

JIP Final Report

Human Rights-Based Approach to Disability and Health in Development Cooperation: Perspectives from the South.

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1. Summary

Disability and health are human rights issues. The mainstreaming and implementation of these development themes is a complex process both in North and South particularly because many actors are involved under the peculiar development cooperation system. We have highlighted some of the main challenges in our previous work.¹ While the disability case study in the previous research focused on Northern actors, it did not focus on the Southern stakeholders at the other end of the spectrum. The study on health focused on mainstreaming and implementation in the South but did not go deep enough. In the current research, we introduce the human rights-based approach (HRBA) as a beneficial tool in the analysis of disability and health. The HRBA is more effective than single thematic issues such as disability or public health. Therefore, we took HRBA and elaborated it and used it as our analytical tool in the operationalisation process in this study. Particular focus of the disability study was on self-determination of Southern stakeholders in development cooperation activities in Uganda with the special attention to the experiences of deaf women on the grassroots. On the other hand, the health study explored the role and contribution of donors in the countries' efforts to further the right to health through government and civil society organisations.

2. Introduction

“Wherever we lift one soul from a life of poverty, we are defending human rights. And whenever we fail in this mission, we are failing human rights.”
(*Kofi Annan* – Former UN Secretary General)

Contemporary human rights discourses can be traced back to the United Nations Universal Declaration of Human Rights (UDHR) of 1948 (Annas, 2005). In 1986 the United Nations (UN) made a Declaration on the Right to Development which establishes the view that development is a human right (Andreassen and Marks, 2006). Rights such as the right to “enjoy the best attainable state of physical and mental health” have been emphasized in many other charters such as the International Covenant on Economic, Social and Cultural Rights (ICESCR) and in Article 16 of the African Charter on Human and Peoples Rights (United Nations, 1966; African Union, 1981; Gruskin at al, 2005; Singh, Govender and Mills, 2007). Hence, the HRBA has

¹ The previous JIP project was titled “Health and Disability in International Development Policy” (2006-616 JIP-01). The current project emanates from this research. Our long-term vision is to build on this work as a long-term program that can develop analytical tools to help improve performance outcomes and lasting benefits for the beneficiaries of donor assistance. We envision a 3rd year social action project to be implemented on the ground in recipient countries.

emerged as a critical tool in the analysis of international development (Gruskin, Mills and Tarantola, 2007; Gruskin, 2006; Sarelin, 2007; Byrne, 2005; Hamm, 2001).

Whereas human rights is a normative concept based on international human rights laws, international development cooperation must reflect the rights-based approach (Sarelin, 2007:461). This is because development and human rights can be viewed as intertwined (Hamm, 2001: 1005). The human rights approach to development assistance, as articulated by the Human Rights Council of Australia in 1995 affirms “that a body of international human rights law is the only agreed international framework which offers a coherent body of principles and practical meaning for development cooperation, [which] provides a comprehensive guide for appropriate official development assistance, for the manner in which it should be delivered, for the priorities that it should address, for the obligations of both donor and recipient governments and for the way that official development assistance is evaluated.” Hence, the HRBA is an analytical tool for designing, implementing, monitoring and evaluating development intervention programs (Gruskin, Mills and Tarantola, 2007).

Literature on the Human rights Framework – Five Approaches to Human Rights

Stephen Marks (2001) discusses five approaches in the human rights framework relevant to development. Firstly, human rights are indivisible, interdependent, interrelated and of equal importance and hence their realisation must be taken holistically. This holistic approach and the ‘full realisation’ of all rights is emphasised in a number of documents such as Article 28 of the UDHR, in Declaration on the Right to Development, the 1993 Vienna Declaration and Program of Action, and in the Maastricht Guidelines on Violations of Economic, Social and Cultural Rights, adopted by a team of experts in 1997, and by the 1998 UNDP’s policy paper on *Integrating Human Rights with Sustainable Human Development* (Marks, 2001; UNDP, 1998). As paragraph 2 of Article 6 of the Declaration on the Right to Development states, equal attention and urgent consideration should be given to the implementation, promotion and protection of civil, political, economic, social and cultural rights” (United Nations General Assembly, 1986).

In contrast, historical practice has treated civil and political rights (CPR) as of immediate applicability and the economic, social and cultural rights (ESCR) as of relative importance realised progressively (Marshall, 1965). Yet, this gradualism ideology is still prevalent in some countries, most notably South Africa in subsection 2 of Article 27 of the otherwise progressive Bill of Rights (Wamai, 2006). A second approach regards development *as* a right not as charity (Katsui and Kumpuvuori, 2008). This is manifested in the Declaration on the Right to Development (DRD) wherein development is a matter of justice and hence any intervention has to be rights-based and focused and not merely charity.

Thirdly, states and other non-state actors are seen as having a legal obligation to fulfilling the rights (whether perfectly or imperfectly) (Marks, 2001; Sarelin, 2007; Katsui and Kumpuvuori, 2008). This accords transnational obligation and gives legitimacy to interventions guided by international law (Khan, 2005). Under ICESCR Article 2 while states have *positive* obligations to take “deliberate, concrete and

targeted [steps] towards the full realization of the rights”,² they can do so “individually and through international assistance and co-operation, especially economic and technical” (UN, 1966). The responsibilities or duties approach is further enshrined in such normative instruments as the UDHR (Article 29:1), African Charter on Human and People’s Rights (Article 27), preamble to the 1966 International Covenants on Human Rights, DRD (Article 2:2), and Convention on the Rights of the Child (Article 5) (Marks, 2001).

A fourth approach in the human rights and development framework is that of participatory action and community mobilisation. “The most effective means of enhancing people’s capabilities is to facilitate their own social transformation through participation in the decisions that affect development” (Marks, 2001: 16). The means to achieve this is through *education* and *teaching* as mentioned in the preamble of the UDHR. Marginalized groups of people must be involved into the mainstream development discourse (Katsui and Kumpuvuori, 2008). Engaging people empowers them not only to claim their right but also expands their opportunities to realise the right (Sarelin, 2007: 477). Human rights education can contribute to development in five ways: it can help mobilise support for the marginalised people’s quest for social justice; promote understanding of development rationale; help secure effective participation in development process; help hold to account public officials; and help to monitor development activities (Dias, 1997: 52-53).

The fifth approach is based on Amartya Sen’s capabilities approach and its definition of deprivation in his Nobel Prize winning book, “Development as Freedom” (Sen, 1998). In this approach, deprivation of basic needs such as food, health and education makes a person incapable to function. Such a person is robbed of the basic rights and freedoms enshrined in major principles of UDHR and the ICESCR such as the right to life and health (Nussbaum, 1999).

As we can see the foregoing, the HRBA conceptualises underdevelopment as a form of violation of human rights (Marks, 2001; Hamm, 2001; Sarelin, 2007). The practice of rights-based approaches in international development cooperation today is most poignantly manifested in the 2000 UN Millennium Development Goals and the 2002 Monterrey Consensus of the International Conference on Financing for Development. Under ICESCR Article 2 while states have *positive* obligations to take “deliberate, concrete and targeted [steps] towards the full realisation of the rights”,³ they can do so “individually and through international assistance and co-operation, especially economic and technical” (UN, 1966). The latest UN Convention on the Rights of Persons with Disabilities has an independent provision on international cooperation as a transnational obligation (Katsui, 2008-a). Taking into account the Declaration on the Right to Development, international development cooperation has a key role in furthering the realisation of core basic human rights such as health and education to all peoples including those with disabilities.

² General Comment No. 14, supra note 30, paragraph 30; General Comment on the Nature of States Parties Obligations, General Comment No. 3, at 9, paragraph 130, U.N. Doc. E/1991/23, paragraph 9 (1990).

³ General Comment No. 14, supra note 30, paragraph 30; General Comment on the Nature of States Parties Obligations, General Comment No. 3, at 9, paragraph 130, U.N. Doc. E/1991/23, paragraph 9 (1990).

3. The Project: Description and Research Methodology

Our main objective was to investigate the perspective of the Southern stakeholders under the operationalisation of development cooperation to disability and health respectively. HRBA was an analytical tool throughout the research with a special focus on the self-determination of Southern stakeholders. In order to attain the objective, we conducted two case studies. The first focused on the operationalisation of a HRBA to disability in development cooperation activities in Uganda from the perspective of Ugandan deaf women (Katsui) and the second focused on ethical considerations in resource and program prioritisation in donor health interventions in Kenya and Ethiopia (Wamai). We both devoted one-three months in the field for the research to collect data with qualitative methods, namely interviews of key informants and observations of relevant activities.

