distinctions and divisions removed. Correspondingly, the ratification of the Constitution of the Republic of South Africa on 10 December 1996 by then-president Nelson Mandela, ushered in a new legislative era with regard to the promotion and protection of socio-economic rights.

The present South African social security framework has its overarching mandate in the Constitution; this constitutional imperative is—to reiterate and expand—rooted in a human rights approach redolent in founding values of dignity, equality and freedom, and the building of participation and voice of the excluded. Whereas other states have more of a bottom up approach to the development of social security, South Africa has, due to the history of injustice and inequality, adopted a top down approach (Olivier, 2008). Section 27 of the South African Constitution provides that everyone has the right of access to health care services, sufficient food and water, and social security, including if they are unable to support themselves and their dependents, appropriate social assistance. The state is constitutionally required to take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of this right. The rights guaranteed in the Constitution are, furthermore, not capable of being viewed in isolation as they are inter-related and mutually supportive (Constitution, 1996) as is also entrenched in the CRPD; which recognizes the universality, indivisibility, interdependence and interrelatedness of all human rights and freedoms.

This indivisible nature of human rights, and more specifically socio-economic rights was apparent in the case of *Grootboom* when the court enunciated on the interrelatedness of the socio-economic rights in the Constitution and delineated the state's obligation in this regard. The respondents, comprised of 510 children

and 390 adults, had moved from their informal squatter settlement and illegally occupied private land earmarked for formal low-cost housing (*Grootboom* 2001). They were subsequently evicted from the private land, rendering them homeless. The respondents launched an urgent application to the High Court for an order requiring the appellants to meet their constitutional obligations and provide adequate temporary shelter or housing to the respondents. This obligation would precede the obtainment of permanent accommodation or basic nutrition, shelter. Relief was granted to the respondents, with the High Court ordering that the appellants provide the respondents with shelter. The appellants, represented by all spheres in government responsible for housing, challenged the correctness of this order and appealed against it in the Constitutional Court (*Grootboom*, par 6–8).

The court, in deciding the extent of the state's obligation vis-à-vis socio-economic provisioning, reflected on the meaning and import of the "right of access to" as contrasted with "the right to" and found the two phrases to denote distinctly different obligations. The court contemplated that the "right of access," as entrenched in the Constitution, recognizes that housing entails more than bricks and mortar but also encompasses other rights such as a right to access available land, access to appropriate services such as the provision of water, removal of sewage as well as access to financing of all of these, including the building of the house itself (*Grootboom*, par 35).

*Grootboom* correctly highlighted the intersection between all the socio-economic rights in that the right of access for one cannot be divorced from the right of access to the other rights and that realization of one right would mean the realization of the other.

Furthermore, the "right of access" suggests that not only is the state responsible for the provision of this right, but also other agents within society, including individuals themselves have a part to play. In order to ensure that this multi-actor responsibility is actualized, the state needs to create an enabling and conducive environment through legislative and other measures, so that these rights can be accessed and actualized by people at all economic levels of society, taking into account the different participatory economic levels in society (*Grootboom*, par 37).

In this regard, *Grootboom* made an important distinction between those who can afford to access socio-economic rights and those who cannot afford to access socio-economic rights with a concomitant different state obligation in this regard. With regard to those who can afford to pay, the state's primary obligation lies in unlocking the system and ensuring a legislative framework to facilitate access. Furthermore, programs in place for social insurance via contributory participation is an important delineator of the state's fulfilment of its obligations. On the other hand, for those who cannot afford to pay, issues of development and social welfare take center stage and state policy needs to encompass both these participatory groups. For the impoverished, the state has in place programs to provide adequate social assistance to those who are otherwise unable to support themselves and their dependents (*Grootboom*, par 36). In both cases, state policy is the nub of the issue with regard to the right of access as concerns both groups.

The court, in considering the state's fulfilment of its obligation to provide the right of access to housing, indicated that the extent of the state's obligation is defined by three key elements *viz*: (1) the obligation to take reasonable, legislative and other measures; (2) within its available resources; (3) to achieve the progressive realization of a right. In determining reasonable legislative and other measures, it opined a reasonable program must clearly allocate responsibilities and tasks to the different spheres of government and ensure that the appropriate financial and human resources are available. Furthermore, the program of intervention must be capable of facilitating the realization of the right, and the measures adopted to do so must be reasonable in both their conceptualization and implementation (*Grootboom*, par 38–41).

In determining whether the measures adopted by a state are reasonable, the court opined that it is not enough to put in place legislation; rather the state is obliged to act in order to achieve the intended result via well-directed policies and programs implemented by the executive. Even so, the court stressed that in order to be reasonable, measures cannot leave out of account the degree and the extent of the denial of the right they endeavor to realize. In this regard, those whose needs are the most urgent and whose ability to enjoy the rights are most in peril must not be ignored by the measures aimed at achieving the realization of the right. (*Grootboom* par 39–41).

In the South African context, the court highlighted that the term “progressive realization” had the same meaning and import as contained in Article 2.1 of the ICESCR and as expounded by the UN Committee. The Committee indicated that progressive realization imposes an obligation to move as expeditiously and effectively towards realization of the goal of economic, social and cultural rights thus reflecting the realities of the real world and the difficulties involved for any country in ensuring full realization of these rights. The court further indicated that “progressive realization” means that legal, administrative, operational and financial hurdles should be examined and, where possible, lowered over time to progressively facilitate accessibility (*Grootboom* par 45).

The indivisible nature of socio-economic provisioning, as highlighted in *Grootboom*, underpins the need for a multi-faceted approach to the issue of HIV/AIDS and disability. For example, decent housing plays a key role in the prevention of opportunistic infections, such as diarrhea, tuberculosis and other respiratory diseases that lower the body's immune system, accelerating HIV/AIDS induced disablement. Also, the lack of access to basic water, refuse removal and proper sanitation are also directly attributable to the high prevalence of these preventable infections and also shorten the period between HIV infection and the onset of AIDS. Therefore, a multi-faceted approach would entail access to the right nutrition, to health care services, transport to health facilities, adequate sanitation and housing, psychological counselling, income support, vocational rehabilitation and other poverty intervention measures that reduce their vulnerability to AIDS. All these factors play a key role in the intervention for PLHIV, as underpinned by

*Grootboom*, and the right of access to these socio-economic rights should be facilitated by state parties for all economic levels of society.

Also, using *Grootboom dicta*, a further argument is made for a social model approach to PLHIV so as to ensure that all the right interventions are put in place to keep AIDS induced disability at bay and also to better deal with it, by putting in multi-faceted measures that take into account the nature of the disease. In the context of disability and PLHIV, the realization of their human rights entails more than to ARVs and free primary health care but also entails the realization of the right of access to adequate socio-economic conditions. This mandate involves, as underpinned by *Grootboom*, lowering any hurdles to the full realization of these rights, progressively and over time. While rightly so, the realization of the socio-economic rights of individuals cannot be divorced from the economic, social and cultural circumstances of a state, there is an onus on state parties to put in place measures that take into cognizance those whose rights are most in peril and enjoyment under threat. In the HIV/AIDS disability discourse, this means a multi-faceted approach to and HIV/AIDS related intervention.

*Grootboom* was a landmark judgment that clearly delineated the multi actor responsibility involved in the right of access to socio-economic rights. This allows for citizens and other civil society groups to work more synergistically with the State in responding to the AIDS disablement challenges in an enabled conducive environment, further reinforcing that dealing with HIV related disability issues is a multi-actor responsibility of all concerned.

### **Quo Vadis—Some Thoughts and Considerations**

A holistic approach is needed that responds to the specific needs of HIV/AIDS related disablement. The nature of these disablement issues require a coordinated and concerted effort to promote human rights which efforts should take into consideration core developmental social services such as inter alia rehabilitation, continuing care and mental health, active linkages with the labor market and access to financial support. The tangible link between an adequate response to HIV related disablement challenges and the realization of socio-economic rights cannot, therefore, be overemphasized. Proper intervention measures need to be formulated so as to articulate an adequate and informed response to addressing the need to prioritize HIV disablement challenges. Over time, disability policies and laws need to be continually reviewed and strengthened, with any barriers lowered over time in order to ensure the attainment of the obligation by the states and towards a holistic multi-actor responsibility approach to HIV/AIDS related disability.

