

Disability and Poverty in the Post-2015 Development Agenda

David Alenga

Introduction

The Millennium Declaration among other things reaffirmed the importance of tackling poverty with a sense of urgency, explaining why governments committed themselves to “making the right to development a reality for everyone and to freeing the entire human race from want.”¹ This notwithstanding, the Millennium Development Goals (MDGs) have so far not been able to comprehensively address poverty across the board, because of its overemphasis on aggregate results. What this has done is to produce a misleading picture of the anti-poverty campaign by structurally leaving out the most excluded segments of society to serve policymaking convenience². Marginalized groups are accorded a very insignificant mention in the MDGs in both its indicators and targets. A consequence of this is that persons with disabilities-- the most excluded segment of society by way of access to social, economic and political activities-- continues to grapple with poverty on the fringes of society.

The recent report of the UN Secretary General’s High Level Panel of Eminent Persons on the Post-2015 Development agenda conceded that the MDGs “did not focus enough on reaching the very poorest and most excluded people.”³ Similarly, Robert

¹ United Nations Millennium Declaration, accessed from <http://www.un.org/millennium/declaration/ares552e.htm>

² Chronic Poverty Research Center, “Annual Report October 2008 to September 30, 2009,” accessed on May 12, 2013 from http://r4d.dfid.gov.uk/PDF/Outputs/ChronicPoverty_RC/CPRCAnnualReportDFIDyear4forR4D.pdf

³ Final Report of the High Level Panel of Eminent Persons “A New Global Partnership: Eradicate Poverty and Transform Economies Through Sustainable Development,” accessed on June 2, 2013 from

Zoellick former President of the World Bank Group said “persons with disabilities and their families – who are disproportionately represented among the world’s poorest and most vulnerable” have to be at the heart of the global quest to wrestle down extreme poverty. He warned that failure to do so would mean “the Millennium Development Goals simply cannot be met unless disability concerns are addressed – especially those targets related to education and health.”⁴

Research has proven that disability is both a cause and consequence of poverty, manifested in the form of the high levels of prejudice and discrimination that keeps persons with disabilities out of mainstream society and its opportunities. There is a general belief among the poor that persons with disabilities are the “poorest of the poor” and most excluded in society⁵. The World Bank also estimates that nearly 20% of the poorest people in the world are persons with disabilities. There are approximately 80 million people officially living with some of disability or the other in developing countries. As staggering as this figure may be, it is also worthy of note that millions others remain undocumented and therefore statistically unaccounted for⁶. Inappropriate

<http://www.post2015hlp.org/wp-content/uploads/2013/05/UN-Report.pdf>

⁴ Statement of Robert B. Zoellick President of the World Bank Group, “Making the MDGs Inclusive: Empowerment of Persons with Disabilities and their Communities Around the World,” accessed on May 24, 2013 from <http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTHEALTHNUTRITIONANDPOPULATION/0,,contentMDK:22501550~menuPK:282554~pagePK:64020865~piPK:149114~theSitePK:282511,00.html>

⁵ Narayan, D. and Petesch, P. (2002), “Voices of the Poor: From Many Lands,” World Bank.

⁶ Masakhwe, Phitalis Were (2005), African Conflicts and Disability Toll, *Disability World*, 24. Accessed on May 2, 2013 from http://www.disabilityworld.org/06-08_04/gov/conflicts.shtml

conceptualization of disability centered on the traditional medical model is one of the prime reasons why persons with disabilities do fall through the cracks of society⁷.

Notwithstanding the overwhelming evidence that proves that there is a direct link between poverty and disability, the problem still persists. We ask in this paper why this is the case. How can change be made? Who are the duty bearers? To address these questions and similar ones, this paper builds on the recommendations of the High Level Panel of Eminent Persons regarding the need to make the Post-2015 Development Agenda as inclusive as possible by re-emphasizing the link between poverty and disability as not just a development issue but one that is a fundamental human right. We set out to achieve this goal by substituting the traditional medical and rehabilitation model of disability for the social model. It is our contention that the first step towards mainstreaming disability into the global development agenda is to offer the right conceptual basis for understanding what disability is.