The Disability Study in Uganda

Katsui's study elaborated the operationalisation of a HRBA in the framework of development cooperation activities in Uganda. Special attention was paid to the experiences of different stakeholders in the activities, particularly deaf women on the grassroots. This perspective enabled the understanding that the operationalisation of HRBA to disability in development deeply involves negotiation between HRBA and charity-based approach. This negotiation was analysed and further connected to the concept of solidarity (Katsui, 2009).

When it comes to the methodology, organisations of persons with disabilities (DPOs) as well as individual persons with disabilities (PWDs) were actively involved in the research process right from the beginning to set the research agenda. In addition to consultations with key informants in the field, this study applied participatory research method as a secondary objective of the research so that the research process and findings did not exploit the researched people merely as a source or object of research, but were empowering to them. This research method is based on the human rights principle of participation. The method is challenging in the Southern context (Katsui and Koistinen, 2008) but nevertheless imperative particularly because the target groups were relatively powerless people in their social structure. Three research assistants who are women with disabilities themselves facilitated the fieldwork and assisted with local and personal knowledge on disability in Uganda. Before and after the fieldwork, continuous dialogue has taken place with many DPOs and individual PWDs concerning Katsui's writings. Interviews and observations were digitally recorded and transcribed under the consent of the research participants/ informants. The collected data was analysed thematically. Whenever the results were published or presented in public, the draft papers were first sent to the interviewees for review and comments. The participation has dramatically increased as time goes, thereby more relevant knowledge has been created. Katsui's second visit to Uganda in December 2008 with the travel scholarship from the Nordic African Institute also facilitated the communication with the Ugandan disability activists and PWDs. However, deaf women at the grassroots, who have not learned any language/mother tongue, were only interviewed through their family members and did not participate in the research process as much as others. This was a limitation and challenge that this study could not overcome with this short period of the research project timeframe.

Limitations of the Research

To some extent, the participatory method succeeded in enabling Southern stakeholders under the selected activities to be meaningfully involved in the research process and created relevant knowledge for them as well as academic knowledge to fill the literature gaps. However, we also found out through our experiences that a participatory research approach requires long-term commitment and investment of various resources, which a research project of this kind cannot overcome. This finding through our research approach has some implications in our academic findings as well.

The Health Study in Kenya and Ethiopia

This study explored the role and contribution of the Department for International Development (DFID) of the UK and the Japan International Cooperation Agency (JICA) to further the right to health in Kenya and Ethiopia. Taking the two donors and countries as case studies, the study evaluated ethical considerations on such issues as participation, equity, quality, accessibility, affordability and sustainability in health sector financing and programming. The research explored operationalisation mechanisms in which international human rights principles should become reality in Southern countries sought to clarify the role of Southern actors in this process. The findings shed light on development cooperation activities and give voice to the most important lens in addressing health: human rights. The findings also highlight prioritisation strategies for health in the face of limited resources and major healthcare needs, and in aid effectiveness frameworks such as the 2005 Paris Declaration of Aid Effectiveness.

The research used qualitative methods, namely interviews of key informants and quantitative analysis of the donor supported health projects. Diagnostic questions include: considerations and balance given to need vs. other factors in prioritising financing programs/projects; considerations for cost-effective vs. equity strategies to implementation; inclusion of stakeholders at all levels of the program/project cycle; continuous learning and feedback in the development process through evaluation and consultation. Based on the review of the literature on assessing health and human rights, the study developed five discussion areas. The areas comprised: 1) the input of human rights based approaches in framing and informing development planning; 2) the level of participation by local stakeholders in planning and implementation; 3) the donor identification of rights bearers and duty holders; 4) accountability and transparency; and (5) awareness of the obstacles to realizing the right to health (see Wamai's individual report for details). In addition to these, funding levels were evaluated to assess the level of participation by the donors to furthering the efforts towards the right to health in the recipient countries. Results from this study are presented along these thematic areas.

Limitations of the Research

The major limitation of this study was availability of data, time and resources. Senior officials in the donor agencies are usually extremely busy and often out of the country. Thus securing time for consultative meetings within the time allotted for the research in the field proved to be a major challenge. While one can assess policy documents and other data, while those are available, such consultations are absolutely essential for teasing out and clarifying key issues and processes. It is acknowledged that this study could have benefitted much from extensive follow-up consultations but these

were generally thin in detail. Nevertheless, the application of a human rights framework requires availability of verifiable documentation. Such availability may be taken as an indication of robustness in the effort of an actor (or duty bearer) in meeting the human rights principle of transparency and accountability (Sarelin, 2007; Marks, 2001). The research triangulated the consultations with such documentation where available.

4. Results of the Studies

This part presents findings from the two studies respectively. See Appendix 1 for the achievements of the project in terms of our publications and conference presentations.

Findings from the Disability Study in Uganda

Situational Analysis of Disability and Development in Uganda

Uganda is an interesting case in which development and disability discourses meet and have been negotiated. It is a ‘developing country’ or a recipient of development cooperation. At the same time, it has the most progressive constitution, cited as a ‘human rights charter’ (Mawa, 2003).

Development of the Ugandan disability movement

In Uganda, the disability organisations started to be established during the 1970s. The idea of forming a national umbrella organisation of PWDs started around 1976, but was hindered by the war between Uganda and Tanzania in 1979-1987. In 1987, PWDs in the Ruti Rehabilitation Center in Mbarara and the Kireka Rehabilitation Center in Kampala realised the idea of forming the organisation as the National Union of Disabled Persons of Uganda (NUDIPU) (Ndeezi, 2004:10-11). 17 DPOs joined NUDIPU. This was the first of its kind in the African continent (ibid.12). Without assets and money, voluntary work and contributions of members enabled the activities in the beginning. This spirit is said to have led the NUDIPU into “one of the strongest national advocacy and lobbying organisations championing the cause of marginalised groups in Uganda” (ibid.17). The ruling political party, the National Resistance Movement (NRM), has morally facilitated the growth of disability movement (ibid.17).

The main achievements of the Ugandan disability movement include the Ugandan Constitution of 1995. The rights of persons with disabilities were specifically stipulated already in the Constitution 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 realise their full mental and physical potential.” Concrete positive changes, for instance, have taken place in creating political space for representatives with disabilities. After the enactment of the Local Government Act of 1997, affirmative action policy has been introduced to the local government structure for the marginalised groups of people including women, disabled people, youth, workers and the army. Since then, all those groups are represented in Ugandan politics at all levels including the Parliament. More precisely, Uganda has a quota system where five Members of Parliament (MPs) represent PWDs: Four MPs from four regions (Central, East, West, North) and one woman with a disability. Their sign

language interpreters and personal assistants are paid by the government. An interesting fact is that in the 2006 national election, two former MPs representing PWDs stood for the positions outside of the disability quota framework and also passed through. Both of them are women with disabilities (WWDs). Therefore, there are seven MPs with disabilities in the Parliament at present linked to the disability movement. Moreover, 47,000 disabled councillors work in the local government structure, of which half are WWDs. In 1998, the State Minister for the Elderly and Disability Affairs was created under the Ministry of Gender, Labour and Social Development. This Department addresses the issues of disability, though with resource constraint. In 2006, the National Disability Act was adopted which further stipulates the rights of PWDs in Uganda. The visibility of PWDs in the political space is an outstanding achievement of the disability movement in Uganda. At this political level, it is not over-romanticising to mention that the Ugandan disability movement has achieved a lot, although the introduction of the multiparty politics in 2006 to some extent fragmented the disability movement.

The Ugandan disability movement is also visible in the international sphere. Former Member of Parliament representing PWDs, James Mwandah, represented Uganda in the making process of the UN Convention. He has also served as a board member of the Global Partnership for Disability and Development from the beginning. Uganda was one of the first countries to have signed the UN Convention on 30.3.2007, on the day when the Convention opened for signatory. Uganda ratified the Convention in September 2008.