The absence of a more comprehensive human rights approach to the disablement issues facing PLHIV has the potential to undermine the milestones achieved so far with dealing with the challenges brought about by the HIV/AIDS epidemic. It will also impact further on already stretched budgetary allocations, as more and more PLHIV become susceptible to the disability due HIV disablement challenges.

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## Case Law

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## Chapter 12

# The Overrepresentation of Black Children in Special Education and the Human Right to Education

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The right to an education is a recognized civil right in the United States, meaning that children have the right to attend school without discrimination or undue government interference. Although children in the United States have the legal right to attend public schools, this right does not necessarily ensure that every child has equal access to physically, emotionally, and mentally grow, thrive, and develop to the best of their abilities. Neither does this right protect children from prejudices and biases embedded in standardized testing, assessments, and teacher/administrator perceptions. Nor does it include the right to feel safe in the school environment, be free from bullying and harassment, be taught by invested and passionate educators, and attend a school with modern technology and resources. Correspondingly, a civil rights approach to education inclusivity has proved to be insufficient and detrimental for many of the most vulnerable members of society – particularly African American children. As this chapter maintains, this population is subject to disproportionate special education placements that intersect with historical and purposeful marginalization of both people with disabilities and those of color. Accordingly, this chapter advocates for a transition from a civil rights frame to a human rights approach.

This transition from civil rights to human rights is important to this issue for four reasons. First, it challenges notions of whiteness and normalcy as social constructs that continue to oppress racial minorities and the disabled. Second, civil rights are a subset of human rights and as such represent an isolated, problematical approach to securing universal human dignity that disconnects the individual from his or her economic reality and subsequent constraints.<sup>1</sup> Third, the civil right to education is fundamentally different from the human right to education, namely in regards to entitlements to school quality and safety. Last, but certainly not least, a

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1 Modern-day human rights are divided into conceptual categories that comprise civil and political rights (first generation rights) and economic, social, and cultural rights (second generation rights). Human rights are interdependent however in that a violation of one freedom or right creates barriers to enjoying other rights and freedoms.

human rights framework moves the issue beyond the national boundaries of civil rights and into the internationalist space of universal dignity for all persons.

### **Special Education and African American Children**

Children with disabilities can be found across all socioeconomic groups, and many receive accurate disability diagnoses and benefit from special education. Special education is designed to provide – in the least restrictive learning environment possible – resources, learning opportunities, and support services to children and adolescents who have a disability. However, special education services are by no means equitable for all; furthermore, not all who are characterized in need of these programs belong there. Expressly, as a series of reports indicate, Black children are overrepresented in special education categories for cognitive, emotional, and behavioral disabilities at a rate higher than the expected incidence and prevalence of these impairments in the general population (Artiles 2003; Serwatka et al. 1995). In 2006, figures from the US Department of Education's Data Accountability Center show that while African American students only comprised about 17 percent of all US public school students, they accounted for 30 percent of all students classified as severely emotionally disturbed, 31 percent of all students classified as mentally retarded, and 21 percent classified as learning disabled (IDEA Data 2006). This pattern appears nationwide, with data showing that Black males are twice as likely as white males to be identified as mentally retarded in 38 states, emotionally or severely emotionally disturbed in 29 states, and learning disabled in eight states indicating the extent of racial disparities in special education (Parrish 2002).

To be sure, African American children are not overrepresented in all categories of disability, which include the following eight indicators: intelligence, achievement, adaptive behavior, social behavior and emotional adjustment, sensory status, motor skills, and health status (Reschley 1996). Instead, these students are only overrepresented in disability categories diagnosed through subjective tests, evaluations, and assessments (particularly those intended to assess learning disabilities, emotional and behavioral problems, and mental retardation) (Serwatka et al. 1995). This pattern has been formally recognized since the US Office of Civil Rights first started to survey school districts in 1968, yet little has changed.<sup>2</sup> Such racial bias in special education placements however is not limited to African American children. Hispanic children are overrepresented in speech and learning disorders, likely due to English as a second language rather than actual impairment. Asian American children are under-identified in cognitive disabilities, further raising the question of whether or not the special education needs of minority children are appropriately realized (Losen and Orfield 2002).

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<sup>2</sup> It is notable that this pattern was first recognized by a federal civil rights agency rather than the Department of Education.

Once in special education, there is evidence of significant racial differences regarding quality of education, education outcomes, and discipline. Compared to their white counterparts, African American students are more likely to be taught a less rigorous special education curriculum; moreover, these students are likely to receive instruction in segregated or restricted special education classes (Losen and Orfield 2002; Noguera 2003; DOE 2006; Harry and Klingner 2006). They are also more likely to remain in long-term segregated placements instead of transitioning back to the mainstream classroom, which is one of the primary goals of special education (Harry and Klingner 2006). In addition, African American students are more often taught by uncertified or provisionally licensed teachers, graduate with a certificate of attendance or completion instead of a diploma, and have a higher dropout rate (Artiles 2003; DOE 2006). Racial differences between persons with disabilities continue to manifest well past high school and with long-term consequences. For example, Black adults previously in special education classes tend to experience higher unemployment rates, are less prepared for the workforce, and are less likely to attend or complete college (Lipsky and Gartner 1996; Patton 1998; Losen and Orfield 2002). They are likewise more likely to have contact with the criminal justice system (Noguera 2003).

Meanwhile, push-out policies fueled by the rise in zero-tolerance policies have resulted in a dramatic uptick of suspensions and expulsions that disproportionately target African American and Latino students, poor and low-income individuals, and disabled students (Casella 2001; ACLU 2007; Losen and Martinez 2013). For students who hold one or more of these minority statuses, the risks of being pushed out of the system are even higher. A recent report found that 1 in 4 African American middle and high students, and 1 in 5 students with disabilities were suspended during a single school year. These numbers compare to 1 in 14 for white students and students without disabilities (Losen and Martinez 2013). In the 2011–2012 school year the New York Police Department School Safety Division arrested or ticketed more than 11 students each day. Of these, more than 95 percent of arrestees were Black or Latino (NYCLU 2012). The degree to which African American and Latino students have been targeted per this disciplinary policy bolsters the “school-to-prison pipeline,” a phenomenon wherein “undesirable” children from the education system are pushed into the criminal justice system (Watts and Erevelles 2004; ACLU 2007; OJJDP 2012). In a recent report, The US Department of Justice (DOJ) not only formally recognizes the existence of the school-to-prison phenomenon but it unequivocally states that is racially biased (DOJ 2012).

### **Discrimination, Disability, and Whiteness: Legal Precedents and Impacts**

That such a clear, racially biased phenomenon exists today is not surprising (indeed, it may even be a natural consequence) given the structure of the education system and the historical oppression of African Americans and people with disabilities. From its inception, the US federal government was designed to be a constitutionally

weak state with a high level of decentralization, an arrangement that benefited the white propertied class. As such, many enduring institutions, like public education, are also highly decentralized with states and localities responsible for setting the bulk of education policy and funding schools. More than 90 percent of funding for public schools comes from state and local source with over three-fourths of this local contributions derived from local property taxes (Kober and Usher 2012). This arrangement created a two-tier system of public education in which poor students, who are disproportionately African American and Latinos, attend poor schools of low quality whereas middle and upper class children receive a higher quality learning experience. One report estimated that 35 percent of African American students attend schools with high levels of poverty compared to 5 percent of white students (ibid.).

Historically, the designation of education policy, decision making, and funding to individual states allowed states in the American South to institute racial segregation vis-à-vis schools purposefully designed to be inferior to white schools (Slessarev 2011). This practice lasted nearly 100 years and was supported by the prevailing ideology of whiteness. In the United States, whiteness constitutes an identity, an ideology, and an institution that systematically reproduces white skin privilege through time and space, affecting every level of society to become “the most powerful, sustaining myth of American culture since its inception” (Dyson, 2003, 100). Others have called race an “organizing principle of Western social institutions” (to include the institution of education) and declared that modern-day America remains “fundamentally racist” due to its economic, ideological, and political structures that support white skin privilege (Feagin 2001; Bonilla-Silva 2008,12).

