

Chapter 2

Disability and Global Health

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The World Report on Disability published in 2011 by the World Health Organization and the World Bank, amassed a wide range of evidence that, across the globe, people with disabilities have poorer access to health care and poorer health outcomes than nondisabled people. The disparities are especially great in low-income contexts, within which most people in the world find themselves. The disparities relate to almost every aspect of health and health care. Here is a nonexhaustive list, adapted from the World Report, detailing some of these discrepancies:

- People with disabilities are more likely than others to be the targets of violence and hence of intentional injury.
- Rates of nonintentional injuries among people with disabilities are also greater than among others. For example, burns in infancy, which are almost nonexistent in wealthy countries but not uncommon in lower income countries (Frenkel 2002), may occur more commonly among disabled as opposed to nondisabled children.
- People with disabilities have a greater risk of premature death than nondisabled people. In wealthier countries, the life span for many disabled people has increased; this change appears not to be as strong in low- and middle-income countries.
- People with disabilities are more likely not to receive the health care that they seek (across the spectrum of curative, preventive and promotive services); these gaps appear to be greater in low- and middle-income countries.

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- People with disabilities may experience particular barriers to sexual and reproductive health services, partly because of myths about disabled people's asexuality or hypersexuality.
- In the global South people with disabilities may be at greater risk of HIV infection than others, with reduced access to care and support services (see Groce et al. 2013).

These are just a few examples of a pervasive problem. Even at the level of health policies, people with disabilities are commonly excluded or hardly mentioned, as recent analyses of such policies in some low- and middle-income countries have shown (MacLachlan et al. 2012).

It is well established that poor health globally is associated with less access to resources, and that where the rates of illness are highest, the care resources are fewest (Benatar 2013). Public health, furthermore, focuses on the health of populations as a whole and it could be argued that a focus on particular needs, such as those of people with disabilities, would be inequitable because of an implicit assumption among public health practitioners that it is more expensive and time consuming to treat such people. This argument has deep roots, but any reluctance to engage with particular challenges faced by people with disabilities in terms of health, in our view, links to a number of unacceptable prejudices. Chief among these is the belief that disability and impairment are far rarer than they actually are. The WHO's latest estimate is that there are over a billion people with disabilities globally, of whom between 110 million and 190 million experience substantial difficulties (WHO and World Bank 2011). Even if this estimate, which corresponds to about 15 per cent of the world's population having disabilities, can be questioned on a range of methodological grounds, what is clear is that disability is frequently underestimated and therefore radically misunderstood. This underestimation in itself is a political act, an act of misrecognition, even in the field of global health which is centrally concerned with issues of social justice. There is urgent need for good-quality global data comparing access to adequate health care and rehabilitation services for disabled as opposed to nondisabled people, but indications are that disability is associated with compromised health-care access (WHO and World Bank 2011).

A central problem in the field of global health is simply the silence around disability in health policies at local and global levels (MacLachlan et al. 2012; Mannan et al. 2012). As a result, some of the interventions regarding disability and health occur, as they should, at the level of rather basic awareness raising, but fail to move much beyond this. Much of the work in the field is descriptive, demonstrating the issues and the problems, and the World Report summarizes this information well. However, as the report is dependent on existing data, it does not go far beyond this descriptive level. There are rather few reports of evaluated interventions regarding disability and global health. The burgeoning field of global mental health has established a corpus of randomized controlled trials which attempt to assist people with psychosocial disabilities (Patel et al. 2013), but this field is still rather young and the conceptual framework of global mental health is hotly contested (Swartz 2012; see also the chapter by Mills and Davar (2016) in this volume, which takes a critical look at the rapidly developing global mental health field).

In this chapter we seek to identify core conceptual and ideological issues that are crucial for understanding disability in relation to global health but which are under-theorized. We will not review all the work that has been done in the field of global health, but will raise some conceptual and political issues which need to be considered by those interested in disability and health worldwide. We begin our argument by sketching some critical issues surrounding how we think about disability, health and power as they affect the global South. Following this, we focus on disability and health as social issues. This leads to a discussion of the ethics of distribution and exclusion. We then consider what it may mean to rethink global health from a disability perspective, and the implications of this thinking for processes of transformation in global health.