DPOs and development cooperation in Uganda

Development cooperation is a significant part of the Ugandan government, because more than half of the national budget is dependent on donor assistance (USAID, 2005). When it comes to the DPO budget today, all the interviewed DPOs also claimed that they are fully dependent on development cooperation funding. Ndeezi (2004:38) claims that 99% of the DPO budget is coming from abroad. In the 1990s, the number of NUDIPU memberships grew to almost 70 associations, and more capacity was required for the NUDIPU to correspond with the members. The NUDIPU then approached the Danish Council of Organisations of Disabled People (formerly the DSI, presently the DPOD) and began development cooperation activities. The Oxfam UK Kampala Office and the Norwegian Association for the Disabled (NAD) were also the first ones to have supported the NUDIPU. At around the same time, other DPOs also started to be engaged in development cooperation activities. This coincides with the time when the role of civil society started to attract attention in development in general, and when persons with disabilities started to be included at last. These international trends also involved Ugandan DPOs and left “the danger of running irrelevant and unsustainable donor-driven programmes and projects” by undermining local initiatives (Ndeezi, 2004:38). Despite the acknowledged risk, development cooperation has become indispensable for DPOs for running their activities today. Under the resource constraints of the government, “there is tendency (in Uganda) to look at disability issues as donor responsibility” (Kangere, 2003:5) in spite of all the human rights-based laws and the representation structures. Thus DPOs, with the support of the Northern counterparts, are expected to fill the huge gap between laws and implementation (Chairperson of the NUDIPU, 2008).

Deaf women in Uganda

Statistically, 0.3% of the population is estimated to be deaf (excluding hard of hearing), of which 90% are born in to families of hearing parents (Saito, 2007:44). This means deaf persons are few and far between, and most of them do not automatically learn sign language as a mother tongue at home. These characteristics are applicable also in Uganda. The focus of this study is on the experiences of deaf women because they are mostly left at home, both in urban and rural areas of Uganda (Lwanga-Ntale, 2003). “In the rural communities of Uganda, women are basically regarded as some of the objects or assets owned by the husband” (DSI, 2007:3). Thus, disability and related discrimination hits harder on WWDs than on men with disabilities (Ministry of Finance, 2008). For instance, the opportunity for receiving an education is not often given to deaf girls as much as to other siblings. Boys are the first priority, while girls without disability are the second priority. Education for girls with disabilities is considered as ‘a waste of money’ (Gender Officer of UNAD, 2008). Therefore, many deaf girls’ education ends at the primary level, if they get any formal education at all (Gender Officer of UNAD 2008). This was true for Katsui’s interviewees who were deaf women on the grassroots. Consequently, many deaf women are illiterate and do not have good sign language skills either (Deaf MP/ Executive Director of UNAD, 2008), which leads to limited employment opportunities. Many deaf women work as house maids or cleaners for richer families, but are paid little or none, as employers take advantage of their illiteracy and limited communication skills for reporting any maltreatment (Chairperson of the United Young Deaf Women Group, 2008). This is the general picture of the status of deaf women on the ground in Uganda, despite the positive achievements in the political space.

Case Study: How Are the HRBA and Charity-Based Approach Negotiated?

The non-discrimination principle of human rights is significant to PWDs, who have been marginalised from the mainstream (Katsui and Kumpuvuori, 2008). When a HRBA is applied, this principle finally includes PWDs into the mainstream discourse, in theory. In reality, however, properly including marginalised groups of PWDs such as deaf women is challenging within a short timeframe. This part analyses the training activities of Ugandan DPOs as cases, and elaborates on the experiences of deaf women.

A HRBA is often the starting point for DPOs for implementing their training activities on certain topics such as reproductive health, HIV/AIDS and human rights to their members. They aim at disseminating essential information and raising awareness on personal rights to PWDs who have been left behind from mainstream activities. The Ugandan National Association of the Deaf (UNAD) asserts that the challenges in involving deaf people in their development cooperation projects are due to the illiteracy and lack of Ugandan sign language literacy of deaf people (Mukasa and Nkwangu, 2007:4). This involves difficulties for other non-deaf-specific DPOs in fully involving deaf people. The UNAD further problematises the limitation of hitherto funding for accommodating the special needs of the deaf.

General knowledge of WWDs is limited due to deeply rooted discrimination against them, while the capacity of DPOs is also limited. The reality of WWDs implies challenges for deaf women in development cooperation where they do not have

proper communication means, because they often use local signs rather than the established Ugandan sign language, or even ‘gestures (home signs)’ rather than local signs. Naturally, activities involving deaf people starts first and foremost with sign language training, after which the real training takes place. When one deaf woman was interviewed and asked what she had learned from a training course on HIV/AIDS sensitisation organised by a DPO, she answered as follows:

Onion, tomato, orange, banana, matooke (one kind of banana), cassava, greens. Those (signs) are what I remember. I remember so well. Others are clothes, suits, shoes, blouse, skirts. That's all (Deaf Woman E, 2008).

She might have totally missed awareness raising part of the training but learned the signs essential for her living, which is expected to increase her quality of life. Learning communication skills is so fundamental that it is one of the prerequisites to learning of one's own human rights. These preconditions of people with disabilities on the grassroots, especially those of marginalised groups, are often undermined in development cooperation activities. Deeply rooted discrimination against deaf people has been too big to tackle by a DPO within a single development cooperation intervention, partly because of the existing big awareness gap between DPO staff at the headquarter offices and people at the grassroots level. More time, energy and money have to be invested to build the capacity of people at different levels.

On top of the intra-organisational gaps of awareness towards human rights, the peculiar donor-recipient culture that favours the donor - known as development cooperation system (Tvedt, 1998; Hoksbergen, 2005) - is also a hindrance in the operationalisation of a HRBA. The development cooperation system pressures Ugandan DPOs to produce results with the given resources according to the agenda the donors tend to set for Ugandan DPOs to implement (anonymous interviewees due to the sensitivity). Under these circumstances, a HRBA is compromised, and is easily modified into a top-down type of charity-based approach within the framework. As a result, a shift from a HRBA to a charity-based approach takes place in the development cooperation activities for/of PWDs in Uganda.

The experiences of deaf women are only a small part of those of many other PWDs who do not fully benefit from the on-going mainstream and disability-specific activities. That is to say, more vulnerable PWDs, for whom various prerequisites are not secured, tend to be excluded or cannot fully benefit even from disability-specific activities which originate from a HRBA. When disability-specific projects are failing to operationalise the approach, it is even harder for mainstream programmes to apply it because of the lack of expertise and the competence to properly deal with disability issues. The analysis above verifies that when it comes to PWDs, non-discrimination and equality principles are challenging to implement in practice.

Findings from the Health Study in Kenya and Ethiopia

In order to assess the role played by DFID and JICA and the case for human rights approaches to health in Kenya and Ethiopia it is necessary to understand the healthcare scenarios in the recipient countries. Here we briefly summarise the key health indicators for both countries.

Situational Analysis of Healthcare in Kenya and Ethiopia

With a life expectancy of 45 and 48 years, a poverty rate of 45.9% and 82%, HIV/AIDS prevalence of 7.8% and 1.4%, under 5 mortality rate of 114 and 123, respectively, both Kenya and Ethiopia face daunting healthcare challenges. Yet, despite having about half of Ethiopia's population, Kenya's healthcare system is significantly larger than that of Ethiopia (see Wamai's individual report). In aggregate numbers Kenya has more healthcare facilities (5,129 compared to 4,020) and health personnel (59,000 compared to 45,860) as well as a better ratio of population to health facilities (6,263 compared to 18,657) and physicians (6,424 compared to 26,527); the physician population ratio recommended by the World Health Organization is 1:10,000 meaning Kenya exceeds this ratio.

In both countries availability of healthcare services (by facilities and personnel), utilisation as well as outcome indicators such as infant mortality rate are widely unequal across regions and provinces. According to the 2003 *Kenya Household Health Expenditure and Utilization Survey* (KHHEUS), overall utilisation of health services by people reporting being ill was 77.2%; 22.8% did not seek healthcare (Ministry of Health, 2003). Cost and distance to health facility are the main barriers to utilisation. Per capita utilisation in Kenya as per the KHHEUS is 1.92 visits annually. By contrast, utilisation of health services in Ethiopia remains dismally low at 0.36 per capita (or 36%) (FMOH, 2005).

