

EMBODIED INEQUALITIES

IN DISABILITY AND
DEVELOPMENT

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Concluding Remarks: The six A's for understanding disability and development from the perspective of embodied inequalities

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1. EMBODIED INEQUALITIES AS NEW PERSPECTIVES IN DEVELOPMENT

Disability has finally been recognised as both a human rights and development issue at the international policy level, as the CRPD has exemplified. Consequently, disability-specific policies and practices have increased over recent decades, although disability inclusion in the existing mainstream frameworks and practices has not been straightforward. Despite the disability inclusion methodologies applied by the development actors in this book, structural, institutional and systematic as well as personal challenges still exist that make disability inclusion very difficult in practice across different sectors and geographical contexts.

All the book chapters consistently verify that multiple layers of inequalities are embodied in the lives and experiences of persons with disabilities. The right to decent work continues to be hard to attain in global South contexts such as Tanzania (Chapter 6), Sierra Leone (Chapter 7), Ethiopia and Zambia (Chapter 8). Disability-specific interventions have, to a certain extent, had a positive impact and increased the business skills and opportunities of the studied groups of people and individuals (Chapters 6, 7, and 8). However, as long as the free-market economy forces all actors to compete (*equal treatment*), their individual and collective vulnerability affects their *equal opportunities*. At the other end of the spectrum, persons without disabilities also experience embodied inequalities pertaining to disability, which continuously require them to reinforce their attitude towards persons with disabilities if they do not pay careful attention (Chapter 3).

Institutional and structural barriers in terms of policies and laws were also addressed in Chapter 6 related to the Tanzanian legal infrastructure for employment, and in Chapter 4 on sexual and reproductive health rights (SRHR) in Mozambique. Such institutional and thus systemic barriers collectively affect persons with disabilities. As long as legal and policy frameworks remain conventional in understanding disability merely as a medical issue by ignoring the agency of persons with disabilities, these persons tend to be left on

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the periphery of society, as in the case of Mozambique. The same results are achieved when the awareness of existing laws and the policies of rights-holders (as well as duty-bearers) is limited, even when existing laws and policies are relatively progressive, as in Tanzania (Chapter 6).

In addition, attitudinal barriers against persons with disabilities in terms of stigma and discrimination are deeply rooted in society, which is a major obstacle to being part of society (all chapters). The menstrual pain experiences of young Tanzanian females with disabilities eloquently reveal the embodiment of multi-layered inequalities related not only to disability but also to gender and age in the framework of social and cultural norms (Chapter 2). The pain-centred approach unveiled both individual and collective vulnerability (see Heikkilä et al. 2020) due to the intertwined effects of multi-layered inequalities. When the socially constructed normality imposes the assumption that women are healthy and always handle household chores well, young females with disabilities who undergo severe menstrual pain collectively experience agony trying to fit the image of norms and cultural expectations. Accessibility to painkillers further normalises the gender role, even during menstruation, as painkillers are too often inaccessible and unaffordable for the young females with disabilities studied. Thus, Western medicine and coloniality also add a layer to this complexity of inequalities in the global South (Chapter 2). In addition, menstrual pain may be even harder for some individuals than others due to combined effects with their impairments. As a result, these collective and individual embodied inequalities have greatly influenced the psycho-emotional wellbeing of persons with disabilities and their agency, in which they feel inferior to others. This internalised oppression (see Katsui, 2005) further reinforces their lower social status in comparison to others without disabilities and thus perpetuates the deeply embedded social and cultural stigma.

Moreover, globally persons with disabilities struggle to be recognised and seen. ‘Who counts?’ is a fundamental question related to embodied inequality (Chapter 3; Kittay, 2019). As has been demonstrated throughout this book, structural issues perpetuate inequalities and may enable abandonment of persons with disabilities. This is visible in tragedies like failed deinstitutionalisation in Esidimeni (Chapter 3), nuclear disasters (Chapter 5) or during global pandemics. However, the significance of the social and cultural norms around who is recognised as a person should not be undermined as they greatly contribute to embodied inequalities (Chapter 2, Chapter 3, and Chapter 6).

The lens of disability and development, and more precisely the perspective of embodied inequality, offers alternative ways in which to comprehend our ‘normality’, as until now, the notion of normality has excluded persons with disabilities and their perspectives (see Barton, 1993), particularly those in the global South. When society is not inclusive to start with, persons with disabilities are even more excluded and their inequalities multiplied in emergency situations such as nuclear disasters (Chapter 5) and climate change (Chapter 1). In times of crisis, persons with disabilities are disproportionately affected. Many crises such as Hurricane Katrina and the Fukushima nuclear disaster have repeatedly revealed society’s fragility and unpreparedness to be inclusive (Chapter 5). Similarly, when disability continues to be targeted as a mere object and not mainstreamed with agency secured for persons with disabilities, many sectors lack implementation modalities of disability inclusion in practice. For instance, climate change has been a universal challenge, and

its impact has already been disproportionate on groups in vulnerable situations in Nepal and elsewhere (Chapter 1). The COVID-19 pandemic has made the inequalities even more visible; many persons with disabilities, particularly those in the global South, have been the first to lose their jobs and be cut off from indispensable social services, and the last to receive information on prevention measures, if at all (see United Nations, 2020).