Conceptualizing Disability

A very early definition of disability was offered by an umbrella organization of disabled people in Britain called The Union of Physically Impaired Against Segregation (UPIAS). Their working definition sought to make an explicit distinction between disability and physical impairment. They said “impairment is lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body.” For disability, they said it is “the disadvantage of people who have physical impairments and thus excluded from the mainstream of social activities.” Disability is therefore the explicit

⁷ Susan Wendell (1996), “The Rejected Body: Feminist Philosophical Reflections on Disability,” Routledge, New York.

consequence of how society runs its activities by way of access to transportation, education and the labor market, in ways that fails to incorporate accommodations for people with physical impairments.

In that regard, impairment per se does not place a limitation but rather the social construction that is not accommodative is what strokes the limitation. The UPIAS holds society responsible for disabling people with physical impairments. This is how they succinctly describe disability:

It is society which disabled physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this, it is necessary to grasp the distinction between the physical impairment and the social situation, called 'disability', of people with such impairment. Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression.⁸

Because of this inappropriate conceptualization of disability, society's traditional response has been revolving around two main ways of dealing with persons with

⁸ UPIAS, (1976), Fundamental Principles of Disability, Union of the Physically Impaired Against Segregation, London.

disabilities. The first is through the medical process of rehabilitation that ostensibly seeks to correct the “wrong” in a person with the objective of making them fit to live in conventional society. The second approach has been to subordinate the disabled person to the whims of continues care-giving. In the case of the latter, caregivers are appropriated absolute right to run the life of the disabled person.

Thanks to this mismatch, there was a steady evolution in the conceptualization of disability based on the social model. Victor Finklestein, a pioneer of disability scholarship, offered the so-called “materialist” description of disability to highlight the history of disabled people’s campaign to properly define themselves rather than being defined by society⁹. The materialist view leans historical evidence to the exclusion of disabled people from mainstream society. Indeed, following this initiative conceptualizing disability continues to be an evolving concept mainly hinged on social, political and cultural overtures.

Another problem with the understanding of disability is borne out of the tendency to personalize disability, so much that it leaves an absurd room for the cultural stereotypical connotations of disability to flourish. Needless to say, even in cases where government policies seek to address disability they tend to be crafted along the obsolete traditional approach of fixing the problem of impairment in the individual but leaving the social and environmental constructions that causes disablement untouched¹⁰.

⁹ Finklestein, V. (1980), *Attitudes and Disabled People: Issues for Discussion*, World Rehabilitation Fund, New York

¹⁰ Khatleli, Pholoho (1995), “Scholars for All: National Planning in Lesotho.” *Innovations in Developing Countries for People with Disabilities*. Eds. Brian O’Toole and Roy McConkey. Bologna, Italy Lisieux Hall Publications

Most social norms by their very construct are set to berate disability, thereby essentially calling into question the need to invest social and political capital to tearing down the social barricades of exclusion. Going by this logic, the vicious cycle of disability, deprivation, poverty and disenfranchisement is sustained by the existing cultural orthodoxy that crafts the social milieu. Creating inclusive societies will therefore have to be premised on the realization that social transformation is hinged on the right conceptualization of disability—a fundamental paradigm shift.

Instead of justifying exclusion from society on the basis of physical impairment the way forward ought to be driven by relying on the social model to explain disability.

For instance, Michael Oliver, a leading disability scholar asserts that a social model of disability that makes it possible for disabled people to exercise their rights to the public space is inspired by posing such questions as, “What is wrong with society? What social, economic, political and/or environmental conditions need to be changed to facilitate the full enjoyment of all rights by all persons with disabilities?”¹¹

These line of questioning helps create the distinction between the conventional way of trying to understand what is wrong with disabled people, drawn from the medical view of disability. Oliver’s second example challenges disabled people’s approach to society as well. A person with a hearing impairment may for instance, rather than asking whether “it is difficult for me to understand people because I am deaf?” should rather pose the right question like, “is it difficult for me to understand people because they are not able to communicate with me?”