To finance their healthcare sector Kenya and Ethiopia rely significantly on foreign aid (as much as 16% in both). According to the latest National Health Accounts in 2000, the country governments finance 29.6% and 33%, respectively, whereas households spend 53.1% and 36%, respectively (Republic of Kenyan, undated; FMOH, 2003). Although Ministers of Health in Africa agreed at the 2001 Abuja Declaration to spend 15% of their national government budget on health (Organization of African Unity, 2001), in 2005 Kenya and Ethiopia were spending only 7.9% and 9.6%, respectively (Ministry of Health, 2007). At US\$ 19.2 and US\$ 5.6 in Kenya and Ethiopia, respectively, per capita health spending is way below the world Health Organization recommendation of US\$ 34 (WHO, 2001).

Diagnostic analysis of the findings on the donor health activities

Based on the review of the literature on assessing health and human rights, the study developed five discussion areas with the selected donor agencies (see Wamai's individual report). Table 1 summarises the main results from the research after which each is discussed.

Table 1: HRBA in DFID and JICA's health activities in Kenya and Ethiopia

| Human rights principles → | Human rights-informed development policy | Awareness of the context and obstacles to the right | Recipient-country funding levels for health | Local participation and ownership | Transparency and Accountability |
|---------------------------|--|---|---|-----------------------------------|---------------------------------|
| DFID | Ethiopia | ✓ | High | Lower | Moderate |
| | Kenya | ✓ | Higher | High | Higher |
| JICA | Ethiopia | ✓ | Low | Higher | Moderate |
| | Kenya | ✓ | Higher | High | Higher |

Source: Author

How are the donors development policy informed by human rights?

Two levels of assessment are important with regard to this dimension. One is the extent to which donor policies explicitly acknowledge and incorporate the right to health. Secondly is the extent to which donor policies recognise the recipient country-level legal and policy context. We summarise the relevant policy contexts in donor and recipient countries. Both donor countries have recognised (the importance of) human rights in their policy documents towards the recipient countries. Both the UK's 2006 White Paper and the 2007 Health Policy Paper have recognised and incorporated the right to health (O'Neil et al., 2007). We have also cited Japan's Official Development Assistance White Paper 2007 which has affirmative language on the right to health.

At the country level, in Kenya, the country's social development frameworks are contained in the medium-term PRSP (2000 and 2005) and the long-term policy developed for 2003-2030 known as *Kenya Vision 2030: Driving Change in National Development Across Kenya* (Government of the Republic of Kenya, 2007). In Ethiopia, DFID's Country Assistance Plan of 2003 references support for human rights as an important element for achieving improved service delivery (DFID, 2003). Ethiopia's social-development program, the 2002 medium-term poverty reduction strategy paper (PRSP) termed Sustainable Development and Poverty Reduction Program (SDPRP), recognises the need to further development through improving governance and human rights. Ethiopia's second PRSP is titled Plan for Accelerated and Sustained Development to End Poverty (PASDEP). Both DFID and JICA's aid policy to Kenya and Ethiopia are consistent with these country development policies.

In the specific area of health, both Kenya and Ethiopia are working along cycles of strategic plans or frameworks. To work in harmony with the human rights framework donor countries must recognise the recipient countries' health programs. Kenya and Ethiopia's health policies were published in 1994 and 1993, respectively. Implementation of the health policy in Kenya is being pursued in a series of two five-year documents named National Health Sector Strategic Plan (NHSSP) (Wamai, 2009). In Ethiopia on the other hand, to date three five-year strategies called Health Sector Development Program (HSDP) have been developed (ibid.). Both countries pursue decentralization approaches in health developments which strengthen health delivery at regional (in Ethiopia, with steps underway to deepen the process at *woreda* or district level) and district (in Kenya) levels. The Federal Ministry of Health in Ethiopia articulates decentralisation "as an important instrument for the full realization of the rights and powers of the diversified population".⁴ Both donors are working within this decentralisation framework.

Donors' awareness of the context and obstacles to realising the right to health

All the key documents – those guiding ODA in general for donor countries (DFID and JICA) as well as those guiding implementation at the recipient country level (Kenya and Ethiopia) – strongly acknowledge the socio-economic and political conditions and the challenges facing recipient countries. JICA's Country Assistance Program for Kenya document details significant political, economic and social developments and challenges of post-independence Kenya (Government of Japan, 2000). DFID's

⁴ Federal Ministry of Health in Ethiopia, http://www.moh.gov.et/index.php?option=com_content&task=view&id=15&Itemid=56 (accessed April 15, 2009).

Country Assistance Plan (CAP) for Kenya (2004-2007) and for Ethiopia (2003-2005) also details the countries' specific context and challenges towards which the CAP is geared to tackle (DFID, 2004, 2003).

What health activities are the donors involved in?

Table 2 below summarises the healthcare activities DFID and JICA are involved in in Kenya and Ethiopia. Categorisation of the healthcare fields is based on an assessment of the recipient countries' healthcare priorities as stated in the respective health policies and strategies (NHSSP for Kenya and HSDP for Ethiopia) and the core areas of donor activities (German Technical Cooperation, 2003). DFID's support for health in Kenya is detailed in the Essential Health Services (EHS) program whose goal is to contribute to the NHSSP-II and the MDGs for health (Barker and Gathitu, 2009). In Ethiopia, DFID is supporting the training of health workers and has contributed over US\$14 million to the costs of implementing the Health Extension Program (HEP) in addition to supporting salaries for over 16,000 doctors and nurses. In addition, key development partners including DFID, but not JICA, utilize a Health Sector Harmonisation Action Plan (HSHAP) which was integrated into HSDP-III and has been operational since July 2005.

Table 2: Assessment of DFID's and JICA's activities in the health sector in Kenya and Ethiopia, 2003

| | | RSH | Health reforms and decentralization | District/Regional Health Systems | Health financing systems | HIV/AIDS | Infectious disease control (TB & Malaria) | Social Marketing |
|----------|------|--------------------|-------------------------------------|----------------------------------|--------------------------|----------|---|------------------|
| | | Policy development | | | | | | |
| Kenya | DFID | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| | JICA | | | ✓ | | ✓ | ✓ | |
| Ethiopia | DFID | ✓ | | ✓ | | ✓ | ✓ | ✓ |
| | JICA | | | ✓ | | ✓ | ✓ | |

Source: Various.

As the table shows, in Kenya DFID is involved in all the health core areas whereas JICA is involved in only three areas. Again, in Ethiopia, DFID is involved in most of the core health areas. In reproductive and sexual health (RSH) services DFID has funded programs in female genital cutting. Programs for health systems development include those that support capacity building of regional or district (*woreda* in Ethiopia) level administration to deliver basic care and those at the community level including rural integrated primary healthcare. As shown in the table, both donors are supporting this level in both countries. In addition, as indicated in the table, DFID is involved in social marketing in both countries. In Ethiopia, DFID funds a large program in social marketing of condoms and contraceptives. In Kenya, this program is in insecticide treated nets (ITNs). In both countries, DFID funds US-based agencies, the DKT International in Ethiopia and Population Service International (PSI) in Kenya. HIV/AIDS is a key area in which both donors are actively involved. JICA's support in Ethiopia has concentrated on infectious disease control, specifically the control and eradication of polio. In Kenya JICA's flagship health support has been the establishment and development of the leading medical research agency in sub-Saharan Africa, the Kenya Medical Research Institute. Since its establishment in 1979 until April 2006, JICA has supplied over 15 long-term experts and over 40 short-term experts in addition to equipment and funding support worth more than 126,186 million Japanese yen to the Institute (JICA, 2006).

What resources are the donors committing for the health sector?

Table 3 summarises the range of health support provided by DFID and JICA in Kenya and Ethiopia. As can be seen both donors provide financing, technical support as well as equipments. Nevertheless, the level of these resources as well as the mode of transfer for finances differs. In Ethiopia as members of the Donor Assistance Group (DAG) DFID and JICA channelled their financial support through the DAG pooled fund. Following the political crisis in 2005 after the General Elections, the World Bank led a group of donors to develop a new tool called the Protection of Basic Services Program (PBS). Under the PBS funds flow to the government of Ethiopia through a World Bank administered trust fund – one of the largest such Bank portfolios in Africa (about US\$560 million) – ensuring a more scrutinised modality for targeted programs. In addition to the World Bank administered PBS, development partners in Ethiopia also utilise the Health Sector Harmonization Action Plan (HSHAP) for which a Health Pool Fund (HPF) was created upon agreement between the donors and the Federal Ministry of Health (FMOH). This fund is administered by UNICEF. Together with seven other key health sector donors, DFID signed a Joint Memorandum of Understanding on managing the Health Pooled Fund running from 15 November 2007 to 30 June 2010 (Health, Population and Nutrition Thematic Working Group, 2007). A first phase had run from 1 November 2005 and 31 March 2007. JICA is not a member of this working group. However, other donors may join the program.