Power, Disability, and Global Health: Some Critical Issues

Just as there are established associations between poverty and poorer health outcomes, so there are associations between disability and poverty. There are higher rates of disability in poor populations, and disability itself can lead to impoverishment through a range of pathways, including decreased access to education and employment. In contexts where resources are scarce, it falls on family members to care for disabled relatives and as a result these family members may have reduced opportunity to work or to seek health care. The relationship between disability, poverty, and ill health is complex and multidirectional, and any attempts to change the situation will need to take account of this complexity. As Meekosha and Soldatic (2011) demonstrate, to separate health or disability from a range of other social issues related to global imbalances in wealth and power would be a disservice to our understanding of these interrelated issues. Indeed, questions of global justice and rights cannot be fully addressed without considering the bodies and embodied experiences of those on whom global forces of inequality operate, and operate with the most profound consequences (Grech 2009, 2011; Soldatic 2013; Soldatic and Grech 2014). In very many cases, impairments, like ill health, do not just ‘happen’—they are the consequence of social and political arrangements. And the consequences of impairment and ill health are equally socially mediated.

The imposition of power from the global North may appear abstract, but is experienced viscerally by bodies (Meekosha 2011). Nixon (2011), in relation to environmental issues, speaks of ‘slow violence’ against the poor in the global South. This is a useful concept. Historically, overt and easily identifiable violence, including killing, was a well-known feature of colonial regimes; current relationships of power have consequences for bodies even if the pathways are commonly obscured (Grech 2012). Knowledge from the global North about the colonized body, especially the ‘deviant’ or non-normative colonized body, had and continue to have profound consequences for people’s experiences of their lives, and indeed of their own bodies (Mashingaidze 2010). Nowhere is the entanglement between ideas about disability, health, and political deviance more clear than in the history of Robben Island, off

Cape Town, South Africa. This island once housed an asylum for people known as “lepers,” “lunatics,” “feeble minded,” and “insane,” but became far better known as the place where political prisoners opposed to the apartheid regime, including Nelson Mandela, were incarcerated (Deacon 1995; Swartz 2010). There are also links between dominant ideas about race and dangerous sexuality, and ideas about disability and dangerous sexuality. Some of the myths and fears held in the global North about hypersexuality of people with disabilities, and the potential that people with disabilities may have to spread sexually transmitted diseases, are very similar to anxieties about the bodies of black colonized people (Butchart 1998; Frawley 2012; Hook 2012; Shakespeare 2013a; Rohleder et al. 2014).

Disability and Health as Social Issues

At the heart of much of the success of disability movements since the 1960s has been the recognition that disability and ill health are not the same thing. Historically, the field of disability has been seen as falling under the remit of medicine and health care, with medical professionals viewed as experts on people with disabilities and their lives. The social model of disability questioned this medical expertise and, along with other liberation movements, has championed the idea of the insider as the true expert. Disability came to be seen as a political and rights issue as opposed to a medical issue. Thomas (2007, 2012) has shown clearly how both disability and health issues need to be looked at in social terms, as issues intertwined with realities of inequality and intolerance of diversity. She notes further that there are intersectionalities, both between disability and health status, and between these issues and others, which would include gender, race, social class, and sexual orientation, for example. It is not possible, furthermore, to provide practical skills for health professionals on issues regarding health care for people with disabilities without basing these skills in a social analysis. Many of the practical challenges in relation to health care for disability rest on patterns of misrecognition and on health professionals simply not thinking about people with disabilities as mainstream health-care users (Shakespeare and Kleine 2013).

It is important to take these issues further in the global health context. Struggles against the “medical model” within the disability arena have a parallel within the global health movement. The famous Alma-Ata Declaration of the World Health Organization of 1978 defines health as “a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity.” Health is viewed as “a fundamental human right” and “the attainment of the highest possible level of health is a most important world-wide social goal whose realization requires the action of many other social and economic sectors in addition to the health sector” (WHO 1978: para. 2). The Alma-Ata Declaration states further:

The existing gross inequality in the health status of the people particularly between developed and developing countries as well as within countries is politically, socially and economically unacceptable and is, therefore, of common concern to all countries. (WHO 1978: para. 3)

