

Disabilities, Human Rights and International Cooperation

**Human Rights-Based Approach
and Lived Experiences of Ugandan Women with Disabilities**

2012

Hisayo Katsui

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If you are a person with a visual disability and would like to get hold of a Word file of this book, please write to hisayo@welho.com.



VIKE

Foreword

Shuaib Chalklen

United Nations Special Rapporteur on Disability

I'm very pleased to be writing this foreword because of the importance of the subject of mainstreaming disability in development.

As the United Nations Special Rapporteur on Disability my mandate request me to act as a catalyst for international development cooperation and in particular to advocate for the mainstreaming of disability in development cooperation. I have also identified Africa as the region that will receive special attention because of the extent of the needs of people with disabilities on the African continent. In addition women with disabilities are most vulnerable everywhere and the book focuses on all these areas of my mandate.

Much have been spoken about mainstreaming but very little evidence can be found that supports our argument that disability rights are human rights and that inclusive development is the right of people with disabilities. This book is therefore timely as it presents us with some of the facts on the ground and in one of the disability friendly developing countries. It also shows that much more needs to be done to empower women with disabilities to attain true equality.

The book also focuses on the African Union (AU) and its proposals to develop a new disability infrastructure that is a radical departure from the past. The new infrastructure will include mechanisms that will ensure the participation of civil society at the level of the AU and is an encouraging sign for all of us who have lobbied for the participation of people with disabilities in all decisions that may affect them.

There is an ongoing dialogue among disability rights advocates about the need to be prepared for the post Millennium Development Goals discussions and to ensure that the exclusion of the past does not become the new goals of the future. This means that any new global development goals must include people with disabilities and this book will assist activists on the African continent to strengthen their voice and increase their understanding of the challenges we face.

Hisayo Katsui has written a book that will help our understanding of the complex nature of disability and discrimination and I'm pleased to be working with her. I am delighted to recommend this book for all who are interested in development, human rights and disability.

Executive Summary

The objective of this study was to investigate human rights-based approaches of international and development cooperation towards the equality of persons with disabilities in Uganda. As the theme of the study was highly complicated and involved real-life situations of persons with disabilities, a case study method as well as a participatory research approach among others were applied to create evidence-based and in-depth knowledge on the theme, particularly from the viewpoint of women with disabilities and deaf women on the grassroots. The following were established as the main findings.

Finding One: Disabilities as Human Rights Issues Are NOT Norms yet.

Even when international and national laws stipulate that disabilities are human rights issues, mainstream international and development cooperation too frequently tend not to regard disabilities as human rights issues. As a result, mainstream development actors exclude persons with disabilities from their discourse and practices, even policies, and thereby have not only reinforced the status quo but also enlarged the gap between persons with disabilities and peers without a disability. Some of these actors have started to conceptualise disabilities as a human rights issue only recently. Even where some individual mainstream actors comprehend the relevance of including persons with disabilities into their discourse and practices, they do not priorities it through the allocation of resources and thus, on many levels, the impacts remain minimal.

When it comes to persons with disabilities on the grassroots, deaf women in particular, human rights concept is far from their realities. Intersectionality and ontoformativity theories reveal that deaf women on the grassroots often experience negative impacts on their bodies with regards to male dominance, compulsory able-bodiedness and neoliberalism, among others. They are intertwined to create both disabling environments and the under-capacities of many persons with disabilities. On the one hand, these mechanisms too frequently force persons with disabilities on the grassroots to play the passive role of objects in international and development cooperation activities, even when many of them play meaningful roles within their families and communities. On the other hand, international and development cooperation activities are also pressured by the neoliberalistic ideology of efficiency and management, which systematically excludes marginalised persons with disabilities on the grassroots from strategic decision making power.

Despite many improvements in political representation and legal frameworks in Uganda, evidence indicates that disabilities are too often not regarded as human rights issues but rather, are approached in a charity-based manner in which the givers make the decisions regarding what, to whom, when and how much to give. The Ugandan disability movement has been rigorously advocating for mainstreaming disabilities as human rights issues and as part and parcel of development. This advocacy work, however, has faced many internal and external challenges.

Finding Two: Self-Determination Is NOT Self-Evident

In theory, a human rights-based approach presumes the self-determination of rights holders to claim their rights (the objectives) in a human rights-based manner (the means). For that,

both a good capacity of persons with disabilities and an enabling environment are indispensable, while persons with severe disabilities require proper supports for their well-being. The case studies proved huge heterogeneity among persons with disabilities. The gaps often lead to solidarity as a motivation for the more advantaged people to do something for those less advantaged. The modalities of activities are not predetermined by such solidarity but often take the form of empowerment of the less advantaged people. The relational approach to disabilities points out the importance of both individual and environmental considerations to improving the well-being of persons with disabilities both individually and collectively to further the ultimate goal of equality. Thus both empowerment-centred and mainstreaming activities are focused on (the twin-track approach).

At present, the self-determination of persons with disabilities is not as self-evident as the human rights-based approach assumes in theory. Concepts utilising different levels of participation are more useful for comprehending the complex realities of international and development cooperation activities, and for analysing the diverse levels of decision making power. The self-determination of persons with disabilities is too frequently watered down in international and development cooperation activities. It is often replaced by the representation or consultation of a limited number of persons with disabilities, or alternatively by one-off activity.

The case studies imply mutually positive effects between empowerment and mainstreaming, when either one is conducted. At present, however, the needs of many persons with disabilities and their families on the grassroots are simply too huge to meet the prerequisites essential for being able to exercise self-determination rights. Hence, more sustainable and systematic supports are necessary to meet these persons' needs first. At this stage, a top-down approach is actually useful in including hitherto excluded groups into the mainstream discourse and practice. Such top-down activities could gradually shift towards human rights-based activities for more sustainable, positive social change. In other words, as of now self-determination does not necessarily take place without prerequisites.

Finding Three: The Practical Implications of a Human Rights-Based Approach to Disabilities and International and Development Cooperation

Having analysed the case studies in conjunction with existing relevant theories, and having established the evidence-based empirical theory of a human rights-based approach to disabilities and international and development cooperation (Chapter 5), the practical implications are elaborated so that a human rights-based approach is challenged in its negative consequences and operationalised better to fit the realities of persons with disabilities in Uganda, including those on the grassroots.

The first implication is that a human rights-based approach in international and development cooperation discourse, even though not necessarily fully operational yet in practice, is important for including persons with disabilities as equal members of society into mainstream discourse and practice as a natural matter of fact. Lack of reciprocity is not a negative factor for determining that an activity is disempowering. When a human rights-based approach is a continuum to a charity-based approach in practice, activities can start from the reality in which persons with disabilities play passive roles, and even remain there in the sense that they continue to play passive roles, because disabilities are not neutral for many, particularly for "persons with complex dependency needs."

The second implication is on a possible negative consequence of a human rights-based approach if enough attention is not paid to dialogue, negotiation and information dissemination among stakeholders. On the one hand, a human rights-based approach is an effective and powerful lobbying tool for making changes in policy. On the other hand, however, the human rights route is a “cul-de-sac” because it often leads to dichotomy. Implementation, in particular, remains a challenge even after a positive decision is made. Various actors and modalities must be called upon to deconstruct massive mechanisms against persons with disabilities. At the same time, continuous and constructive dialogue, negotiation and information dissemination are necessary among all stakeholders as the third track.

The third practical implication is the fact that transformation takes place as a result of a long-term commitment with a lot of resources, unlike hitherto sporadic activities with limited time and money. A disabilities-friendly modality of international and development cooperation is required to cause dramatic change, and it must go beyond the neoliberalistic ideology embedded within it.

The fourth implication is the continuation of charity-based approaches and human rights-based approaches, as verified in the case studies. This reality implies that a new intervention in the form of international and development cooperation that applies a human rights-based approach could also be linked more directly to existing charities and/or vertical relationships, rather than merely creating separate, new experiments as an “add on.” Hence, operationalisation of human rights-based approaches in conjunction with other existing approaches, modalities and activities becomes important.

Finding Four: The Participatory Research Approach Is a Burden for Many Southern Researched People

A human rights-based approach is required to go beyond the existing system centred on efficiency and neoliberalistic ideology. This lesson also applies to a study concerning persons with disabilities in the academic world. That is, a participatory research approach which enjoys the full-fledged commitment of academic actors and the researched persons with disabilities is ideally feasible in a long-term framework so that sustainable, positive consequences could be realised for many research participants. In reality therefore, within the short-term framework given in a research project such as this one, only a limited number of already rather empowered persons with disabilities can be emancipated to a limited extent. This largely reflects the existing local power relationships and structures. Similarly, participation in a study also depends on personal capacities as well as on the enabling/disabling environments, among others. Each person’s capacities, personalities and environments need to be taken into account, rather than imposing this ideologically formulated research approach into their realities and practices in the same way, on everyone. This is an important lesson learned from this study.

Acknowledgement

The disability movement around the world has led to this book. I am particularly grateful to the Finnish disability movement and activists for giving me the opportunity to become engaged with the Ugandan disability activists, and for encouraging me throughout the study. The trip with Kalle Könkkölä and his personal assistant to Washington inspired me so much that I started this research right after my PhD. I met the late James Mwandha and Ambrose Murangira in Washington. The encounter with these Ugandan disability activists opened my eyes and interests to the Ugandan disability movement. Throughout the studies, these three disability activists made me more and more interested in the disability movement.

When I visited Central Asian countries with Jukka Kumpuvuori for my PhD research, we discussed the possibility of taking on a research project together in the future. I remembered this conversation and turned to him on the research idea of Uganda. With some hesitation in the beginning, he reluctantly (?) joined me. He ended up becoming my most trusted colleague and friend. I cannot thank you enough. Professor Martin Scheinin believed in us and became the leader of our project, which was extremely encouraging because disabilities as academic subjects are still minor. The Institute for Human Rights at Åbo Akademi has hosted this project. Without the institutional support of the Institute, this project would not have been possible. It was a good environment for the project as there was a sister project going on regarding a human rights-based approach to development headed by Professor Markku Suksi. The sister project researchers, Maija Mustaniemi-Laakso and Alessandra Sarelin, have been very supportive, informative and helpful for paving the way for our project. Professor Elina Pirjatanniemi kindly took over the leadership and Kati Frostell took very good care of the project throughout. The Institute of Development Studies at the Helsinki University accommodated me for the first half of the project period. Professor Juhani Koponen was very understanding. My colleagues, Saija Niemi, Sirpa Rovaniemi, Minna Hakkarainen, Henri Onodera, Anne Rosenlew, Aija Rossi, Marikki Stochetti, Tiina Kontinen, Päivi Mattila, and Johanna Hietalahti among others at Helsinki University also helped me in grasping disability issues within a larger context of development, for which I am very grateful. Lecturer Marianne Nylund, my old colleague and friend from the Diaconia University of Applied Science gave me opportunities to teach her students on disabilities and human rights. Professor Ullamaija Seppälä, Ossi Rahkonen and Timo Kyllönen of Helsinki University were all very supportive. I am lucky to have these colleagues at different universities.

When it comes to the Ugandan side, my former research assistant, the late Ruth Nakamanyisa, facilitated this study in various ways to give rise to this opportunity. Her heart warming communications always made me feel important. She passed away during the course of this study, which was one of the saddest things. Edson Ngirabakunzi became part of this project and my supervisee for his PhD. The Ugandan disability movement gave him a nickname, “professor,” which has encouraged the whole project team members to work hard. Prossy Nanyunja, Nararome Rehema, Barbara Nandutu, Benson Tumwesigye, Felix Mugisha, Hope Agwang and Sarah Ojirot helped me to understand lives of women with disabilities, particularly those of deaf/Deaf women. Informal conversations with them consolidated the findings of this study to a great extent. The following people among many others also shared their expertise with me (they are listed here in alphabetical order of surnames): Hellen Asamo, Agnes Aserait, Margaret Baba Diri, Frances Candiru, Beatrice Guzu, Peter Khaukha, Francis Kinubi, Aloysius Kiribaki, Esther Kyoziira, Christine Lule, Sulainman Madada, Florense

Mukasa, Safia Nalule, Juliet Namangulu, Alex Ndeezi, William Nokrach, Janet Owto, Michael Sebuliba, and Florence Nayiga Sekabira. I cannot list the names of everyone involved due to confidentiality, but I am extremely grateful for them.

Makerere University institutionally collaborated with our research project and provided a unique environment for us to work together. Professor Byaruhanga Rukooko and Lecturer Edward Wamala have been particularly supportive and collaborative in this process. Lecturer Lawrence Eron of Kyambogo University also provided me relevant information. I am grateful that our project had a solid collaboration with Makerere University including teachers and students. This involved an exchange project, our teachings in 2010 and a forthcoming one in 2012 on disabilities and human rights.

The following organisations, their headquarter and branch staff helped me greatly and I appreciate it very much (listed in alphabetical order): Abilis Foundation, Action on Disability and Development (ADD), Disabled People's Organisations Denmark (DPOD), Disabled Women's Network and Resource Organisation in Uganda (DWNRO), Finnish Association of the Deaf, Finnish Disabled People's International Development Association (FIDIDA), Legal Action for Persons with Disabilities Uganda (LAPD), Mental Health Uganda (MHU), Need Foundation, National Union of Disabled Persons of Uganda (NUDIPU), National Union of Women with Disabilities of Uganda (NUWODU), Sense International, Threshold Association, Ugandan National Association of the Blind (UNAB), Uganda National Association of the Deaf (UNAD), Ugandan National Association of Physical Disability (UNAPD), United Young Deaf Women Group, Uganda Parents of Children with Learning Disabilities (UPACLED), and Ugandan Society for Disabled Children (USDC).

As for funding, the project received generous support from the Academy of Finland and the Finnish Ministry for Foreign Affairs for the entire period. My study also received funding from the Tokyo Foundation and the Nordic African Institute. The Centre for International Mobility also financially supported our project in the framework of the North-South-South Higher Education Institution Network Programme. Abilis Foundation, VIKE and FIDIDA also provided me with financial support for the publication of this book. I would like to thank their support and confidence in my work.

The United Nations Special Rapporteur on Disability, Shuaib Chalklen, got in touch with me after visiting our research blog site (<http://disability-uganda.blogspot.com/>) as soon as he was appointed to the position. Since then, we have had very interesting discussions on our common interests of disabilities, human rights and development. I am more than grateful for his foreword for this book. Towards the end of the project in April and September 2012, I had the opportunity to visit Addis Ababa and New York with him so as to learn from his activities in terms of policy negotiation, dialogue and information dissemination with various actors including the African Union and the United Nations. He will also provide with me a chance to conduct a joint research project on international cooperation in the field of disabilities in Africa from 2012 onwards. I am humbled.

I am also more than happy to be surrounded by my dear friends and colleagues: Hiro, Atsuko, Eija, Eveliina, Salla, Ninni, JK, Ayako, Naoko I, Natsuki, Tomoyo, Marie, Shin, Masako, Mari, Chiharu, Anniina, Hanna, André, Ninghui, Jian, Elisa, Isamu, Machiko, Yuki, Yuka, Yuko, Keiko, Naoko N, Ikuyo, Yukako, Pia, Mikki, Johanna, Samuli, Petra, Sami, Yumi, Sayaka, Mio, Ingrid,

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September 2012
in Helsinki

A handwritten signature in dark ink, consisting of stylized Japanese characters followed by a checkmark-like flourish.

Hisayo Katsui

Abbreviations

ADA	American with Disabilities Act
ADD	Action on Disability and Development
ADF	African Disability Forum
ADHD	Attention Deficit Hyperactivity Disorder
AFUB	African Union of the Blind
ARI	African Rehabilitation Institute
AU	African Union
AUDA	African Union Disability Architecture
CBA	Charity-Based Approach
CBR	Community-Based Rehabilitation
CEDAW	United Nations Convention on the Elimination of All Forms of Discrimination Against Women
CHOGM	Commonwealth Heads of Government Meeting
CRPD	United Nations Convention on the Rights of Persons with Disabilities
CSOs	Civil Society Organisations
DANIDA	Danish International Development Agency
DFID	Department of International Development
DPOs	Organisations of Persons with Disabilities
DSHAC	Disability Stakeholders HIV/AIDS Committee
DSI/DPOD	De Samvirkende Invalideorganisationer/Disabled Peoples Organisations Denmark
DWNRO	Disabled Women's Network and Resource Organisation in Uganda
ESAU	Epilepsy Support Association of Uganda
EU	European Union
FIDIDA	Finnish Disabled People's International Development Association
GA	General Assembly
GDP	Gross Domestic Product
HIV/AIDS	Human immunodeficiency virus/Acquired immune deficiency syndrome
HRBA	Human Rights-Based Approach
ICT	Information and Communication Technology
IDD	International Day of Persons with Disabilities
LAPD	Legal Action for Persons with Disabilities Uganda
LRA	Lord Resistant Army
MHU	Mental Health Uganda
MP	Member of Parliament
NGOs	Non-governmental Organisations
NORAD	Norwegian Agency for Development Cooperation
NRM	National Resistance Movement
NUDIPU	National Union of Disabled Persons of Uganda
NUWODU	National Union of Women with Disabilities
OHCHR	Office of the United Nations High Commissioner for Human Rights
PAFOD	Pan African Federation of the Disabled
PEAP	Poverty Eradication Action Plan
PRSP	Poverty Reduction Strategy Paper
PwDs/PWDs	Persons with Disabilities
SADPD	Secretariat of the African Decade of Persons with Disabilities

SAPs	Structural Adjustment Programmes
SIDA	Swedish Agency for International Development Cooperation
TAC	Treatment Action Campaign
TASO	The AIDS Support Organisation
UN	United Nations
UNAB	Ugandan National Association of the Blind
UNAID	United Nations Programme on HIV/AIDS
UNAD	Ugandan National Association of the Deaf
UNAPD	Ugandan National Association of Physical Disability
UNECA	United Nations Economic Commission for Africa
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNISE	Uganda National Institute of Special Education
UPACLED	Uganda Parents of Children with Learning Disabilities
USAID	United States Agency for International Development
USDC	Ugandan Society for Disabled Children
WHO	World Health Organisation
WWDs	Women with Disabilities

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Prologue

In December 2004, I was eating dinner with Judy Heumann, then the advisor of disability and development for the World Bank, with Kalle Könkkölä, a Finnish disability activist and the first Member of Parliament with a disability in Finland between 1983-87, the late James Mwandha¹, then Ugandan Member of Parliament, and Ambrose Murangira, the chairperson of the Uganda National Association of the Deaf. All of us were participating in the World Bank Global Conference on Disability and Inclusive Development.² This very night was the beginning of this study.