Table 3: Resources for health provided by DFID and JICA in Kenya and Ethiopia

| Resources → | Financing | | Technical Assistance | Equipment |
|-------------|-----------|------|----------------------|-----------|
| | Gov. | NGOs | | |
| Kenya | DFID | ✓ | ✓ | ✓ |
| | JICA | ✓ | ✓ | ✓ |
| Ethiopia | DFID | ✓ | ✓ | ✓ |
| | JICA | ✓ | ✓ | ✓ |

Source: Field data, JICA office (Nairobi), Printed Development Estimates (MOF, Japan).

The OECD has recently attempted to classify aid for health from its member states. According to this source, Kenya is the 3rd largest recipient of UK aid for health (after India and Bangladesh). In 2006, UK’s commitment for health to Kenya amounted to US\$31 million (OECD, 2008). Aid given to international initiatives such as the AIDS Vaccine Initiative, to agencies such as UNICEF for specific programs as well as to international NGOs is nevertheless classified as bilateral in the OECD statistics. Such aid, comprising up to 21% of bilateral aid to the health sector, cannot be identified by recipient (ibid.). (Data for DFID funding to Ethiopia and JICA funding to Kenya and Ethiopia was not identified.) Overall, most of JICA’s aid to Kenya and Ethiopia is in the form of technical support. Information available from JICA offices in Nairobi do not provide data for funding in the current year but previous data show a significantly higher level of support to Kenya’s health sector than in Ethiopia. In Ethiopia, as per data in the Health Pool Fund, DFID had set targets to contribute GBP 150,000 each for years 2007, 2008 and 2009 (Health, Population and Nutrition Thematic Working Group, 2007).

Local participation and ownership

Short of following a bottom-up led project design process, donors can ensure the targeted population participates meaningfully by involving them in designing the project to be implemented. Key to the participatory development approach is the 1999

Poverty Reduction Strategy Paper (PRSP) required as a condition for assistance by the World Bank and International Monetary Fund (IMF). Both Kenya and Ethiopia have developed two PRSPs each. Development of the PRSP requires community and civil society groups to be part of the process of identifying medium-term priorities in health and other social-development areas. This participatory approach should provide the template for donor involvement in the target populations. Both DFID and JICA affirm using participatory approaches in identifying project areas, for instance in conducting project appraisals through consultants stakeholders are identified and roles of actors are clarified.

When donor projects and programs are implemented by NGOs, this will likely be the focal point for local-level engagement with beneficiaries. The level of engagement with NGOs in Kenya's health sector by DFID and JICA is much higher than in Ethiopia. This is largely because of the fact that the sheer scope of health services in particular and donor aid in general is higher in Kenya. In addition, the donor funding modalities in Ethiopia known as the Protection of Basic Services Program (PBS) is much more restrictive of the operational field of donors. Furthermore, the context of NGO operations in Ethiopia is not very conducive, a situation which has become worse following the passing of a restrictive legislation in 2008 that prohibits any domestic NGO receiving over 10% of its operating budget from foreign sources from carrying out any activity related to furthering human rights (International Center for Not-for-Profit Law, 2009).

JICA's ODA principles emphasise empowerment of communities as a key goal of Japanese assistance. A modality in JICA's ODA which may particularly enhance community participation is the Japan Overseas Volunteer Cooperation (JOVC). For example, in 2006 JICA dispatched 105 JOVCs to Africa and other parts of the world (JICA, 2007a: 82). In Kenya Japan has supported HIV/AIDS programs for the past ten years. In Western Kenya JOVCs are spearheading a project titled "Project for Strengthening of People Empowerment against HIV/AIDS in Kenya" (SPEAK). The JOVCs conduct educational activities in villages with the local young people, renovate the voluntary testing counselling (VCT) centers and also work with regional government officials in formulating regional HIV/AIDS control plans (JICA, 2007: 83). The JOVC program of Japan has a great potential to promote the fulfilment of the right of participation, communication and education in the development process.

Transparency, Accountability and Coordination

Transparency has to do with both availability of information through country offices and web sources, the depth of detail or usefulness of such information as well as the perceived efforts for making the information readily available to all stakeholders including the public. The available information must also be user-friendly for users to make informed decisions. I have rated availability of information about DFID and JICA activities in Kenya as being better than in Ethiopia owing to the difficulty in getting response and useful information. While DFID's websites for both countries contain similar information, it was possible to have discussions with DFID personnel in Nairobi. JICA personnel in Nairobi were readily available. With increased Internet use, availability and accessibility of information about donors has however improved.

Accountability is a critical element of development programming. The human rights framework succinctly demands both donors and recipient countries and implementing

agencies to be accountable in their processes and practices. In an effort to contribute to more accountable development cooperation, donor members of the Development Assistance Committee of the Organisation of Economic Cooperation and Development (OECD) formulated steps towards aid harmonisation and effectiveness. Such documents include the 2003 Rome Declaration on Harmonisation⁵ and the 2005 Paris Declaration of Aid Effectiveness. Both DFID and JICA are parties to these instruments. Towards implementation of the aid harmonisation and effectiveness platforms, Sector-Wide Approaches (SWAp) have been adopted as an in-country development framework. This approach regards the health sector as a comprehensive unified entity in which all actors are geared towards the common objectives detailed in the health policies and strategic plans of the recipient countries. To steer the implementation of the SWAp in Kenya, DFID and JICA are parties to the 2006 Joint Program of Work and Funding (JPWF), the 2007 Kenya Joint Assistance Strategy (KJAS) (for 2007-2012), and the SWAp Code of Conduct developed in 2007 – signed by the head of DFID in Kenya at the time Simon Bland and the Japanese Ambassador Satoru Miyamura as well as other development partners (Kenya Health Sector Wide Approach Code of Conduct, 2007).

In Ethiopia similar documents exist and today there are in both countries donor working groups under the names, in Kenya, Harmonisation Alignment and Coordination (HAC) and, in Ethiopia, Development Assistance Group (DAG). In addition, in Ethiopia there is an Ambassadors' Group (AG). HAC, DAG and AG as well as numerous thematic working groups (TWGs) are the key structures for *donor* coordination. The thematic donor coordination groups for health are Health, Population and Nutrition (HPN) TWG in Ethiopia and the Development Partners in Health Kenya (DPHK). While JICA is not represented in the Ethiopian HPN both DFID and JICA are represented in the DPHK. Both the Ethiopian DAG and Kenyan HAC meets monthly.

5. Discussion of the Findings

Following consultations of various UN agencies during 2002-2003 the UN published a document titled “The Human Rights Based Approach to Development: Towards a Common Understanding Outcome Document” (UN, 2003). The document listed three specifications with regard to development programming:

1. “All programs of development co-operation, policies and technical assistance should further the realization of human rights as laid down in the Universal Declaration of Human Rights and other international human rights instruments.
2. Human rights standards contained in, and principles derived from, the Universal Declaration of Human Rights and other international human rights instruments guide all development cooperation and programming in all sectors and in all phases of the programming process.
3. Development cooperation contributes to the development of the capacities of ‘duty-bearers’ to meet their obligations and/or of ‘rights-holders’ to claim their rights.”

⁵ Rome Declaration on Harmonization, <http://www.aidharmonization.org/ah-wh/secondary-pages/why-RomeDeclaration> (Accessed April 15, 2009).

In this part, we shall locate these three aspects of the HRBA in our two studies to discuss the findings. The Disability study concentrated on the experiences of deaf women on the grassroots concerning development cooperation activities, while the Health study on donors' ethical decision making for operationalising HRBA. Therefore, the first part discuss the operationalisation of HRBA from the perspective of people on the grassroots based on the findings of the Disability study, while the second part on more macro findings of the Health study.