The recognition that health is a sociopolitical and human rights issue has, if anything, become clearer since 1978 (Goldberg 2013). The world has faced and continues to face sociopolitical and economic obstacles in the fight against communicable diseases, notably HIV/AIDS, tuberculosis, and malaria (Remais et al. 2013), and in dealing with an increasing number of people living with noncommunicable diseases including those of lifestyle, such as hypertension and diabetes (Ebrahim et al. 2013), and those associated with ageing, such as the dramatic rise in the number of people living with dementia worldwide, and especially in lower income countries (Prince et al. 2013). The recognition of the sociopolitical embeddedness of health and disease issues, therefore, is not something which is unknown in the global health field—it forms the bedrock of developments in health care and policy affecting most of the world’s inhabitants. It is certainly true to say that there are huge commercial interests at play in how health care travels through the world, with health care increasingly viewed as a commodity which only the rich can afford (Pellegrino 1999; Maketa et al. 2013; Phadke 2013). This is of course a product of the global privatization and commodification of health care in a neoliberal, market-oriented context (Coburn 2000; Horton et al. 2014). Many contemporary global health efforts recognize the centrality of acting on the social determinants of health to achieve health care globally (Marmot et al. 2008).

The global health system, functioning within a global economic system dominated by neoliberal policies, has found profit through marketing technological and pharmacological products, developed with expertise in the global North, to people in the global South (see, for example, Petryna et al. 2006; Towghi 2014). The sociopolitical problem of inadequate health-care systems can in this way be presented as “solved” or at least mitigated by the apparently global technical pharmaceutical fix, an issue which is dealt with more fully by Mills and Davar (2016) in relation to global psychopharmacology.

These analyses from the anthropology of global health may seem to be worlds away from discussions in disability studies, but they are instructive and add a dimension which is crucial to understanding the intersections between disability and global health. We suggested earlier that critiques of the “medical model” in mainstream disability studies echo similar critiques from a global health perspective of a particular manifestation of medical discourse and practice—in short, if the medical model is bad for disability, it is equally bad for global health. The examination of commodified global health practices takes the argument further though. Just as a narrow technicist approach to health care can be used to obscure the socially embedded nature of health and health care, it may also obscure the socially embedded nature of disability. For example, the “Joint position paper on the provision of mobility devices in less resourced settings” prepared by WHO and USAID (2011), notes that assistive devices for mobility are not sufficiently available in low-income contexts. Furthermore, where these devices are available, there are no trained personnel to assist users and potential users of them. Devices may also be inappropriate to the terrain in some cases. Two potential consequences of this situation are, first of all, that wheelchairs and similar devices, even when available, may be underutilized (indeed the sight of unused or broken wheelchairs is common in health facilities in low-income contexts); and second,

the devices themselves may cause health problems. For example, badly fitting wheelchairs and prostheses may lead to pressure sores which, if not properly treated, may lead to death (Chalklen et al. 2006).

Visagie, Scheffler, and Schneider add a further layer to this discussion. In their study of wheelchair provision by health-care personnel in a rural setting in South Africa, they found that “only persons with a better prognosis were referred for wheelchairs, whereas those with poorer prognoses or lower levels of functioning were not referred” (Visagie et al. 2013: 3). Though these practices, as the authors point out, were not sanctioned by formal rules or policies, they expose some of the value issues which may influence decisions made by health-care providers under conditions of constrained resources. There is an implicit assessment here regarding which lives are more valuable and more worth supporting.

It is easy in a context such as this to condemn the behavior of health-care personnel making such choices, and we do not wish to suggest that the choices are correct. In the section which follows, however, we explore the need for a perspective on ethics as it affects both global health and disability issues.

Ethics of Distribution and Exclusion

As we have mentioned, the global maldistribution of resources and opportunities affects both health status and disability, and there are indications that inequality may increase in the future (Benatar et al. 2003; Benatar 2013). In addition, catastrophes, disasters, and global climate change pose major threats both to public health and to the participation of people with disabilities in society at large (McMichael 2013). Though there is now a burgeoning literature on disability, disasters and climate change, and health issues (Mitchell and Karr 2014), it remains the case that the particular vulnerability of people with disabilities in the global South to the health effects of climate change and disasters is not always considered. In an excellent recent review, McMichael (2013) highlights how vulnerability is repeatedly mentioned in relation to poverty, and at times in relation to what may be termed psychosocial disability issues, but disability as a whole is not given full attention. It is probably not surprising that given the scale of environmental threats to the world, some anthropologists of global health have written:

Although global health conceptually includes all peoples regardless of social, economic, and political contexts, its ethical and moral commitment is to the most vulnerable. However, and given the impending and hitherto unprecedented scale of global catastrophe that environmental destruction, mass species extinction, and anthropogenic climate change presage, global health might benefit from redefining the vulnerable to include all of us. (Janes and Corbett 2009: 169)