James D. Wolfensohn, then the President of the World Bank, and Amartya Sen, Nobel Prize winner of Economics in 1998, were the two keynote speakers. Does this mean that disabilities are finally mainstreamed? Is diversity celebrated, or is it just a “token diversity”?

The conference dealt extensively with what the title of the conference promises but with only a limited number of African representatives. Among the crowd, the Ugandan delegates were outstanding. For instance, the Ugandan delegation included a personal assistant for the late James Mwandha and Ambrose Murangira’s sign language interpreter. Both of the Ugandan delegates were either speakers or panellists in the official conference programme and played important roles in the conference. On the other hand, most representatives from other Southern countries came by themselves without their personal assistants and interpreters, if they came at all -this most likely due to a lack of resources to travel all the way from their countries. Contrarily, some Northern delegates attended with two personal assistants or sign language interpreters. Northern delegates were overrepresented, whereas Southern ones were underrepresented to discuss the inclusive development concerning Southern countries. Is this just a coincidence? Or is this a perpetuated reality of development practice? Why is Uganda different from other African countries in the global age?

I became very interested in Uganda and learned to know that a handful of Members of Parliament with disabilities represent persons with disabilities in Uganda. I clearly remember having posed many questions to the two Ugandan representatives concerning the Ugandan disability movement. The Ugandan realities sounded so different from the Central Asian countries that I had been concentrating on for my PhD. It was particularly of interest to me that Uganda has a quota for Members of Parliament with disabilities based on an affirmative action policy, while Könkkölä in Finland has not managed to go through to the Parliament after 1987, not to mention the political challenges faced in Central Asian countries. When disability rights is a global issue and is infringed upon around the world -in both the North and the South- hitherto knowledge, money, models, and material transfers from North to South become highly controversial in the field of disabilities and development. This is true because none of the Northern countries has ever achieved disability rights yet to date. Experiences of the Ugandan disability movement need to be elaborated to learn from. This was my intuitive feeling then and the starting point of this study. It was a very dynamic period

1 Please see more about him on <http://disability-uganda.blogspot.com/2010/11/in-memory-of-james-mwandha.html>.

2 Please see more about the conference on <http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTSOCIALPROTECTION/EXTDISABILITY/0,,contentMDK:20245996~pagePK:148956~piPK:216618~theSitePK:282699,00.html>

in the global disability movement as it was moving towards the formulation of the United Nations Convention on the Rights of Persons with Disabilities that was to be adopted in 2006 and to enter into force in 2008.

After coming back to Finland, I was commissioned to conduct an evaluation study of Abilis Foundation on four countries (Katsui, 2006-a&b). I included Uganda as one of the four because I was fascinated by the political achievements of the Ugandan disability movement. When I was looking for a woman with a disability who could be my research assistant for the evaluation study, the late Mwandha introduced me to several young female candidates, all of whom had university degrees. This meant that the achievements had not remained at the level of policy but also in practice. My interests in Uganda increased as I learned to know more about it. The assistant, the late Ruth Nakamanyisa,³ was also very talented. The success of this evaluation study in applying a participatory research approach for a better understanding of the complex local realities through the lens of the assistant with a disability, led me to use a similar approach in a bigger study as well. After the evaluation study, I mobilized the present research project team members and formulated the research proposal with a special focus on the full participation of Ugandan persons with disabilities in the research project. We all, including the late Mwandha and late Nakamanyisa, got very excited about this project.

³ Please see more about her on <http://disability-uganda.blogspot.com/2010/11/in-memory-of-ruth-nakamanyisa.html>.

1. Introduction

At present, the number of persons with disabilities around the world is estimated over a billion or 15% of the whole population, of whom 2-4% experience significant difficulties in functioning (WHO and the World Bank, 2011:29). 80% of them are estimated to live in the global South (WHO, 2003; United Nations/Division, 1999). The realities for many persons with disabilities are devastating: only 5-15% of people who require assistive devices and technologies have access to them (WHO, 2012); the global literacy rate for persons with disabilities is as low as 3 % and 1 % for women with disabilities (United Nations, 2006); 17% of the poor people are occupied by persons with disabilities according to the World Bank (Haar, 2005). That is, persons with disabilities, particularly those in the global South, tend to be largely ignored both by their own governments and international communities. A **Human rights-based approach to disabilities** incorporates the largely neglected part of the world population into the mainstream development and human rights discourse.

The **United Nations Convention on the Rights of Persons with Disabilities** (CRPD) opened for signature on March 30th 2007 and entered into force on May 3rd 2008. The CRPD has been making permanent positive changes in many countries already from the participatory process of making the Convention. This is the first Convention of the century and significant because it finally paid attention to one of the most marginalised groups of people around the world. The CRPD has accelerated the use of human rights-based approaches to disabilities and development both in policy and practice. From the global perspective, one important remark to make about the Convention is that “**International Cooperation** (Article 32)” was included as a stand-alone provision, which was not the case for the Conventions for the rights of women and children. That is, extraterritorial obligation is stipulated. This Article has various implications, particularly towards the participation of persons with disabilities from the South. It “provides a comprehensive normative framework, as well as specific guidance, for mainstreaming disability” (United Nations Economic and Social Council, 2009:17). For instance, major international agencies and Northern countries have rapidly made “dynamic change” to their policies and programmes to include disabilities in their international cooperation and development aid policies and to practice also, to some extent, reflecting on the Convention (Lord et. al. 2010: 31). That is, international cooperation has been highlighted to support national efforts in this field. However, its role is yet to be widely recognised and more research is needed on the role of international cooperation (United Nations Human Rights Council, 2010).

The human rights ideology has four **theoretical significances** to the discourse on disabilities and development. The first significance of this approach is that it involves all human beings in the mainstream discourse, including the most vulnerable groups of people such as persons with disabilities. Secondly, the approach requires rights-based actions instead of charity, which has predominated. Thirdly, the approach stipulates state obligation to secure the human rights of the people concerned. Fourthly, this approach demands extraterritorial obligations, which is the biggest difference compared to the social model of and approach to disabilities. These four significances are the most prominent ones for persons with disabilities in the global South towards attaining the ultimate goal of equality (Katsui and Kumpuvuori, 2008:234). That is, this approach has become an important means of development intervention both at national and international levels. Today, human rights and development are interdependent concepts (Hamm, 2001). This research focuses on human rights-based

approaches to disabilities and development with two case studies of development cooperation activities in Uganda and one case study of international cooperation in Africa.

The focus on Africa is timely because the African Decade of Persons with Disabilities (2000-2009) was extended until 2019 to “promote inclusive development and human rights for people with disabilities” (The African Decade of Persons with Disabilities Secretariat, 2010). **Uganda is an interesting case** where development and disability discourses encounter and have been negotiated. It is a Southern country. At the same time, it has the most progressive Constitution that is cited as a “human rights charter” (Mawa, 2003). Moreover, Uganda was one of the first countries that acknowledged sign language as the official language for Deaf people in its Constitution in 1995 together with Slovak Republic and Finland (Lapiak, 2003). Furthermore, Uganda has the affirmative action quota system for five Members of Parliament to represent persons with disabilities, which is an outstanding achievement of their disability movement (Ndeezi, 1999). This peculiarity of Uganda is the reason to be chosen as our case country, so as to elaborate the theme of disabilities and development with the focus on human rights-based approaches. Special attention was paid to experiences of women with disabilities, particularly deaf women on the grassroots, in order to understand heterogeneity and the complexity of disabilities in the process of operationalising human rights-based approaches.

This book firstly presents relevant concepts, theories and contextual frameworks in Chapter 2. This chapter paves the way for understanding the following discussions. Chapter 3 explores the methodology of this study to explain selected methods. These two chapters reflect on the epistemological background of the author and thus, are important to readers for understanding the specific perspective taken in this study. Chapter 4 is based on empirical findings from the selected three case studies: HIV/AIDS project activities, the general assemblies of organisations of persons with disabilities (DPOs), and international cooperation for the making of African Union Disability Architecture (AUDA). Subsequently, Chapter 5 connects the theories of human rights-based approaches and the empirical findings and further, creates a new evidence-based empirical theory of human rights-based approach. Chapter 6 shifts to a global context to comprehend hitherto debates in this particular context. This chapter also connects findings to existing social movement theories. Chapter 7 is dedicated to methodological discussions on the participatory research approach to disabilities in Uganda. The research experiences are linked with the empirical findings. The final chapter, Chapter 8, summarises main findings and answers the set key questions. At the same time, the validity of the study is elaborated, while areas of further research are suggested.

2. Conceptual, Theoretical and Contextual Frameworks

This chapter is dedicated to defining and introducing concepts, theories and contexts that are crucial for this study.

2.1. Disabilities and Persons with Disabilities¹

The Convention for the Rights of Persons with Disabilities (CRPD) recognises in its Preamble that “disability is an evolving concept and 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.” The World Report on Disability (WHO and the World Bank, 2011:4) also cites Leanardi et al. (2006) and stresses that “disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors).” This kind of relational approach to disabilities started to gain more support. Shakespeare (2006:57) also suggests a relational approach between intrinsic and extrinsic factors. That is to say the definition of disabilities today does not concentrate only on the medical and individual aspect of impairment (known as medical model) but also on other relevant aspects including social (known as social model), environmental as well as psychological aspects. At the same time, such a relational approach captures not only the negative aspect but also the “positive dimension of social relations which enable” persons with disabilities (Shakespeare, 2006:57). “For a long time, it was assumed that challenges were natural and unavoidable consequences” of impairment (OHCHR, 2010:5) but this holds true no longer due to the “profound shift” in disabilities as human rights issues enshrined in the Convention. This is the world trend. However, the Report also recommends improving disabilities data collection so that the data around the world could be comparable and benchmarked, and points out that the shortage of which has delayed national efforts in promoting the human rights of persons with disabilities (WHO and the World Bank, 2011:267). In other words, a uniform definition of disabilities is non-existent.

Defining disabilities is often perplexing. Each country and sometimes even different people in the same country have their own definitions of disabilities (ex. Ethiopia in Tsega, 2003), which is natural due to the diversity of persons with disabilities and their contexts. The following table briefly summarizes major models/approaches to disabilities:

¹ Part of the text was published in the following:

- Katsui, H. (2008) “Vammaisen Ihmisen Identiteetti: Milloin Haluat Tulla Kutsutuksi ‘Vammaiseksi?’” *Kynnys Mielipidelehti* No.3 2008. P.9. (in Finnish) and also in English on <http://disability-uganda.blogspot.com/2008/01/identity-of-disabled-people.html>

Model/Approach	Cause	Solution
Traditional	Misbehaviour of family or that of oneself in former life	Punishment/Guilt
Charity-based	Unmet needs	Provision
Medical	Impairment	Rehabilitation/Treatment
Religious	God's will	Acceptance
Social	Discriminating society	Social change
Political	Asymmetrical power	Participation
Human rights-based	Violation of rights	Human rights-oriented action

Therefore, the title of this sub-chapter is not “disability” but “disabilities” in plural.² For instance, in Nordic countries on the one hand, one of the biggest challenges for many persons with disabilities is not social discrimination as such but the severe climate including heavy snow (Traustadóttir, 2004). On the other hand, lack of glasses causes more functional challenges to those in Uganda, and as many as 35% of persons with disabilities are those with visual impairment (Ministry of Finance, Planning and Economic Development, 2008:7-8). Another example is the status of albinos in some East African countries such as Tanzania, where they are not only socially marginalised but also targets of witchcraft-related killing (The Associated Press, 2009). This is far from the reality in the global North. In India and Egypt, infertility is culturally understood as an impairment (Inhorn and Bharadwaj, 2007), while it is not much on the agenda of the global disability movement today except where it pertains to the reproductive health rights of persons with disabilities. Obesity, alcoholism (Herndon, 2011), Attention Deficit Hyperactivity Disorder (ADHD) (Vehmas, 2011:164), invisible chronic diseases (Jung, 2011) among others are all ambiguous. In other words, disabilities are situational and contextual (Tossebro, 2002 cited in Traustadóttir, 2009:13) and cultural relativism is relevant. Traustadóttir continues to point out that disabilities are also relative. For instance, medical measurements and indicators change over time for defining impairments, and new diagnoses appear. Social constructionism is, thus, also relevant. Shakespeare (2006:55) cites Danermark and Gellerstedt (2004:350): “Only by taking different levels, mechanisms and contexts into account, can disability as a phenomenon be analytically approached.” A holistic and non-reductionist (ex. cultural, economic and biological reductionisms) approach is needed (Shakespeare, 2006:56).

In development discourse, Amartya Sen's Capability Approach (1999) redefined development as freedom and well-being measured not by income and consumption but as freedom and choices and thus opportunities. Freedom is affected by “three conversion factors: personal characteristics (such as metabolism, physical condition, sex, reading skills, intelligence), social characteristics (such as public policies, social norms, discriminating practices, gender roles, societal hierarchies, power relations), and environmental characteristics (such as climate,

² Nederveen Pieterse (2000:134) asserts in a different North and South discussion context, “Part of the problem is that the language of social science and politics invites the use of the singular - modernity rather than modernities, capitalism rather than capitalisms, industrialisation rather than different types of industrialisation. This generalising language is in use across the political spectrum, right to left, and is inhospitable to nuanced political thinking.”

infrastructure, institutions, public goods)” (Robeyns, 2003 Cited in Frediani, 2010:176). This deconstruction of a development concept is informative to the disabilities definition which, however, cannot accommodate the very diversity of persons with disabilities such as persons with profound intellectual and psychosocial disabilities. This part is further elaborated in the following sub-chapter on self-determination. The aforementioned are a few examples to explain why a universal definition has been difficult in practice. Conversely, elaboration on the concept of persons with disabilities and/or disabilities in each country implies the diverse realities of lives of persons with disabilities in that specific context. That also means that substantive equality is more relevant to persons with disabilities than formal equality that treats everyone as alike and thereby reinforces inequality.

Disabilities as a word are a negative form of ability and thus “normalcy” (cf. McRuer, 2006:85). This term of disabilities, therefore, could cause the labelling of some as “others” or differentiate persons with disabilities from norms in a certain context. “Label us able” was the title of an evaluation report of the disability aspect in the Finnish development cooperation (STAKES, 2003), while “people with different abilities” was coined as a politically correct word for persons with disabilities by Judith LeBlanc in 1998 to change the expectation of people without a disability and to increase the self-esteem of the concerned people (Centro Ann Sullivan de Peru, undated). Some might even argue, “Actually, we are all disabled in some way, aren’t we?” Ingstad and Eide (2011:1) even call them “the heroes of everyday life.” However, such terminologies and concepts can undermine the very tendency towards actual negative experiences of persons with disabilities, including impairments (Shakespeare and Watson, 2002) and “real and material distinctions” (McRuer, 2006:157). The risk of “able-bodied containments” that can diffuse or universalise disabilities as “really about all of us” leads to a “society that does not have to take disabled claims to rights” (ibid.). Movements sometimes use this universalism -and such “moments are desirable”- but they must be “temporary or a contingent universalisation of disability” (ibid.). Therefore, having acknowledged the possible negative effects of using this terminology, this study chooses to use this word to politicize and problematise such a reality. “Critical de-composition” of norms is important (ibid.158).

McRuer (2006:72) argues that “locations where disability identities emerge will always be interrogated and transformable” and “sustaining our understanding that who we are or might be can only have meaning in relation to who we are not (yet).” His cross-examination of queer theory and disability studies eventually suggests post-identity worlds as “other worlds” (ibid:202), because identities consist of many components vis-à-vis nonidentity of the normative (ibid.1) and a reconstruction of normalcy (Watson, 2002:519; Murugami, 2009). Thus queer theory suggests investigating positionality vis-à-vis the normative such as compulsory heterosexuality and able-bodiedness (McRuer, 2006:1). In other words, “persons with disabilities” are often only part and temporal identities, which leads to the necessity of applying the intersectionality theory.³ This is one of the relevant ways of analysis in this study⁴, although disability is not merely about social oppression that can be socially deconstructed, as presented in this sub-chapter. This will be further elaborated in the following sub-chapters.

³ The Intersectionality theory will be introduced more in detail in the Methodology Chapter (Chapter 3) when presenting data and analysis.

⁴ McRuer’s Crip theory (2006) will be revisited later in this book in Chapter 6.

Having summarized these theories, it is totally “misleading to assume that persons with disabilities will speak with one voice” (Shakespeare, 2006:106).

2.2. Women with Disabilities



Picture on the left: one of my research assistants with a physical impairment and the author are standing in front of a building at Makerere University. She benefited from the affirmative action policy of the government stipulated in the Universities and Tertiary Institutions Act 2001. She gained admission and scholarship during her study at the University. There was no tuition fee for them then. The Union of students' with disabilities facilitates peer support in the University. As the University was going through graduation ceremonies, there were many graduates with gowns on campus. The Wavah Broadcasting Service (WBS) news on 17 February 2008 broadcast the graduation ceremony of the university and presented challenges of the graduates to get employment. In 1980s when the University was the only one, it was easier for the graduates to find jobs. But today, there are more than 30 universities and many graduates are unemployed. Makerere graduates used to be employed by the government, which remains still the biggest employer but positions are scarce. “You have to create your jobs by yourselves” was the message of the news. While walking with the assistant, some people give kind attention to her, some do not pay attention at all, and others gaze. Even one male passer by asked, not her but the author, “What’s wrong with her legs?” This question demonstrates that persons with disabilities are “wrong” and thus not normal members of society. McRuer (2006:2) conceptualizes this naturality of able-bodiedness as compulsory able-bodiedness, in which system persons with disabilities are located and regarded as deviant. While she was in the university, she stood for the students’ parliament and went through. She bought candies worth 20,000 shillings and distributed them to voters to gain their support. She recalls that some used 100,000 shillings for their campaign. This information is relevant to the forthcoming general assembly activities of DPOs in Chapter 4.

