
“Disability-Rights-Movement in East Africa:

The Role and Impact of Self-Representation of Persons with Disabilities

on National, Transnational and Regional Level”

Corina Hoffmann

Max Planck Institute for Social Law and Social Policy,

Division: Inclusion and Disability,

Munich/Germany

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Abstract:

In developing countries interest groups can be of crucial influence for political as well as social change. However, in these countries stakeholders not only face limited financial capital but at times also lack professional education and skills to contribute on the political floor or advocate 'successfully'. Moreover scarce resources (e.g. money, government will, attention, etc.) more often lead to an "intra-sectoral dilemma" where similar interest groups compete against each other for these limited resources - creating conflicts instead of power coalitions. The adoption of the UN Convention on the Rights of Persons with Disabilities (UN CRPD, 2006) is of great importance to foster universal human rights and inclusion of persons with disabilities. The convention is regarded as an integral part of a movement that has affected a shift from the so-called medical model to the social model, a change of how disability should be perceived: from an individual deficiency or deviation as a constructed norm as such to a problem rather created within and by the society – denoting the paradigmatic change. The slogan "Nothing about us without us" is symbolic for the strive of persons with disabilities for inclusive human rights implementation. While the author's general research interest is about the implementation of the UN CRPD in East Africa, this paper I will focus on how interest groups as stakeholder advocates, represented by umbrella organizations are included in the process of implementing the UN CRPD within Uganda, Kenya and Tanzania.



Introduction

Little significant interest groups research has been done on Sub-Saharan African states. As Thomas/Hrebenar (2008) link interest groups to democracy development they point out that the external setting for interest groups in developing countries in general differs from the more commonly studied political systems of developed countries. Hence they call for using existing interest group theory but adapting it to the circumstances of the developing democracies since they manifest characteristics which are particular to them. According to them there are five patterns influencing interest groups and the interest group system in developing countries: a) restricted autonomy of interest groups from their authoritarian past, b) special interests are often viewed as illegitimate even in new democracies, c) informal groups are the norm opposed to associational interests, hence many interests may be informal and not institutionalized, resulting in often unofficial and loosely organized groups, d) there are less formalized strategies and tactics, not because they are not known but rather due to having no experience of them being used, and e) interests and interest groups are less significant vehicles of representation. They summarize these characteristics as interrelated factors which explain why “the knowledge of the role and importance of interest groups and their acceptance as a political vehicle is generally very low in developing democracies” (Thomas/Hrebenar 2008: 7).

The UN Convention on the Rights of Persons with Disabilities (UN CRPD) is a human rights treaty which was adopted in 2006 and came into force in 2008. It is both a development and human rights instrument as it promotes the full and effective participation and inclusion of persons with disabilities within society. The convention also marks the so-called paradigmatic change from attitudes and approaches where persons with disabilities were considered objects of charity, social protection and medical treatment to subjects of human rights, able to make decisions on their own behalf, claim their rights and capable of being active members of society. While disability is understood as an evolving concept, the Preamble of the UN CRPD acknowledges that “disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (UN CRPD, Preamble (e), 2006).

WHO estimates that approximately 15% of the world’s population are persons with disabilities, 80% of whom live in developing countries (World Report on Disability 2011). Despite their high numbers, persons with disabilities belong to the most vulnerable and marginalized groups in society. They face



stigma, unemployment, lack of resources and poverty, inter alia, and, hence, are often excluded within society.

In general, the focus of my research studies how the UN CRPD is being implemented in East Africa, in particular within Uganda, Kenya and Tanzania. It seeks to analyze in a comparative way which different forms the implementation is taking on in each country, how different kind of stakeholders and advocates are involved in the process and which aspects and characteristics may cause different approaches and strategies in the implementation of the UN CRPD.

Article 4 of the UN CRPD sets out the obligations on states parties. In particular article 4 (3) calls upon state parties to consult and involve persons with disabilities:

“In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.” (UN CRPD, 2006)

In particular, disabled people's organizations (DPOs) and their national umbrella organizations and representatives are referred to and consulted the most. The slogan ‘Nothing about us without us’ relies on the principle of participation and presents the belief that no decision shall be made affecting persons with disabilities without their full and active involvement.