Since the 1970s, critical race theorists characterize “race” as a social construction that was organized to maintain the status quo by benefitting white people (Haney Lopez 2000; Williams 2003). While a robust discussion of racial relations and racial formation is beyond purview of this piece, the history of the US is one colored by white supremacy, beginning with the genocide of Native Americans, Colonialism, the forced enslavement of Africans. The systemic oppression of individuals and groups deemed “non-white” would be supported through a social construction of race in which “race” is touted as a “meaningful” category of difference predicated on a hierarchal ideology. According to racist tautology, people of color are situated as culturally, intellectually, physically, and morally inferior to their white counterparts. This status was not only bestowed upon dark-skinned individuals but also to their knowledge systems, cultural practices, daily ways of life, and community formations (DuBois 1973; Frazier 1997).

Given the enduring 400-years plus context of state-sponsored racism in this nation, perhaps it is fitting that the first recognition of education as a civil right was by ending school segregation through the US Supreme Court case, *Brown v The Board of Education (1954)*. Although the decision declared racially segregated schools unconstitutional, the ruling did not declare education a fundamental human right for all persons, an argument based on the omission of education as

an explicit right in the Constitution (Slessarev 2011). As such, the *Brown* decision falls short of instituting a human right to education for US children in three primary ways: 1) segregated education for children with disabilities continued, 2) systematic, institutional, and interpersonal racial biases were not negated, and 3) economic inequality continues to reproduce a two-tier system in which the poor attend sub-par, resource-scarce schools while those with more money enjoy a higher quality of education, opportunities, and enrichment activities.

It took nearly 20 years after *Brown*, before white and non-white children with disabilities received the right to education through a series of similar court cases and legislation.<sup>3</sup> In 1975 the passage of the Education for All Handicapped Children Act (EAHCA), later renamed the Individuals with Disabilities Education Act (IDEA) represented a step forward for disability rights. IDEA guarantees any child who meets the disability criteria established by the act a free appropriate education in the least restrictive environment (US DOE, 2010). This lag in civil rights for persons with disabilities is notable because this group shares many of the experiences and characteristics of groups recognized as racial minorities in the US. While not a monolithic group, people with disabilities are often subjected to prejudiced attitudes, systemic discrimination and institutional constraints as they face socially-created political, social, and cultural barriers that prevent full participation in daily and social life.

This disability-based discrimination is justified through perceptions of inferior corporeal and cognitive differences that fall outside the socially constructed ideas of normalcy (Striker 1999). The concept of “normalcy” can be traced to mid-nineteenth century Europe. Mired by revolutions and political turmoil, efforts to restore social order included measuring, quantifying, and regulating bodies. In this context, state-authorized ideas about “normal” citizens have traits desired by the State: whiteness, masculinity, and able-bodiedness – all characteristics of the dominant class (Foucault 1979; Davis 1995). People who fell outside these ideal-type constructions were correspondingly judged against this constructed myth of normalcy and perceived as deficient in some way, justifying an infrastructure of exclusivity (Connor 2008). To be sure, this practice of discriminatory characterization against persons with physical and cognitive impairments was not the sole domain

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3 Two court cases in particular were instrumental in securing the rights of disabled children to an education. The ruling in *Pennsylvania Association for Retarded Children (PARC) v. Commonwealth of Pennsylvania* (1972) prevented states from denying full access to free public education and related services to children with MR up to age 21, established standards of appropriate treatment for MR, and decreed that children with disabilities be served in the least restrictive environment possible. That same year, *Mills v. Board of Education of District of Columbia* (1972) also prohibited school systems from denying education services to any child regardless of disability. Many of these provisions would form the groundwork for the forthcoming Education for All Handicapped Children Act (EAHCA) of 1975, PL 94–142, later renamed the Individuals with Disabilities Education Act (IDEA) (Martin et al. 1996).

of Europe. These discourses are evident within a historical US context as well, reaching a feverish pitch during the Eugenics Movement in which tens of thousands of “imbeciles” were sterilized against their will in the early twentieth century.

Analogous to the work done in critical race theory with regard to racism, disability studies (DS) treats “disability” as a social construct defined by the historical, socio-cultural, political, ideological, and economic conditions of a society rather than the presence/absence of impairments (Groce 2006). As does race, the construction of a disability varies across time and space with such characterizations reflexively shaping the public attitudes and exclusionary practices that circumscribe the daily experiences and human rights of disabled people (ibid.). The dynamic nature of “disability” and its definitions is relevant to the issue at hand because it influences what symptoms we think of as constituting an impairment, and what impairments become appropriate for special education services. This is particularly the case for emotional, mental, and behavioral problems which have become increasingly medicalized and subsumed in the medical model of disability that undergirds special education placements (Conrad 1992). The intermingling of inferior stereotypes and exclusion is most evident via the medical model, which hinges on an evaluation of deficit in the individual. The medical model is flawed in its failure to accept impairments and behavioral differences as a natural part of human diversity and its inability to account for the structural-based factors that affect daily life, learning, health and health outcomes.

Subsequently, the intersection of whiteness and normalcy converge in the medical model of disability in a manner that racial minorities and poor students are classified as an “other” under the guise of a disability and pushed out of the mainstream classroom (Gallagher 1999). While students can no longer be legally segregated by race, teaching and administrators can remove problematic students if they have a disability diagnosis (Devine 1996; Sewell 1997; Reid and Knight 2006). Once a student allegedly meets the subjective criteria of an emotional, cognitive or behavioral disability, then he or she can justifiably be removed from the mainstream classroom. Critical researchers believe that special education functions as a dumping ground for students with behavioral problems and a means of removing difficult or underperforming students (Norby et al. 1990; Artiles and Trent 1994; Noguera 1995; Artiles 2003). For example, research shows that African American males who spoke in Ebonics, a recognized dialect of the English language, were frequently targeted for special education assessments and placements (Neal et al. 2001). This bias is often exacerbated by the fact that teachers and administrators are predominantly white and from privileged backgrounds. Additionally, these and other push-out practices have worsened through initiatives such as No Child Left Behind, one of the largest federal education reforms acts to date that links federal funding to a school district’s test scores and incentivizes the removal of underperforming students from the test pool results.

To contextualize the current classroom state of special education and the medicalization of deviant behavior, it is imperative to briefly revisit *Lora v. Board of Education of the City of New York* (1975), which was pivotal in the medicalization

of emotional and behavioral problems as a disability worthy of special education placements (Martin et al. 1996). This was a class-action suit filed by the parents of African American and Hispanic students assigned to inferior, segregated day schools for the emotionally disturbed. At issue were a number of students who had a minimum IQ of 75 (and were thus not intellectually disabled) and were diagnosed with emotional problems that either impaired their ability to learn in a regular classroom or rendered them disruptive to the learning environment. While charges of racial inequality served as an initial justification for the class-action suit, the parent plaintiffs shifted their argument to accommodate the allegation that their child's right to treatment was violated through the segregated school placement. Whereas the court clearly decided that education inequality of any type was unacceptable, more ambiguous was whether the students' rights were violated due to racial discrimination or rather disability discrimination vis-à-vis the right to treatment. In addition, while this case extended special education rights to emotionally disturbed children, it is important to note that no definition for "emotionally disturbed" or diagnosis protocol was established through this ruling, leaving the door open for subjectivity and bias to continue (Stanford Law Review 1979). A key outcome of this case is the establishment of improved efforts to better identify students in need of special education and the reaffirmation of children to the rights to treatment and due process as established in the Constitution.