Picture on the right: a deaf woman with a deafblind girl with severe intellectual and physical disabilities sitting in her wheelchair. The girl was stabbed by her mother-in-law who had taken care of her, and was brought to a church. The deaf woman is taking care of her in the church premise. This picture depicts part of the Ugandan gender disparity, of the expectation of females to take care of other members in community and the tendency of irresponsibility of males, even where they are closer family members. At the same time, the care giver’s role of the deaf woman should not be missed, because it speaks the diverse roles: not only passive but also active in different situations.

The UN Convention recognizes in its Preamble that “women and girls with disabilities are often at greater risk, both within and outside the of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation” and emphasizes “the need to incorporate a gender

perspective in all efforts to promote the full enjoyment of human rights and fundamental freedoms by persons with disabilities.” It also has a stand-alone article on “women with disabilities” (Article 6):

Article 6 Women with disabilities

1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.

2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

One of the approaches to elaborate on the diversity of “persons with disabilities” is to understand gendered experiences of disabilities because not all persons with disabilities are on equal status. Women with disabilities tend to face both gender discrimination and disabling barriers (WHO and the World Bank, 2011:262). Meekosha (2004:4) claims that the “gendered experience of disability reveals sustained patterns of difference between men and women.” For instance, women with disabilities earn less than men with disabilities (WHO and the World Bank, 2011: 239). Another statistic estimates that whereas the literacy rate of persons with disabilities is 3% world wide, that of women with disabilities only 1% (UNESCO, 2008 cited in Groce and Bakshi, 2008:8). This study focuses on the perspectives of women with disabilities to understand their lived experiences on the theme of this study by bearing in mind the heterogeneity among them.

2.3. Deaf People and Sign Language

Another approach, among many others, to elaborate on the diversity of “persons with disabilities” is to understand experiences of deaf persons. Statistically, 3-4% of persons with disabilities are deaf people (Corker, 2002). 0.3% of the total 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. Nevertheless, the World Federation of the Deaf (2012-a) claims that “sign languages are the natural languages for Deaf people.” The distinction has to be made on “Deaf” and “deaf.” The Deaf people’s movement defines Deaf people as a linguistic minority who use sign language instead of verbal communication. In this respect, Deaf people are a cultural and linguistic minority in a phonocentric world. That is, when Deaf people choose the cultural model in some context, they reject disability identity, which is important in the concept of Deaf (Skelton and Valentine, 2003). In other words, Deaf people are both deaf and Deaf (Padden & Humphries, 1988 cited in Corker, 2002).

A study on Deaf people in 93 countries (Haualand and Allen, 2009:8) asserts, “For Deaf people the major barrier is lack of recognition, acceptance and use of sign language in all areas of life, and lack of respect for Deaf people’s cultural and linguistic identity.” This perspective is

repeated in the UN Convention that mentions deaf persons concerning their rights to specific culture and linguistic identity including sign languages and deaf culture. It also stipulates the rights to education for the deaf in “the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.” Deaf people and sign language are deeply interconnected through identity and culture.

Similarly, the World Federation of the Deaf (2012-b) critically reviews the current educational system that violates the linguistic human rights of Deaf children to learn in their mother tongue of sign language. It continues that inclusive education without meaningful interaction with classmates and teachers all the time is inappropriate.

The invention of cochlear implant has changed the bioethical discourse in Northern countries where implants are available and accessible. It has become an “ethical paradox” for parents of pre-lingual deaf children between a cure of a health condition and linguistic choices (marginalisation of already marginal sign language). Bioethical arguments tend to be dichotomised in a universal and theoretical or sometimes political manner that implantation is ethically right or wrong to all deaf children (Kermit, 2010:93; Shakespeare, 2006:115) This is too limited and essentialist in describing diverse realities among children with implants. Empirical knowledge on the linguistic experiences of such children and people is only beginning to accumulate. Due to the high cost of the device, surgery and post-surgical therapy, the vast majority of implants take place in Northern countries. In the 2011 Resolution of the World Congress of the World Federation of the Deaf at Durban, South Africa, it was decided that the Federation will prepare a position paper on cochlear implant (World Federation of the Deaf, 2012-c).

2.4. Global South and North

The Global **South** refers to so-called “developing countries” and the recipients of development cooperation, while **North** refers to “developed countries.” The concept of “development” is not universal and thus countries cannot fit into this simple dichotomy between “developed” and “developing.” For instance, many “developed countries” do not necessarily fit into the category when a human rights perspective is applied. This North-South solution is to politicise “development” rather than to capture the world in a geographic specificity (e.g. Australia). The borderline between the North and the South has been blurred in disabilities discourse because no country has achieved equality for persons with disabilities. For instance, the first countries to acknowledge sign language as the official language for Deaf people in Constitutions were Slovak Republic, Uganda, and Finland in 1995, Czech in 1998, and Thailand and Venezuela in 1999 (Lapiak, 2003). Another example is Mexico which vigorously addressed the need to stress the human rights of persons with disabilities in United Nations Assembly in 2001, which led to the process to make the UN Convention. In other words, both the North and the South started to pay attention to the human rights of persons with disabilities only recently (Katsui, 2006-c:86).

This binary division is not to simplify the complex realities but to facilitate our analytical understanding on the complexities from a different perspective, without essentialising as if

Southern countries are all the same. The diversity of Southern countries and different cultures are acknowledged. Meekosha and Soldatic (2011:1389) recommend as follows; "It is important to contextualise violations of the rights of disabled people not only in terms of the struggles in the global North, but also in terms of power relations between the North and South and within the global South." Kim (2011:95) points out further that "Power dynamics between recipients and providers of help, their national representations, and the symbolic value of bodily transformation through medicine contribute to the hierarchy between cultures and the positioning of enabled bodies over disabled bodies." Similarly, Alex Ndeezi, the Deaf Member of Parliament representing persons with disabilities states, "Because our situation is not like the one in Europe, [it is] actually a very different situation. So when we talk about human rights, they are not the same form in different countries. ... In Uganda, issues are handled in a different way" (personal interview on 28 January 2008 in Kampala). Thus the intention of this study is not to "idealise" North and to make South look "behind" as Kim criticises (2011:94) but to elaborate on specific contexts and experiences in the South by politicising "development."

2.5. Persons with Disabilities in the South

80% of the world persons with disabilities are estimated to live in the South (WHO, 2003; UN/Division, 1999). Despite the significant number in the South, access to various services is limited in the South (Borg et al. 2011). For instance, 5-15% of people who require assistive devices and technologies have access to them (WHO, 2012). This explains the next statistics: 17% of the poor people are occupied by persons with disabilities according to the World Bank (Haar, 2005). Furthermore, 90% of African children with psychosocial disabilities die before age 5, and 70% of African adults with disabilities are unemployed and live in poverty (United Nations Population Information Network cited in the Ministry of Finance, 2008:6). The vicious circle of disabilities and poverty is "obvious" (Yeo and Moore, 2003; Benedict and Eide, 2011:5). That is, persons with disabilities in the South are largely ignored both by the governments and international communities. Disability Studies is not an exception in this trend (Grech, 2011:87). The UN Convention highlights in its Preamble "the fact that the majority of persons with disabilities live in conditions of poverty, and in this regard recognizing the critical need to address the negative impact of poverty on persons with disabilities." This poverty problem is quite relevant to many persons with disabilities, because one in five of the world's persons with disabilities are impaired through malnutrition (Oliver, 1996-a). Disability and poverty tend to have a mutual relationship of cause and effect (Yeo, 2003: 572-3), which has been hard to be empirically establish in detail due to lack of large scaled and longitudinal data on persons with disabilities in the South (Mitra, Posarac and Vick, 2011). Existing quantitative studies show tendencies of persons with disabilities in the South to become poorer than peers without a disability, while the definition of disabilities as well as methodology are not standardized. Thus the results are not comparable across countries (ibid.; World Health Organisation and the World Bank, 2011). The study of Mitra, Posarac and Vick (2011) compares data on persons with disabilities and those without a disability in 15 countries in the South, and reveals the inter alia tendency of higher prevalence of disabilities among poor, the significantly lower educational attainment of persons with disabilities compared with peers without, and the lower employment rate of persons with disabilities compared with peers without. The same report also clarifies tendencies of vulnerability of households with members with disabilities with fewer assets and higher expenditure on health. Even though the report is cautious about generalising the result to be applied to all Southern countries due to challenges

pertaining to research on disabilities in different Southern contexts, it is noteworthy to find a rather clear correlation between disabilities and poverty in such comparable data. World Vision International Uganda (2008:42) enlists many statistics and their sources under “disability fact sheets.” Some of them include the followings:

- 50% of the impairments are preventable and poverty-related, while 20% is caused by malnutrition (DFID).
- 98% of children with disabilities in the South do not go to school (UNESCO).
- 500,000 children become visually impaired every year due to lack of vitamin A (UNESCO).
- 70% of blindness and 50% of hearing impairment of children in the South is either preventable or treatable (WHO).
- In Africa, 80% of people with epilepsy receive no treatment (WHO).

Meekosha (2006) presents a list of patterns of women with disabilities in the South:

- Poverty hits harder on women and girls due to patriarchal property ownership structures
- Aid is less likely to reach women and girls who are less able to compete in situations of scarcity
- Disabled women are more vulnerable to domestic violence
- Disabled girls are likely to find their access to education even more limited than girls in general
- Women disabled by war have few resources to survive
- Disabled women who are sexually abused are likely to have few if any social supports or options
- Disabled women are less likely to be accepted as refugees by industrially advanced countries (eg Australia prohibits the immigration of people with disabilities). (*Abu-Habib, 1997; Meekosha and Dowse, 1997; Snyder, 1999; Charowa, 2002* all of which are cited in Meekosha, 2006)

Naami et al. (2012:191) points out the intersection of disabilities, gender, poverty, cultural beliefs and practices for women with disabilities in Ghana. Hellen Asamo (personal interview on 31 January 2008 in Kampala), current Member of Parliament representing persons with disabilities in Uganda, explains why girls with disabilities do not get education opportunities compared with girls without a disability. She claims that parents look at a girl child as a bride price for which her husband pays something to the parents. However, as women with disabilities are not expected to get married, parents do not educate them because they do not “benefit” from them through “bride wealth” (Groce, London and Stein, 2012:24). She explains that this is an African-wide phenomenon. The same issue was pointed out by Alex Ndeezi, the Deaf Member of Parliament (personal interview on 28 January 2008 in Kampala). The World Federation of the Deaf (2012-a) claims, “the rights of Deaf people are often overlooked, especially in developing countries. ... Most of the Deaf people do not get any education in developing countries and approximately 80 % of the world’s 70 million Deaf people do not have any access to education. Only about 1-2 % of the Deaf get education in sign language.

Particularly the situation of Deaf women and children is weak.” In the North in the late 18th Century, sign language was disadvantaged at night in the dark (Cooper, 2012). This is still often the case in many places in the global South today. More recently in 1960s and 1970s, foreign sign languages were introduced to many Asian and African countries through charity, religious, and development actors, which to some extent affected indigenous sign languages. Still today, American Sign Language is influential (Harayama, 2010). Many deaf children meet other deaf only in schools (ibid). Thus lack of education opportunities for deaf children is not only an issue of education per se but also one of an acquisition of a mother tongue. When it comes to medical services, there are only six rehabilitation doctors in the whole African continent, all of whom are located in South Africa, whereas Europe has 10,000 and United States more than 7,000 (Haig AJ et al. 2009. Cited in World Health Organisation and the World Bank, 2011).

Nevertheless, drawing from Ingstad’s (1997) anthropological study, Grech (2011:89) calls the inferior images of Southern persons with disabilities “myths.” For instance, another study in Kenya (Harayama, 2010) similarly claims that colleagues of Deaf workers often try to learn sign language to communicate with them. Harayama (ibid) analyses that Kenyan people typically speak their own mother language, English and Kiswahili at the very least and learning another language is not considered a barrier as much as in Northern countries where only one or few languages are spoken. He further continues that a total lack of an education system for deaf pupils until recently even favoured them to start education for deaf pupils in sign language in 1983 without going through bilingual or oral education history as many Northern countries have faced. Cooper (2012) points out that dyslexia is not recognized in communities that do not rely on writing. Benedict and Eide (2011:5) also call for attention to contexts by introducing an example of disability pension in South Africa, which serves to uplift persons with disabilities, while the equivalent in Northern countries “traps” them to be excluded from the labour market. They explain that the level of living and social participation is linked to work in the North, while they do not depend on work in the South. Hellen Asamo (personal interview on 31 January 2008 in Kampala) articulates some inter-linkages between economic poverty and discrimination in lives of Ugandan women with disabilities. Subsequently, she introduces positive changes and diversity among women with disabilities:

I know there is poverty. Most of them (women with disabilities on the grassroots) are single parents. They are not yet married. Those are the challenges they have. People can never believe that they can get married. So that is a challenge. But in terms of most of them, we are trying to empower them with economic empowerment to see that they can have money in their pocket. And our story is that when we have money in our pocket, nobody looks our disability. They look at the “madam,” they don’t call you disabled but “madam” because you have money. So we tell them to get money and educate your children. ... To me, society has changed somehow to look at us as women first and as disabled, later. So you see these girls (with disabilities) are getting married and oh, this was previously not something associated with disabled ladies. ... I’m telling you to go to the grassroots because the picture that you are getting is that one. ... It depends on where you go. In some places people look ok. In some places they are very poor. In some places they are just coming up (Personal interview on 31 January 2008 in Kampala)

Furthermore Grech introduces Derrida's (1976) deconstruction theory to explain how Northern actors use binaries in the discourse, position themselves as superiors whereby they become dependent on the South, and create linkages between discourse and material intervention. This homogenization process is similar to what the Northern feminists went through in 1980s (Grech, 2011:89). Harayama (ibid.) suggests that the discourse should not be to "rehabilitate" or "integrate" deaf people into mainstream but to learn from those deaf people who have succeeded in creating their own employment opportunities in an innovative manner under the circumstances in present Kenya. These anthropological studies, however, do not problematise the reality in which persons with disabilities often are included as subordinates rather than as equal members of society. McRuer (2006:17-19) argues that flexibility is a condition of postmodernity approach in which persons with disabilities are not regarded as absolute deviance in this recognized diversity in many cultural representations any longer but still subordination to hegemony. In this sense, in reality it is often "token diversity."

Having acknowledged the impossibility to depict typical contexts in the South, Grech (2011:91) nevertheless enlists relative settings in the South which are absent in the North:

- Engagement in complex and diverse livelihoods often in the informal sector (especially in rural areas) rather than dependence on the Western one-job remunerated employment (e.g. labour-intensive agriculture, petty trade, gathering of firewood and water, labour in kind, etc.).
- The presence of dual economies: households (especially those in rural areas) frequently have one foot in the market and the other in subsistence.
- Unreliable and/or missing markets: for example, the credit market in poor rural areas.
- Unequal land distribution (often a result of colonial appropriations and allocations).
- Rural-urban divide in formal services (e.g. access to health and education, equipment, programmes and markets). Around 75% of the extreme poor live in rural areas (World Bank 2008).
- Dependence on natural resources for livelihoods and consequently high levels of risk and vulnerability to environmental stresses and shocks (e.g. droughts, floods, climate change, etc.)
- The absence or lack of a welfare system and other formal safety nets (e.g. health, education, unemployment benefits, etc.)
- The persistence of strong social ties and close-knit communities, and the influence of culture, ideologies and beliefs.

The World Report on Disability (2011) of the World Health Organisation and the World Bank debunks the "myths" and proves the "marginalised realities" of persons with disabilities around the globe based on a huge number of scientific studies and thus, with evidence. Kalle Könkkölä, a famous international disability activist from Finland, commented in one of the launch events of the Report in Helsinki on 13 December 2011 that "What we had known for long from our own experiences was now proved scientifically as truth and facts." The human rights discourse involving Southern contexts thus prevails. Hence, this perspective also becomes important in this study for understanding the challenges and opportunities of persons with disabilities in the very Southern contexts, not by homogenising and generalising the contexts but through

engaging in the nuances of the contexts. That means in the research practice that relevance of human rights is always questioned. Southern countries and cultures in conjunction with the global structure are too diverse to deeply understand in any study of this kind. Thus this study focuses on Uganda, to take its epistemological background more into account by learning from the criticism against human rights discourse in terms of contextual universalism.

2.6. Disabilities and Persons with Disabilities in Uganda



Picture on the left: an “introduction” (engagement ceremony) of the daughter of a Deaf man, who is sitting in front of the couple, second from the left under the decorated tent. He is a lecturer on sign language at Kyambogo University, and the ceremony was held on the premises of the University where the family lives. Many Deaf friends of his were invited to this ceremony. Two sign language interpreters were present for the whole ceremony. The couple are kneeling down to ask for permission for their engagement. To be more precise, the groom kneels down, and the bride sits on the mattress which seems to symbolise the hierarchical relationship between them; man is higher and woman lower. The people under the tent are all men wearing dark suit jackets and white skirt-shirts, while women -even the mother of the bride- are busy preparing food in the kitchen and thus cannot observe the event. Many female guests including the author wore the traditional dress, *Gomes*.

Picture on the right: a man with a physical impairment drawing pictures and earning money on one of the busiest streets in downtown Kampala. He spreads many pictures on the ground showing his talent. There is only one coin in the box. “Beggars” are few on the street. CHOGM preparation displaced all beggars away from the street, the research assistant claims. She learned to know this fact by watching a TV news report stating so. “People with disabilities are visible in Uganda,” says staff C of a Northern DPO (personal interview on 18 February 2008 in Kampala). “It’s a positive visibility, not beggars. You see them all over in ordinary life activities. This is really amazing when you think of the economy of this country.” Then the author asked, “How did it happen?” She answered, “That is NUDIPU and all the other DPOs’ efforts. It’s the human rights-based approach.”