It is for the multitude of approaches of and towards interest groups of persons with disabilities within the implementation process of the UN CRPD, the setting within developing countries as well as the little research done on interest groups in an also transnational comparative analysis in general which suggest to take a closer look at their structural performance.

In order to do so, so far 22 expert interviews have been conducted in Uganda, Kenya and Tanzania in 2012 and 2013. On national levels interviews covered experts from parliament (MPs) and ministries (governmental and related stages), monitoring agencies and semi-independent-governmental institutions (intermediate stages) as well as interest groups of persons with disabilities and non-governmental institutions/organizations (independent stage). Moreover a number of interviews were also conducted on international level with expert of the *East African Legislative Assembly*, the *East African Federation of the Disabled*, the *African Rehabilitation Institute* (an under-organization of the African Union) and the *African Decade of Persons With Disabilities*. Interviews were then analyzed using qualitative research methods.



Some of the findings suggested to be paying greater attention to the particular role of interest groups of persons with disabilities in their characteristics and settings of external and internal circumstances as well as to the pattern of collaboration between government and its respective institutions and representatives of persons with disabilities.

The Role of Umbrella Organizations

The three largest countries with the highest population in East Africa - Kenya, Uganda and Tanzania - together with Rwanda and Burundi make up the East African Community (EAC), a federation of East African states to promote regional integration. Of these currently five EAC member states Burundi is the only country which has not ratified the UN CRPD. Unlike, for example, the EU, this prevents the East African Community from formally confirming the Convention. Its implementation in East Africa, however, is of particular importance:

"Households with a person with a disability have higher rates of poverty than households without disabled members. As a group and across settings, people with disabilities have worse living conditions and fewer assets. Poverty may lead to disability, through malnutrition, poor health care, and dangerous working or living conditions. Disability may lead to poverty through lost earnings, due to lack of employment or underemployment, and through the additional costs of living with disability, such as extra medical, housing, and transport costs." (WHO, World Report on Disability 2011: 39-44 and 263)

Uganda, Kenya and Tanzania have signed the UN Convention on the Rights of Persons with Disabilities in 2007 and ratified in 2008 and 2009 respectively. Uganda and Tanzania also opted for the Optional Protocol¹.

As acknowledge in Article 4 (3) of the UN CRPD and reflected by the slogan "Nothing about us without us" persons with disabilities play a significant role in the implementation of the Convention. On the one hand including PwDs in the implementation process suggests for an optimal framework, a more coordinated course of procedures and sustainability of actions by including the people

¹ UG 30.03.2007/25.09.2008, with Optional Protocol; KE 30.03.2019.05.2008 without Optional Protocol; TZ: 30.03.2007/10.11.2009, with Optional Protocol

addressed by the Convention. Government representatives, non-governmental organizations and other stakeholders involved in the process of implementation, therefore, increasingly consult persons with disabilities in order to make the implementation of the UN CRPD as inclusive and all-embracing as possible. Most notably organizations of persons with disabilities (disabled people's organizations, DPOs), which organize themselves collectively as representatives of PwDs, are approached. These DPOs also exist in Uganda, Kenya and Tanzania. Furthermore, they have established national umbrella organizations and due to this role are therefore, most often, the primary stakeholders consulted.²

On the other hand, the inclusion of persons with disabilities and their representatives is not self-evident or a matter of course, however. The adaptation of existing and creation of specific laws and regulations, policies and other measures to protect and guaranty the rights of persons with disabilities are often only the results of the long and continuous efforts of dedicated stakeholders in the respective countries:

„After ratification all our efforts were directed to lobby for the enactment of the national legislation in that respect. (...) Picking from experience, waiting for the government bureaucracy (sic) to set all the Systems on track to sing and walk disability in their daily plans, programs and budgeting would delay basic rights.” (SHIVYAWATA 2011: pp 1-2)

The role of being important stakeholders which is ascribed to them by Article 4 (3) of the UN CRPD but also which they apply to themselves is an essential cause for including PwDs and their representatives as consultants, mainly in form of DPOs and their umbrella organizations.