¹¹ Oliver, M. (1990), *The Politics of Disablement*, MacMillan, London.

Cultural belief systems in some parts of the world enforces the dehumanization of persons with disabilities—belief systems that are too entrenched to be changed overnight. An observer, commenting about the cultural dimensions of disability in Africa said, “Some sections of society consider them an accursed group, others subject them to various abuses that cumulatively make them bitter against Society”¹². Despite signing and ratifying international conventions of human rights, governments are constrained by the absence of a corresponding political constituency to champion institutional transformations. Financial and policy limitations could limit even the most well-intentioned goals of inclusion. We are therefore faced with a situation in which disability policy concerns have become “the least prioritized and inadequately factored section of the national budget and planning.”¹³

Like the UPIAS, the UN Convention on the Rights of Persons with Disabilities (UNCRPD) describes disability as a “pathology of society.” Disability from this logic is the failure of society to remove the impediments that colludes with physical impairments in excluding disabled people from being active participants of social life¹⁴. Beyond the physical dimension, disability is a multilayered phenomenon which is reinforced by a complex web of social interactions that increases and further exposes disabled people to poverty. Equally important is the fact that it is central to the human rights discourse.

¹² Kwei, R. “The Deaf and Hard of Hearing.” Daily Graphic 2002, November 27: 11

¹³ Masakhwe, Phitalis Were (2005), African Conflicts and Disability Toll, Disability World, 24. Accessed on March 2, 2013 from http://www.disabilityworld.org/06-08_04/gov/conflicts.shtml

¹⁴ United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

Impact of Disability on Society

For the most part, the impact of disability transcends the limited scope of the individual disabled person. It has both direct and indirect effects on society as a whole. Current UN estimates puts the cost of disability on society at 25% of the entire population¹⁵, both in direct and indirect terms. The indirect form takes the form of the opportunity costs of income foregone as a result of incapacity and those borne by care givers. Then the direct cost is manifested in the form of travel, access and treatment. A related study about the cost of disability on society carried out in India showed that the indirect cost of disability on the families of disabled people “amount to perhaps four to five times” the direct cost on the 32 million disabled people in India back in 1991.¹⁶

A similar study carried out in Tanzania showed that the mean consumption rate of households with a disabled person was almost 60% less than the national average. The World Bank says the impact of long term disabilities accounted for a little over 30% of Disability Adjusted Life Year (DALY)¹⁷s globally. The greatest chunk of the costs of disability is borne by female kinsmen, which also indicates just how disproportionately the burden of disability is shared within households with disabled persons. Offering care to the child with disability adds to the workload of women that are already living on the

¹⁵ Leandro Despouy, (1993), “Human Rights and Disabled Persons” (Study Series 6), Centre for Human Rights Geneva and UN New York

¹⁶ S. Erb and B. Hariss-White, Adult Disability, (1999), “Poverty and Downward Mobility: The Macro and Micro Picture from India,” Paper presented to the Development Studies Association Annual Conference, 13th September 1999, University of Bath.

¹⁷ It is the most regularly used indicator to measure the impact of diseases on a particular location.

margins of poverty, not to mention the opportunity cost of engaging in the caregiving. In other instances, children would have to forfeit school to take care of disabled relatives.

Exclusion has inadvertently contributed in nurturing a pervasive “dependency syndrome mindset” amongst disabled people. This is given credence by the fact that unlike other forms of socially engineered exclusions, persons with disabilities have to contend with additional needs that are disability specific before there can be any talk of inclusion. Some practical examples include the need for assistive devices, accommodation and psychological support. A person with a mobility challenge will definitely need to be able to address this specific personal limitation before thinking of access to education, employment and what have you. The dependency syndrome is manifested in the erosion of self-esteem borne out of shame and the fear of rejection by others, which overtime crystallizes into developing a very entrenched pessimistic outlook.