This study focuses on persons with disabilities in Uganda. Therefore, it is natural to elaborate on the definition in Uganda neither to essentialise nor impose a certain definition of disabilities which is different from culture to culture even within a country. This is an important point of departure on a study pertaining to disabilities.

The Ugandan government defines disability as “a substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environment barriers resulting in limited participation” and a person with a disability as “a person having physical, intellectual, sensory or mental impairment which substantially limits one or more of the major life activities of that person” in its Persons with Disabilities Act 2006 of Uganda. The Report published by the Ministry of Finance, Planning and Economic Development of Uganda (2008:2) defines in a similar manner saying, “Defining disability is complex and controversial. Though arising from physical or intellectual impairment, disability has social implications as well as health ones. ... The social model makes the case that disability is the outcome of the interaction between a person and their environment and thus is neither person-specific nor environment-specific.” They are theoretical definitions at the policy level.

When it comes to the Ugandan disability movement, the definition leans more to the social model, which focuses on discrimination and social oppression as the disabling barriers. Previously, it was close to what is called the “medical model” in which negative consequences were due solely to the impairments of individuals. Currently, disability activists use what is called the “social model” by focusing on the environmental and social barriers to be removed:

(The definition of disability) is always evolving, but what we are adopting now is a social model of disability. It was previously a medical model. So, we are looking at more of the environment which is disabling them. Interaction of the person with the society, and how you face the society is what we are looking at in disability. The environment that defines disability acknowledges that if the environment is favourable, such a disability can, in a way, be avoided. So we are adopting the social model (Executive Director of NUDIPU, personal interview on 31 January 2008 in Kampala).

People with epilepsy, psychosocial disabilities and multiple disabilities such as deaf-blind have lately started to be recognised also as groups of persons with disabilities. Their organisations recently joined the Ugandan disability movement (Chairperson of the NUDIPU, personal interview on 31 January 2008 in Kampala).

Statistically, the Uganda National Census 2002 estimated that 4% of the population had disabilities, while the Uganda National Household Survey of 2005-2006 estimated 7% (Ministry of Finance, 2008:1). Further, the Uganda Demographic and Health Survey 2006 shows that overall disability rate is as high as 20%. The gap is due to the differences in methodologies among the studies. The last one used the persons’ functional abilities rather than physical characteristics depending on international standards (ibid.7). The following table is the official dis-aggregation of “disability by type” using the statistics from the National Census 2002 and National Household Survey 2005-6 by the Ugandan government today:

Disability by Type

Difficulties/Type	% in 2005- 2006	% in 2002
Seeing	35.17	22
Mobility Problems	24.46	34
Hearing	20.43	15
Taking Part In Social Activities	6.63	7
Psychological, Emotional	4.33	8
Communication	3.97	4
Other	1.97	5
Personal Care	1.64	1
Learning	1.41	4
Total	100	100

(Source: Ministry of Finance, 2008:8) (Graphed by the author.)

As for the understanding of disabilities on the ground, both social and medical models fail to some extent. The movement has been mainly led by persons with physical disabilities, and people on the grassroots believe that those with “a visible/physical disability” are persons with disabilities (NUDIPU, 2007:16). A medical diagnosis is not accessible or available for many. This has also reinforced people’s image of disabilities as easily observable impairments. For instance, many of the interviewees with hearing impairments self-diagnosed their conditions and claimed as “deaf” even though some were actually “hard of hearing” persons according to the global North classification.⁵ Likewise, most of the deaf-blind members of the DPO in Uganda were not actually deaf-blind according to the international standard (Staff A of a Northern DPO, personal interview on 30 January 2008 in Kampala). This is due to the lack of medical service accessibility (ibid.; Chairperson of the United Young Deaf Women Group, personal interview on 4 February 2008). A diagnosis is often subjective rather than objective in Uganda today, while disabilities data on an objective assessment is largely missing and “self-reporting” is often the only available data in the South (Mitra, Posarac and Vick, 2011:24).

The Ugandan Ministry of Finance Report (2008:10) also points out that disabilities was defined as inabilities reflecting on the community’s understanding on disabilities. Persons with disabilities are considered as “weaker,” “less able” and/or “abnormal,” not to mention the directly discriminating terminologies used such as “a curse” and “a burden” particularly during the conflict. The Report (ibid.) claims that local terms defining disabilities are “derogative” and reinforcing stigmatization and exclusion of persons with disabilities in Uganda (ibid.viii). One extreme example of such attitudinal barrier in Uganda is the infanticide of babies born with impairments (World Vision International Uganda, 2008:25). Erving Goffman’s stigma theory (1963) is thus relevant to disabilities. Misconception pertaining to the causes of disabilities is rampant in all studied areas, especially in rural areas regarding witchcraft, which has delayed prevention or denied a search for proper medical treatment (Ministry of Finance, 2008:16;

⁵ This causes conflicts between UNAD and the organisation of the hard of hearing, as the target group is the same but the former promotes sign language and the latter, the hearing aid (Executive Director of NUWODU, 8 December 2008 in Kampala).

United Nations Social and Economic Commission, 2012). World Vision International Uganda (2008:32) enlists the “common myths in Uganda on the causes of disabilities” as follows:

- It’s the result of witchcraft (blindness, albinism, epilepsy)
- Punishment of sin or a curse from God (learning disability + mental illness [sic])
- The result of incest
- Punishment by ancestral spirit
- The result of a failure to observe cultural norms in reference to eating and touching certain foods or other items.

The Ugandan Ministry of Finance Report (2008:20) also exemplifies the reality of persons with disabilities related to their well-being levels in the following table:

Categories of Well-being Showing the Number of Persons with Disabilities in Iganga District

Well-being Categories	Characteristics	No. of Disabled Persons
Rich	- have vast land - have two wives - are employed (bicycle repairers) - have semi-permanent houses - can afford having good food	1
Fairly rich	- have a plot of land for cultivation - educate children in UPE - can manage to eat twice a day - have many wives	5
The poor	- lack land - are unemployed - rent land for digging - children do not go to school	22
The very poor	- have no food - have no accommodation -survive on offerings from the community members - have no houses for accommodation	7

The well-being captured in the above table is centred to economic indicators and thus too narrow in scope to grasp the comprehensive picture on well-being. However, the information speaks eloquently on a clear tendency of persons with disabilities. Since the inception of the Ugandan Poverty Eradication Action Plan (PEAP) in 1997, which is equivalent to the Poverty Reduction Strategy Paper (PRSP) of other countries, poverty was reduced from 56% to 31% over the 10 years among the general population (ibid.viii). The above table indicates poverty (poor and very poor) as high as 83% among persons with disabilities in the studied district,

which is much higher than the average benchmark. This partially reveals severe realities of persons with disabilities in Uganda.

Due to such negative connotation involved in the term “persons with disabilities” in Uganda, defining it involves serious identity issues. The technical definitions of persons with disabilities applicable to the term are not dependent on different situations and contexts, as discussed above. The Ugandan government has an affirmative action policy favouring the inclusion of marginalised groups of people, including persons with disabilities, into politics. In addition, the study focuses on international and development cooperation activities targeted mainly for persons with disabilities, in which they are directly and/or indirectly affected from said activities while non-disabled neighbours might not be. In other words, individuals might identify themselves positively as “persons with disabilities” under different circumstances. In short, the identity of “persons with disabilities” seems to be quite mixed and needs more nuanced attention in this research. Therefore, a similar approach is applied to this study as gender, where the concept is used for socio-cultural notions of masculinity and femininity as a whole, and includes a variety of experiences that are not necessarily only limited to negative ones. For instance, Shakespeare (2006:56) suggests a holistic approach to disabilities rather than a reductionist one. However, the study does not directly exchange the gender concept of feminist studies with that of disabilities because such an exchange requires a “rigorous critical scrutiny of the implications” (Samuels, 2011:54). Samuels instead claims to go beyond a single-term approach (ibid.55).

It is also noteworthy to mention in the end of this sub-chapter that following the definition of Uganda is not without the problem of cultural relativism. Part of the cultural relativism challenge is overcome by reflecting on the very Ugandan definition of disabilities. However, the definition is “evolving” and has most probably left out many more persons with different conditions who could very well be categorized as persons with disabilities. For instance, those with AIDS and those with infertility are not included in the discourse on disabilities in Uganda today (cf. Ameen, 2010) despite their medical conditions and discriminatory social environment. Many more new types of disabilities might be added as time goes. Thus, not only does the identity of persons with disabilities need to be seriously taken into account, the evolving nature of disabilities does as well. That is, the definition itself already reflects on many of the issues concerning disabilities today and thus is very important.

2.7. Deaf Women in Uganda



Picture on the left: a Deaf shopkeeper in the taxi terminal market. She speaks Ugandan sign language. She says there is no problem with her customers because she can show the prices written down for them. These places were the fruit of advocacy by Kampala district councillors, she says. Many deaf women have the skills of tailoring and hairdressing. Many are engaged in petty business such as this kind of shop keeping. She says, "My dream is to build my own house." Her immediate next shop is also taken care of by one Deaf woman. Another Deaf woman owns the shop, and she only takes care of the selling. The neighbour shopkeeper had stayed at home for three years before she got this job. She gets 2000 shillings per day and works without any holiday on weekends. She wants to learn the skills of hairdressing and looks for a sponsor.

Picture on the right: a Deaf teacher of knitting at the Ntinda School for the Deaf. She sells her own and students' knitting products. The author bought some products from her for souvenirs.

As mentioned before, deaf persons are few and far between, and most of them do not automatically learn sign language as a mother tongue at home. This is also characteristic of Uganda. As most of the population lives in rural areas in Uganda, this distance between deaf people is a challenge. Dear Woman C used to live in a rural area and currently resides in Kampala. She compares the lives there and here:

The situation in town and in the village is different. ... In a village, communication is a problem. But here in Kampala, you can easily get friends and communicate with friends. You can easily meet the Deaf. But in a village, you might have deaf people around but you don't know who is deaf. You cannot communicate with one another (personal interview on 4 February 2008 in Kampala).

She met another deaf for the first time in her primary school. That means, the identity as a Deaf is hard to be established for deaf women in rural areas in Uganda. Thus, it is not natural to learn a sign language when born as a deaf in Uganda. Only those who are educated in schools for the Deaf can speak the Ugandan sign language. Others without education use local sign languages or a "gesture system" of home signs. Deaf woman A who is a sign language instructor says, "There are many, especially ladies who are oppressed and have never seen even sign language. There are many" (personal interview on 4 February 2008 in Kampala). Similarly, a situational analysis study on sex education for deaf children could not include those who could not speak any language even when all children were identified at schools (Kiribaki et al., 2008:7). That conversely implies that deaf children who are out of school are most likely not to have any mother tongue.

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). Deaf woman C explains the reasons why:

So many deaf people have never been to school. That's why many deaf people do their own income generating activities like knitting at home, even if they can work in some places like a hotel to serve. They ask, "How are you going to communicate?" So, they start to work at home. There are many deaf suffering here. There are many deaf who are making tablecloths, but another challenge is how to sell those products. That's our challenge. For example, when I do some business, they come and see you and say, "Ah, you are kasiru ("stupid"), signing? Let me go to another seller." You feel so discouraged. When you sell by yourself, a hearing

person can say, "Come, come!" But we cannot say it. There are few who are sensitised who can come. But very few buy our things. ... It has happened to me. I have experiences of that (personal interview on 4 February 2008 in Kampala).

In the male dominant culture in Uganda, women are subjected to obey men (DSI, 2007:3; Gender officer of UNAD, personal interview on 28 January 2008 in Kampala; Alex Ndeezi, personal interview on 28 January 2008 in Kampala). "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, the same report claims, disabilities and related discrimination hits harder on women with disabilities than on men with disabilities. The aforementioned Ministry of Finance Report (2008:ix) also points out that girls and women with disabilities "are more negatively affected by poverty due to social and cultural constructs." Women have no right to own land, only husbands do (Ibid.27). Furthermore, husbands often divorce women with disabilities. In such case women with disabilities tend to be left with poverty. Another example is on education. The opportunity for receiving an education is not often given to deaf girls as much as to other siblings. A deaf woman C and deaf woman B share their experiences:

I started in 1993 and the education went well. When it was time for P-6 and I was approaching the exam time, I asked my father to pay for the school fee, but my father concentrated on drinking and not helping. He told me, "Since you are deaf, there is nothing that I can do for you." And he concentrated on drinking and took care of the other children and left me behind (personal interview on 4 February 2008 in Kampala).

I have a problem at school. My father died in 2005. Now some other relatives cannot support me going to school. They try to contribute to the other siblings. Four other siblings are at school, but only I stay at home. When I ask a sponsor, they refuse. I have no work, and I just stay at home (personal interview on 17 February 2008 in Kampala).

Boys tend to be the first priority, while girls without a disability the second priority. Education for girls with disabilities is considered as "a waste of money" (Gender Officer of UNAD, personal interview on 28 January 2008 in Kampala). Therefore, many deaf girls' education ends at the primary level, if they get any formal education at all (ibid.). One Ugandan nation-wide statistic shows a clear gap between the number of enrolled boys with disabilities and that of girls with disabilities in primary schools; 82,537 and 68,022 (Uganda Human Rights Commission, 2009:31). Even after the introduction of the government's Universal Primary Education in 1997, which officially entitled four children (at least two girls) per household to receive free education in principle, those benefiting from this policy are mostly children with physical disabilities among children with disabilities. Moreover, the policy applies only to children, so individuals who have already reached adulthood and youth with disabilities have not benefited from it. This has been hardly addressed in existing literature (Groce and Bakshi, 2009:2). The majority of deaf are among those who do not benefit from the policy (Ministry of Finance, 2008:41). The following table shows the "Number of children with disabilities by Grade" in the whole country in 2001 (Uganda Human Rights Commission, 2009:27). As is clear from the table, the drop-out rate tends to be very high, even when children with disabilities are enrolled in primary schools (P1-P7), while many are left without any education at all. In other words, this table sheds light on the achievements of the government and those who benefit from

education opportunities stipulated in the national legal framework. However, it remains silent in its investigation on the many more that do not have such access. Moreover, mere enrolment does not show actual attendance and quality of the education, which are more relevant for the well-being of children with disabilities in practice.

Disabilities	P1	P2	P3	P4	P5	P6	P7	Total	%
Mental[sic]	12,526	7,808	7,223	6,153	5,123	3,802	2,788	45,424	26.24
Visual	6,487	5,396	6,981	6,734	5,904	4,873	3,941	40,316	23.28
Hearing	10,750	7,998	8,767	7,970	7,970	4,166	2,643	48,354	27.93
Physical	7,506	5,424	6,607	6,478	6,478	4,304	3,243	39,049	22.55
Total	37,269	26,627	29,578	27,335	22,574	17,145	12,615	173,143	100

When it comes to quality of education, a Deaf woman C (personal interview on 4 February 2008 in Kampala) says, “we had no sign language, but copied from those students with hard of hearing. We didn’t have teachers who can sign at school. We learned from the ones who had hard of hearing.” “Sign language in school is a new thing,” says Alex Ndeezi, the Deaf Member of Parliament (personal interview on 28 January 2008 in Kampala). As the above table is too simple in its dis-aggregation of disabilities categories in terms of impairments, deaf children are not differentiated from hard of hearing children and those with milder hearing impairments. It is easy to assume that enrolment rates of deaf children are much lower than that of children with milder hearing impairments because the illiteracy rate among Ugandan deaf people are as high as 95% (Development Research and Technology, 2008:53), which implies an even higher illiteracy rate among deaf women. This was true for the interviewees of this study who were deaf women. Consequently, many deaf women are illiterate and do not have good sign language skills, either (Alex Ndeezi, the Deaf Member of Parliament/ Executive Director of UNAD, personal interview on 28 January 2008 in Kampala). This in turn leads to limited opportunities. Thus, including these deaf women is “time-consuming” because “we have to use a lot of explanation. We have to take them a lot into practical training. If you talk one thing, you have to go back twice so that they understand it. So we come with different means like drama and the rest of it just for them to understand the message better” (Gender officer of UNAD, personal interview on 28 January 2008 in Kampala).

Even when one has the literacy of Ugandan sign language, the sign language interpreter costs 20,000 shillings per day. Even when one needs the interpreter only for one hour, it adds up to 40-50,000 shillings when transportation cost is also covered. Similarly, a sign language course for 3 months costs 150,000 shillings, excluding the registration fee of 5,000. One deaf woman working as a shopkeeper told the author that she gets 2,000 shillings per day for her salary. Thus employing an interpreter is far too expensive for many deaf people who are sign language literate, while learning the sign language itself is extremely expensive for deaf people in Uganda. In this context, Hellen Asamo, a Member of Parliament representing persons with disabilities and the chairperson of NUWODU (personal interview on 31.1.2008 in Kampala) says that “the sign language is somehow new,” even though local signs and family signs have had a long history “as old as mankind.” Nevertheless, Alex Ndeezi, the Deaf Member of Parliament claims that Uganda has the best sign language interpreters in Africa as they are trained at a university level (personal interview on 28 January 2008 in Kampala).

The author once happened to watch TV news between 12 and 13 o'clock on the Ugandan Broadcasting Cooperation (UBC) with simultaneous sign language interpretation. This reaches only those who have electricity, TV accessibility and sign language literacy, which in practice does not mean many deaf people. Nevertheless, it is interesting to note that this service exists in Uganda.