The chapters in this book show that *equal opportunities* require reasonable accommodation (Article 2 of CRPD) due to such embodied inequalities (see also Heikkilä et al., 2020). Yet the private sector and many other sectors have no exceptional rules for persons with disabilities. The current global system and rules are largely based on ableism (UN Special Rapporteur on the rights of persons with disabilities, 2020). As a result, many persons with disabilities disproportionately continue to be left out due to embodied inequalities. Non-provision of reasonable accommodation is a violation of human rights, as stipulated in the CRPD. Nevertheless, this is still widely misunderstood by too many stakeholders of the current global system. This is one of the main points in this book that we have tried to make clear through local evidence and the lived experiences of embodied inequalities.

2. EMBODIED EQUALITY AND THE ROLE OF DECOLONIALITY IN DEVELOPMENT PRACTICE

By bringing together contributors from the interface of development and disability and through the collaborative insights from the NGOs, this book clearly and widely demonstrates the challenges and grassroots realities of inclusive societies. It consistently indicates that it is high time for our society to think and act in an alternative way in terms of a disability-inclusive society, both locally and globally. The chapters of this book suggest that embodied equality is realised through discourse, material means, contextually and structurally (Chapter 1) and requires the formulation of alternative methodologies such as applying decolonial lenses, as suggested in Chapters 2 and 8.

Pertaining to embodied equality in the global South, applying decolonial lenses would entail development practice that disrupts, for instance, the site of *coloniality of knowledge* to enhance full social inclusion of persons with disabilities (see Behari-Leak & Mokou, 2019). The perceived superiority of Eurocentric culture and universality of its knowledge is still largely present in the development practice. The full acknowledgement of persons with disabilities in the global South as knowledge producers is one of the first steps towards disrupting coloniality of knowledge. Local and personal accounts of disability, or the embodied knowledge of persons with disabilities, is a vital resource for understanding disability and development.

As suggested in Chapter 8, NGOs and other development actors need to reflect more critically on their own works and apply decolonial lenses to their work. This would mean stronger engagement in decolonial dialogues and thereby in the development of new practices and methods that draw from intellectual, social and cultural resources of Southern contexts. It is time to move beyond focusing only on what disability inclusion in the global South is not and move away from reinforcing colonial relationships.

3. TOWARDS EMBODIED EQUALITY

The next question is how to implement this idea of embodied equality in practice through the perspectives of disability and development. Based on the rich empirical data and analysis of the chapters in this book, we would like to propose the following six A's as strategies: availability, accessibility, affordability, assistance, accountability, and affection.

3.1 Availability

The selected case studies found that fundamental rights are often not secured or available to persons with disabilities in the global South. Their profound lack of education (Mizunoya, Mitra and Yamasaki, 2016; WHO and the World Bank, 2011), combined with the regular hindrance of menstruation among girls (Chapter 2), results in a huge inequality of opportunity. In many cases, lack of education and illiteracy means that these people have extremely limited employment opportunities. Equal opportunities are not frequently attainable for persons with disabilities (Meekosha, 2008, 2011; Reed-Sondaval & Sirvent, 2019), even in peaceful times, and they deteriorate even further in crises and disaster situations (Chapters 1, 3 and 5). Opportunities need to be available to persons with disabilities on an equal basis to others. For this to happen, reasonable accommodation and affirmative action is needed, and the most basic services and opportunities must be available. Far too often, stigma and prejudice hinder these people from equal opportunities. This conversely means that their psycho-emotional wellbeing also hinders them from taking active agency in their decision-making for grasping equal opportunities, as they have been made passive by limited opportunities. Furthermore, the diversity among persons with disabilities needs more acknowledgement, so that those with profound intellectual and multiple disabilities are not excluded. We shall come back to this point under Assistance.