Frequently DPOs and the national umbrella organization are the ones which also point towards a serious dilemma: not only do Uganda, Kenya and Tanzania lack formal detailed laws and basic resources such as budgets to implement the Convention accordingly but more often the lack of actual political will hinders the transmission of the Convention into practice. Hence, DPOs and umbrella organization (may) also act as a barometer towards implementation, assessing and indicating on the actual efforts made by their respective governments.

² DPOs as follow are understood as more or less formally organized groups of persons with disabilities, each usually made up my people with the same or similar impairments: i.e. persons with autism, albinism, blind etc. Umbrella organizations are understood as at least one organization comprised of a number of different DPOs meant to be working together and representing the interests of all member DPOs with one voice. These are in UG: NUDIPU and NUWODU; in KE: UDPK; in TZ: SHIVYAWATA.



Cleavages

1. Grass-Root Dilemma: Stakeholder Diversity versus Selective Representation

The role which is commonly attributed to DPOs shall be a starting point to having a closer look.

In particular three observations can be made:

- 1) Umbrella organizations often predominantly represent persons with physical impairment.
- 2) Representative of umbrella organizations (i.e. directors) often also belong to the groups of the physically impaired.
- 3) In addition, lead representatives of DPOs and umbrella organizations alike often have a rather minor impairment themselves.

The consequences are manifold. However, attention should be given to the tendency of umbrella organizations to represent persons with disabilities un-equally, i.e. by the fact that persons with mental, cognitive, chronically illnesses, multiple and severe impairments are less present. Moreover, umbrella organizations mostly operate in urban areas, while the majority of the population in Uganda, Kenya and Tanzania live in a rural environment (WHO, World Report on Disability 2011: 28).

These observations are revealing insofar as they sharply contrast with the commonly diverged image of umbrella organizations representing a uniform, near homogeneous group of people – those of “persons with disabilities”.

2. The Intra-Disability Dilemma: Competing for Resources

A combination of existing resource scarcity, a) of necessary financial resources, and b) power, especially in form of the possibility to influence the will of particular members of the government, but also the government as a whole, and c) the number of different organizations leads to conflicts over power and resources among each other.

Thereby DPOs act in different forms:



- I. They act as representatives and stakeholders of each specific group of people according to the form of medical impairment, such as visually or hearing impaired, people with epilepsy, etc.
- II. In addition, a number of these specific DPOs often form coalitions and unite in at least one national umbrella organization³, which shall speak with one voice for the interests of all persons with disability nationwide and represent them to the respective governments and other stakeholders such as non-governmental organizations and so on.

As already pointed out with regard to the grass-root dilemma described above, umbrella organizations are coalitions of their member organizations only⁴. In this respect, it is also important to be aware of the condition that, strictly speaking, only the interests of its members may be represented.

A thorough and complete representation of the whole extent of the various interests of all persons with disabilities by national umbrella organizations, therefore, cannot be guaranteed. The result is an over-representation of some specific groups of PwDs, while under these circumstances the influence of others may be deprived.

The scarcity of resources and the large number and diversity of DPOs eventually lead to the above mentioned competition, which may vary temporarily as well as in its degree. If internal arguments within umbrella organizations add to the situation, unforeseen consequences may arise: since national umbrella organizations are the predominant consultant for the government, NGOs etc. internal arguments and conflicts among the interest groups in coalition may lead, inter alia, to a lack of credibility and efficiency of these umbrella organizations. Eventually it may also result in the rejection of joint collaboration on the part of government officials etc. It would have serious negative consequences for the implementation of the UN CRPD and the rights of people with disabilities.

3 In some countries such as i.e. Uganda more than one umbrella organization exists: while NUDIPU represents all persons with disabilities, NUWODU in particular acts for the special interests of women with disabilities.

4 For an example refer to Tanzania: "The Tanzania Federation of Disabled People's Organizations" (SHIVYAWATA) is a coalition of 9 member organization: Tanzania Albino Society (TAS), Tanzania League of the Blind (TLB), Tanzania Association of the Physically Handicap (CHAWATA), Tanzania society of the Deaf (CHAVITA), Tanzania Association of the Deaf – Blind (TASODEB), Tanzania Association for the Mentally Handicap (TAMH), Kilimanjaro Association of Spinal cord Injuries (KASI), Psoriasis Association of Tanzania (PSORATA) und Tanzania Users and Survivors of Psychiatric Organization (TUSPO). See Shivyawata profile, as per Dec. 2012.



