Routledge
Taylor & Francis Group

# Human Rights Based Approach to Disability in Development in Uganda: A Way to Fill the Gap between Political and Social Spaces?

HISAYO KATSUI & JUKKA KUMPUVUORI

*Institute for Human Rights at Åbo Akademi University, Finland*

ABSTRACT *Human rights have become one of the key concepts both in theory and practice of disability studies. The trend is applicable also to the discourse of disability in development: disability in "developing countries". This paper investigates both the theory and practice of human rights based approach to disability in development. The case study is on Uganda, which has succeeded in creating political space for persons with disabilities while their social space has not been developed as much. Both interviews and literature reviews illustrate the argument. On the basis of the findings from the Ugandan case, we analyse the gap between political and social spaces from the perspective of the human rights based approach, and summarize the significances of the approach to disability in development, and also the challenges in its operationalisation.*

## Introduction

This article investigates the human rights based approach to disability in development in so-called "developing countries". While the theoretical part of the article is more general, the examples and the conclusions focus on the case of Uganda. Scrutinizing the rather new phenomenon of the human rights based approach to disability in development, the article gives a strong impetus for further research.

The article is divided into four parts. The first part presents the problems of previous interventions on persons with disabilities (PWD) in general. The chapter reveals the general ignorance to the issue of PWDs in development, and the underrepresentation of PWDs in interventions. The second part centres on the human rights based approach to disability in development, which elaborates on human rights in the situation of the vulnerable group of PWDs. The third part introduces the case of Uganda, a country which has

Correspondence: Hisayo Katsui, Institute for Human Rights at Åbo Akademi University, Gezeliusgatan 2, 20500 Turku, Finland. Email: hisayo.katsui@helsinki.fi

created political spaces for PWDs, but has not been as successful in creating social spaces. This part is enriched by evidence gathered from interviews conducted in two studies (Katsui 2006; for more see Katsui's ongoing research at http://disability-uganda.blogspot.com/). The interviews were collected in Uganda in summer 2005 and spring 2008 respectively. Finally, the fourth part analyses the gap between political and social spaces from the perspective of the human rights based approach to disability in development, and concludes our article by summarizing the implications of the human rights based approach to disability in development and the challenges evident in the practical realisation of the approach.

Disability study is multidisciplinary in nature. This article is written by two scholars from different fields, namely social science and law. Hence, the analyses utilized in this article are also multidisciplinary: evidence-based situational analysis combined with legal and theoretical ones. That is, the conclusions drawn in the article are the results of the effective combination of different methods of analysis.

### Problems of Previous Interventions on PWDs in Development

This chapter provides an overview of previous interventions on PWDs in development in general. The key focus is on the role of PWDs and their empowerment status. The general ignorance to this issue as a whole is revealed, as well as the underrepresentation of PWDs in the interventions.

At present, the percentage of PWDs in the total world population is estimated to be 10–12% (World Bank 2007). However, national statistics vary due to differing definitions and the present conditions in each country. More developed countries tend to have a higher number due to (1) longer longevity; (2) more developed medical technologies; (3) the inclusion of the newly diagnosed and persons with mental disabilities; and (4) better statistical systems that cover the whole population (Katsui 2005:24). The second factor has prolonged life expectancy, especially that of the severely impaired people who would have died, should certain medical technology have not been yet developed. Conflicts and HIV/AIDS epidemics increase the number of PWDs in many other countries. For instance, in post-conflict Cambodia the ratio of PWDs is as high as 20% (Wiman 2004), and 95% of new HIV infections occur in the South (UNCDF 2003). At the same time, only 10% of people living with AIDS in Africa receive some treatment (*Mainichi Shinbun* 2005). In this regard, cultural relativism becomes an important dimension in disability discourse. The concept of "disability", in particular, is diverse. In any case, PWDs tend to be marginalised in each local setting. This is further clarified in the following.

Of the world's PWDs, 80% are estimated to live in the South (WHO 2003). Despite the significant number in the South, only 2% receive some kind of support (United Nations 2000, San 1999). This may explain the fact that 17% of poor people are PWDs, according to the World Bank (Haar 2005). That is, PWDs in the South are largely ignored both by governments and interna-

tional communities, and are not represented in the mainstream agencies in development.