Many deaf women work as housemaids or cleaners for richer families, but are paid little or none, as employers tend to take advantage of their illiteracy and limited communication skills for reporting any maltreatment (Chairperson of the United Young Deaf Women Group, personal interview on 4 February 2008 in Kampala; Gender officer of UNAD, personal interview on 28 January 2008 in Kampala). Many others, especially in rural areas, dig gardens for their daily consumption. The Report of the Ministry of Finance introduces an interview excerpt of an elderly blind man preferring to become deaf than blind as deaf can dig, but blind cannot (2008:24). However, in all studied sites of the Report (ibid.27), it was observed that people tend not to buy anything from persons with disabilities. Discrimination is severe and multiple:

Generally the Langi culture considers women to be inferior to men and therefore a deaf woman is a very inferior person. Marriage is very difficult for deaf women as men only use, impregnate and abandon them. A deaf girl who gets pregnant is chased away from home. Deaf women in the rural areas who get married suffer a lot because they are always beaten up even if it is a deaf-to-deaf marriage. The men claim that the deaf women just sit on their back sides waiting for food. But educated deaf women in urban areas can even marry non-disabled men and will live comfortably. So education is the key for deaf women and the only sure way out of poverty and suffering," said a deaf woman in Lira (Ministry of Finance, 2008:54)

They (Deaf friends of mine) stay with friends mostly because of communication. Even I do. If my father and mother didn't know how to communicate with me, why wouldn't I go to my friend who can communicate with me, rather than staying at home alone? Whatever I do, they laugh at me. So things are so bad there. You are so disgusting. So you end up going to friends who can communicate with you. These days, I encourage people to stay in their friends' places rather than at home (Deaf woman C, personal interview on 4 February 2008 in Kampala).

Another challenge for deaf women in Uganda is the lack of opportunity for education on reproductive health rights. As many do not have any mother tongue, they tend to have little knowledge on reproductive health. The gender officer of UNAD tells her story on a trainee:

It is a very painful story to tell. You know, even though they look pregnant, many of them don't know what is happening to their own bodies. They don't know that their babies are growing in their womb. So they don't know that they are expected to give birth after 9 months. This has already been happening. When I went to a training of deaf women, I saw a pregnant woman in the Lira district. I asked her, "Are you due to give birth soon?" and she said, "I don't know." She was feeling the contractions already, and pain. At night during the training, she was about to give birth without any preparation, none! So we

had to carry her to the hospital at night. The hospital said, "You have to buy the mama kit, the kit for delivery. You cannot use our clothes." But she came only with her clothes. So my training was disorganised because I had to run and buy things for this lady and bring them to the hospital. If she had been aware of the fact that the baby was growing in her stomach and knew that she was supposed to give birth after 9 months, this would not have happened (personal interview on 28 January 2008 in Kampala).

The gender officer is deaf woman herself and sighs, "There are so many people that we have to sensitise outside there because we have a problem of language." In his research, Murangira (2012) also points out the inaccessibility of existing medical care for majority of deaf persons in Uganda. Sexual violence against deaf women is too rampant.

Last year we heard that a man of 55 years old raped a 6-year-old deaf girl. He was arrested when he was raping her. So they arrested the man. In the court, it was said, "He raped the idiot." That's how they see it. He raped the idiot and so he was released. We as the UNAD got really, really mad about it and wrote about it in newspapers and questioned, "Are we idiots? Look at us. How can you even think of setting the man free? When the Constitution talks of the protection of human rights, it does not talk of idiots. It talks about every one of us in Uganda." Later on, he was rearrested and sentenced to prison. But this is only one case. There are so many problems unsolved out there. There are so many that are never solved. Even as we speak, even in January this year, we had 3 cases of rape in Kampala only, even before the end of the month. Three cases have been filed. In just one month. It's not even one month. How about the end of the year? How many cases shall we have? If we have 3 cases in Kampala only, how many in Western Uganda? How many by Easter in Northern Uganda? (Personal interview on 28 January 2008 in Kampala)

The status of deaf women on the grassroots in Uganda is quite diverse, despite the positive achievements in the political space, which will be elaborated shortly. One of the positive aspects for deaf women in Uganda is that sign language for Deaf people is recognised in its Constitution of 1995. However, even many Members of Parliament do not know this (Alex Ndeezi, the Deaf Member of Parliament, personal interview on 30 January 2008 in Kampala).

In Uganda, the UNAD is a strongly institutionalised DPO serving the interests of deaf/Deaf people. Staff A of a Northern DPO assures:

This (UNAD) is the strongest in Africa. There is no other organisation. In the disability movement, normally the deaf are the weakest in all those countries I've visited. They were severely marginalised (Alex, Ndeezi, personal interview on 30 January 2008 in Kampala).

During the last few years, however, Deaf women started to establish their own organisations. This has caused some fragmentation among Deaf/deaf people. At the same time, a Deaf male youth complained, "deaf men have limited opportunities because development cooperation activities are for women, women and women. As men, we have fewer opportunities. African women hate deaf men" (personal interview on 6 December 2008 in Kampala). Under the circumstances, the experiences of deaf women in Uganda in the study contribute to understanding the highly complex realities, and to further advance academic theory on the

human rights-based approach to disabilities and development in the South with their lived evidences.

2.8. Human Rights-Based Approach and Charity-Based Approach⁶

The entering into force of the UN Convention has accelerated the recognition that disabilities are human rights issues. Persons with disabilities are entitled to human rights on an equal basis with others because human rights are universal, in the rhetoric of theory and policy at least. The core message of the Convention is that “people with disabilities should not be considered ‘objects’ to be managed, but ‘subjects’ deserving of equal respect and enjoyment of human rights” (WHO and the World Bank, 2011:10). Today, a human rights-based approach (HRBA) has begun to replace its theoretical counter-approach, a charity-based approach (CBA) at policy level and in theory, and to some extent also in practice. The following example of the Swedish Agency for International Development Cooperation (SIDA) is illustrative of this trend:

*In the past, the terms used were aid or development assistance, or that Sweden sent money to the poor. Today, the term used is development cooperation since it is a matter of cooperation rather than providing money: cooperation between people, between international bodies such as the UN and EU, and between the peoples and governments of countries. **It is not a matter of charity, but a matter of the right of people to avoid being poor** (SIDA, 2005 emphasis added).*

The Finnish Minister for International Development, Heidi Hautala (2012:6), calls the present Finnish development policy a “human rights-based development policy.” Similarly, the Ugandan Ministry of Finance (2008:52) also claims, “Disability is not about pity or charity, it is a rights issue.” In this “paradigm shift” (NORAD, 2012:18), however, both “charity” and “rights” are often taken for granted, which leaves significant room for interpretation. Thus, it causes difficulty for analysing more concretely the actual impact of the selection of both the terminology and the approach as practical tools beyond the general image.

A charity-based approach has a long history. It can go as far back as Medieval times where, for instance in England, religious groups established hospitals for people in need (Brenton, 1985). A more modern use of the word charity means benevolent giving by those who have more to those who have less. The important implications here lie in the power relationship between the givers and receivers, where givers voluntarily make decisions to fill the gaps of the needs of the receivers or so-called “beneficiaries.” The decision-making power of the beneficiaries, therefore, is limited in this approach that conceptualises disabilities as individual problems (European Commission, 2010:29). Charity organisations and a charity-based approach have historically served to innovatively fill the gaps of existing needs. Nevertheless, this approach has been heavily criticised because it gives the impression that the problems have been solved, it does not challenge the fundamental structure, which is the root cause of the situation, and

⁶ Part of this sub-chapter was published in the following:

- Katsui, H. (forthcoming) “The Challenges of Operationalising Human Rights Approaches to Disability in Central Asia.” In M. Rassell and E. R. Iarskaia-Smirnova (eds.) *Disability in Eastern Europe and Former Soviet Union*. Routledge.

further, because of the mechanism inherent in it, which takes away the decision making power and/or ownership from the beneficiaries. The criticism is found both in Disability Studies (e.g. Barnes, 1991) and in Development Studies (e.g. Murphy, 2000).

In the North, a human rights-based approach is rapidly replacing a charity-based approach to overcome its shortcomings and to change the paradigm, at least in theory. A human rights-based approach is often understood in the legal framework through a narrow definition. For instance, people who are discriminated against and aware of their rights file a court case when their rights are violated. This justiciability is mentioned often as a core part of this approach (Teranaka, 2006:81). It is often understood as a normative strategy based on the international laws as norms (Seppänen, 2005:8). Thus, when a human rights-based approach is narrowly defined, it has a strong linkage to international law (ibid:33) as well as to national legislations. On the one hand, the linkage to international law is a powerful tool when all countries have ratified at least one of the seven core United Nations human rights treaties, and 80% of states have ratified four or more (Office of the UN High Commissioner for Human Rights, 2006:5). On the other hand, the linkage to laws demands legal procedure which is not necessarily easily accessible for all, particularly for those in the South.

A wider definition conceptualises a human rights-based approach in a variety of ways in the operationalisation beyond the law discipline. It could be both means (Frostell, 2006:3) and goals (Uvin, 2004:123). The process for achieving human rights is prioritised (Uvin, 2004:165). When a human rights-based approach is used as a means, it caters to the principles of empowerment, participation, non-discrimination and accountability with the priority on vulnerable people (Lundström-Sarelin and Mustaniemi-Laakso, 2007). That is, the process becomes participatory and transparent with equality in decision-making and a sharing of the outcomes of the process among involved stakeholders (Sengupta, 2000b:21-22 cited in Uvin, 2004). As a result, the analysis with a human rights-based approach can give insight into the distribution of power (OHCHR, 2006:27). The UN agencies (2003) define the uniqueness of a human rights-based approach as follows:

- 1) Assessment and analysis in order to identify the human rights claims of rights-holders and the corresponding human rights obligations of duty-bearers as well as the immediate, underlying, and structural causes of the non-realization of rights.*
- 2) Programmes assess the capacity of rights-holders to claim their rights, and of duty-bearers to fulfil their obligations. They then develop strategies to build these capacities.*
- 3) Programmes monitor and evaluate both outcomes and processes guided by human rights standards and principles, and*
- 4) Programming is informed by the recommendations of international human rights bodies and mechanisms. (UNESCO, 2003:3.)*

The Office of the United Nations High Commissioner for Human Rights (OHCHR) is one of the main actors promoting a human rights-based approach in development cooperation. This study reflects the definition of the human rights-based approach by the OHCHR (2006). However, this does not mean that the study takes rights for granted. On the contrary, the study poses questions on the legitimacy of a human rights discourse in the South without elaborating on the Southern epistemological background.

The distinction between a charity-based approach and a human rights-based approach can be simplified and summarised in the following table. However, the dichotomy is neither crystal-clear nor ontological. One has to bear in mind that there is a great risk of over-simplicity and even the question of dichotomy in itself (Katsui, 2008-b). This distinction was intended to work as an analytical tool for this book.

	Goal	Individuals	Responsibilities based on
Charity-Based Approach	Filling the gaps of (often material) needs	Objects of charity, “beneficiaries”	Discretion of givers, no obligations
Human Rights-Based Approach	Fulfilling aimed human rights in a human rights-sensitive manner particularly for the most marginalised people	Subjects as rights-holders as well as duty-bearers in different contexts	National and international law-oriented obligations and accountability for fulfilling the rights of individuals

Inspired by (Lundström-Sarelin and Mustaniemi-Laakso 2007; OHCHR, 2010:10) and created by the author.

The theoretical significance of a human rights-based approach to disabilities in the South would be summarised as follows: The first significance of this approach is that it involves all human beings in the mainstream discourse, including the most vulnerable groups of people such as persons with disabilities. Secondly, the approach requires rights-based actions instead of charity, which has predominated. Thirdly, the approach stipulates state obligation to secure the human rights of the people concerned. Fourthly, this approach demands extraterritorial obligations, which is the biggest difference from the social model of disabilities. These four significances are the most prominent ones for persons with disabilities in the South towards attaining the ultimate goals of equality and equal opportunity (Katsui and Kumpuvuori 2008:234). This study investigates the aforementioned theoretical significance in realities of women with disabilities, particularly deaf women, in the case studies on development cooperation activities in Uganda and international cooperation in Africa. The study, however, does not take human rights, development cooperation, and global inequality for granted, which will be elaborated further in Chapter 6. The study acknowledges that the human rights ideology of Northern disability studies is the fruit of theories based in the Northern context which is different from the Southern one in terms of “culture, economy, history, community and relationships of power among others” (Grech, 2011:88). The intention of this study, therefore, is not to transfer a human rights-based approach to disabilities and development to Southern contexts, but to elaborate on such phenomenon: not to re-establish the views on the two approaches but to scrutinize them in a specific context. Thus, the study questions whether a charity-based approach is purely “evil” as it has been perceived and theorised in both disabilities and development discourses. International and development cooperation activities

are too frequently justified by good intention and will. Townsend and Townsend (2004: 272) introduce two different types of ethics: deontological ethic which justifies actions by motivation when “they meant well,” while consequential ethic justifies actions by outcome when “the end justifies the means.” As various methods are still in the pilot stages (Dement, 2001), the development cooperation system tends to legitimate itself with deontological ethic. This argument applies to a study on a human rights-based approach to disabilities and development. Therefore, it is important to research and document the practices of new modalities and their outcomes including this approach. In Chapter 5, the oppositional and hierarchical understanding of the two approaches is contested and deconstructed based on found evidences (cf. deconstruction of Derrida).

2.9. Organisations of Persons with Disabilities

As the above definition and discussion on two different approaches reveals, the participation of persons with disabilities themselves as subjects/right-holders becomes of importance in operationalising a human rights-based approach. Organisations of persons with disabilities (DPOs) have made “a substantial contribution to the evolution of the understanding of disability, and they have been a pillar in lobbying for and formulating the CRPD” (European Commission, 2010:72). Thus DPOs are focused on in the study. DPOs are commonly run and managed by persons with disabilities for the realisation of the human rights of persons with disabilities. They used to be separate from organisations for persons with disabilities run and managed by persons without a disability. In the latest history in United Kingdom, for instance, organisations for persons with disabilities have been heavily criticised by disability activists and scholars of disability studies for controlling disability discourse and reinforcing negative social perception of disabilities as personal tragedy (Oliver, 1996-b). The disempowering effect of the helper and helped relationship was then elaborated on in general social theory on disabilities (Finkelstein, 1981).

Today, due to the diversity among both DPOs and organisations for persons with disabilities, the distinction is becoming blurred (Shakespeare, 2006:153-166). In terms of constituencies, cross-disability organisations (ex. organisations of women with disabilities), single and impairment-specific organisations, and umbrella organisations are all organisations of persons with disabilities. “Sister organisations” refer to DPOs in different sites/countries working for the same type of constituencies. Disability organisations are dynamic, evolving and highly complicated in terms of their impacts, let alone their historical and present contexts. Also due to the diversity of disabilities itself, for instance, a representative with a physical disability does not necessarily understand the realities of the deaf, the blind, those with psychosocial or intellectual disabilities, or those in totally different contexts. Thus it is not the aim of this study to categorise, let alone dichotomise, different disability organisations into empowering or disempowering. In this study, DPOs are focused on to investigate the theme, firstly to locate those who identify themselves as persons with disabilities (both on the level of individual and collective identity) in Uganda. Secondly, this is done to elaborate on their international and development cooperation activities with Northern partners/donors. “The number one reason for any disabled person in Uganda to join an organisation or to form one is to try to make a way out of poverty. The expectations from the membership are therefore that an organisation can channel funds for income generating projects or provide other services that can improve their lives immediately. Unfortunately, the donor priorities are on advocacy” (DSI, 2007:40-1).

Another typical challenge of DPOs is that umbrella DPOs work in competition with its member DPOs who often have own agenda, which tend to weaken and fragment disability movements (NORAD, 2012:41). These issues are discussed more in the case study contexts.

2.10. Discrimination⁷

The new UN Convention defines “discrimination on the basis of disability as any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.” “Reasonable accommodation” means “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms” (Article 2). In legal terms, reasonable accommodation is immediate and inherent for individuals with disabilities to a “reasonable” extent, while positive measures are progressive for group. That is, both reasonable accommodation and positive measures are “soft” in wording, as the former is only to a “reasonable” extent, while the latter only in a progressive and not an immediate manner. Soft wording is one of the weaknesses of the Convention, one that has the potential to water down the effects (Scheinin, 2012).

Direct discrimination is the most obvious. In this case, one is unfavourably treated both personally and directly due to his/her attribution. For instance, the discrimination against a person with a disability in his/her job-hunting although s/he is qualified. Direct and institutional discrimination is, for instance, when some rights for persons with disabilities are forbidden by law. Justiciability can be exercised against the former type of direct discrimination especially, and is conceptualised as “hostile discrimination” (Kam, 2008). Indirect discrimination, or what Kam (2008) describes as “benevolent discrimination,” is more subtle. For instance, a person with a disability is served with a cup of coffee in own room and cannot access a coffee room for socialising with other employees, even if s/he is employed. A charity-based approach also fits this type of discrimination, when, for instance, charitable and paternalistic acts are directed at a person with a disability without his/her willingness and need. For instance, during the colonization -particularly in 1950s and 1960s in Uganda- a number of charity and religious organisations institutionalised persons with disabilities and perceived to have done “a big favour as their basic needs were being met as compared to those who were on the street begging for a living” (Ministry of Finland, 2008:4).

Positive discrimination has also attracted attention today. Affirmative action, for instance, is a form of positive discrimination, in which a person with a disability can get a job over a more qualified person without a disability, for instance. This measure is taken when discrimination

⁷ Part of this sub-chapter was published in the following:

- Katsui, H. (2009-a) “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.

against persons with disabilities is too severe to promote the ultimate goal of equality. In Uganda, the affirmative action policy of the government is reflected in the exercise of the representation of persons with disabilities in all levels of politics.

2.11. Self-determination and Well-being

The UN Convention recognizes in its Preamble “the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices” and considers “that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them.” Current history shows how easily self-determination of persons with disabilities could be deprived from them. In this sense, highlighting self-determination is an important milestone. The UN Secretary General, Ban Ki-moon, calls for inclusive society and development “by, for, with” persons with disabilities (United Nations, 2011). In other words, individual and collective self-determination power, particularly the latter, is essential for the well-being of persons with disabilities where “inter-dependence” is more important than “independence” (European Commission, 2010:33). For instance, Karr (2011) claims self-determination is one of the important predictors⁸ for quality of life of persons with disabilities that encompasses well-being. Her study on American, Nepalese and Zambian persons with disabilities shows that environment plays a more important role in promoting self-determination than do characteristics of the person, including intelligence level (Karr, 2011:76-7).