5.1. HRBA in Disability Interventions in Uganda

In the context of the Disability study, as was aforementioned, development cooperation activities between DPOs of North and Uganda starts with the motivation of a HRBA but too frequently end up in a charity-based approach in practice. Hence, the studied development cooperation activities represent neither a purely HRBA nor a charity-based approach, although DPO staffs claim that they are applying a HRBA. The mechanism was explained in terms of disability-specific root causes and development cooperation system: both local and global (Katsui, 2009). At each decision-making process at different levels, both approaches are negotiated to fit better to the circumstances and the actors concerned. The power gaps between different stakeholders of development cooperation activities are huge, which makes the situational analysis by rights-holders (PWDs) themselves extremely difficult without enough preconditions to be met such as right to language for deaf women. When rights-holders, particularly the most marginalised groups of people, do not have enough capacity to claim the rights, this HRBA alone fails to reach its objectives of all human rights. This is the fundamental weakness of this approach (Katsui, 2005). Therefore, on the basis of this argument, the Disability study discusses the importance to connect a HRBA to the theoretical counter-approach of charity-based approach.

Charity-Based Approach as a Cutting Edge of a HRBA Analysis

In Northern disability studies, the understanding of a charity-based approach has often been based on the altruism of persons without a disability, and unintentional negative discrimination in which persons with disabilities are viewed as inferior. This approach is thereby believed to reinforce the power relationship in theory. "There is a paradox here. The public perception of charities is very positive" (Shakespeare, 2006:153). That is, many others do not even problematise the charity-based approach to disability. Shakespeare (2006:3) claims, "[R]ights alone are not sufficient to promote the wellbeing of disabled people, and that charity - defined broadly as love and solidarity - must also play an important part."

When this debate is transferred to a Southern context, charity becomes an indispensable aspect of the reality of many persons with disabilities on the grassroots because they are recognised as 'the vulnerable among the poor' (Wilkinson-Maposa et al. 2005:42). Katsui's interviews clarified that the neighbours, friends and family members of PWDS -even though they are poor themselves- give support to PWDs. On the one hand, this reality frequently perpetuates the continuing of many PWDs on the grassroots to play the passive role of objects also in development cooperation activities. On the other hand, charity is a way of survival when no institutionalised support is available, as is often the case in Southern countries. This kind of informal help is not stipulated in legal documents, but yet next to sustainable as a culture,

though help could be sporadic. This philanthropy culture is not regarded as problematic for Ugandans. Moreover, the above case study analysis implies the possibility that a HRBA has to start at the level where PWDs are often used to playing the passive role of objects. The deaf women researched in Uganda, for instance, cannot start demanding their rights to education when they have not secured their fundamental rights of language. In these regards, the charity-based approach cannot be undermined as a solely negative approach of intervention without taking the specific context into consideration. Future analysis of the HRBA to disability in development should, rather, pay more attention to the negotiation of these approaches and elaborate on how and when the ‘beneficiaries’ start to feel a sense of empowerment and further, recognise themselves as ‘rights-holders’. For that, both the human rights and charity concepts should be scrutinised in future research. Particularly, the differences in the concepts between Northern counterparts and Uganda would be of interest.

Solidarity Connects the Two Approaches?

Despite the differences between persons with disabilities among and within countries, solidarity often plays an important role in connecting them, especially those with the same or similar impairments (see the deaf people’s case in Saito 2007:108). Solidarity is an interesting concept to explore in the discussion between human rights-based and charity-based approaches. Laitinen (2003:232) defines solidarity as being made up of a “collective responsibility, equality and being on the side of the disadvantaged.” Inspired by the list of characteristics presented by Laitinen, we would rephrase the following as characteristics of solidarity: a collective identity, an awareness of equality (or a problematisation of inequality) and an ability to articulate the priorities of the most marginalised groups of people (Katsui, 2009).

Solidarity coupled with other strong motivations lead to concrete action by the advantaged people for and/or with the disadvantaged people towards equality. Within the case study setting, solidarity was exercised when there were ‘advantage gaps’ between actors, such as between deaf women on the grassroots and the deaf leaders of DPOs, and between the Ugandan and Northern DPOs. Expressions used, such as ‘our sisters and brothers’ (Chairperson of NUDIPU, 2008) when a Ugandan DPO describes their constituency, and ‘sister organisations’ (Halmari, 2003:107; DSI, 2007) when Northern partner DPOs describe their Southern partners reveal part of the motivation for why they are involved in the activities. When advantage or capacity gaps result in the social exclusion of disadvantaged people, solidarity can be an initial way of including excluded people based on a good intention. In theory, solidarity as a motivation for action and as a starting point can lead to both charity-based approach and HRBA in a given specific situation. Therefore, solidarity as a good intention does not predetermine its consequence in terms of action (or modality for achieving the goal of equality) that follows, but can be a common factor in both approaches in this context.

The precondition for solidarity in developmental activities is a power gap, which cannot be changed over a short period of time. For instance, a single intervention of a DPO can hardly change this structural demography among them. Thus, solidarity-oriented action first has to be exercised under this power to the most disadvantaged ones. The empowerment and capacity building of the disadvantaged people, therefore, are one of the first activities to frequently take shape in giving, such as service

provision, material delivery and various trainings. This top-down approach in the framework of DPOs is applied to maximise the benefits of the disadvantaged people in the situation, so as to first fill any necessary preconditions for further activities, possibly ones carried out utilising a HRBA. At the same time, the patterns of behaviour in society, in which persons with disabilities are playing the role of objects of charity, reflect the actions taken both by DPOs and persons with disabilities on the grassroots. Furthermore, a development cooperation system imposes short-term activities with limited resources. Thus, DPOs end up in putting in practice aspects of a charity-based approach, with or without intention, due to the circumstances. In this way, the stakeholders' choices are made, with reason, between the charity-based and human rights-based approaches.

5.2. HRBA in Donor Health Interventions in Kenya and Ethiopia

The research findings on health are analysed against the three key questions based on the UN Common Understanding document: 1) Do all programs of development cooperation, policies and technical assistance by donors such as DFID, JICA and other international agencies in Ethiopia and Kenya further the realisation of human rights? (2) Do human rights standards guide all development cooperation and programming in all sectors (health) and in all phases of the programming process these donors and actors are involved in? (3) Do the agencies' development intervention contribute to the development of the capacities of "duty-bearers" to meet their obligations and/or of "rights-holders" to claim their rights?

To start with, many important questions arise in donor health interventions from a human rights framework. These include the following. Given the enormous need in health, what priorities should donors focus on? Who should decide what those priorities should be? Should priorities be determined on the basis of need, i.e., to the most marginalised people, on what is more cost-effective or on political biases? An example where this thinking is especially paramount is in the HIV/AIDS area with numerous intervention approaches and hundreds of millions of dollars. There are many other questions. For example: Should the donor programs support vertical (stand alone) or systems approaches? What evidence do we have to support which works best to improve overall population health? What balance should there be in resource targeting between curative services and preventive public health? Since private healthcare systems target those who are able to pay, in resource-limited settings what macro-organisational mix will best promote the delivery of services within the right to health framework? It is impossible to cover all these questions in this research project. The questions will remain for future more detailed, longer and resourced research. In analysing DFID's and JICA's support for the health sector in Kenya and Ethiopia on the basis of the above three questions from the UN Common Understanding, the following observations can be made.

As we pointed earlier, numerous international treaties and programmatic documents have established health as a human right. DFID's and JICA's development policies guiding support for health in Kenya and Ethiopia are informed by this human rights framework. Hence it can be said that these donors' are furthering the realisation of health as a human right. While this is easy to establish on the basis of the policy documents, the field consultations did not confirm the human rights language and discourse as readily or always used by the development experts. This may be because

of the sensitivity of the question of human rights common among government officials, particularly in Ethiopia. More fundamentally, furthering the right to health raises the question of what is actually required to realise that right. Adequate resources are needed as well as good leadership and management. Clearly DFID and JICA funding for health should (together with other donors) be geared towards increasing the per capita health spending in Kenya and Ethiopia to reach WHO recommended US\$34 (WHO, 2001), which is currently at US\$ 19.2 and US\$ 5.6, respectively. In addition, the WHO Task Force on Health Systems Research (2005) has clearly emphasised in a report with a similar name that the MDGs will not be attained without strengthening the health systems. While both DFID and JICA are supporting this area involving capacity building of health management at the district/*woreda* level in Kenya and Ethiopia, there is clearly currently not enough effort to meet the challenge.