Disability in development (along with social and human development) has finally started to gain recognition in international recommendations which formerly focused on economic growth as development. For instance, world governments signed the Millennium Declaration (commonly known as the Millennium Development Goals (MDGs)) to tackle the increasing inequality between the rich and the poor, and to halve extreme poverty by 2015. Development cooperation has become an important aspect of globalisation, at least in theory. Despite the increasing recognition of the rights of poor people in international policy, actual implementation is not as impressive. For instance, the prioritisation of military security over human security is evident: "for every \$1 that rich countries spend on aid, they allocate another \$10 to military budgets" (UNDP 2005:8). If this tendency continues, the shortfall in the money required to achieve the MDGs is expected to increase from \$46 billion in 2006 to \$52 billion in 2010 (United Nations 2006). Furthermore, the MDG has not even mentioned disability. Recent history has proved that unless PWDs are specifically mentioned among the "vulnerable groups of people", "marginalized people" or "poor people", they tend to be forgotten (Dube 2005). As a consequence, most of the international poverty reduction process has excluded PWDs, intentionally or not.

Human rights based approaches to disability in development incorporate this largely neglected part of the world population into mainstream discourses on human rights, disability, and development. This approach will be scrutinized in the next chapter.

**Human Rights Based Approach to Disability in Development: A Way to Create Political and Social Spaces?**

Development interventions in the field of disability have traditionally been based predominantly on fulfilling the material needs of PWDs. These interventions represent charity-based approaches. In practice this means providing technical aids, nutrition and health services, for example. Typically, charity-based approaches fail in empowering PWDs to make their own decisions about their own lives and to achieve ownership of their selves. Needs are identified by development professionals, thus resembling the medical model where medical professionals were criticized for similar behaviour. It is evident, however, that the human rights based approach to disability in development is arising rapidly in the horizons of discussion on the subject of disability in development, in parallel with the development of the social model of disability in Northern countries and the demands to develop it further. That is, human rights have become an important concept to address with regards to disability issues both in the North and the South.

The essence of the human rights based approach to disability in development is based on the premise that it creates claims to those who possess rights and freedoms, and through this mechanism creates, for the claim-holders, a new level of ownership of their lives.

The human rights based approach to disability in development first identifies the international norms that are valid in a certain context. This is done by examining and interpreting the international human rights instruments in a disability-sensitive and relevant manner. After identifying the relevant human rights norms, the approach identifies relevant stakeholders in the context. This is done by analysing the different positions of legal entities, such as a person, a group of people and a state, and designating the positions of claim-holders and duty-holders in different settings – not necessarily merely legal or political but also social, cultural and economical.

Through this process of identifying relevant human rights norms, it is possible for claim-holders and duty-holders to examine the situation from the human rights based point of view. This also gives the claim-holders the opportunity to invoke duties based on international human rights law. In the human rights based approach to disability in development, claims are based on international human rights law and are therefore transparent. Thus, it becomes possible for external actors to express their opinions regarding the situation.

On the grounds of a wider understanding of non-discrimination, states, among other duty-bearers, also contract positive duties stemming from the international human rights norms on equality and non-discrimination. This is an explicit component of the human rights based approach to disability in development. By recognizing the duty-constituting feature of international human rights law on non-discrimination, the approach leads to the notion of positive state measures. That is, states, among other duty-bearers, will need to fulfil their obligations when the human rights based approach is applied, because they have signed and thus expressed their commitments to the existing international human rights laws.