However, there is a more important piece to this ruling and that is the issue of education and economic inequality. While the ruling acknowledges that, "to afford equality of opportunity so far as we can, we depend primarily on education. The free public system of education is the great equalizer ... But the system is – and perhaps by its nature must be – inadequate to lift fully the burden of poverty, of discrimination and of ignorance that so many of our children carry," it is further noted that the decision was not predicated on economic differentials between students. Indeed, according to the court, "discrimination against those with less ability to manipulate a system fair on its face because of greater knowledge, skill, assurance and initiative cannot be deemed unconstitutional."<sup>4</sup> This sentiment has been repeated in other cases that challenged the reproduction of economic inequality via the education system. For example, the Supreme Court declared in *San Antonio Independent School District v Rodriguez* (1973) that the right to education does not extend to the equitable allocation of state and local funds to all public schools in a given state. As such, the court recognizes the importance of education but makes clear that this alone does not support a positive entitlement to education.<sup>5</sup> In short, while the courts have affirmed a civil right to education for students with disabilities and students of color in a negative sense, this merely prevents the government from outright barring students from public schools because of identity variables and does not entitle students to a quality education.

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4 LORA v. BOARD OF ED. OF CITY OF NEW YORKNO. 75-C-917. (456 F.Supp. 1211, 1978)

5 (*San Antonio Independent v. Rodriguez*, 411 U.S. 1, 1973).

The issue of school quality, or rather, unequal schools, is one of the primary ways that a human right to education differs from the current civil rights approach favored in the US (NESRI 2006). The former United Nations Special Rapporteur on the Right to Education, Katarina Tomasevski, developed the concept of the “4 A’s” to guide the right to education: availability, accessibility, acceptability, and adaptability (Tomasevski 2001). A human right to education can be envisioned as one in which all children receive a quality education adapted to his or her needs; such a provision works to uplift and develop the child’s full potential and respects the inherent dignity of students by establishing respectful classrooms. It also eliminates harmful disciplinary practices and potentially provides an equitable distribution of resources across school districts and encourages parent, student, and community participation (Tomasevski 2001; NESRI 2006). In comparison to the negative expression of a civil right, a human right to education is expressed as a positive right or entitlement. Similarly, many (if not all) economic rights are positive, such as the right to employment, social security, and safe affordable housing. Entitlements, however, have a mixed history of public and political support with regard to the state, with conservative opinions preferring a market-based approach to providing the necessary features of life.

### **Conclusion: Towards Human Rights**

The entitlement to quality education is just a small piece of the modern-day human rights movement, which recognizes personhood via frames of dignity, justice, rights and freedom; such notions of personhood are analogously expressed vis-à-vis a series of international declarations and covenants predicated on the principle of shared human vulnerability (Turner 1993; Thomas and Brunsma 2013).<sup>6</sup> While not legally binding, these international documents detail the rights and freedoms that should be afforded and guide nation-states in the implementation of human rights processes. Governments around the world, including the US, have affirmed the importance of education, but many restrain from instituting education as a human right, indicating that there is a difference between support and implementation of the right to education (Tomasevski 2001). To illustrate, in a 2013 statement on the right to education the US representative to the UN Human Rights Council, Ambassador Eileen Chamberlain Donahoe acknowledges US support of education while stating reservations on education quality:

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6 The Universal Declaration of Human Rights, adopted by the United Nations General Assembly in 1948 is generally upheld as the principle expression of modern human rights and freedoms. It consists of 30 articles and together, with the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural rights comprises the International Bill of Rights.

The United States strongly supports the right to education ... As is well known, the United States notes that it is not a party to the International Covenant on Economic, Social, and Cultural Rights, nor the associated Optional Protocol. Further, in joining consensus on this resolution, *the United States notes that it does not recognize any change in the current state of conventional or customary international law*. We also firmly believe in the importance of quality in education, and of increased attention to it, but *note concern with any attempts to add to the right to education vague components that are difficult to define and quantify* ... (Donahoe 2013, emphasis added)

It is argued that many human rights can only be accessed through education, particularly rights associated with employment and social security (Tomasevski 2001). However, this is an incomplete argument, so long as economic rights remain unrecognized as they do in the US. In other words, the right to gainful employment is not guaranteed for any US citizen regardless of education attainment, but the chances of securing gainful employment and a satisfying work life are increased through education. While education ostensibly “unlocks” other human rights, the interdependent and interrelated nature of human rights means that other rights also “unlock” education. For instance, the right to health and quality health care from cradle to grave better enables access to early interventions, medications, or services to address issues that might impact future development and learning. Economic, social and cultural rights are vital to childhood success and achievement because we cannot depend on the education system alone to correct the literal and figurative ills of society and meet the complex needs of disabled children, nor should we. The best resources and teachers will rarely be enough to combat the other social determinants (e.g. nutritious food, exposure to violence, inadequate housing) that contribute to a positive school experience and engaged child. From this vantage point of interrelated and inalienable rights, we engage in a discussion of rights and freedoms that wraps-around the human existence rather than addressing issues in isolated and unconnected silos (e.g. health care, social welfare, education). Indeed, the fragmentation or silo-system of service delivery is such that the children with multiple, interconnected needs may have difficulty accessing necessary services and resources (Aron and Loprest 2007).

This reading of the potential of human rights when compared to civil rights is by no means new. Illustratively, the limits of civil rights were espoused by notable leaders in the Civil Rights Movement such as Rev. Martin Luther King, Jr. and Malcolm X who foresaw that voting rights and desegregation would not bring equality to Black America. Racial inequality, they recognized, sharply intersected with an unjust economic structure that denied poor people the rights to security, safety, livelihood, employment and healthcare.<sup>7</sup> We see this discourse present

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7 Worth noting is that the Black Panthers, a powerful and influential group in the Black liberation movement also worked for economic equality and provided support services to thousands of poor people through their Survival Programs. For example, they

in the aptly-named March on Washington for Jobs and Freedom at which King delivered his famous ‘I have a dream’ speech on 28 August 1963. The reasons for the move towards human rights was largely twofold, beginning with the recognition that poverty would continue to be an oppressive structure for people of color and that the government should be held accountable for economic inequality. Second, African American struggles were intimately connected to the struggles of people of color all around the world, particularly with regard to then anti-imperial campaigns waged in Africa and Asia. The linkage of national struggles to international issues is a vital component of human rights for two reasons. First, we are all human worthy of dignity and freedom by virtue of shared humanity. Thus, we as a people can never realize universal human rights so long as education is denied to individuals, people with disabilities are marginalized and discarded, and dark-skinned people are oppressed by whiteness. Second, the international arena provides a mechanism to hold the state accountable for human rights violations through United Nations tribunals.

There are no simple solutions to the overrepresentation of African American children in special education, to the use of disability resources in the oppression of others, and to the school-to-prison pipeline that is funneling a generation of minority children into jails and prison. These problems are complex and challenge us to ask bigger questions beyond issues of inclusivity. Human rights will not come easy to the US, but that does not mean that change will not come. We owe it to our children, and to ourselves as people and community members to support a bottom-up social movement (in whatever way possible) to reorganize society into one ordered by justice, freedom and dignity.

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recognized the importance of proper nutrition for school-age children and pioneered the first free breakfast program for school children. Although the program was ultimately dismantled in the wake of extensive FBI harassment against party members, the idea of providing free or reduced-price breakfast and lunches to needy students became adopted by the state with the 1975 National School Breakfast Program (Brown 1993).

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# Chapter 13

## “Becoming Disabled”: Towards the Political Anatomy of the Body

Nirmala Erevelles

In an essay entitled, “Shape Structures Story: Fresh and Feisty Stories about Disability,” Rosemary Garland-Thomson (2007) vividly describes how shape (i.e. the visible body) “carries story; it makes story visible, in a sense it is story” (114). To make her point, Garland-Thomson refers to the “tongue dancing” of quadriplegic sociologist, John Kelly, at the end-of-the-conference dance at the one of the Annual Meetings of the Society for Disability Studies (SDS). Seated in “a big, bright red, motorized [wheelchair] ... complete with hand tray in front, puff stick, high back, and straps across his limbs and chest for support,” Kelly “dances” with his tongue, the only part of his body that he can move independently. Garland-Thomson describes his dance as follows:

His face is incredibly animated as he goofily and seductively bobs his tongue from side to side to the beat of the music ... some graceful, others playful, most erotic. ... His tongue curls, extends, sways, touches his nose, undulates, thickens, and wiggles ... . Of course the eroticism of tongue dancing is lost on none of us. On the dance floor, John leads and the rest of us follow, discovering the exquisite oral pleasure of watching his alternately phallic and labial movements and simultaneously watching our own awkward tongues explore new shapes and spaces. (121)

Garland-Thomson’s account of Kelly’s tongue dancing, which foregrounds the subject as both thing and event, rewrites so many scripts. Such multivalent foregrounding renders visible the extent to which her narrative embodies in rich detail the post-humanist turn in contemporary theory (Deleuze and Guattari 1987; Haraway 1990; Grosz 1994; Shildrick 2009). With simple oscillations of his tongue (doing), the material-discursive apparatuses of Kelly’s body intervenes, transforms, and reworks normative notions of what bodily matter (tongues) can do when performing outlaw actions (dancing) rife with both rhythmic and erotic possibility. As such, from a “critically disabled position,” the “crip’s tongue” does the “*severely* performing work” of defiantly refusing compulsory able-bodiedness (McRuer 2006, 30). Correspondingly, Kelly “remaps the public sphere and reimagines and reshapes the limited forms of embodiment and desire proffered by the systems that would contain us” (31).