In addition to strengthening health systems through resources and capacity building, a major priority health area in both Kenya and Ethiopia is HIV/AIDS. Article 16 of the UN Declaration of Commitment on HIV/AIDS, emphasises that “the full realisation of human rights and fundamental freedoms for all is an essential element in a global response to the HIV/AIDS epidemic” (UNGASS, 2001). Currently both countries have over a million cases of persons living with HIV. Although many persons are receiving ARVs, this is only about half of those who need the drugs. Furthermore, according to the recent Demographic and Health Surveys (2005 in Ethiopia and 2003 in Kenya), and the 2007 AIDS Survey in Kenya, HIV prevalence has steadily increased despite the many millions of dollars spent in the last decade. Hence although, the efforts by DFID and JICA are certainly important and do go towards furthering this right, much more needs to be done to significantly bring down the rate of infection and provide ARVs to all those who need them.

With regard to question two, human rights standards should guide the health development cooperation in all phases of programming or project cycle, i.e., from policy design to implementation, monitoring and evaluation. In order to fulfil this objective, participation of the primary stakeholders, the targeted population, is imperative. However, in the context of complex political and donor cleavages meaningful participation by the targeted population will usually be difficult to achieve unless people are organised in a group such as a community organisation of an NGO (Hakkarainen et al, 2003). The PRSP mechanism potentially allows extensive public participation. However, as donors usually work with or channel funds through government or other international agencies, such as the Global Fund, UNICEF or the WHO, ensuring true participation of target population is impossible. In addition, although both DFID and JICA affirm using participatory approaches, it is clear that project design is based on secondary data such as government reports rather than real field consultations and empirical analysis. Project appraisals through consultants with different stakeholders may not result in meaningful participation. For example, although Japanese cooperation with Ethiopia is formulated through “policy dialogue meetings” such meetings do not include Japanese or Ethiopian NGOs, or the regional governments in Ethiopia. JICA’s JOVC program has the best possibility to enhance participation by the targeted population.

The third key element of the UN Common Understanding document requires that development interventions contribute to the development of the capacities of “duty-bearers” to meet their obligations and/or of “rights-holders” to claim their rights. To

meet this demand, donors must first and foremost accept this notion that they are duty bearers and their target populations are rights holders. This research did not establish this understanding in DFID and JICA in either Kenya or Ethiopia. Although the international human rights framework under the Right to Development places obligations on donor states to support the fulfilment of the recognised rights discrepancy between recognising the right and recognising obligation is evident (O'Neil et al, 2007). Nevertheless, support for human resources and sustainable healthcare delivery mechanisms such as health facilities and flow of medical supplies are key components for enabling the realisation of the right to health. Two programs emerge demonstrating the donors' efforts in this regard.

In Ethiopia, DFID is supporting the country-wide program, HEP, aiming to train two female high school graduates in each *kebele* (village or community of about 5,000 inhabitants) to become Health Extension Workers (HEWs) who provides basic health services. HEWs are posted at health posts and have support of the health centres and administration at the woreda level. By June 2007 17,653 HEWs had been trained and deployed, and over 8,850 health posts had been built. Estimates for reaching all rural communities with basic health services are 30,000 HEWs and 15,000 health posts.⁶ In Kenya JICA's flagship program is the Kenya Medical Research Institute (KEMRI). Established by a Japanese grant in 1979, JICA has supplied technical support, equipment and funding support worth more than 126,186 million Japanese yen (JICA, 2006). During May 2001 to April 2006, JICA had 15 and 48 long-term and short-term technical experts, respectively, working in KEMRI while a further 21 Kenyan experts were training in Japan. KEMRI is the leading medical research institute in sub-Saharan Africa and has developed testing kits for Hepatitis B Virus (HBV) HIV.

6. Concluding Remarks

Our research project covered three developing countries, namely Ethiopia, Kenya and Uganda and attempted to analyse the actions and processes in development cooperation activities in disability and health from a human rights perspective. This research project aimed at the following objectives:

- To explore the operationalisation mechanisms in which international human rights principles are applied in Southern countries and clarify the roles of Southern stakeholders,
- To highlight best practices in prioritisation strategies for disability and health with limited resources,
- To connect Southern marginalised people to Northern people as stakeholders through human rights dialogue.

Our conclusion will comment on each of these areas while giving recommendations.

Operationalisation mechanisms in applying human rights principles in Southern countries

In international law, states are the primary duty-bearers of human rights. However, we have also seen that from the UN Declaration on the Right to Development, all actors

⁶ Source: <http://www.dfid.gov.uk/casestudies/files/africa/ethiopia-hep.asp>.

engaged in development have an obligation towards the rights-holders. The operationalisation of rights in the South is complicated because the development arena comprises numerous actors engaged in diverse roles from funding to implementing to policy-making to research. This study has tried to clarify the roles of Southern stakeholders. Although donors like DFID and JICA often make explicit statements referring to human rights in their policy documents, there are major gaps in translating international declarations to practice. A critical level is the donor country team in the recipient country as these may lack guidance as well as the training on linking human rights to implementation (O’Neil et al, 2007) while also facing often un-conducive political climate. In the Disability study, it was observed that Ugandan DPOs are playing the role of filling the huge gap of operationalisation with the support of their Northern counterparts particularly in terms of meeting the urgent needs and building capacity of PWDs on the grassroots. Without their interventions, PWDs are largely left behind from mainstream development activities of the government and donors. As the preconditions for PWDs to benefit from a HRBA are not taken into account under the current development cooperation system, they do not fully benefit even from disability-specific activities. Development cooperation activities involving PWDs disproportionately tend to end up in a charity-based approach.

Recommendation: Ensuring that development interventions in the South are informed by a human rights perspective, donor policy documents need to clarify the references on human rights with practical steps and link them to obligations. Donor country teams working in the South must then adopt and instrumentalise those clarifications and linkages because they often are the ones who originate policies and country documents. Furthermore, any development cooperation activity needs to pay careful attention to the most marginalised people and their conditions so that they could also benefit from the existing mainstream development activities. Without it, development activities will further marginalise PWDs and other marginalised groups of people, and deny them from becoming capable rights-holders to claim their own rights.

Practices in prioritising ‘best’ strategies in disability and health interventions

In the context of limited resources, prioritisation is imperative. Prioritising the most marginalised people should be one of the characteristics of a HRBA. Yet in the philosophical discourse on allocation of limited resources, there are various competing approaches namely cost-effectiveness, prioritisationism and egalitarianism or equality.⁷ Each of these approaches would have different justifications. The human rights framework is largely informed by egalitarianism where equalisation is the key concern. Where a number of interventions can be applied to alleviating disability or disease, cost-effectiveness principles demand the implementation of that intervention which uses less resources for the same outcome, as measured by Disability-adjusted-Life Year (DALY) (Galaraga, Colchero, Wamai and Bertozzi, 2009). In improving (or achieving equalisation of) the wellbeing of people with disability or disease, the human rights perspective is instrumental in justifying prioritisation to the most marginalised.

⁷ This discourse was the topic of a two day conference on Ethical Issues in the Prioritization of Health Resources, the 4th Annual International Conference of The Harvard University Program in Ethics and Health. Boston USA, April 23-24 2009. Wamai participated in the conference.

However, it is often not the case in practice as a HRBA tends to reflect local power structure (Alston, 2005:806). Therefore, already advantaged people benefit more from a HRBA, if careful attention is not paid to the marginalised people. Under the current development cooperation system, the most marginalised people are left behind further by interventions, as the Disability study observed. Long-term commitment and continuous support with enough resources becomes important. One interesting initiative of Ugandan DPOs in the area of HIV/AIDS advocacy started as a voluntary group of people alerted by the urgent reality of PWDs. Beyond the differences of impairments, they started to advocate together for the importance of including PWDs as an important target group of the Ugandan government national efforts against the HIV/AIDS epidemic. DPOs tend to work separately to serve the impairments-specific needs of own constituencies. However, they used this cross-disability approach to gain visibility of PWDs to national discussion on HIV/AIDS (more about it, see Katsui, 2008-b).