3.2. Affordability

Even when services and opportunities are available, many persons with disabilities cannot afford them. Where assistive devices, medicines or other technological advances exist, they are too expensive and remain the privilege of only richer groups of people both locally and globally. Persons with disabilities are not always poor, and some of them adjust well to the current systems. Nevertheless, too often they are poor, as this book chapters exemplified. Persons with disabilities need more resources for the same opportunities due to their impairment-related needs such as medications, additional transportation costs and assistance (see Sen, 1999, 2005; Nussbaum, 2003). Amartya Sen focused particularly on the poverty situation at the starting point and introduced the capability approach, which elaborated on the different capabilities that people have. Households with family members with disabilities tend to be bigger, as more family members are more likely to be needed for the caregiving roles. As a result, these families have more mouths to feed (Eide et al., 2011). In this way, whole households are affected by disability; not only socially in terms of stigma but also economically. Therefore, affordability is an essential aspect to take into account.

3.3. Accessibility

Even when services and opportunities are available and affordable, many persons with disabilities cannot enjoy them if they are inaccessible. More precisely, when these services are physically inaccessible to persons with physical disabilities, and information-wise inaccessible to those with sensory disabilities as well as those with intellectual disabilities, for instance, these people cannot enjoy them on an equal basis with others. The one-size-fits-all approach, based on assumed normality, excludes not only persons with disabilities but also many other people who do not fit the norm, such as adolescents, pregnant women, older people, mothers with babies and many who belong to several of these categories. Universal design and means of reasonable accommodation are central for securing accessibility for persons with diverse disabilities, and would benefit not only persons with disabilities but many others.

3.4. Accountability

The aforementioned three A's have been acknowledged (e.g. WHO and OHCHR, undated; Lecovich and Carmel, 2009). However, if there is no mechanism for accountability or for monitoring and evaluation, they continue to remain voluntary goals and aspirations that can only be implemented when the demands of rights-holders, political will and resources are in place. There is an observed imbalance among these three, as a result of which organic change has too frequently not taken place. This is fortified by the trend of the shrinking space of civil society in many countries of the global South. As most countries have ratified the CRPD and promised to strive for Agenda 2030, they are also responsible for being accountable for and transparent in their implementation as well as non-implementation of laws and policies. When this accountability mechanism is not self-critical, as has often been the case in the state reports submitted to the UN Committee of the Rights of Persons with Disabilities, disability inclusion and mainstreaming remain a marginal, voluntary goal. When competing with other pressing priorities, this goal is often considered non-urgent and is not paid sufficient attention, which means that resources are not allocated. Rights-holders need more capacity to play the role of a watchdog, and duty-bearers need to abide by their duties, including accountability, with a mechanism in place. A responsive state is called for (Heikkilä et al., 2020).

3.5. Assistance

What is additionally relevant for many persons with disabilities is assistance, due to the very nature of embodied inequalities. Assistance, including assistive devices and technologies, increases the likelihood of enjoying human rights (Borg et al., 2012). To expand this discussion, the social protection system has a great opportunity to reduce inequalities (UN Special Rapporteur on the rights of persons with disabilities, 2015). Needless to say, those with profound intellectual and multiple disabilities need assistance. Many persons with diverse disabilities require daily assistance, but many others do not. Especially when the aforementioned three A's are in place and the living environment is enabling, many do not need regular assistance. When assistance becomes an entitlement of persons with disabilities, they and their families have greater opportunities and choices in their lives.

3.6. Affection

The aforementioned A's are, however, not yet in place globally, especially in Southern contexts. Love and affection, in turn, have filled the gaps for a long time, in the form of care by mothers, sisters and grandmothers, and support from extended family members and neighbours or by passers-by. In fact, love and affection are an indispensable part of all our lives, including the lives of persons with disabilities (Shakespeare, 2006; Katsui, 2012; 2020). This is particularly evident in the global South, where family is often the minimum unit rather than individuals, as is the custom also in many countries in the global North. When the human rights discourse continues to highlight the human rights of individuals and disability inclusion based on individualism, as exemplified in Chapter 2, affection perhaps becomes an antithesis in this discourse.

The perspectives of disability and development, as well as the unpreparedness of our local and global society to COVID-19 pandemic, enable us to reconsider the kind of love and affection that is available in community living in the global South and North. It underlines the importance of the informal mechanisms of care and the networks of connection that manifest through social relationships and community. These informal mechanisms and relationships are instrumental in the lives of many persons with disabilities in the global South, in "enabling access to resources and often survival in the absence of formal safety nets" (Grech, 2009). This has been also manifested in the COVID-19 pandemic responses not only in the global South but also in the global North. Drawing from the aspect of affection, we note that the intellectual, cultural and social resources of the global South can provide vital resources for development and disability equality (Connell, 2011). This is an important lesson to be learned from the decolonial understanding of disability.

Through using different contexts in the different book chapters, we have tried to inform the readers how profoundly inequalities are embedded in our society and pronounced as embodied experiences of persons with disabilities. In the 21st century, such systematic discrimination against these people due to their disabilities cannot be justified in any way. This is one of the clear messages of this book.

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