In practice, however, the human rights based approach has been applied in very different ways, depending on the different actors. Uvin (2004) categorises four types of interaction between human rights and development discourses in practice. In the first, human rights terminologies are incorporated in classical development discourse through claims that development cooperation has been contributing to said rights all along. In this method, the incorporation of a superficial usage of human rights terminology depoliticizes the underpinning root problems, yet legitimizes the status quo. The second type is political conditionality, where human rights terms are imposed when aid is given. This is practiced in particular by the largest aid agencies. In this type, the self-determination of the South is badly ignored, and as such the intervention itself is not human rights based. Third, human rights can be "added on" by implementing new programs based specifically on human rights objectives. In this approach, human rights are not mainstreamed but implemented in a limited context only. In the fourth type, human rights are seriously taken into account where the mandate of development is redefined in human rights terms. As a result, social change takes place with a new paradigm of inseparable development and rights components. "Development as freedom" (Sen 1999) exemplifies this last approach. The practice, therefore, is supposed to change as a result of this approach but success is limited (Uvin 2002:8). Consequently, "vagueness dominates" in the practice of the human rights

based approach due to the discourse remaining at a theoretical level and not reaching the practical level (Uvin 2004).

**The Sensitivity of Uganda to Disability in Development in Practice**

Uganda is an interesting case, where development and disability discourses meet and have been negotiated. It is a "developing country", in other words, a recipient of development cooperation. At the same time, it has the most progressive constitution, cited as the "human rights charter" (Mawa 2003). In this regard, Uganda has applied the human rights based approach to some extent in practice, especially in terms of the civil and political rights of PWDs. The rights of PWDs are specifically stipulated in the Constitution of 1995 as follows: "Persons with disabilities have a right to respect and human dignity and the State and society shall take appropriate measures to ensure that they realize their full mental and physical potential". Concrete positive changes have taken place in creating political space for disabled representatives.

The Local Government Act of 1997 is an interesting example of affirmative action to disempowered groups of people including women, PWDs, youth, workers (Kharono 2003) and the army (European Disability Forum Bulletin 2001). Since then, these marginalised groups of people are represented in Ugandan politics at all levels, including Parliament. Uganda has a quota of five Members of Parliament (MPs) to represent the disabled population: four MPs from four regions (Central, East, West, North) and one woman with a disability. An interesting fact is that in the 2006 election, two MPs formerly representing PWDs stood for the mainstream positions outside of the quota framework, and were also elected. Both of them are women with disabilities (WWDs). Therefore, there are seven MPs with disabilities in the Parliament at present. In interviews, these MPs claim that this is a clear, positive sign of mainstreaming PWDs. Moreover, 47,000 disabled councillors work in local government structure; half of them are disabled women. Disability has become positively visible in the political space of Uganda.

Ugandan representation has also been visible in the international arena. For instance, Ugandan PWDs played an important role in the process of elaborating the new United Nations human rights convention. In December 2001, the UN General Assembly adopted a resolution to establish an ad hoc committee to consider proposals for a Comprehensive and Integral International Convention to Protect and Promote the Rights and Dignity of Persons with Disabilities. Uganda was represented at the ad hoc committee and the Working Group by Mr James Mwandha, who is a disability activist and former member of the Ugandan parliament, and has also acted as the leader of the Ugandan delegation. The stakeholders organised the first ever Commonwealth Conference for Persons with Disabilities in the run-up to the Commonwealth heads of Government in Kampala in November 2007 (Matovu 2007, Mwandha 2006, 2007).

The creation of policy and political space that has occurred during the last two decades is regarded as an important achievement among the interviewees,

although some challenges remain when economical, social and cultural rights are taken into account.

The political space, particularly at national and international levels, does not automatically secure social space at a more individual level, where economical, social and cultural rights in Uganda often take place. First of all, acquisition of political space faces challenges: (1) the multi-party system which challenges the foundation of disability movement as an ''appendage of NRM (National Resistance Movement)''; (2) the failure of the disability movement to challenge the government; and (3) the competition between non-state and state actors on resources and recognition (DSI 2007:7). In addition, the Department for Disability and Elderly Affairs is under the ''poorest and the most marginalized of all ministries'' (DSI 2007:7). This could imply that the political space does not necessarily meet the needs of the people at the grassroots level without proper allocation of resources.