Though they note the issue of particular vulnerabilities, these authors are correct in stating that all people are vulnerable to the health effects of environmental catastrophe. The strong probability is that all the issues well known to affect health and health care for people with disabilities—including access to health care, physical

and attitudinal barriers, and secondary health complications through lack of management or mismanagement of impairments—are likely to be increased under times of social strain, social instability, and resource constraints. Indeed, within the Nazi system’s abuse of concepts of public health to justify genocide, part of the reason given for murdering people with disabilities was on the grounds that scarce resources in times of war should not be squandered on people deemed economically unproductive (Evans 2010).

Rethinking Global Health from a Disability Activism Perspective

Let us return now to the Alma-Ata Declaration, which defined health as “a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity” (WHO 1978: para. 2). If we examine this definition wearing a disability activism lens, we are forced to confront the implication of the phrase “not merely the absence of disease or infirmity.” Here, the “absence of disease or infirmity” is positioned as a necessary, though not sufficient, condition for health. It is not altogether clear what the WHO means by “infirmity” and the term seems to be taken for granted as self-explanatory in much writing about global health. Indeed, in a recent thoughtful article on the need for changing paradigms in the global health context, Bhatia and Rifkin repeatedly mention what they term “control of disease and infirmities” (2013: 460). These authors, in keeping with developments in how health and health care are understood, are critical of the dominance of reference to biomedical approaches to “control” disease and infirmity, and they correctly point out that the determinants of health, and hence key solutions to health problems, are sociopolitical and economic. But, along with many other authors, they do not question the idea that “infirmity,” like “disease,” needs to be controlled. Dictionary and commonsense definitions of “infirmity” suggest an overlap with the term “impairment” as used in the disability context. And many of the struggles in the disability movement have been precisely against the idea that impairment should be controlled—or even be thought of as being controlled—in a similar way to how we think about controlling disease (Oliver 1998; Nussbaum 2007). Looked at this way, quite apart from any other problem with the Alma-Ata Declaration and how it has come to be used, it is possible to see an element of disablism built into the very definition of health. By definition, a person with an impairment (“infirmity”) cannot be seen to be healthy. This bias in the definition of health can be argued to be unintentional or even unconscious, and there are many in the global health field who would probably be offended by the accusation of disablism. But new developments in disability studies and especially in the contemporary application of psychoanalytic insights to understanding disablism (Watermeyer 2013) would argue that it is precisely these unconscious, unexpressed biases—these silences—which hold power to continue to exclude and oppress people with disabilities. The unexpressed and unacknowledged is much more difficult to deal with than is the overt expression of hostility or exclusion.

It has become increasingly clear that the Alma-Ata definition of health, which forms the bedrock of much global health policy and practice, has its limitations, partly because of an implicit bias towards biomedical solutions, as Bhatia and Rifkin (2013) suggest. Furthermore, as Huber et al. (2011) propose, the very notion of “control” of disease or infirmity may be inappropriate in a contemporary context, and may in fact always have been inappropriate. They go on to note how the focus and goals of global health should not be about eliminating disease or infirmity, but about the opportunities and capacities people have to manage themselves and their health in their specific contexts. This goal of self-management is not without its critics, including those linking it to neoliberal ideologies, that is, “responsibilization” or the idea that the individual is responsible for his/her health despite the fact that drivers of health conditions are sociopolitical and economic (see, for example, Ellison 2014; Foley 2009). Nevertheless, the core idea here of appropriate adaptation to context will be familiar to anyone working in the field of disability. This does not mean that the context itself should not be interrogated and changed, but rather that the principle of contextuality, of living with impairment or with illness, represents an attack on conventional notions of biomedicine as a universal source of cure. This attack, coming as it now does from the field of global health, has clear resonance with the attacks on the “medical model” in disability studies. Consider a recent contribution by a medical sociologist discussing the goal of research in the global health field:

Medical and public health interventions come with promises of relieving the burden of suffering, curing disease, enhancing wellbeing, preventing the onset of disability, and—the ultimate trump card—saving lives. The underlying notion is that much contemporary disease causes unnecessary pain and anguish, which can be effectively avoided or manipulated with public health interventions such as screening or vaccination campaigns and biomedical treatments. These promises are tied into regulatory, organizational, and behavioral scripts ... Inevitably, however, such scripts underestimate the complexity of the social world and unintended consequences multiply. Hence, the reality of health workers and patients no longer matches the promises, requiring remediation work to realign interventions and expectations. (Timmermans 2013: 3)