This study pays attention to the fact that self-determination alone is not enough. Firstly, for those persons with profound intellectual difficulties or psychosocial disabilities, careful supports for decision makings, therefore, are important. The European Disability Forum (2007) has a position paper on “persons with complex dependency needs” to ensure their human rights are on an equal basis with others. Shakespeare (2006:146) similarly discusses “extensive dependency.” The Harvard Project on Human Rights (2008) produced a self-advocacy book for people with disabilities to support their decision making and self-advocacy actions based on human rights. The project pays careful attention to those with psychosocial and intellectual disabilities in particular. As much as taking self-determination away is a violation of human rights, the non-provision of necessary support is also a violation. Swenson (2008) recommends “funding supports according to an order of selection that ensures basic safety for everyone before seeking total freedom or self determination for anyone” in the era of neoliberalism. Vehmas (2011:162) also argues, “People with intellectual disabilities, as people in general, tend to be more competent and active with those people with whom they have a long-term, intimate relationship than they are with those whose interactions with them are more occasional and clinical.” Self-determination in the context of disabilities, therefore, entails a sound support aspect when necessary. Vehmas stresses that an “accepting environment” is important for “exhibiting their agency.” That is, Amartya Sen’s Capability Approach (1999) alone cannot capture the diversity of persons with disabilities when “agencies,” persons with disabilities in this case, are presumed to make choices. This critique also applies to the positioning of persons with disabilities only as active subjects in a human rights-based approach.

⁸ Other predictors are employment and advocacy experiences (Karr, 2011:80).

Secondly, self-determination alone is individualistic and perhaps even Eurocentric, particularly in a context where community and more group-oriented identities, including family and clan, are stronger. The “dimensions of subjectivity and relationality are fundamentally intertwined” (White, 2010:164). Thus this terminology, and human rights terminologies in general, require more attention to background social, political, cultural and historical conditions (Kennedy, 2004:12; Batiwala, 2007:89). This study acknowledges that a one-size-fits-all approach is not applicable in different contexts, particularly in the South. Therefore, the study uses this concept only as one of the analytical tools in the specific contexts of the selected case studies. In the case studies, how it is decided who affects the decision making and how much they participate, rather than self-determination as such, become analytically useful and usable. This concept of participation, however, will be problematised later on.

In this study, well-being refers to “a social process with material, relational, and subjective dimensions. Well-being may be assessed at individual and collective levels, but at base is something that happens in relationship – between individual and collective; between local and global; between people and state” (White, 2010:158). The ultimate goal of this social process is equality. This definition is, therefore, different from a neoliberal approach of reducing the poverty of poor people. White (ibid.159-160) explicates three significances: 1) the focus of well-being targets people with a positive concept rather than stigmatizing them as “others” and attributing to them different forms of labels, 2) it is an actor-oriented focus which emphasizes “strengths” rather than “needs,” and recognises the multiplicity and integrity of people’s lives, forged in a complex mix of priorities, strategies, influences, activities, and therefore outcomes, and 3) it is centred in the person’s own priorities, perspectives and experiences and not only externally “objective” measures of welfare. The “centrality of relatedness” and “social connectedness” in one’s life is relevant to many Southern contexts that are not individualistic (cf. Miles et al, 1996). Hence, cultural sensitivity becomes of importance also through this concept. White claims that “Relationship must be at the centre of policy as well as analysis. Promoting the well-being of poor and excluded people will thus mean transforming the terms on which they engage with others and others engage with them, at structural as well as more immediate levels” (White, 2010:171).

There is a gap in the existing literature in this specific theme. Well-being research has been largely quantitative (ibid.165). “To understand the lived experiences of people with disabilities, more qualitative research is required. Measures of the lived experience of disabilities need to be coupled with measurements of the well-being and quality of life of people with disabilities” (WHO and the World Bank, 2011: 46-7). Hence, this study tries to fill in this gap by interrogating the experiences of persons with disabilities under the specific modality of a human rights-based approach that entails self-determination as a key concept through which light is shed on well-being as well. The study does not, however, focus merely on the measurement and interpretation of well-being as such.

2.12. International cooperation and development cooperation⁹

The UN Convention recognises “the importance of international cooperation for improving the living conditions of persons with disabilities in every country, particularly in developing countries.” From the global perspective, one important remark to make about the Convention is that “International Cooperation” was included as a stand-alone provision (Schultze, 2007), which was not the case for the Conventions for the rights of women and children.

Article 32 International cooperation

1. States Parties recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities. Such measures could include, inter alia:

- (a) Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities;*
- (b) Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices;*
- (c) Facilitating cooperation in research and access to scientific and technical knowledge;*
- (d) Providing, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies.*

2. The provisions of this article are without prejudice to the obligations of each State Party to fulfil its obligations under the present Convention.

That is, extraterritorial obligation is stipulated. This Article has various implications, particularly towards the participation of persons with disabilities from the South, and “provides a comprehensive normative framework, as well as specific guidance, for mainstreaming disability” (United Nations Economic and Social Council, 2009:17). The current United Nations Special Rapporteur on Disability, Shuaib Chalklen, also stresses the importance of disabilities-inclusive international cooperation (United Nations Economic and Social Council, 2012). For instance, major international agencies and Northern countries have rapidly made

⁹ Part of this sub-chapter was published in the following:

- Katsui, H. (2009-b) “Towards Participation of Persons with Disabilities from the South: Implications of the Article 32 of the Convention.” In J. Kumpuvuori & M. Scheinin. (eds.) *The United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives*. P.138-158.
- Katsui, H. (2008-c) “Why International Cooperation to Deal with Disability? Politics of the Article 32 of the Convention.” 4th Biennial Disability Studies Conference. 2-4 September 2008. Lancaster, UK.
- Katsui, H. & Kumpuvuori, J. (2009-a) “Vammaissopimuksen fraasi ‘samalla tavalla muiden kanssa’ käytäntöön Ugandassa.” *Kynnys Mielipidelehti* No.4 2009. (In Finnish.) In English on <http://disability-uganda.blogspot.com/2009/11/others.html>

dynamic changes to their policies and programmes to include disabilities in their international cooperation and development aid policies -and also practice, to some extent- reflecting on the Convention (Lord. et. al. 2010: 31). For instance, the United Nations Partnership to Promote the Rights of Persons with Disabilities among relevant UN agencies and its Multi-Donor Trust Fund was created in 2011. Some international development agencies started to include persons with disabilities in their policies and practices even prior to the era of the Convention. For instance, the United States Agency for International Development (USAID) made a policy on inclusion in 1997. In 2005, Uganda was selected as a pilot country for implementing the policy (DSI, 2007:17). That is, international cooperation has been highlighted to support national efforts in this field. However, not all persons with disabilities are included. Northern countries are also diverse and their practices are not monolithic. For instance, a Norwegian evaluation report on development support in terms of disabilities found that the main focus was on persons with physical disabilities and those with milder disabilities, although projects claim to target all persons with disabilities (NORAD, 2012:12). Moreover, the same report reveals that hitherto activities overwhelmingly focus on medical approaches for change rather than human rights-based approaches (ibid.23). Similarly, a Finnish evaluation study also claims that most of disabilities-specific activities are based on “dominant social welfare approach” and thus cannot influence communities and countries (STAKES, 2003:80). The report manifests, “Most of Finland’s development co-operation has not regarded disability issues as human rights issues” (ibid.81). Development cooperation activities in the field of disabilities are fragmented and less effective with very little collaboration among donors including DPOs and NGOs in practice (NORAD, 2012:37&66), while statutory services are non-existent in many Southern countries. For instance, most of the works mandated to the Ministry of Gender, Labour and Social Development of Uganda are done by NGOs (Safia Nalule, personal interview on 15 February 2008 in Kampala).

The idea of including an independent article of international cooperation was introduced during the ad hoc committee sessions, which were followed by the 8th and last session of the committee during which the article was finally included under the consensus. Southern countries vigorously supported the idea and pushed it through into the Convention. In order to reach consensus, there was a heated discussion among the states, particularly between the Southern and Northern countries –such as those from the EU and Japan– that had been anxious about this idea during the 7th session.

One of the controversial points was to what extent the aspect of development cooperation would be highlighted under the theme of international cooperation by articulating extraterritorial obligation without undermining the primary duty of each country. Development cooperation can be defined as “the practical work that is undertaken with the aim of improving the position of developing countries. It is implemented as country- and region-specific cooperation and multilateral cooperation” (Ministry for Foreign Affairs of Finland, 2006). That is, the dichotomy of so-called “developed” and “developing” countries is the underpinning presumption in which “developed countries” and “developing countries” implement “practical works” for the betterment of the latter. International cooperation, on the other hand, is not limited to the relationship between “developed” and “developing” countries. It is a common effort of involved countries to achieve a shared goal. The ad-hoc committee came to a consensus to include international cooperation as a standalone provision and

highlighted the development cooperation dimension of international cooperation under this Article. Southern countries claimed that it was “essential to complement national efforts,” while Northern countries associated this article with an obligation to development cooperation and economic assistance. The availability of resources from the North to the South, therefore, was implicitly negotiated with the understanding that not only money but also information and experiences are to be shared amongst the various stakeholders. In a human rights-based approach to disabilities and development, extraterritorial obligations are one of the strengths, particularly when persons with disabilities are a minority in every country setting and the international disability movement is expected to facilitate their voices to be heard. In the Convention, these obligations were embedded into this Article. However, the role of international cooperation in the realm of disabilities is yet to be widely recognised and more research is needed on it (United Nations Human Rights Council, 2010).

An interesting observation is the fact that the international disability movement has not largely questioned the development agenda and its implication to persons with disabilities (Grech, 2011:95). Is this part of an isomorphism in which Southern actors started to assimilate to the Northern discourse, as assumed by Grech? Or is a human rights-based approach including this international cooperation aspect genuinely relevant to Southern actors in the field of disabilities? Or are existing arguments on North and South too generalised and not reflecting on the diversity of both North and South? Bearing these questions in mind, this study focuses on this international cooperation, particularly development cooperation, by leaving enough room for both positive and negative implications.

Another observation related to international and development cooperation is the concept of “others” which is commonly used throughout the Convention. For instance, Article 12 stipulates “States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.” As states are the primary duty-bearers, “others” are assumed to be other citizens of the same territory and thus persons without a disability. However, this interpretation is not simple in practice, particularly when the context is in a Southern country such as Uganda. First of all, what happens when “others” in the same country or community do not enjoy human rights such as right to education, right to work and effective access to justice? The Convention mentions all human rights to promote, protect and ensure (Article 1). However, they are mostly not accessible and ensured even to “others” particularly in a Southern country such as in Uganda. Does it mean that persons with disabilities under such a circumstance also have to suffer from not enjoying the rights “on an equal basis with others”? The first observation leads to the second discussion: in practice, is the Convention only for persons with disabilities in a Northern country where human rights have been relatively more promoted, protected, and fulfilled already? This is a largely overshadowed discussion so far but is worth taking into account not to ignore the circumstances in Southern countries when operationalising the Convention in practice, as the majority of persons with disabilities live in the South. A question, therefore, is posed, “Could ‘others’ mean persons with disabilities in the North for those in the South?” Or is the concept of human rights too individualistic and Eurocentric that it is not legitimate at all in the South to begin with? Different interpretations on “others” justify and legitimize or deny international and development cooperation. Thus investigating a human rights-based approach in a Southern context is more than needed to understand its real (both positive and negative) implications.

International and development cooperation in general as part of globalisation have been heavily criticized for their externality and lack of internal/indigenous discourse (Escobar, 1995), isomorphism (Tvedt, 1998), hegemonic nature (Nederveen Pieterse, 2000) as well as for their concentration on policy, administration and empowerment while remaining apolitical and ahistorical towards macroeconomic policies and international power dynamics (Nederveen Pieterse, 2002), to name a few. In the field of disabilities and development, Benedict and Eide (2011:1) similarly criticize the North as culturally arrogant for “assuming what seems important and relevant is the same all over the world.” Although it is too simplistic to generalise the North as only good or bad, the frequently occurring global scale inequalities which occur not only in the South but also in the North as well as in the relationships between the two (the arena in which international and development cooperation, in particular, take place) should not be taken for granted. A study on global inequality in international and development cooperation needs to be cognisant of this world structure because neoliberal development, technology included, is not gender- (Momsen, 2010:5) and disability-neutral (Albert, McBride, and Seddon, 2004:12). For instance, “appropriate technology is not accessible and what technology is available is not amenable” for the needs of poorest people (ibid.). This theme will be revisited towards the end of this book in Chapter 6.

2.13. Twin-track approach

Various modalities have been developed for the well-being of persons in the South in the discourse of international and development cooperation. For disabilities and development, the twin-track approach is famous and widely accepted (ex. United Nations, 2004; DFID, 2004; Naughton, 2011; European Commission, 2010; Bergwall, 2010). This approach first started as a strategy for gender and development as a fruit of the United Nations World Conference in Beijing in 1995, when the women in development approach proved to be insufficient and did not challenge the structures of power in gender relations (Bell, 2000:3; Skotnes, 2011). Many donor and international agencies started to use this approach for gender and development since then. However, after 10 years of the Beijing Conference, a number of evaluations have revealed that 1) gender equality had low priority and little enthusiasm, 2) the focus has shifted to other areas such as environment, and 3) no systematic reporting of results has ensued (Skotnes, 2011:3). Despite the challenges and opportunities experienced in the realm of gender and development, the disabilities and development discourse follows the same path and uses its key concepts and approaches.

The Ugandan government has also adopted this twin-track approach to disabilities (DSI, 2007:10). The approach emphasises that both mainstreaming and disabilities-specific empowerment activities are indispensable for the human rights of persons with disabilities. “Mainstreaming implies that all development interventions are planned and implemented in such a way that people with disabilities, their needs, rights and potentials, are taken into account on equal terms with those of other population groups” because “[t]here are people with disabilities in any target or beneficiary group” (STAKES, 2003, 69). One of the main problems faced by persons with disabilities is the exclusion from the mainstream. Nagata (2007, 31) says that mainstreaming is more important than empowerment. Despite the fame of this approach, mainstreaming has not been on agenda until very recently (Albert, 2006). Particularly at the programme and project levels, the mainstreaming of disabilities in

development cooperation is “relatively new” (United Nations Economic and Social Council, 2009:3). Findings of a study in Uganda on mainstreaming disabilities into development (Mulumba, 2011:79) as well as those of a Swedish report (Nilsson and Granberg, 2010:7) indicate that the monitoring of implementation is largely missing even when disabilities are mainstreamed at a policy level. The Ugandan report also points out that development partners have not supported a sustainable approach in this field, while the Swedish report states that both the Swedish and Southern partner countries lack knowledge, capacity and a supporting system with regards to the human rights of persons with disabilities. The findings partly explain the phenomenon in which mainstreaming examples of international and/or development cooperation are still few (ex. USAID and Australia), while disabilities-specific activities have been more popular. This phenomenon is related to the tendency that targeted specific activities “give short term results and empower the rights-holders,” whereas “more efforts, resources and time” are required for mainstreaming initiatives with long term and sustainable results (NORAD, 2012:78). Consequently, mainstreaming activities are not well documented and demonstrated yet (ibid.79; Nilsson and Granberg, 2010). Without proper monitoring and indicators of mainstream activities, human rights of persons with disabilities could become “more and more invisible” (Nilsson and Granberg, 2010:8). The present study touches upon this phenomenon and uses this approach as an analytical tool to understand the dynamics and challenges of international and development cooperation.

In 2009, the Finnish Ministry for Foreign Affairs also established a “3-track” approach by adding one more approach, that of including “disability in policy dialogue, country negotiations and multilateral cooperation and information dissemination” (European Commission, 2010:122). That is, the continuous negotiation efforts in disabilities inclusion are still relevant. This aspect will be elaborated upon more in the following case study findings.

2.14. Ugandan Context¹⁰



¹⁰ Part of this sub-chapter was published in:

- 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.
- Kumpuvuori, J. & Katsui, H. (2009) “Achieving Human Security with Political Advocacy: Linking Ugandan and Finnish DPO Advocacy Work to Article 14 of the UN CRPD.” In J. Kumpuvuori & M. Scheinin. (eds.) *The United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives*. P.208-225.
- Katsui, H. (2008) “Ugandan Vammaisläike: Vammaisten Naisten Poliittisia Saavutuksia ja Sosiaalisia Haasteita.” *Kynnys Mielipidelehti* No.2 2008. P.6. (In Finnish) and in English on <http://disability-uganda.blogspot.com/2008/05/ugandan-disability-movement-political.html>

Picture on the left: a “ghetto” area in Kampala. When it rains it is flooded with water, garbage and faeces from public toilet wholes. Even during a sunny day as in the picture, a lot of places were flooded and were difficult for the author to walk around. In Kamwokya ghetto, a group of persons with disabilities live side by side. They are all from the Northern area of Uganda who had escaped from the war and settled down there.

Picture on the right: a busy street in Kampala downtown. Rich people, including some persons with disabilities, here have huge houses with many bedrooms, maids and drivers, a handful of cars and so forth. The disparity is big between rich and poor people also among persons with disabilities. One DPO, Legal Action for Persons with Disability, has been significantly supported by rich individuals within Uganda such as the Queen of Buganda, several Ministers and so forth. They have donated a building, million shillings money, computers etc. (Lawyers with disabilities, personal interviews on 19 February 2008 in Kampala). They lobbied media and also got free publicity in radio and TV programmes.