In reality, a number of PWDs do live positively due to the vigorous efforts of disability representatives in politics. Examples of two groups of PWDs are introduced to support this argument: shopkeepers with disabilities in Kampala and students with disabilities at higher education institutions. Firstly, many shopkeepers in a market area in Kampala benefit from political representation, as they can keep their shops in one of the busiest spots. In the interviews, they explained that they gained the spots after the vigorous activism of their representative in Kampala district to reserve the accessible and busy spots for PWDs. The shopkeepers were mostly people with physical disabilities and deaf people who helped each other in their respective work. Another example of the positive effect of political representation is the affirmative action policy of the government, which enables many students with disabilities to enter higher education institutions. The students get extra points on the entrance examination markings and also get financial support during their study. As a result, these PWDs have become positively visible as part of the society.

The resource constraint of the government, however, negatively affects the majority of other interviewed PWDs at the grassroots level, as they do not have proper preconditions such as sign language skills and interpreters, assistive devices, medications and accessibility so as to benefit from participation in the social space. Those who managed to collect enough capital to establish a shop, or who managed to complete secondary education, have benefited, while the majority of PWDs often fail to reach that level and so cannot fully benefit from the positive change in the political space.

In general, the leadership of the MPs with disabilities is making changes, particularly at policy level, while the capacity of the local councillors with disabilities and the available resources are too limited to make a difference at present. This became clear in the interview statement by the former Minister of State for Elderly and Disability Affairs, Florence Nayiga Sekabira (Zeitzer 2004). Current MPs with disabilities and the Minister Sulaiman Madada also pointed out the same issue of resource constraint in the interviews conducted in February 2008. Despite political mainstreaming, actual interventions of the government and private sector are not targeting PWDs at the grassroots level, which reinforces the limited social space available to them. PWDs make up of

38% of the Ugandan population affected by poverty, which is a clear overrepresentation (Ugandan Government 2006). The overwhelming poverty limits the social space of PWDs. In particular, PWDs lack education, which is a crucial limiting factor in their ability to engage in social space (Nakamanyisa 2005). Half of PWDs have never been to school, while only 4.6% had received secondary and tertiary education (DSI 2007:2). Many interviewees have not gone to school due to the discrimination of society and poverty, which deeply affects the decision making of their family members. Those who have a good academic background, still – after the affirmative action policy of the government (Article 32 of the 1995 Constitution) – face severe discrimination in the employment market. Multiple poverty and discrimination at different levels have hindered PWDs from full participation. The deeply rooted discriminative factors against PWDs are many, particularly in the social space, even if political space is secured for their representatives:

> Then what came out of the parents was that they were not educated and most likely most of their disabled children did not go to school because of *so many other factors*. Like some of them lack school fees, others were saying they are burden, others were feeling useless. (Ugandan DPO Project Coordinator N, emphasis added)

In particular, WWDs are more deprived of their social space and decision-making power because most of the cultures of the different ethnic groups in Uganda are patriarchal (DSI 2007). "Men generally own and control everything including women. In the rural communities of Uganda, women are basically regarded as some of the objects or assets owned by the husband" (DSI 2007:3). Many interviewees who are WWDs themselves expressed in a synchronized voice that they have "sex by chance, not by choice". There is a surprising statistic that 22% of the studied WWDs were raped in their first sexual encounter (Mulindwa 2003:32). This example of low negotiation power for safe sex epitomises the vulnerability of WWDs. As a result of severe discrimination at different levels, PWDs tend to want concrete materials:

> They want concrete things which benefit them, whether you have given them blankets, food, sheets, you know, things which are more material rather than skills and knowledge. (Ugandan DPO Staff M)

That is, the discriminating society makes PWDs prefer a charity-based approach at present, while the disability movement has advocated a human rights based approach to disability in Uganda. The deeply rooted discrimination at different levels is not tackled by mere political representation with limited commitment of resources, and thus low priority. Therefore, this structural mechanism explains the gap between the well-known political space and the more hidden reality of limited social space. This is one of the big challenges to realising the human rights based approach to disability in Uganda.