These discursive possibilities immanent in Kelly's disabled body so effectively disrupt the medico-scientific discourses of anatomy. They analogously re-invest the physiological functions of the tongue with erotic actions that transform (bodily) matter as we know it, enabling what Deleuze and Guatari have called newer "world-becomings." As a result, the SDS end-of-conference dance phenomenon becomes a discursive-historical-temporal space wherein erotic pleasure finds itself reiterated in the pulsing gyrations of Other awkward tongues. Such frames instantiate the possibility of a temporal radical social movement led by an army of outlaw anatomical parts. Note here that Garland-Thomson's title ("Shape Structures Story") refers not to the sovereign subject/body but rather to body parts/organs (the tongues) as an obscene excess (Bodies without Organs). This excess proliferates a plethora of erotic affects (story). Quite simply, what Garland-Thomson describes echoes Elizabeth Grosz's theorization of the "desiring machine" as one that "opposes the notion of unity or oneness ... [and] is fundamentally nomadic not teleological, meandering, creative, nonrepetitive, proliferative, unpredictable" (1994, 168).

The radical rewriting of "crip subjectivity" via the "desiring machine" is cause for celebration because it represents disability as erotic possibility, a far cry from normative ableist representations. Even so, it is with much trepidation that I resist the seductive power of the erotic immanent in this narrative. My unease does not arise because of the dissolution of the sovereign humanist subject. Rather, my enthusiasm is muted in the realization that such posthumanist "becomings" – into assemblages/desiring machines/erotic apparatuses – are presented as autonomous from the historical materialist conditions of social life. The critical significance I place on historical materialist conditions is necessary to foreground the social relations/encounters between bodies/subjects/organisms that occur in the fluid and always incomplete process of becoming-in-the-world. Here bodies/subjects/organisms encounter one another, often in violent collision. Accordingly, some dismemberments into the Body-without-Organs are not just discursive, but instead inform a brutal materiality that coheres with the hierarchical binary of Self/Other, separated and yet at the same time connected via the social relations of transnational capitalism. In this chapter, I consider the epistemological dilemmas inherent in conceptualizing anatomy as radical possibility and offer what I term "the political anatomy of the body." Rather than theorizing anatomy as natural/biological or as transgressively discursive, I argue instead for an analysis that situates anatomy and its posthumanist counterparts, assemblages, within the social relations of production and consumption of transnational capitalism. Specifically, I analyze disability not as anatomy gone awry, but instead as a historical materialist construct that supports both exploitative as well as productive notions of embodiment at the critical junctures of race, class, gender, and sexuality.

By engaging the "political anatomy of the body" in this chapter, I also bring to light a fraught connection between the rampant dominance of neoliberal ideologies and the posthumanist fragmentation of the anatomical subject. According to David Harvey (2007), neoliberalism is a theory of political economic practice that presumes that human well-being can best be advanced when all forms of solidarity

are dissolved in favor of temporary contractual relationships in the market place. Such relationships celebrate flexibility, private property, individualism and personal responsibility. Based presumably on humanitarian ideals of human dignity and individual freedom as central values of civilization, neoliberalism hails the market as the freest space to mediate all human relationships in that it encompasses greater geographical range within more flexible time-space contractions (Harvey 2007). This limitless characterization coincides with what Donna Haraway has previously termed "a polymorphous information system" (1990, 161). It is here then that posthumanist theories have an uncanny resemblance to neoliberal rhetoric by likewise celebrating fragmentation, flexibility, and freedom from the structural constraints of the social. I say this while recognizing that posthumanist theories are critical of the rights-based approach within liberal notions of humanitarianism that reproduce the oppressive aspects of the humanist subject. Posthumanist theories also reject the individualism inherent in neoliberal discourses for the relational notion of affect where "emotions align some bodies with others, as well as stick different figures together, by the way they move us" (Ahmed 2004, 195). Accordingly, Sara Ahmed describes emotion as a materialist construct that engages the very modes of being and in doing so becomes a critical site for potential social action.

On the one hand, I am admittedly skeptical of the alchemical potential of affect in face of the violent social relations of production and consumption that connect a Self/Other obfuscated by neoliberal ideologies fixed to unchecked exploitation within transnational capitalism. On the other hand, I argue for a transformative theory that critically engages the historical conditions and social relations within which bodies/subjects "become" disabled, raced, gendered, and/or queered. Here, posthumanism's desiring-machines cannot support the seamless horizontal current of flow between intercorporeal entities. Such entities, now interrupted by hierarchical social relationships wherein productive desire is constitutive of *some* bodies, engenders through consumption the seared, divided, ripped-apart, mutilated flesh of other bodies. Becoming-in-the-world correspondingly foregrounds a dialectical tension between the historical and the contemporary. It analogously considers conflicts between production and consumption, desire and need, continuities and discontinuities, and the conditions of possibility and the violence of its limits.

Set adjacent to the contemporary context of a posthumanist leftist politics, which is focused more on affect and instability, I may be accused of reintroducing a master narrative that renders difference unimaginable. However, my method is of unraveling. By evoking the metaphor of skeins, I consider a thread-bare pastiche of seemingly disconnected events/episodes/phenomena, whose frayed edges demand a closer reading of the historical continuities/discontinuities that connect them in a disorderly, desperate fashion. I hone in on those frayed edges wherein outlaw subjectivities are formed via random and local contexts of violence. In marking these continuities/discontinuities, I maintain that the violent social relations which have sustained a "long history" of the trafficking of organs/appendages produce disabled subjects at the intersections of race, gender, and

sexuality. To situate this analysis, I utilize three texts that make visible different phenomena, events, and social relations which cohere around the political anatomy of body parts (assemblages) and occur within the transnational contours of colonialism, postcolonialism, and neoliberalism: Hortense Spillers's *Mama's Baby, Papa's Maybe: An American Grammar Book* (1987), Nancy Schepper-Hughes's *Rotten trade: Millennial Capitalism, Human Values and Global Justice* (2003), and Margrit Shildrick's *Dangerous Discourses of Disability, Subjectivity and Sexuality* (2009).

### **The Political Anatomy of the Body**

I open with a discussion of "anatomy." Etymologically, "anatomy" was originally derived from the Greek word for "up" (*ana*) and "cut up" (*tome*). Our current knowledge of human anatomy is accordingly derived from not only the structure and form of biological organisms and their relationship to various organs (being), but also to the act of performing a detailed investigation of some phenomenon/organism (knowing/doing). Nevertheless, "anatomy" has come to encapsulate more than the physiological body and its associated organs. To illustrate, Michel Foucault (1977) describes the "political anatomy of the body" in reference to the "the mechanics of power" which produce subjected, practice and docile bodies. In contemporary posthumanist contexts, where subject-effects have replaced Enlightenment's sovereign subject, it would be more precise to claim that Bodies-without-Organs (BWO) have permeated transnational space. Deleuze and Guattari (1987) describe the BWO as displacing the organism (the humanist subject) in order to embrace "flows of intensity, their fluids, their fibers, their continuums and conjunctions of affects" (162). As such, the body-subject "becomes" an unstable assemblage – a collage of molecular effects that traverse the boundaries of human/non-human/machine – like Haraway's transgressive cyborg (1990).