According to a study by the charity, Action for Disability and Development (ADD), disabled people are so marginalized from mainstream society so much that they are not even considered necessary targets of systematic academic research. The report further says “where research has been done, it has often been done by Northern non-disabled academics. Disabled people may be used in the research but this is often done to add legitimacy to the work, rather than really allowing disabled people to control or influence the agenda. The results therefore often miss disabled people’s real main issues or concerns.¹⁸”

¹⁸ Yeo, Rebecca (2001), “Chronic Poverty and Disability” Accessed on May 19, 2013 from http://r4d.dfid.gov.uk/PDF/Outputs/ChronicPoverty_RC/04Yeo.pdf

Challenges of Disability in Developing Countries

Thanks to effective public policy measures in advanced industrialized countries, physical impairments no longer constitute an impediment to the inclusion of persons with disabilities in the activities of society. This notwithstanding, significant challenges still remain in developing countries where a lethal combination of cultural stereotypes and weak political will deter the drive towards creating inclusive cities within the framework of human rights cities. Besides, it is also startling to acknowledge that whilst most developing countries have signed and ratified such global conventions such as the UN Declaration of Human Rights, The Convention on the Rights of the Child, the Convention on the Rights of Persons With Disabilities and a host of others, persons with disabilities continue to remain on the fringes of societies.

It is estimated that there are approximately 80 million people officially living with some form of disability or another, the vast majority of them are in Africa. Again, Africa continues to witness an increase in the number of disability cases as a result of violent conflicts, poor primary health care services and preventive medical opportunities. The lives of these 80 million persons with disabilities are characterized by deprivation, poverty, malnutrition, marginalization and servitude on all fronts.

In the light of these conditions, equality of social opportunities is just unthinkable for the simple reason that addressing them as subjects of human rights is considered a non-starter. As discussed in the preceding section, historically, disabled

people have been excluded from mainstream society for many years. Their exclusion in developing countries particularly represents a sad attitude of ignorance borne out of superstitious labeling.

Cultural belief systems in Africa enforces the dehumanization of persons with disabilities—belief systems that are too entrenched to be changed overnight. One observer, commenting about the cultural dimensions of disability in Africa said, “people with disabilities are often isolated, discriminated against and considered inferior. While sections of society consider them an accursed group, others subject them to various abuses that cumulatively make them bitter against Society¹⁹”

Under a dispensation of culturally-inspired prejudices and discrimination there are very little prospects of disabled people being able to break into the mainstream of society by engaging socialization institutions such as schools, recreational facilities or even the labor force. Despite signing and ratifying international conventions of human rights, governments in developing countries are constrained by the absence of a corresponding political constituency to champion institutional transformations. Partly, financial and material scarcity could limit even the most well-intentioned policy of inclusion, as a result of which disability policy concerns have become “the least prioritized and inadequately factored section of the national budget and planning” according to Maskhwe (2005).

A related challenge takes the form of the tendency to personalize disability, so much that it leaves an absurd room for the cultural stereotypical connotations of

¹⁹ Kwei, R. “The Deaf and Hard of Hearing.” Daily Graphic 2002, November 27: 11

disability to flourish. Khatleli et al (1995) surmise that even in cases where government policies seek to address disability they tend to be crafted along the obsolete traditional approach of fixing the problem of disability in the individual whilst doing nothing to the social and environmental constructions that causes disablement. In other words, there is no provision for a rights-based policy approach to disability.

What We Know

The most pressing challenge for persons with disabilities is more of poverty and less of their disability, research has shown²⁰. As discussed in the preceding section, disability is therefore at the heart of the poverty reduction drive, largely because of the sheer numbers of disabled people that are not being reached by ongoing poverty reduction programs. We have also mentioned that the vicious cycle of poverty that they are exposed to is a reflection of how deeply they are excluded from society. Exclusion is typically the result of the poor understanding or in extreme cases total lack of knowledge of what disability is. It goes without saying that this phenomenon cuts across multiple levels of contemporary society.