**Political and Social Space Gap from the Perspective of a Human Rights Based Approach to Disability in Development: a Concluding Remark**

When a human rights based approach to disability in development is used here as an analytical lens for investigating the contemporary Ugandan situation, neither the empowerment nor the mainstreaming of many PWDs is yet achieved in many senses. The political representation of PWDs both at national and international levels indicates that Uganda has mainstreamed PWDs at least to the political space. Some, such as shopkeepers in a market at Kampala city and students with disabilities, have benefited from the positive changes, yet many others remain, preferring the charity-based approach due to the discriminative surroundings. However, this is not to say that the latter group should not be incorporated into activities of the human rights based approach. Mainstreaming is one way to empower people. Thus, not to mainstream a person because they are not yet empowered is merely a gesture of avoiding them. For instance, the Ugandan representatives were empowered during the drafting process of the UN Convention by participating in the series of ad hoc committee meetings. Both empowerment and mainstreaming mutually reinforce the ultimate goal of equal opportunity.

Another practical lesson from Uganda is that political space does not secure the mainstreaming of PWDs in other spaces, including the social one. This fact implies that gaps exist between disabled leaders and general PWDs, or more precisely, that there is diversity among so-called "PWDs". Political representation has secured the group rights to participate, while individual rights require a more elaborate and sensitive approach to accommodate this diversity. In short, the study reveals difficulties in the operationalisation of the human rights based approach to disability in development in spite of all its theoretical significance.

On the basis of the preliminary findings, the implications and possible challenges of the human rights based approach to disability in development can be summarized as follows. One implication of this approach is that it effectively draws all human beings into mainstream discourse, and includes the most vulnerable groups of people such as PWDs. Second, the approach requires rights-based action instead of charity, which has been predominant. Thus, the actual change must take place in the operationalisation. Third, the approach stipulates state obligation to secure the human rights of concerned people. Fourth, this approach demands transnational obligations, which is the biggest difference between the human rights based approach and the social model of disability. These four implications are the most prominent ones for PWDs in the South for creating social and political spaces, leading towards the ultimate goals of equality and equal opportunity.

These very implications, however, result in difficulties in the actual operationalisation. The first point means that disability must be tackled. Disability is a complex phenomenon that requires positive changes at all levels. The lack of these positive changes has reinforced the vulnerability of PWDs so far. PWDs constitute a diverse group, and as such, face challenges that cannot be addressed merely by making changes to the lives of their

"representatives''. Thus the implication directly indicates the difficulty in its operationalisation. The second implication challenges the fundamental parts of society where PWDs live, such as the governmental legal system, education, employment and family life. In some sense, charity is easier because it does not challenge structural problems which reinforce the status quo of discrimination. The third implication is now operationalised to a limited extent. Although a rights-based ideology prevails, the lack of resources of the Ugandan Government and the low prioritisation of disability issues too often justify limited statutory interventions in this area. The final implication infers that international interventions involve many actors from different countries, meeting under a different context. Therefore, the implementation itself is complex in this term as well. We believe these are the possible reasons why the ideology has become popular, while its operationalisation has not attracted much attention. This is the very aspect that needs further investigation. Existing literature has not focused on how positive political changes have improved the quality of life of PWDs at the grassroots level (Kangere 2003). Further research must fill this gap in order to investigate sustainable social change for PWDs in Uganda and elsewhere in the South.

## Acknowledgements

## References

DSI (The Danish Council of Organizations of Disabled People) (2007) *Country Strategy Paper Uganda 2007–2011* (Copenhagen: The Danish Council of Organisations of Disabled People) (unpublished report).

Dube, A. (2005) *Participation of Disabled People in the PRSP/PEAP Process in Uganda.* Available at: http://disabilitykar.net/docs/uganda_prsp.doc (accessed 3 July 2007).

European Disability Forum Bulletin (2001) *The National Union of Disabled Persons of Uganda, "For a Full Participation''.* Available at: http://www.disability.dk/site/viewdoc.php?doc_id=399 (accessed 11 July 2007).

Haar, A. T. (2005) *Discussion Article: People with Disabilities Excluded from Millennium Goals?* Newsletter of Dutch Coalition on Disability and Development No. 11. Available at: http://www.dcdd.nl?2810 (accessed 18 November 2005).

Kangere, M. (2003) *Development in Disability: The Uganda Experience.* Available at: http://www.dcdd.nl/data/1067944239230_Development%20in%20Disability%20paper%20(Maria%20Kangere).pdf (accessed 11 January 2006).