Extensive Consequences

The scarcity of resources which were already mentioned also reflects in a more or less prevalent government will to implement the UN CRPD. It is associated with the distribution of funds, the amendment and adoption of laws and regulations etc. However the national umbrella organizations joint stakeholders of persons with disabilities also compete with other interest groups, advocates and stakeholders of groups from economy, politics, etc. for these scarce resources.

Having said this, maladjustments within umbrella organizations can be observed: contrarily to following a common agenda and speaking with one voice, representatives of DPOs within umbrella organizations often still predominantly follow individual interests of their member organizations. Since these representatives are often affected by physical as well as minor impairments only, conflicts within the umbrella organizations also have an important impact on working and collaborating with the respective governments.

In addition, a in some respects somewhat little reflected (self-) perception and understanding of DPOs as a homogeneous group - hence "persons with disabilities" - also results in problems, as it neglects substantial differences between the various impairments and the individual person's needs. Unfortunately this occurs not only by persons without disabilities but it also happens among the groups of PwDs. Causes for the latter can be accounted for little awareness among DPOs themselves. It often seems that representatives themselves are not aware of this problem as within umbrella organization they try to speak with one voice; on the other hand, however, they still tend to pursue more individual objectives in regard to the implementation of the UN CRPD. The needs and consequences for other persons with disabilities are getting neglected in spite of the collaboration within and coalition as national umbrella organizations.

1. Consequences on National Scale

The consequences of the grass root- and intra-disability-dilemma may have serious consequences for an all-embracing and inclusive implementation of the UN CRPD.

In collaboration between the government and disability interest groups under-representation of certain groups of persons with disabilities might be the case, despite general participation of people with disabilities. In addition, there may be an undue preference of PwDs with minor and primarily

physical impairments. As a result of representation by umbrella organizations conclusion can be drawn that some persons with disabilities tend to be more equal than others.

The diversity and complexity of the stakeholders and interest groups involved are evident by pointing towards the made observations. Accordingly, these circumstances should be kept in mind when analyzing the collaboration of all stakeholders but also when assessing a participatory approach.

2. Consequences on International Scale

When implementing international treaties states usually do not work in total isolation. Interdependencies and efforts for regional integration have rather gained more and more importance in the wake of globalization. However, international cooperation is not just related to governments but can also be observed when looking at regional and transnational networks, i.e. such as international coalitions of interest groups. As such national DPOs, umbrella organizations and stakeholders from Uganda, Kenya, Tanzania and also other countries use joint conferences, workshops and meetings in order to exchange ideas, learn from best practices of other members and develop common strategies for the implementation of the UN CRPD.⁵

Within the EAC special attention should be paid to Kenya's influence on other member states, hence on Uganda and Tanzania as well. On the one hand side, Kenya domestically comes with important resources, such as the political will to implement the UN CRPD, but also to actively include persons with disabilities in this process. To a certain extent fiscal resources are also allocated, in order to i.e. implement and monitor disability mainstreaming in all Kenyan ministries⁶.

"With the creation of a National Development Fund for PWDs, the Government availed 2.7m USD to the Fund in FY 2009/2010, which has increased to 7.9 million USD in FY 2011/2012 and will continue to increase in the future; [] One of the oldest Trust Fund in Kenya established in 1981, the National Fund for the Disabled of Kenya, whose patron is the president, currently receives 0.8 million USD annually from the Government to

5 Among others the East African Federation of the Disabled (EAFOD) and the Ecumenical Disability Advocates Network (EDAN) respectively are examples of such transnational networks operating within East Africa and even beyond.

6 Since 2009 the government of Kenya seeks to implement disability mainstreaming in all public government institutions (EAC 2012: 19). A set of indicators is used to monitor the actual implementation regularly by analyzing reports which every such institution has to turn on a quarterly basis.



enhance provision of appliances, equipment, economic empowerment and institutional infrastructure for PWDs." (EAC 2012: 20)

On the other hand, for the implementation of the UN CRPD Kenya puts much emphasis on its legislation, in particular with regard to legislative regulations and amendments adapting to the new Kenyan constitution which came into force in 2010. The jointly operated *Census Committee* by the government and disability stakeholders shows that despite the participation of representatives of PwDs an all-embracing implementation of the UN CRPD still requires continuous and mutual efforts; among others, more attentions should be paid to common language used as an example. to give the used language / word choice more attention.