Recommendation: A claim to human rights is effective when people act as a group (OHCHR, 2006:4). As HRBA is often used by NGOs rather than large organisations because of the pitfalls of this approach (Uvin, 2004:166), involving NGOs is an important strategy for paying deserving attention to the most marginalised people in the South so that identification of priorities are rightly figured out. In prioritising certain strategies, geographical areas, diseases or target population it is important that programs and projects do not neglect broader issues as marginalisation results from structural factors in society. Further attention should be paid to the diversity of the groups of people (ex. “persons with disabilities”).

Connecting Southern marginalised people to Northern people as stakeholders through human rights dialogue

This research project concentrated on development cooperation activities as an arena of operationalising a HRBA. International cooperation as a transnational obligation has increasingly gained its necessity as a means of human rights operationalisation in the South (for example, the UN Declaration on the Right to Development, and Article 32 of the UN Convention on the Right of Persons with Disabilities). However, development and international cooperation are not the only means for improving the human rights situation of the marginalised people in the South. There are many more means including macro change of “free trade” and globalisation that need serious human rights analysis. Even in the analysis of development cooperation whose impacts are much smaller compared with the free trade, it was observed that both mainstream development activities and disability-specific activities are not fully able to increase enough capacity of the rights-holders. That is, Northern resources are increasing the marginalisation even with the deliberate efforts of development.

Although the emergent global civil society movement of the last decades and programs promoting global citizenship⁸ have played an important role in raising public consciousness in the developed countries (Anheier, Glasius and Kaldor, 2001), solidarity of Northern stakeholders to Southern marginalised people is still not enough (Katsui, 2006). North-South partnerships while may be based on mutuality lack

⁸ See for example the program by Oxfam GB: <http://www.oxfam.org.uk/education/gc/> (accessed April 27, 2009)

equality (Hakkarainen et al, 2003: 46). In addition, Southern actors often have little participation in setting the aims, priorities and targets set (Wamai, 2006). All countries prioritise the improvement of their own situations, which has been part of the de-motivation of Northern countries on their transnational obligation (see the case of Japan in Katsui, 2008-c). On the other hand, programs promoting volunteering and participation of Northern citizens such as the Japanese JOVC program enhances the human rights dialogue.

Recommendation: There is a critical need to reform development cooperation to reflect the human rights based framework through increasing human rights education both in the North and in the South. Solidarity characterised as a collective identity, an awareness of equality and an ability to articulate the priorities of the most marginalised groups of people (Katsui, 2009) is important for connecting largely ignorant Northern stakeholders to the human rights dialogue. Expanding programs such as the Japanese JOVC which allow ordinary Northern citizens, aside from the experts, to be part of development intervention on the ground in the South can contribute to this agenda. Furthermore, solidarity as a motivation would be even stronger if coupled with a long-term vision of a HRBA.

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- Chairperson of the NUDIPU. Personal interview at Kampala on 31.1.2008.
- Chairperson of the United Young Deaf Women Group. Personal interview at Kampala on 4.2.2008.
- Deaf MP/ Executive Director of UNAD. Personal interview at Kampala on 28.1.2008.
- Deaf Woman E. Personal interview at Kampala on 17.2.2008.
- Gender Officer of UNAD. Personal interview at Kampala on 28.1.2008.

Appendix 1. List of Publications

All the published articles mentioned the financial contribution of the Tokyo Foundation to the study in their acknowledgement. The first project in 2006 did not pay enough attention to the dissemination of the findings. We learned the lesson and tried to more actively disseminate our findings during this project period (this is also reflected in the financial report where more money is allocated for the conference participation and other information dissemination activities).

Publications directly related to the project:

Katsui:

- Kumpuvuori, J. & Katsui, H. (forthcoming) “Disability, Human Rights and Human Security: case study on human rights advocacy activities of organisations of persons with disabilities in Uganda and Finland.” Spanda Foundation Quarterly Newsletter. Vol. III No.1. Shortly available at <http://www.spanda.org/publications.html>
- Katsui, H. (2009) “Negotiating the Human Rights-Based Approach and the Charity-Based Approach in Development Cooperation Activities: Experiences of Deaf Women in Uganda.” In T. Veintie & P.Virtanen (eds.) *Local and Global Encounters: Norms, Identities and Representations in Formation*. Renvall Institute Publications 25, Helsinki. P.9-28.
- Katsui, H. (2008) *Downside of the Human Rights-Based Approach to Disability in Development*. Working Paper Series of IDS at Helsinki University 2/2008.
- Katsui, H. & Kumpuvuori, J. (2008) *Human Rights-Based Approach to Disability in Development in Uganda: A Way to Fill the Gap between Political*

and Social Spaces? Scandinavian Journal of Disability Research. Volume 10 Issue 4. P.227-236.

Wamai:

- The health system in Kenya: Analysis of the situation and enduring challenges. *JMAJ* 2009;52(2) (March-April).
- Reforming health systems: the role of NGOs in Decentralization – lessons from Kenya and Ethiopia. *Working Papers*, Vol. VI, ISTR Conference. Barcelona Conference, <http://www.istr.org/conferences/barcelona/WPVolume/Wamai.pdf>

For the **previous JIP project finding (2006-616 JIP-01)**, the followings were also published.

- Katsui, H. (2008) Mainstreaming Disability Issues in Japanese and Finnish Development Policies and Practices. Working Paper Series of IDS at Helsinki University 1/2008.
- Wamai, R.G. & Katsui, H. (2008) “Health and Disability in International Development Policy.” The SYLFF Newsletter No.21 August 2008. P.6-8.

Conference and seminar presentations directly related to the project:

Katsui:

- “Human Rights-Based Approach to Disability in Uganda: Case Study on General Assemblies of DPOs on Right to Vote” NNDR Bi-annual Conference: Challenging Positions in Disability Research - normativity, knowledge and praxis. 2-4.4.2009. Nyborg, Denmark. Available at <http://www.ndr.no/eng/Conferences/Paperpresentations/41-paper>
- “Is Participatory Research Approach a Burden for the Researched People?” Finnish Society for Development Research Conference: Knowledge, Development and Academic Partnership. 12.2.2009. Helsinki, Finland.
- “Human Rights-Based Approach to Disability in Development.” Institute of Development Studies Research Seminar. 7.10.2008. Helsinki, Finland.
- “Negotiating Human Rights-Based Approach and Charity-Based Approach: Development Cooperation and Experiences of Deaf Women in Uganda.” Global and Local Encounters Seminar. 25.9.2008. Helsinki, Finland.
- “Why International Cooperation to Deal with Disability? Politics of the Article 32 of the Convention.” 4th Biennial Disability Studies Conference. 2-4.9.2008. Lancaster, UK.
- “Challenges of Disabled People’s Organisations in Operationalising Human Rights-Based Approach to Disability in Development: Towards Sustainable Positive Change.” 8th International Conference of the International Society for Third-Sector Research (ISTR). 9-12.7.2008. Barcelona, Spain.
- “An Academic Study on Human Rights-Based Approach to Disability in Development.” CRPD-Added Value? Seminar. On 20.5.2008. Helsinki, Finland.

- "Operationalising a Human Rights-Based Approach to Disability in Development: the Case of HIV/AIDS Project of Ugandan Disabled People's Organisations." Paper presented in Development Research Conference. On 8.4.2008. Helsinki, Finland.

Wamai:

- 4th Annual International Conference of The Harvard University Program in Ethics and Health. Boston USA, Thursday, April 23, 2009 - Friday, April 24, 2009.
- "Human Rights-Based Approach to Health in Development". Presentation of the Faculty Undergraduate Research Initiative (FURI), Northeastern University, Boston USA, March 26, 2009.
- "Mapping Health Systems Development in sub-Saharan Africa". Poster presented at the Northeastern University Research Expo 2009, Boston USA, Thursday March 26, 2009.
- "Reforming health systems: the role of NGOs in Decentralization – lessons from Kenya and Ethiopia". Paper presented at the ISTR 8th Conference. Barcelona, Spain July 9-12, 2008. Available at <http://www.istr.org/conferences/barcelona/WPVolume/Wamai.pdf>
- "Health challenges in Africa and the role of NGOs". Presentation at the 19th Annual Johns Hopkins International Philanthropy Fellows Conference, Barcelona, July 6-9, 2008