These transgressive posthumanist discourses appear at first glance to be rife with unimaginable possibility for the disabled subject/body. In medico-scientific discourse, normative anatomy refers to a closed system of biological organization that disallows variances/vagaries/vulnerabilities (Garland-Thomson 2007). Therefore, disability in medico-scientific discourse represents an anatomy gone very wrong: structure and form do not adhere to normative standards and, more often than not, stubbornly resist correction via medical intervention. Relegated as the sovereign's much denigrated Other, the disabled subject becomes "an obscene excess" of molecular parts which weld human/non-human/machine together. This amalgamation underscores an uneasy temporal unity that simultaneously threatens dispersal into incoherent, disparate, and impermanent effects (Puar 2007). Refusing its historical association with lack, disability re-emerges as an outlaw ontology that challenges the oppressive wholeness of normativity by embodying Deleuze and Guattari's concept of the rhizome. As Petra Kupperts writes such categorization of disability "produces an abundance of meanings that do not juxtapose pain

and pleasure or pride and shame, but allow for an immanent transformation, a coming into being of a state of life in this world, one that is constantly shifting and productive of new subject/individual positions" (2009, 226).

Kuppers' radical conceptualization of disability as outlaw ontology deconstructs the sovereign subject and unhinges normative conceptions of the biological body/anatomy. However radical these possibilities may be, there remains a real danger in describing disabled bodies using such an extreme level of abstraction. What are the material implications when, as Karen Barad puts it, "matters of 'fact' are replaced by matters of signification (no scare quotes here)" (2003, 801)? According to Barad, matter does not appear to matter at all in social constructionist perspectives because representation overshadows the possibilities of a transgressive performativity. In fine-tuning and extending Judith Butler's theory of performativity to incorporate "material and discursive, social and scientific, human and non-human, and natural and cultural factors," Barad rescripts matter as an active agent (808) such that agency is not an attribute of the autonomous, humanist subject but instead reflects "the enactment of iterative changes to particular practices through the dynamics of intra-activity" (827). Barad names this analytic "agential realism" and extends performativity to include not just the discursive but also the material nature of social practices. Though Barad insists on a materiality that also includes the historical (in her hopes to exceed the stranglehold of language), her articulation of the historical remains in the discursive realm. Indeed, her notion of the historical continues to replace the social relations of class with the "technologies of signs and their concrete surfaces" (Ebert 2008, ix).

While Barad offers a compelling argument for how the body's materiality (anatomy and physiology) matter in the process of materialization, she fails to explain *why* matter matters in specific historical contexts. This question, "why," is also categorically dismissed within posthumanist discourses that attribute a linear cause/effect property to it. In contrast, posthumanist theorists embrace with much enthusiasm Deleuze and Guattari's claim that the "truth of the matter is that *social production is purely and simply desiring production itself under determinate conditions ... There is only desire and the social, and nothing else*" [emphasis in the text] (1987, 29). Rejecting the posthumanist accusation that asking the "why" question is inextricably linked to a reductive cause-effect relationship, I argue that "why" locates the desiring subject within the social relations of production and consumption in transnational capitalism. Thus, the analytic focus of this essay, in the reading of the three texts to follow, is on the historical conditions that locate the desiring assemblage/BWO within a web of complex and intersecting social relationships where membranes touch much more than just words, experiences, and concrete objects to include the market, exploitation, violence, and often death.

## Colonialism, Slavery, and Bodies-Without-Organs

Hortense Spillers's (1987) essay, "Mama's Baby, Papa's Maybe," locates the origins of African American subjectivity in the transatlantic slave trade which starts with the unimaginable violence during the Middle Passage. Spiller maps the continuation of such violence through the dehumanization of slavery; and finally concludes by deconstructing dominant conceptualizations of the contemporary "Black Family" as a tangle of pathology. Her analysis pierces the body to expose "the hieroglyphics of the flesh" whose "undecipherable markings" become the cornerstone of an American grammar that denies African Americans their respective subjectivities by making their bodies become "both the physical and biological expression of otherness" and "physically and generally powerless" (67).

Integral to Spillers' evaluation of black subjectivity is the deliberate and violent process by which the body is transformed into a commodity without gender, without genitalia, and without subjectivity. This commodification is so abject that it exists even outside kinship relations (the most fundamental of social units) such that its very aimlessness constitutes it as "an effective social and economic agent" (74). Analogously, within the specific transnational conditions of colonialism, the becoming of black disabled bodies is likewise an intercorporeal phenomenon that foregrounds a violent hierarchical context largely ignored by contemporary theorists. Here disability appears not just as physical variation nor as linguistic trope, but as the actual bloodied markings on the black body. Take for example William Goodell's account (quoted in Spillers's essay):

The smack of the whip is all day long in the ears of those who are on the plantation, or in the vicinity; and it is used with such dexterity and severity as not only to lacerate the skin, but to tear out small portions of the flesh at almost every stake (221). The anatomical specifications of rupture, of altered human tissue, take on the objective description of laboratory prose – eyes beaten out, arms, backs, skulls branded, a left jaw, a right ankle, punctured; teeth missing, as the calculated work of iron, whips, chains, knives, the canine patrol, the bullet (67).

While Spillers describes these markings on the flesh as "the concentration of ethnicity," I argue that these same markings on the flesh, quite simply, also produce impairment. Impairment in this sense is not just biological/natural; it is produced in a historical, social, and economic context wherein the very embodiment of blackness and disability "bears in person the marks of a cultural text whose inside has been turned outside" (67).

When the imbrication of blackness and disability produces violent markings on enslaved bodies, the assault on these subjectivities is even more profound. Take, for example, one historical account of the detailed specifications provided as instruction to the crew of one of the most famous ships associated with the Middle Passage (*The Brookes*) on how to most profitably cram its human cargo on board:

Let it now be supposed ... further, that every man slave is to be allowed six feet by one foot four inches for room, every woman five feet ten by one foot four, every boy five feet by one foot two, and every girl four feet six by one foot ... The owner of *The Brookes*, James Jones, had recommended that "five females be reckoned as four males, and three boys or girls as equal to two grown persons." (1987, 72)

As the above passage indicates, bodily boundaries collapse and collide, stretch and shrink. The categorical permeability of boundaries has scant regard for the sovereign subject, because complex computations of equivalency are not bound by bodily limits. It is impossible to praise the fragility, malleability, and instability of such bodily boundaries borne out of so much violence as either transgressive or transformative. More profoundly, the intercorporeal permeability between un-gendered, un-named, and un-remarkable bodies (except for their economic value as cargo) further erodes any form of subjectivity that these bodies could claim for themselves where the historical conditions of a nascent colonialist transnational expansion of capitalism responsible for this violent reconfiguration of the flesh. Thus, even though the deconstruction of the sovereign subject is cause for celebration, how does one celebrate in the face of so much violated and wounded flesh?

Taken together, the enslaved black disabled body, now un-gendered, with flesh fissured, and organs in disarray uneasily exists within a posthumanist analytic which conceives the BWO as "regimes of signs, flows of libidinal energy, coding" (Lecerle 2005, 42). In this context, the enslaved body becomes "the source of irresistible, destructive sensuality" and "a thing, becoming *being for* the captor" (67). This contradiction was enabled through the determined efforts of the master to intervene in the most intimate social relationships between his slaves – their kinship ties – by transforming them into an economic asset for profit. Because it was necessary that the children born to the slave mother would not belong to her but to the master who owned her, the formation of kinship ties between slaves was prohibited, instantiating complicated social arrangements to ensure that slaves were unable to sustain these ties. Patrimony, in particular, was frowned upon because the father figure (whether he was the slave owner or the male slave) could not/would not claim his children. These claims/non-claims enabled the possibility of inheritance (both economic and social) and added an unwanted complication to the economic enterprise of slavery that had by necessity to be erased. In sum, presumed unfit to uphold kinship relations via economic transaction, and granted a non-subjective status, African/American male slaves were transformed into impaired, un-gendered, and racialized Bodies-without-Organs.