Uganda is an interesting country in which disability and development discourses meet and are negotiated. It is a Southern country. At the same time, it has the most progressive Constitution, cited as a “human rights charter” (Mawa, 2003).¹¹ In Uganda, the disability organisations started to be established during the 1970s. The idea of forming a national umbrella organisation of persons with disabilities started around 1976, but was hindered by the war between Uganda and Tanzania in 1979-1987. In 1987, persons with disabilities in the Ruti Rehabilitation Center in Mbarara and the Kireka Rehabilitation Centre 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. Current Member of Parliament representing women with disabilities, Safia Nalule, recalls:

When we come to fight for a common cause, sometimes people would come with individual interests. And instead of advancing the general interests of a community, you know, they bring in their personal issues. But what I observed at that time when the disability movement was taking off, they were more of looking at the issues of disability as issues of a community rather than individual issues. I think that helped us so much (Safia Nalule, personal interview on 15 February 2008 in Kampala).

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 the disability movement (ibid.), thus in other words the President¹² on the one hand.

¹¹ This does not guarantee that the whole legal system is human rights-based. For instance, Section 130 of Uganda's Penal Code Act uses discriminatory terminologies such as “idiot” and “imbecile” for women and girls with disabilities, let alone legal practices. Also, Human Rights Watch (2012) alerts many human rights violation in practice. For instance, demonstration of April 2011, “walk to work” to address rising fuel and food prices led to killing of nine demonstrators by the government security force with lethal weapon against non-armed citizens.

¹² Nalule is concerned about this because when someone else will take the President's position, the disability issues will not be on agenda any longer. In 2008, the President called a meeting with the disability movement. Seven DPO representatives and five Members of Parliament representing persons with disabilities were originally going to meet him in spring. Prior to that, a “strategy meeting” was held on 7 February 2008 among stakeholders to discuss on agenda and documents to submit to the President. The main agenda was the implementation of the existing laws and ratification of the UN Convention. However, the Members of Parliament did not invite “bright”

DPOs, on the other hand “don’t simply criticise (the government). If you criticise you are an opposition” (Acting chairperson of the National Council for Disability, personal interview on 4.2.2008 in Kampala). This has been the stance of many Ugandan DPOs to date. Disability is not a conflictive, political threat which has enabled the disability movement to grow fast (Staff B of a Northern DPO, personal interview on 15 February 2008 in Kampala).

Already in the beginning of the disability movement, Ugandan DPOs applied human rights-based approaches into their activities (DSI, 2007:21). A study of Lang and Murangira (2009:36) also echo “Uganda has developed progressive, human rights-based disability policies” with “one of the strongest” disability movements in Africa (ibid.39). Actually, a staff member C of a Northern DPO (personal interview on 18.2.2008 at Kapmala) was very surprised to come from own “very welfare-oriented” country and observed the human rights-based approach, which was an “eye-opening”:

When I came here (in the 1990s), it was really eye-opening for me. They are really tough here in Uganda, and think about disability as a human rights issue. But of course there is the explanation that if you don’t have the money for the welfare system, you have to shout and get inclusion.

Staff A of a Northern DPO also recalls the time and claims that human rights-based approaches were introduced from South to North (personal interview on 30.1.2008 in Kampala). The Affirmative Action Policy 1989, for instance, promoted representation of marginalised groups including persons with disabilities to uplift them. In the Constituent Assembly for the formation of the Constitution in 1995, the late Eliphaz Mazima, a disability activist with a physical disability and the first elected chairperson of the NUDIPU represented persons with disabilities. As a result, the Constitution succeeded in having many clauses related to persons with disabilities. How the late Mazima managed to convince other delegates, especially other vulnerable groups, has become a legend among present disability activists (Millward et al.2005; Hellen Asamo, personal interview on 31 January 2008 in Kampala). Asamo explained that late Mazima mobilized moral support of women who are traditionally to be blamed for giving birth to children with disabilities. Consequently, the Constitution (1995) includes the following clauses, among others:

“Rights of PWDs.

35. (1) PWDs have a right to respect and human dignity and the State and society shall take appropriate measures to ensure that they realize their full mental and physical potential.

(2) Parliament shall enact laws appropriate for the protection of PWDs.”

“big-headed” ones and rather invited those who “cannot articulate key issues better than them so that they remain strong in the eyes of the President” (anonymous, personal communication via e-mail on 16 March.2012). In any case, Alex Ndeezi, the Deaf Member of Parliament, stated that the meeting of the Members of Parliament with the President led to the ratification of the Convention in September 2008 (his speech in the general assembly of NUDIPU on 8 December 2008 in Kampala). Disabilities and politics are highly relevant in the Ugandan disability movement, which will be further interrogated in the case study on general assemblies of DPOs in Chapter 4.

That is, they were applying human rights-based approaches even before they started to be engaged into development cooperation system. This is an important piece of fact that is against the understanding that human rights discourse comes from the North, and thus imposing human rights-based approach is Eurocentric or imperialistic (cf. Kennedy, 2004:18, Uvin, 2004:17). That is, it is misleading to presume that a human rights-based approach is Northern exclusive or North-oriented. The Ugandan disability movement deliberately used this human rights-based approach for making political space even before the era of the new UN Convention for the Rights of Persons with Disabilities.

The following is the major national legal framework relevant to persons with disabilities in Uganda:

1. The Parliamentary Elections Statute of 2006 provides for 5 representatives of PWDs in Parliament, at least one of whom should be a woman and the use of a sign language where applicable;
 2. The Children's Statute of 1996 stipulates early assessment of disabilities among children for appropriate treatment, rehabilitation and education;
 3. The Local Governments Act, of 1997 provides for representation of PWDs (female and male) at all local government levels;
 4. The Uganda Communications Act of 1997 provides for development of techniques and technologies that facilitate accessibility to communications services by PWDs;
 5. The Uganda Traffic and Road Safety Act of 1998 stipulates that PWDs shall not be denied driving permits on the basis of their disability etc.
 6. The UNISE Act of 1998 provides for establishment of the Uganda National Institute of Special Education, training of teachers for children with special needs as well as special education teachers;
 7. The Land Act of 1998 provides that any transaction on customary land that discriminates on PWDs shall be null and void;
 8. The Universities and Tertiary Institutions Act 2001 provides for affirmative action for admission of PWDs to universities and tertiary institutions. This Act repeals the UNISE Act of 1998 and UNISE is merged with Kyambogo University.
 9. Uganda Foundation for the Blind, Ordinance 1956 (cap 58), 2000
 10. Equal Opportunities Act, 2006, which has just been passed by parliament
- (DSI, 2007:9)

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 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 for the marginalised groups of people including women, persons with disabilities, youth, workers and the army.

Since then, all those groups are represented in Ugandan politics at all levels including the Parliament. Uganda has a quota system where five Members of Parliament represent persons with disabilities: Four Members of Parliament from four regions (Central, East, West, North) and one woman with a disability. Their two sign language interpreters and personal assistants are paid by the government (Margaret Baba Diri, Member of Parliament, personal interview on 19 February 2008 in Kampala). An interesting fact is that in the 2006 election¹³, two former Members of Parliament representing persons with disabilities stood for the positions outside of the disability quota framework and also passed through. Both of them are women with disabilities (Margaret Baba Diri and Florence Sekabira). Both mentioned in their interviews that they wanted to try in the mainstream so that there would be more persons with disabilities (Margaret Baba Diri, personal interview on 19 February 2008 in Kampala; Florence Sekabira, personal interview on 19 February 2008 in Kampala). Therefore, there were seven Members of Parliaments with disabilities in the Parliament linked to the disability movement. Moreover, over 50,000 disabled councillors work in the local government structure (Lang and Murangira, 2009:37), of which half are women with disabilities at district and sub-county levels, while parish and village have only one councillor representing persons with disabilities. That means, persons with disabilities were identified, mobilised and organised for elections (Ministry of Finance, 2008:122), which in itself has some implications. NUDIPU with the great resource supports of a Northern DPO quickly mobilised the local persons with disabilities for those political positions (Staff A of a Northern DPO, personal interview on 30 January 2008 in Kampala). "However, apart from the national level (parliament), at the lower levels persons with disabilities representatives have not been successful in influencing decisions due to poor leadership and lobbying skills" (DSI, 2007:13). Late James Mwandha, a former Member of Parliament, (personal interview on 25 January 2008 in Kampala) states, "At that level when you are an MP, you are respected. You don't want to show openly that you discriminate against me. But at lower levels, oh yes, people discriminate them. In the communities, people are openly discriminating you."

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 disabilities, though with resource constraint. In 2003, National Disability Council was established to bridge communications between the government and persons with disabilities. In 2006, the National Disability Act was adopted which further stipulates the rights of persons with disabilities in Uganda. The Act articulates that Uganda is taking a human rights-based approach in its laws:

The objects of the Act are—

- (a) to promote dignity and equal opportunities to persons with disabilities;*
- (b) to develop and promote the participation of persons with disabilities in all aspects of life as equal citizens of Uganda;*
- (c) to encourage the people and all sectors of government and community recognize, respect and accept difference and **disability as part of humanity and human diversity;***

¹³ Parliamentary election took place also in 2011. This election is quite related to the case study on general assemblies of Ugandan DPOs. Therefore, discussion on the 2011 election will be introduced only in Chapter 4 of this book.

- (d) to eliminate all forms of discrimination of persons with disabilities on ground of their disabilities;**
- (e) to encourage all sectors of government and community to promote and include disability issues into all economic, political and social development policies and programmes;**
- (f) to promote positive attitude and image of persons with disabilities as capable and contributing members of society, sharing the same rights and freedoms as other members of society (emphasis added).**

This human rights-based approach to disabilities is one of the achievements of the disability movement. Many signs of improvement on the grassroots have been observed over time (ibid.104-107). Nevertheless, majority of persons with disabilities remain unaffected (ibid.107) and implementation gaps are observed (Lang and Murangira, 2009:6). The Ministry Report (ibid.x) introduces cases in which the councillors with disabilities “face with an uphill task” as their proposals are “watered down as ‘un-researched’ and in many cases they do not get implemented.”

“We, as representatives of PWDs, do our best in advocating for our rights. However, talking is all we do. We are allowed to talk, talk and talk but our programs are not implemented. They claim we are quarrelsome and hot tempered” (Chairman, Finance Committee, Lwabenge, Masaka) (ibid.82).

The comparison on expenditure in fiscal year 2007-2008 between different National Councils for Children (41%), Women (21%), Youth (19%), and Disability (19%), (Lang and Murangira, 2009:21) implies marginal thematic position in the government. In some cases, persons with disabilities are not representing in statutory committees due to lack of qualification of disability councillors (Ministry of Finance, 2008:81). Socially constructed roles for women also hinder women with disabilities to participate actively into politics (ibid.82). This lack of capacity and ignorance, particularly of women with disabilities in the male-dominant culture, are observed challenges. Disability councillors are minority in number and have difficulties in making their voices heard. The disability councillors are empowered, while trickled-down effects are yet to be observed to persons with disabilities on the grassroots (ibid.94). The Report points out, “The majority of cases people with disabilities remain largely disempowered and mostly have their issues decided for them and not necessarily with them” (ibid.94). The National Council for Disability was established to monitor all national implementations including violation of rights of persons with disabilities, and is supposed to have District and Sub-County Councils for Disability in all districts. The funding for their activities are “too small” and even get diverted through Community Development Department (ibid.111-112: Acting chairperson of the National Council for Disability, personal interview on 4 February 2008 in Kampala). Moreover, the councils at district levels or lower are currently involved in implementation of policies, which is contrary to their mandate. Also, representatives of different Ministries often defend their Ministries in the Council (ibid.). “The challenge of the government is that it looks at NUDIPU as the key stakeholder in it, because when we approach them, they say, ‘But what is NUDIPU doing? This is their work.’ But you know, NUDIPU cannot reach each and everywhere, up to the last person in the village” (ibid.). Lack of clear guidance confuse their roles among different stakeholders, which has created the vacuum of monitoring

and implementation mechanism and consequently resulted in little implementation of relevant laws and policies for persons with disabilities. These are a few of the many practical challenges to the operationalisation of a human rights-based approach in practice, which will be investigated further later on in details in the case study contexts.

In 2006, National Policy of Disability in Uganda was issued by the Ministry of Gender, Labour and Social Development. The visibility of persons with disabilities in the political space is an outstanding achievement of the disability movement in Uganda. This mainstreaming succeeded in empowerment of persons with disabilities and reducing stigma against them particularly right after 1997 (ibid.83). At this political level, it is not over-romanticising to mention that the Ugandan disability movement has achieved to a great extent, although the introduction of the multiparty politics in 2006 to some extent fragmented the disability movement. "The multiparty system is threatening the cooperation and cohesion of the disability movement. For that matter the fear is that capacities already built are likely to be sidelined because of political differences, while the restriction by party discipline is limiting opportunities to represent concerns of PWDs. In addition, the loss of trust is undermining the effectiveness and performance of PWDs/DPOs as they can hardly pursue a common advocacy agenda" (DSI, 2007:39). Furthermore, the positive effects of mainstreaming into politics are decreasing as "Leaders had become selfish and were only interested in getting their votes than improving the well-being of the PWDs" (cited interview excerpt in Ministry of Finland, 2008:83). At the same time, severe discrimination in society also hinders persons with disabilities to stand for positions to compete with candidates without a disability. As some positions as disability councillors are reserved for them, society pressures them to remain there only (ibid.90). As a result, affirmative action tends not to be benefiting grassroots (ibid. 84).

It is also noteworthy to mention that the Ugandan Ministry of Finance, Planning and Economic Development (2008), one of the key Ministries, published a very interesting report, "Disability and Poverty in Uganda: Progress and Challenges in Poverty Eradication Action Plan Implementation 1997-2007." The report critically reveals realities of persons with disabilities by paying attention to their heterogeneity. Many life stories are illustrative. Another report came from the Uganda Human Rights Commission (2009:v) that reviews existing international and national legal frameworks and tries to raise awareness on the rights of persons with disabilities not only to the public but also to persons with disabilities themselves.

As has mentioned, the development in the political and legal sphere has been outstanding. However, legal practices have not been reflected much even in court cases due to severe discrimination. The gender officer of Ugandan National Association of the Deaf (UNAD) (personal interview on 28 January 2008 in Kampala) introduces a court case in which the criminal bribed judges and was set free against the claim of deaf couple whose baby was sacrificed¹⁴ by this man. Then UNAD intervened and provided an interpreter so that the couple

¹⁴ The gender officer tells that sacrifices of babies are many in Uganda. The chairperson of the United Young Deaf Women Group (Personal interview on 4 February 2008 in Kampala) explains that it is one form of witchcraft. Babies and children are often targeted for this purpose. Witch doctors are also called "traditional healers." The sacrifice cases are increasing: 3 murders reported to police in 2007, 26 in 2009 proportionally with the growth of the economy (Whewell, 2010). Many clients come to seek for wealth (ibid.). The author watched on the UBC TV news on 4 December 2008 that children aged between 2 and 14 are targeted. It said many parents started to

could file the case properly, as the criminal himself made up the file. As a result, he was arrested. This example shows multiple levels of legal challenges including lack of interpreter, lack of accessible form of information when illiterate, and possibility of bribery among others.

The Ugandan disability movement is also visible in the international sphere. Former Member of Parliament representing persons with disabilities, late 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 March 2007, on the day when the Convention opened for signatory. Uganda ratified the Convention in September 2008.

Development cooperation is a significant part of the Ugandan government, because more than half of the national budget is dependent on donor assistance (USAID, 2008). 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 the Ugandan 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 donor community, are expected to fill the huge gap between laws and implementation (Chairperson of the NUDIPU, personal interview on 31 January 2008 in Kampala).

3. Methodology

3.1. Objective and Key Questions

The objective of this study is to investigate human rights-based approaches of international and development cooperation towards the equality of persons with disabilities in Uganda. The study focuses on the lived-experiences of Ugandan women with disabilities, particularly that of Ugandan deaf women on the grassroots. The study aims to answer the following four key questions to elaborate on the theme:

- 1) How do different stakeholders perceive “Human Rights” in the framework of international and development cooperation activities? How are the perception gaps reflected to the international and development cooperation modality and practices?
- 2) How can persons with disabilities play a significant role in making a human rights-based approach into the fourth category of Uvin (2004) by working primarily in the third category?
- 3) What are the practical implications of a human rights-based approach?
- 4) How can research empower the involved people through their participation in its research process? What are the possibilities and challenges of participatory research on disabilities and development?

The author’s previous studies implied perception gaps in “human rights” among different actors in development cooperation activities (Katsui, 2006-c). Some tendency was found that DPO staff is more likely to be familiar with the discourse on human rights, including the concept of human rights, while persons with disabilities on the grassroots are largely not. Thus the research *firstly* focuses on this phenomenon and clarifies the **perception of “human rights” among different stakeholders** in the framework of international and development cooperation activities involving women with disabilities. The study pays special attention to women with disabilities, particularly deaf women, because they are mostly left at home both in urban and rural areas (Lwanga-Ntale, 2003). This is an important perspective also due to one of the disability specific characteristics of diversity, as recognised in the Preamble (i) of the CRPD. The viewpoint and experiences of deaf women on the grassroots enables us to understand the multiple layers of realities in international and development cooperation. At the same time, the study investigates how the perception gaps and/or consistency are reflected in the international and development cooperation modality and practices.

Secondly, the study focuses both on the theory and practice of a human rights-based approach, namely by using the four categories of Uvin (2004). Uvin categorises four types of interaction between human rights and development discourses in practice. In the first, human rights terminologies are incorporated into classical development discourse through claims that development cooperation has been contributing to said rights all along. In this method, the incorporation of a superficial usage of human rights terminology depoliticizes the underpinning root problems, yet legitimizes the status quo. The second type is political

conditionality, where human rights terms are imposed when aid is given. This is practiced, in particular, by the largest aid agencies. In this type, the self-determination of the South is badly ignored and as such, the intervention itself is not human rights based. Third, human rights can be “added on” by implementing new programs based specifically on human rights objectives. In this approach, human rights are not mainstreamed. They are implemented in a limited context only. Many Ugandan DPOs have disabilities-specific international and development cooperation projects specifically targeted to persons with disabilities, which are categorised in this third type. In the fourth type, human rights are seriously taken into account where the mandate of development is redefined in human rights terms. As a result, social change takes place with a new paradigm of inseparable development and rights components. “Development as freedom” (Sen, 1999) exemplifies this last approach. The practice, therefore, is supposed to change as a result of this approach but success is limited (Uvin, 2002:8).