With a population of more than 43 million people⁷ and as the economically⁸ strongest member of the East African Community Kenya also exercises significant impact on the region. Due to its size and strong economic position⁹ in the region Kenya largely influences the East African Community and thereby the other member states as well. This way considerable pressure is put on Uganda, Tanzania, Rwanda and Burundi.

Frequently it is suggested that neighboring countries should take after the Kenyan example and do it alike by copying (from) the Kenyan model for implementing the Convention. Yet in these cases it is forgotten that the Kenyan approach – by focusing on the legislation – may or does not necessarily be the right solution for other countries.

After all what needs to be kept in mind is the time pressure Kenya is exposed to after adopting its new constitution; in fact it should not distract the attention from deficits in its sustainable process and therefore could have unintended negative effects on emulating countries taking after the Kenyan example without deliberate consideration.

7 Kenya has the second largest population within East Africa. While Tanzania places first with a population of 48 million people, Uganda places third with 36 million inhabitants, all in 2012. Rwanda marks 11.5 million people and Burundi around 10 million in 2012. See World Bank (a) 2012.

8 In 2012 Kenya's economy had a GDP of 40 billion USD. In comparison: Tanzania 28 billion USD, Uganda 20 billion USD, Rwanda 7 billion USD and Burundi 2.5 billion USD. See World Bank (b), 2012.

9 In 2008 Kenya's share of intra-EAC-export trade with Uganda and Tanzania amounted to 67.2%. Tanzania constituted 20.1%, while Uganda's share made up 12.7%. See EAC 2010: 18.

Conclusion and Transferability of the Case Studies

Based on the observations and remarks made it was shown which significant role DPOs and their national umbrella organizations play in regard to the implementation of the UN CRPD.

Due to, inter alia, Article 4 (3) of the Convention and the demand for effective participation in decision making PwDs are increasingly being consulted in the process of implementation and act as representatives of 'persons with disabilities' in general. While no indicators were found regarding pattern b) as described by Thomas/Hrebenar (2008), it can be concluded that pattern e) has less impact under the particular circumstances in Uganda, Kenya and Tanzania since all signatory states of the UN CRPD are obliged to consult the interests of PwDs.

A diverged (self-) perception of DPOs combined with a lack of professional staff education, at times, and strategic professionalism can be identified as related to Thomas/Hrebenar (2008) pattern d). While pattern c) can be identified as internal and external competition and conflicts over scarce resources, resulting into deficits and a loss of efficiency among stakeholders, pattern a) related to still existing structures and hierarchies of the countries' authoritarian past are prevalent in collaboration between interest groups and the government, and eventually also in terms of the implementation of the UN CRPD. The consequences may be a protracted process of implementation and indeterminateness, as well as a pertaining risk of an either increased or decreased consideration of certain groups of persons with disabilities, i.e. on grounds of medical impairment, severity or even regional dispersal.

Hence, it is apparent how manifold the role of umbrella organizations and representatives of persons with disabilities is and it stresses the point of the importance of including a larger number of various representatives of PwDs in consultations, yet it also cautions not to over-estimate the role of individual stakeholders in being able to represent *all "persons with disabilities"*.

Although this paper is based primarily on research conducted by expert interviews in Uganda, Kenya and Tanzania in the years of 2012 and 2013, it can be assumed that the identified observations, efforts and obstacles are not exclusively a problem of the three countries analyzed but rather share, as Thomas/Hrebenar (2008) mention, some common characteristics which can be found in many developing countries and even beyond. Future research on disability interest groups in developing countries should, therefore, pay increased attention to the identified ambivalences and contradictions of representation, influence and impact as well as the diverse role of disability stakeholders based on the pertained perception by the government, other institution and



organizations as well as by representatives of PwDs themselves. Based on the current state of knowledge it is expected that the findings of this paper can also be observed in other signatory states of the UN Convention on the Rights of Persons with Disabilities and thus are transferable to a wider range of countries.



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