Similarly, the erosion of enslaved African/American female subjectivity is illustrated in Spillers's work via *Incidents in the Life of a Slave Girl* (1973), an autobiography by Linda Brent/Harriet Jacobs. Located in a context where rape by the master was a normative experience for black female slaves, Brent describes a fraught relationship between herself and Mrs. Flint, her mistress. Suspecting that her husband was having sexual relations with his slave, Mrs. Flint, consumed with jealousy, would visit Brent at night time assuming the role of a ghost and attempt to

“ride” the victim “in order to exact confession, expiation, and anything else that the immaterial power might want” (Spillers 1987, 76). Spillers (1987) in this example alludes to a discourse of madness associated with each of the three protagonists: a) the “madness” of the master that “arises in the ecstasy of his unchecked power”; b) the “madness” of his wife who, through impersonating the sexual power of her husband, “attempts to inculcate his or her will into the vulnerable, supine body” of his slave; and c) the attempts by Mrs. Flint to convince Brent that these nightly visitations were the hallucinations of an immoral “mad” woman.

The articulation of desire – born out of violence, abuse, and hierarchy – underscores the degree to which intercorporeal intimacies traverse with impunity the boundaries of race, gender, and sexuality in a complex queering of outlaw (mad) desire. Significantly, the only who can enjoy the “freedom to experiment, explore, peek outside of the limits, journey there and back again” (Gibson 2006, 95) is the master, Dr. Flint. From a materialist perspective, the queering of this enslaved body occurs in specific historical context where femininity loses its sacredness at the precise moment when outlaw flesh becomes the primary commodity of exchange. Thus, Spillers’ essay marks how the imbrication of race and disability locked in an unending cycle of perpetual assemblage/disassemblage (disability) of the enslaved subject simultaneously also locates desire firmly within the social relations of production and consumption in the gratification of both profit and pleasure for the Master.

### **Assemblage as Commodity Fetish**

To read the enslaved dismembered bodies in Spillers’ essay via the concept of the assemblage brings to the fore a disorderly conflation of intermingled bodies which are themselves fragmented by frequent violent lashings (both real and metaphorical) into their molecular components. These assemblages enunciate the violence via shifting morphologies: they first become (human) cargo; they then assumed the registers of (human) property; last, but certainly not least, these enslaved figures finally emerge as the embodiment of dangerous deviance. Situated alongside histories of colonialism and slavery, such enunciations permit a further atomization that in turn instantiates a more thorough commodification that is intimately linked to medicine. To illustrate, an advertisement from the *Charleston Mercury* (dated 12 October 1838), announces the following:

To planters and others – Wanted, fifty Negroes, any person, having sick Negroes, considered incurable by their respective physicians, and wishing to dispose of them, Dr. S. will pay cash for Negroes affected with scrofula, or king’s evil, confirmed hypochondriasm, apoplexy, diseases of the liver, kidneys, spleen, stomach and intestines, bladder and its appendages, diarrhea, dysentery, etc. The highest *cash* price will be paid, on application as above, at No. 110 Church Street, Charleston. (Goodell quoted in Spillers 1987, 68)

According to Deleuze and Guattari, becoming-other is committed to unravelings, contingencies, fluidities, contradictions. In the above placed example, the constitutive effects of race, disability and the market coalesce to effectively unravel the boundaries between bodies/subjects and de-stabilize their internal organizations. Consequently, captive flesh is re-configured into its atomized constituents, and, in the process, enacts an objectification so complete that the "entire captive community becomes a living laboratory" (Spillers 1987, 68), Moreover, iterative inscriptions of disability as "abject," "useless eater," and "undue burden" are transformed so that (black) disabled fragmented bodies become highly valued commodities to be exchanged in the market by their masters for "the highest *cash* price."

Because assemblages "become" within the plane of immanence and are subject to the constant flux of reterritorialization and deterritorialization, it is difficult to mark continuities in different historical periods. However, an analysis that recognizes both the continuities and discontinuities between the black dismembered enslaved bodies in Spillers' essay and the contemporary practice of organ trafficking where the bodies of low-income white/people of color are also dismembered (now "voluntarily" however) into organs enables a productive reconsideration of transnational markets. While clearly, the historical context is radically different now, there are still continuities present within these seemingly discontinuous events/phenomena/effects. More significantly, a materialist reading of the political economy of "becoming disabled" illustrates how the discursive notion of the assemblage may actually enable the neoliberal mantra of uninhibited production/consumption in transnational markets

Nancy Scheper-Hughes (2003) essay, "Rotten Trade: Millennial Capitalism, Human Values and Global Justice in Organs Trafficking," graphically describes the gruesome context of advanced medical procedures and bio-technologies which have produced a new market for "skin, bone, blood, organs and tissue." These organs are mostly harvested from donors who are people of color living in economically depressed communities throughout the world. In this thriving market for Organs-Without-Bodies, Scheper-Hughes considers how the ideal conditions of an "open" market economy have thereby put into circulation "mortally sick bodies traveling in one direction and 'healthy' organs (encased in their human packages) in another direction, creating a bizarre 'kula ring' of international body trade" (197). If we conceive of these commodified organs as assemblages, then their radicalness lies in an extreme permeability across bodily boundaries. This permeability pays scant attention to the cultural, political, and social differences mediated at the intersections of race, class, gender, ethnicity, and sexuality. Scheper-Hughes explains how:

new forms of "social kinship" and biosociality are invented to link strangers, even political 'enemies' from distant locations, described by the operating surgeons as "a perfect match – like brothers," while the pair are normally prevented from seeing, let alone speaking, to each other ... . Who, for example, would

imagine that in the midst of the longstanding religious and ethnic hostilities and an almost genocidal war in the Middle East, one of the first “sources” of living donors for Israeli kidney transplant patients would be Palestinian guest workers, or that, as recently as March 2002, Israeli patients would be willing to travel to Istanbul to be transplanted in a private clinic by a Moslem surgeon who decorates his waiting room with photos of Ataturk and a plastic glass eye to ward off evil ... ? (200)

Clearly the radical potentiality of assemblages to promiscuously cross borders is potential cause for cosmopolitan celebration with regard to the formation of new hybrid subjectivities that have little allegiance to sociopolitical nations and sociocultural states. Even so, like Scheper-Hughes, I offer a word of caution: this transnational circulation of Organs-without-Bodies does not occur outside of class antagonisms and their corresponding social relationships that emerge within the historical conditions of transnational capitalism. Thus, for example, “becoming” an assemblage is also subject to the political economy of radical possibility as well as its oppressive and exploitative limits. In fact, as Scheper-Hughes has pointed out the vast majority of organ donors come from impoverished communities where access to health care and other basic necessities of life (materialism) is almost negligible. Moreover, just as in contexts of slavery, there is no dissolution of sovereign subjectivity because these bodies-as-assemblages have historically been conceived as outside of even the most liberal notions of humanness. As such the social relations/connections/collages that are intrinsic to the radical potential of the assemblage are dis/enabled by hierarchies that situate both “agency” and “becoming” within a brutal political economy where “a new form of globalized ‘apartheid medicine’ that privileges one class of patients, organ recipients, over another class of invisible and unrecognized ‘non-patients,’ about whom almost nothing is known” (199) and are allowed to proliferate with any critical interrogation.

Scheper-Hughes describes these new transplant transactions as a “strange blend of altruism and commerce; consent and coercion; gifts and theft; science and sorcery; care and human sacrifice” (199). While such economic transactions are very different from those I described in the previous section, given that these transactions occur in a “free” market rather than in a slave economy, they nevertheless transform Bodies-without-Organs and Organs-without-Bodies into mere commodities, now for the edification of neoliberal posthuman visions. Unfortunately, just like Spillers, Scheper-Hughes does not even once mention disability, even though disabled assemblages proliferate in organ trafficking. When organ harvesting occurs under medically unsafe conditions, bodies become disabled even while their own organs are bought in an attempt to make other bodies non-disabled. Here, again, disability is clearly not an attribute or thing but a “becoming” constituted by matter that moves between bodies with varied and unstable effects – another good example of the transgressive assemblage. However, it is important to remember that these becomings do not occur despite but actually

because of the ways in which the social relations of race/gender/sexuality are mediated via the class antagonisms of capitalism. Thus, it is here again that it is possible to map out both the continuities/discontinuities where racialized bodies become disabled bodies at the very moment when the flesh is transformed into a commodity fetish for lucrative profits within transnational capitalism.