This quote could be edited with the change of only a few words to reflect long-standing concerns in the disability field. Once again, the goal of preventing disability is presented with what may be regarded by readers familiar with disability studies as a degree of naïveté, given the complexity and ferocity of debates about preventing disability (Shakespeare 2013b). Clearly, there is a great deal of synergy between contemporary thinking in global health and disability studies, but it appears that the contribution of disability studies thinking to global health has not yet been optimized. The questions at the interface between global health and disability should, perhaps, not just be “How can disability issues be better integrated and taken seriously in global health programs?” but also “How can global health learn from disability research and activism?” It is with some suggestions regarding this latter question that we conclude this chapter.

Transforming Global Health Through Disability Thinking

In his work on issues of disability and the global South, Grech (2009, 2011) notes that the gaze of disciplines constructed in the colonizing world has been brought to bear as a form of expertise ostensibly to “solve” problems of the global South but also as a form of disciplinary control. Max-Neef (2005), furthermore, notes that the huge problems of the world, including those of poverty, environmental degradation, and issues of health, cannot be solved by disciplines working alone but require a broader, transdisciplinary perspective. In this regard, disability studies, which by its nature should be interdisciplinary (and questioning of the boundaries between disciplines), have much to offer global health.

MacLachlan et al. (2012) propose that for global health to be truly inclusive, the needs of people with disabilities must be taken into account. The mechanism by which this is proposed, though, is not primarily through new technologies or products, but rather through processes of care (MacLachlan 2009). There are many specific issues to consider, including the complexities of community-based rehabilitation (see Kuipers and Sabuni (2016) in this volume; Mannan and MacLachlan 2013), but underpinning all the practical steps and programs which need to be considered is an orientation towards creating and sustaining supportive networks for people through their lives. This emphasis is very different from seeing global health as being solely about the elimination of disease and/or impairment.

African thinking on disability has emphasized the importance of interrelatedness of people within the contexts in which they live (Mji et al. 2011; Owusu-Ansah and Mji 2013). Ideas about independence as a goal for people with disabilities are questioned in an African context in which mutuality and supportive networks are considered to be what make people human (Owusu-Ansah and Mji 2013). It is no coincidence that ideals of independence are associated with ways of thinking which tend to be dismissive of a range of indigenous practices, including practices related to how people live their lives in the context of disability and ill health. These indigenous practices, which are commonly community based and dependent on social networks, constitute an obvious challenge to views of global health as a set of discrete technological challenges which can be solved by the export of technologies and products developed in the global North (Smith 1999; Farmer 2003).

Conclusion

The idea that humanness is best understood in the ways in which all people depend on and are responsible for others has resonance with research into the ethics of care. In the field of disability, Kittay (2013) has shown how care for a person with a severe impairment is not only worth doing but also part of being human. Tronto (2010, 2013), along with Kittay, notes that foregrounding the work of care requires a new kind of politics—a politics which recognizes and even values vulnerability, and which

makes care work visible. It is a truism that throughout the world, most health care, as well as most care for people with disabilities, occurs in private domestic spaces and not as part of large-scale formal interventions. The substantial literature that is now available on the lives of people with disabilities, including the burgeoning corpus of disability life writing (Couser 1997, 2004, 2012), attests powerfully to this fact. Disability studies not only emphasize the social and political determinants of both disablement and health problems, but also suggest a way of approaching global health challenges. This is by understanding interrelatedness, respecting and supporting empowering social practices, building solidarity, and creating a society which allows for and supports a range of bodies. If, in a disability study paradigm, the “medical model” was historically part of what has been termed “enforcing normalcy” (Davis 1995), then disability studies have much to offer global health. A key challenge is for people who work in the area of disability, especially in the global South, to help global health as a paradigm, or a set of paradigms, begin to question the “normalizing” assumptions of current health practices. True inclusion in global health is less about reaching common, taken-for-granted health goals than it is about supporting people through their lives, and in the varied contexts within which they live.

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Grech, S.; Soldatic, K. (Eds.)

2016, XXVIII, 613 p. 14 illus., Hardcover

ISBN: 978-3-319-42486-6