It is against this background that those of us within the disability movement believe that the MDGs are not just a symbolic commitment to addressing poverty but a real life issue for us. We cannot help but agree with the UK's Department for International Development (DFID) that "challenging exclusion is central to reducing poverty and meeting the MDGs." Strengthening the commitment comes from

²⁰ Ibid

recognizing that the poverty faced by over 10% of the world's population living with disabilities is now an urgent human rights issue. Going by the tenets of Article 32 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD), all aspects of international development programs have to be "inclusive of and accessible to persons with disabilities."

Despite this provision, disability has all but been relegated to the lowest rung of the discourse of mainstream international development thus overlooking the fact that disability is a critical crosscutting issue that has definitive ramifications on development. Because of its crosscutting nature, it has to be addressed on an integrated plane. In the meantime, the gains from integrating them into mainstream society will ultimately supersede the costs on society. Clearly, the avenues and opportunities for action have been created by the framework of the UNCRPD as well as within the UN mechanism. This is further complemented by the enthusiasm of a very vibrant global disability movement that is open to further engagement with policymakers at all levels.

It is worth acknowledging that a great deal of progress has been made in terms of better incorporating disability into the global development agenda, as captured by the recent report of the High Level Panel of Eminent Persons. The report recommends that "the next development agenda must ensure that in the future neither income nor gender, nor disability, nor geography, will determine whether people live or die, whether a mother can give birth safely, or whether her child has a fair chance in life." Towards this goal, the report is seeking to ensure that the Post-2015 era is as inclusive as possible such that it "Leaves no one behind" on account of "ethnicity, gender, geography, disability, race or other status."

Another critically transformative nature of the recommendations of the report is that, it is calling for the establishment of disaggregated indicators which will work to fulfill the goal of not leaving anyone behind, coupled with the need to ensure that all targets reach all social groups, with 19 specific references to disability, thereby addressing the shortcoming of the Millennium Declaration. The report is the outcome of exhaustive consultations with the disability community, which in and of itself signals a great leap forward.

Where Do We Go From Here?

The quest towards mainstreaming a disability inclusive global development agenda cannot be treated in isolation to the integral role of disability as both a subject of development as well as a fundamental human rights issue. To this end, it is imperative to hold governments to their obligations within the current human rights framework, such as the UNCRPD. This should therefore be the foundational principles to build the Post-2015 development agenda. To illustrate some of the critical contending issues at play, we believe that there has to be explicit reference to the question of disability in the national targets, with a specific focus on education, gender and health. Doing so is consistent with harmonizing disability as an indispensable facet of development in line with existing mechanisms such as the UNCRPD.

Among other things, when it comes to the targets and goals under education, gender equality, social protection and participation in governance the next phase of development policy must make deliberate provisions for the inclusion of “universal

design and “reasonable accommodation” to the evolving process of achieving maximum inclusion of persons with disabilities into mainstream society.

For us in the disability movement, another salient part of development policies that can better serve us within the scope of the Post-2015 agenda has to begin by making a clear distinction between the type of policies that can be disability specific and those that have to be disability inclusive. Both are critical in achieving a truly effective and inclusive global development agenda. Some of the examples of best practice that have produced good results are the “twin track” approach to disability adopted and implemented by the UK’s Department for International Development (DFID). It is hinged on making this clear distinction so as to enhance the effectiveness of implementation of policies at all levels.

Through this approach DFID has been able to offer tailored support to persons with disabilities in its development programs through inclusion where necessary and the implementation of customized programs to fit the needs of specific categories of disabled people through disaggregation. Experience has shown that some of the programs targeting disabled people require different degrees of modifications to suit their diverse conditions. The need for modifications is justified by the fact that it sets the basic standards for full inclusion especially targeting those hard to reach. There is certainly no need to redesign existing policies to make them broadly inclusive but rather a conscious effort to incorporate modifications into current policies with the view of achieving the highest possible level of inclusion. Indeed, towing this line requires a concerted determination to ensure that these are pursued in a very integrated manner

ranging from country programming and interventions targeting the multiple dimensions of addressing the poverty faced by the millions of persons with disabilities globally.