How does one then theorize the assemblage as commodity? Can the fracturing of the body/subject be a cause for celebration, in this case? What relevance has the plane of immanence in the contexts of improper couplings between bodies mediated by the exploitative relationships of consumption and production? It is in light of these questions that Young (2009) is critical of the contemporary trend in cultural theory where post humanist scholars eschew metanarratives because he argues that these trends displace an historical understanding of class relations within contemporary transnational capitalism. In *Capital*, Volume 1, Marx explains:

The commodity is a mysterious thing, simply because in it the social character of men's labor appears to them as an objective character stamped upon the product of that labor; because the relationship of the producers to the sum total of their own labor is presented to them as a social relation, existing not between themselves, but between the products of their labor ... . There is a definite social relation between men, that assumes in their eyes, the fantastic form of a relation between things ... . This is what I call the Fetishism which attaches itself to the products of labor, so soon as they are produced as commodities, and which is therefore inseparable from the production of commodities. (Marx, et al. 1978, 320–21)

Thus, it is possible to see how becoming disabled is an historical event where disability also has a use-value that is deployed simultaneously with race to justify the creation of assemblages or Organs-without-Bodies. Moreover, I argue that it is the actual act of impairment that is used both to create and at the same time to justify this construction. However, by reading disability as "natural," rather than as an historical event, what is obscured are the social relationships that produce disability as lack. And so, I argue that the use-value of disability lies in its deployment as a commodity fetish in transnational capitalism.

### **The Political Economy of Affect**

Affect is yet another concept deployed in posthumanist discourses. According to Sara Ahmed (2004), in affective economies, "emotions *do things* [author's emphasis], and they align individuals with communities – or bodily space with social space – through the very intensity of their attachments" (119). Ahmed's definition enables recognition of disabled subjects as social subjects located within reciprocal relationships that bind them to other bodies, and that, in turn,

bind them to communities. This is because, according to Ahmed, emotions (affects) do not reside *in* bodies but *between* bodies. In other words, Ahmed's argument enables affective relations between assemblages that do not have to claim humanist notions of subjectivity.

While posthumanist theorizations of affective economies may be especially useful for theorizing reciprocal care-giving relationships among persons with severe/cognitive disabilities, they nevertheless conceive of such a relationship solely in metaphorical terms. In so doing, such an approach inadvertently eschews the materialist context within which these relationships occur.

Indeed, such a context is instrumental in determining the nature of the relationship between care-giver and care-recipient. To clarify, I draw on the work of feminist disability studies scholar, Margrit Shildrick (2009), who considers the intersectional feminist politics of care within transnational contexts within an affective economy. Shildrick stresses that her project does not so much highlight the social, political, and economic inequities of globalization as it critically and affectively engages globalization as "the experiential nature of living-in-the-world-with others" (149). While Shildrick recognizes the unequal yet paradoxically connective distances between the non-disabled Third World woman and her disabled First World counterpart, her focus is on the affective relationships that arise out of these intercorporeal associations, which she argues opens up spaces to re-imagine more ethical possibilities.

To illustrate, Shildrick shares a story about her partner, Janet Price, who requires a care-giver due to Multiple Sclerosis. Many of the care-givers in the agency that she employed were immigrant women, often refugees. Price celebrates these relationships, which affords her a distinct degree of intimacy:

One of the care workers, for example, a Sri Lankan woman, once asked whilst she was showering me, "Why don't you cut your pubic hair?" Although we were undoubtedly intimately connected intercorporeally – her hands on my naked body – her words had a profound effect, making me feel anxious and disturbed. What for me brought up questions of whether I would ever be able to be sexually active again, probably seemed to her – coming from a different cultural context – a straightforward query about the maintenance of bodily hygiene and propriety. For both of us the moment caught the strangeness of coming together, the instant at which self-familiarity is unsettled and opened up new modes of becoming otherwise. (as quoted in Shildrick 2009, 161–162)

Price's account makes visible the dilemma of difference that often rudely emerges in the intimate context of care. Expressly, the non-disabled care worker (a stranger), due to the intimacy of her labor, is enabled to ask a very personal question that causes the recipient (Price) much existential anxiety. Price is simultaneously aware that the intrusive question is actually a pragmatic one which concerns efficient care-giving. The care-giver's question and Price's reflection render clear an intercorporeal interaction which transforms them both. It is such becomings

that Shildrick argues can transform this intercorporeal (caring) relationship from oppressive labor into affective possibility.

I argue that Shildrick's argument inadvertently reproduces a neoliberal logic where bodies connect and disconnect at will, bound by fleeting affective relationships as they circulate in social space. She joins with Michael Hardt (1999) to locate caring work outside the exploitative logic of production and consumption by calling it immaterial/affective labor that is cooperative rather than exploitative. However, the continued existence of the racial and gendered division of labor in caring work disputes this claim. For example, Evelyn Nakano-Glenn (1992) and Grace Chang (2000) have described the exploitation of "disposable domestics" – women populating both the formal and informal economy in search of work, displaced from their homelands as a result of colonial and neocolonial legacies, and offered the only jobs that continue to be both gendered and raced, and, as a result, continue to remain low-waged jobs. That they live their lives in immense jeopardy as undocumented migrant workers, as a result of their non-recognition as citizens and as potentially disabled people as a result of real physical injuries that occur on the job is no cause for celebration. In fact, in many ways their experiences reflect the experiences of the slave women I began this essay with, whose *becomings* have always been mediated via the social constructs of race, gender, sexuality, and disability. Thus, as Silvia Federici (2008) has argued, introducing "affective labor" into this discussion transforms the necessary reproductive labor that women have historically done for centuries into a "labor of love" that exists outside capitalist relations. Here, Federici repeats the materialist feminist argument that "capitalism is built on an immense amount of unpaid labor, that is not built exclusively or primarily on contractual relations: that the wage relation hides the unpaid slave-like nature of so much of this work upon which capitalist accumulation is premised" (7). More specifically, Federici's argument also hints at how the notion of affect may, in fact, unwittingly, reproduce neoliberal ideologies that obscure the intrusion of market forces into the intimacy of everyday life.

But I want to take Federici's argument even further. Neither Federici nor Nakano-Glenn nor Grace nor most feminists have taken disability into account in their analyses. In fact, when feminists have engaged disability, disabled people are located mostly within the context of consumption and seldom if ever located within the context of production. However, if affect is located within the political economy of transnational capitalism, it would be possible to recognize the ways in which affective relations may uphold the oppressive logic of neoliberalism at the intersection of race, class, gender, disability, desire, and care.

## **Conclusion**

I began this chapter by celebrating the erotic power of anatomy (dancing tongues) unmoored from normative notions of subjectivity to dis-assemble into the the Body-without-Organs/Organs-without-Bodies. But as I have pointed out via the

three examples in this chapter, these posthumanist transgressions unwittingly echo the neoliberal logic where bodies are free to assemble/disassemble (becoming disabled) to form affective (partial/temporary) relationships that celebrate flexibility, desire, and freedom unmediated by the political economy of transnational capitalism. Moreover, I have also argued that the radical possibilities that inhere from transgressive formations of the erotic and unruly assemblage are dependent on the exploitative relations that forcibly disassemble/re-assemble (disability) Other Bodies-without-Organs/Organs-without-Bodies that serve as disposable commodities for the accumulation of profit for transnational capitalism. As such, I am arguing that by refusing a historical materialist analysis of affective relations, we may too easily miss how “becoming disabled” (assemblage/BWO/OWB) could be “too obviously [committed] to administer to the [masters] own lusts, and make a gratification of their wicked desires profitable as well as pleasurable” (Spillers 1987, 76). At the same time, resisting the association of disability with lack, I argue that disability as erotic desire can only be enabled under conditions that refuse the neoliberal logic that celebrates fragmentation, flexibility and freedom from the structural constraints of the social (desire). Failure to do so would make even the radical project of posthumanism an alibi for neoliberalism.

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