Katsui, H. (2005) *Toward Equality: Creation of Disability Movement in Central Asia* (Helsinki: Helsinki University Press).

Katsui, H. (2006) *Maximizing Ownership: Experiences of Disabled People under Abilis Interventions* (Helsinki: Abilis Foundation) (unpublished report).

Kharono, E. (2003) *Review of Affirmative Action in Uganda.* Available at: http://www.wougnet.org/Documents/UWONET/Report_on_Review_of_Affirmative_Action.doc (accessed 11 July 2007).

*Mainichi Shinbun* (2005) AIDS: Sekaino Kansensha Hajimete 4000man-nin Toppa (AIDS: AIDS positive people reached to 40 million, not available in English). (21 November 2005.)

Matovu, C. M. (2007) personal communication on 25 July 2007.

Mawa, M. (2003) *Human Rights and Development in Uganda: Reflections on the Constitutional Provisions of the Right to Development.* Available at: http://www.crvp.org/book/Series02/II-8/chapter_ix.htm (accessed 19 December 2005).

Mulindwa, I. N. (2003) *Study on Reproductive Health and HIV/AIDS among Persons with Disabilities in Kampala, Katakwi and Rakai Districts: Knowledge, Attitudes and Practices* (Kampala: DWNRO).

Mwandha, J. (2006) *The Report on the Eight Session of the UN Ad hoc – committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities* (unpublished report).

Mwandha, J. (2007) personal communication on 18 July 2007.

Nakamanyisa, R. (2005) *Evaluation Study on Abilis-funded Projects in Uganda* (unpublished report).

San, Y. (1999) Social sustainability and the future of social policy: empowering disabled persons in the ESCAP region, in: R. Wiman & T. Partonen (Eds), *Putting People at the Centre of Sustainable Development* (Saarijärvi: Gummerus Printing).

Sen, A. (1999) *Development as Freedom* (Oxford: Oxford University Press).

Ugandan Government (1995) *The Constitution of the Republic of Uganda, 1995.*

Ugandan Government (2006) *National Policy on Disability.*

UNCDF (United Nations Capital Development Fund) (2003) *Microfinance and HIV/AIDS.* Available at: http://www.cgap.org/docs/DonorBrief_14.pdf (accessed 24 November 2005).

UNDP (2005) *International cooperation at a crossroads: aid, trade and security in an unequal world.* Human Development Report 2005. Available at: http://hdr.undp.org/reports/global/2005/pdf/HRD05_overview.pdf (accessed 14 November 2005).

United Nations (2000) *Fundamental Rights of Disabled Persons constantly violated around the World.* Available at: http://www.scienceblog.com/community/order/archives/L/2000/A/un000169.html (accessed 1 September 2004).

United Nations (2006) *Human Rights Day 2006.* Available at: http://www.un.org/events/humanrights/2006/factsheet4.shtml (accessed 8 August 2007).

Uvin, P. (2002) On High Moral Ground: The Incorporation of Human Rights by the Development Enterprise. *The Fletcher Journal of Development Studies*, 17, pp.1–11. Available at: http://fletcher.tufts.edu/praxis/archives/xvii/Uvin.pdf (accessed 26 September 2007).

Uvin, P. (2004) *Human Rights and Development* (Bloomfield: Kumarian Press).

WHO (World Health Organisation) (2003) *Access to Rehabilitation for the 600 Million People Living with Disabilities.* Available at: http://www.who.int/mediacentre/news/notes/2003/np24/en/ (accessed 1 September 2004).

Wiman, R. (2004) Personal Communication on 8 November 2004.

World Bank (2007) *Data and Statistics on Disability.* Available at: http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTSOCIALPROTECTION/EXTDISABILITY/0,,contentMDK:21249181 ~ menuPK:282717 ~ pagePK:148956 ~ piPK:216618 ~ theSitePK:282699,00.html (accessed 26 July 2007).

Zeitzer, I. (2004) Uganda: Interview with Florence Nayiga Sekabira, Minister for Disability and Aging, *Disability World*, 25. Available at: http://www.disabilityworld.org/09-11_04/gov/sekabira.shtml (accessed 25 July 2007).