Thirdly, light is shed on the practical implications of a human rights-based approach. When a human rights-based approach is used as a means, it caters to the principles of empowerment, participation, non-discrimination and accountability with a priority on vulnerable people (Lundström-Sarelin and Mustaniemi-Laakso, 2007). That is, the process becomes participatory and transparent with equality in decision-making and a sharing of the outcomes of the process among the involved stakeholders (Sengupta, 2000b:21-22 cited in Uvin, 2004). As a result, an analysis with a human rights-based approach can give an insight into the distribution of power (OHCHR, 2006:27). This part, therefore, analyses ownership and decision making power of women with disabilities, particularly those of deaf women, to understand how persons with disabilities themselves are involved in the making of their society of non-discrimination in conjunction with international and development cooperation activities. Empowerment through self-determination is central in this part. The research aims to make practical implications to disabilities-sensitive modalities in international and development cooperation, particularly to the marginalised group of women with disabilities even among “persons with disabilities.”

The fourth questions are not as much about the substance of the research as they are about its methodology. Nevertheless, these are important questions for a number of reasons (more in detail in the following part). The study took these questions to investigate a human rights-based approach within research on disabilities and development. More precisely, the participatory research approach in this research was analysed pertaining to its feasibility, effects (both successes and failures) and the lessons it yields.

3.2. Case Studies

As the theme of the study is highly complicated and involves real-life situations of persons with disabilities, a case study method was applied to create evidence-based and in-depth knowledge on the theme, particularly from the viewpoint of women with disabilities and deaf women. Inter-relationships and the patterns and tendencies among different stakeholders, including women with disabilities, were investigated. Otherwise equality, or conversely inequality, without context is “too abstract and formal to address the complex workings of power in varying social settings” (Nussbaum, 1990 Cited in Repo, 2011:13). For answering the set key questions, the following three case studies were selected. The widely accepted “twin-track

approach" (United Nations, 2004; Naughton, 2011) was paid careful attention to in these case studies.

The **first case study** was on a development cooperation project on HIV/AIDS among a number of Ugandan DPOs (IDDC, 2009). This project was analysed at two levels: firstly on the mainstreaming activities of the project into national policy and practice against HIV/AIDS were elaborated. Secondly, analysis focused on empowerment activities, namely HIV/AIDS training activities to answer the second key question of the study. The **second case study** was on the general assemblies of the Uganda National Association of the Deaf (UNAD) and the National Union of Disabled Persons of Uganda (NUDIPU) in which important and relevant questions pertaining to the well-being of persons with disabilities were decided upon among representatives with disabilities around the country. The **third case study** was on international cooperation for soliciting the African Union Disability Architecture. All cases were relevant for answering the fourth key question. A **cross-case examination** and **literature review** tried to ensure the external validity of the study.

3.3. Participatory Research Approach¹

3.3.1. Theories on the Participatory Research Approach

The basic ideology behind the participatory research approach is the acknowledgement that marginalised groups have specific knowledge about their own lives which needs to be valued. The aim is to reduce distance in terms of power between the researcher and the "research subjects." In practice this means an increased level of participation by the "subjects." McRuer (2006:159-165) poses a question on writings of academics which should be decomposed to move away from "Western culture according to a subject-object model" in which persons with disabilities are located too often in the object position under professional-managerial ethos. The academic world and "our very bodies are caught up in, or even produced by" neoliberalism that demands "order and efficiency" (ibid170). The discipline development studies started to focus on participation by local people in the 1970s in the modality rapid rural appraisal (RRA) (Havel, 1996), which then developed into the participatory rural appraisal (PRA) in the 1980s and 1990s (Chambers, 1983, 1992, 1993, 1997). The participatory approach became important for development learning and action. Along with the development of action-reflection research, agro-ecosystem analysis, applied anthropology and field research on farming systems were established around the ideology of participation by "the poorest of the poor" in the research process (Chambers, 1997). In the 1980s the ineffectiveness of externally imposed and expert-oriented forms of research and planning became increasingly evident. Major donor and development organisations also began to adopt a participatory approach (Cooke and Kothari, 2002: 5). However, participation in research by persons with disabilities in Southern countries

¹ Part of the texts in this sub-chapter is from the following:

- Katsui, H. & Koistinen, M. (2008) Participatory Research Approach in Non-Western Countries: Practical Experiences from Central Asia and Zambia. *Disability and Society*, Volume 23, Number 7.
- Katsui, H. (2007) "Onko tieteellinen tutkimus liian etäistä? Osallistuvaa tutkimustapaa etsimässä." *Kynnyks Mielipidelehti* No.3 2007. P. 8.
- Katsui, H. (2009) "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. (unpublished conference paper)

is rare (Stone and Priestley, 1996; Turmusani, 2003). There has been a major lack of research on disabilities and poverty until very recently (European Commission, 2010:70).

Development of the participatory research approach in the discipline of disability studies was more recent, as the role of persons with disabilities in research has received increased attention in the North only from the late 1980s and early 1990s (Barnes, Mercer, and Shakespeare, 1999). It was then that disability research began to be heavily criticised for medicalising disabilities and not making positive changes in the lives of persons with disabilities (Barton, 1992, cited in Carmichael, 2004). The social model of disabilities has played an important role in changing the paradigm of doing disability research. Disability activists and scholars have promoted increased participation by persons with disabilities in research on the basis of the social model framework. The emancipatory research approach was promoted to advance the interests of oppressed groups, to enable their empowerment in the research process and to create usable knowledge to challenge the discriminating structure (Deepak, 2012; Finkelstein, 1999; Priestley, 1999, cited in Walmsley and Johnson, 2003:38). The participatory approach explores relevant issues for persons with disabilities in the form of a partnership with persons with disabilities. This means that persons with disabilities are expected to play an active role in the research. A key demand for the emancipatory paradigm has been that there should be meaningful input by persons with disabilities at all stages of the research process (Barnes, Mercer, and Shakespeare, 1999). The difference between the participatory and emancipatory approaches could perhaps be encapsulated in the level of power that the “research subjects” have, this being much greater in the latter. Emancipatory research is as much a form of political action as it is research (Walmsley, 2001). Both approaches aim at empowerment and equality as their ultimate goals. For further discussions on the development of and differences between the participatory and emancipatory approaches see, for instance, Zarb (1992), Oliver (1997), Ward (1997), Barnes, Mercer, and Shakespeare (1999), Mercer (2004), Bailey (2004) and Walmsley (2001).

On the one hand, the general **strengths of a participatory research method** are that such a research 1) can be based on local perceptions and priorities, 2) can rapidly collect large amounts of data, 3) captures diversity, 4) increases the voice of the most vulnerable, 5) empowers the stakeholders, among others. On the other hand, its general **weaknesses** are that such a research 1) is maybe too context-specific, 2) is maybe over-influenced by power relations, 3) poses difficulties in controlling who attends, 4) leads to unrealistic expectation, 5) may make some people more vulnerable, among others (Mayoux, 2006:119). The study, therefore, tried to maximise the strengths of the method, while minimising its weaknesses. Namely, other methods were also applied in this study to secure the validity of the study, especially so as not to be too context-specific and biased towards existing power relationships. Participation of Southern persons with disabilities as researchers is highly recommended in today's discourse on disabilities, development and human rights (European Commission, 2010:71).

3.3.2. Definition of the Participatory Research Approach in This Study

In this research, the participatory research approach is defined as follows:

The Participatory Research Approach aims at the participation of the researched people in the research process, thereby filling some of the power gaps between the researchers and the researched people. In this approach, therefore, the researched people are active research participants rather than passive object of the research when they want to be. The research process includes identifying the research questions, planning and designing the research, collecting data, analysing and interpreting the data and sharing the results. When the research participants can share their input based on their own experiences, the research can create relevant knowledge for them. The participation, however, is not compulsory. The research participants can make the decision on when and how to participate and not to participate in the research. The ultimate goal of this research approach in the study is that the research outcomes are evidence-based and thus useful and usable to the disability movement towards the equality of persons with disabilities.

However, the researcher cannot give a false expectation regarding the research. She has to be clear about her research outcomes in that she cannot promise a dramatic change because the research is only part of the society and because any single research of this kind cannot make such a significant change within the limited resources. (Uploaded to our blog site on 29 September.2007)

Many excerpts of interviews are included in this book to bring forth the voice of Ugandan persons with disabilities. The author, however, acknowledges the power of “discipline” by selecting only some parts of interviews (cf. McRuer, 2006:185). Therefore, the last paragraph is of particular importance so as not to over-romanticise any impact that a study can create with such a short period of time between 2007 and 2012. A realistic understanding of outcomes is essential.

3.3.3. Participatory Research Approach in the Research Project

It is argued that the high expectations set for the emancipatory approach will be difficult to sustain, unless short- and long-term progress is demonstrated (Barnes, Mercer, and Shakespeare, 1999). It is particularly challenging for a cross-cultural study such as this one. Hence, the decision of the team was to apply a participatory research approach rather than an emancipatory one. As part of a research project entitled the “Human-Rights-Based Approach to Disability in Development: Interplay of Disability-Sensitive Development Cooperation and National Policy in Uganda,” the project members support the ideology of emancipatory disability research based on the human rights of persons with disabilities (Oliver, 1997, 2002; Barnes, 2001; Walmsley, 2001), and have paid attention to the **power relationships among the team members** as well as the researchers and research subjects. For instance, the members belonging to the projects consist of three funded researchers (Edson Ngirabakunzi, Jukka Kumpuvuori and the author) and one affiliated researcher who gets funding from another source (Paul Emong): three persons with disabilities (Ngirabakunzi, Emong and Kumpuvuori) and one without a disability (the author); two Finnish-based (Kumpuvuori and the author) and two Ugandan-based (Ngirabakunzi and Emong); three males (Ngirabakunzi, Emong and Kumpuvuori) and one female (the author). We paid particular attention to including Ugandan researchers who are based in Uganda and those with disabilities, due to the selected participatory research approach principle of meaningful participation. The peer researchers have held meetings to exchange ideas, findings and challenges throughout the

research period. For instance, whenever any draft paper was ready, the others were always ready for comments. The team members have also written co-authored academic article(s):

- Ngirabakunzi, E. & Katsui, H. (2009) "The Right to "Decent Work" of Persons with Disabilities: Article 27 of the Convention and the Case of Uganda." In J. Kumpuvuori & M. Scheinin. (eds.) The United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives. P.115-136.
- Kumpuvuori, J. & Katsui, H. (2009-a) "Achieving Human Security with Political Advocacy: Linking Ugandan and Finnish DPO Advocacy Work to Article 14 of the UN CRPD. In J. Kumpuvuori & M. Scheinin. (eds.) The United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives. P.208-225.
- Kumpuvuori, J. & Katsui, H. (2009-b) "Disability, Human Rights and Human Security." Spanda Foundation Quarterly Newsletter Vol.III.No.1.P.14-20.
- 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.

Ngirabakunzi visited Finland two times for project meetings and attended a meeting in New York, while Kumpuvuori and the author visited Uganda two times respectively. In this project, we wanted to stress mutuality also in this regard.

The project established its **research project blog site** at <http://disability-uganda.blogspot.com/> as an interactive forum for exchanging ideas, information and experiences on disabilities, human rights, and development. This site has been actively utilised as a space to present preliminary findings, events, publications and later to give space for stories written by Ugandan persons with disabilities whom the team members met during the visits. Statistically, almost 50,000 hits were recorded since its establishment. Among others, the present United Nations Special Rapporteur on Disability, Shuaib Chalklen, got in touch with the author through this site for collaboration. This blog site is going to be replaced by a group, "human rights, disability and development," that was established at Facebook (<http://www.facebook.com/groups/356646744361590/>) in January 2012.

The research project team also succeeded in negotiating a column space on "Kynnys Mielipidelehti," the **newsletter of one of the Finnish DPOs**, the Threshold Association. These writings were published in the newsletter in Finnish, while an English version of them was published in the aforementioned blog site:

- Katsui, H. & Kumpuvuori, J. (2009-a) "Vammaissopimuksen fraasi 'samalla tavalla muiden kanssa' käytäntöön Ugandassa." Kynnys Mielipidelehti No.4 2009. (In Finnish.)
- Katsui, H. & Kumpuvuori, J. (2009-b) "Akateemista esteettömyyttä kaikilla mausteilla, kiitos." Kynnys Mielipidelehti No.1 2009. P.6. (In Finnish.)
- Katsui, H. (2008-d) "Ugandan Vammaisliike: Vammaisten Naisten Poliittisia Saavutuksia ja Sosiaalisia Haasteita." Kynnys Mielipidelehti No.2 2008. P.6. (In Finnish.)
- Katsui, H. (2008-e) "Vammaisen Ihmisen Identiteetti: Milloin Haluat Tulla Kutsutuksi 'Vammaiseksi'?" Kynnys Mielipidelehti No.3 2008. P.9. (In Finnish.)
- Katsui, H. (2007) "Onko tieteellinen tutkimus liian etäistä? Osallistuvaa tutkimustapaa etsimässä." Kynnys Mielipidelehti No.3 2007. P. 8. (In Finnish.)

The project team members organised a teaching course on human rights and disabilities both at Åbo Akademi University, Finland, between 30th November and 8th December 2009 and Makerere University, Uganda, between 15th and 19th March 2010. Another one is forthcoming in October 2012. The teaching courses were important for this research to engage young students and teaching staff in and expose them to the preliminary findings and knowledge created in this project.

3.3.4. Participatory Research Approach in This Study

In addition, each study tried to apply a participatory research approach in respective studies and this one is not an exception. At the **planning stage**, the author contacted nation-wide DPOs in Uganda, particularly those of women with disabilities, to ask for their research interests. One DPO, the National Union of Women with Disabilities of Uganda (NUWODU), made a list of topics of interest for research and shared them with the author via e-mail.² At this stage, staff of the former "De Samvirkende Invalideorganisationer (DSI)," presently the Disabled People's Organisations Denmark (DPOD) located in Kampala, Uganda, was also instrumental in sharing information about their experiences and knowledge on the Ugandan disability fraternity. A physical meeting was held with the Finnish Disabled People's International Development Association (FIDIDA) to learn about their research interests.

In the beginning of 2008, the author visited Uganda for the first time. The author met staffs of the following Ugandan DPOs and Disability NGOs including Action on Disability and Development (ADD), Disabled Women's Network and Resource Organisation in Uganda (DWNRO), Legal Action for Persons with Disabilities Uganda (LAPD), Mental Health Uganda (MHU), Need Foundation, National Union of Disabled Persons of Uganda (NUDIPU), National Union of Women with Disabilities of Uganda (NUWODU), Sense International, Ugandan National Association of the Blind (UNAB), Uganda National Association of the Deaf (UNAD), Ugandan National Association of Physical Disability (UNAPD), United Young Deaf Women Group, Uganda Parents of Children with Learning Disabilities (UPACLED), and Ugandan Society for Disabled Children (USDC).

During the study, the author engaged in a continuous dialogue particularly with the following DPOs:

- National Union of Disabled Persons of Uganda (NUDIPU) (Uganda)
- National Union of Women with Disabilities of Uganda (NUWODU) (Uganda)
- Uganda National Association of the Deaf (UNAD) (Uganda)
- United Young Deaf Women Group, currently United Deaf Women Organisation (Uganda)
- Disabled Persons Organisation Denmark (DPOD) (Denmark)
- Finnish Disabled People's International Development Association (FIDIDA) (Finland)
- Finnish Association of the Deaf (Finland)
- Abilis Foundation (Finland)
- Threshold Association (Finland)

² The e-mail with identified and urgent needs of research was received by Beatrice Guzu, the executive director of NUWODU, on 24 July 2007. The fact that the author started working for this research project on 1 July 2007 exemplifies the participation of DPOs already from the initial stages of the study.

The findings have been delivered to them whenever any draft paper, such as a conference paper or article is written to be published. Their **comments and input** have been included in the papers and publications before they were presented or published. They have been extremely instrumental in formulating the study from the beginning and throughout. Moreover, the relationship has gone beyond this study framework. For instance, some Ugandan DPO asked for the author's comments on their next project proposal, while FIDIDA asked the project team to train Finnish DPOs on the theme of a "Human Rights-Based Approach to Disability in Development" (which was held on 15 April 2009. More details are found at <http://disability-uganda.blogspot.com/2009/04/jukka-and-hisayo-as-trainers-of-human.html>). The established relationship and trust will surely continue beyond the study period.



A group picture was taken with the seminar participants organized with FIDIDA on the "Human Rights-Based Approach to Disability and Development".

This research has been supported by several **research assistants** (See Attachment 2 for the terms and conditions, and Attachment 3 for the certificate given after completion). The main assistants were Ugandan women with disabilities, while a few sign language interpreters without a disability also helped with the communication with Deaf/deaf persons. During the author's stay in Uganda in January-February 2008 and December 2008, she stayed in the home of a woman with a physical disability. She gave important local knowledge and insights to help the author understand the complexity of the disability movement in Uganda as well as challenges of daily household chores in her life. Another woman with a physical disability was instrumental in guiding the author around on weekdays during her first stay. The author learned how society reacts to her while walking with her and using public transportation means with her. The author chose to move around using public transportation means -that is what most persons with disabilities would do in their daily lives- so that she could gain experiential knowledge about their daily lives. One deaf woman facilitated some of the meetings with deaf women on the grassroots, and interpreted the communication on the weekends as the sign language interpreter. She had the skill of lip reading and oral speech,

which enabled these interviews with grassroots deaf women. She guided the author in how to interview deaf women on the grassroots. For instance, when the author asked one of them, "Could you introduce yourself?" she interpreted it into signs. The interviewed deaf woman remained silent. Then the research assistant immediately told the author that she should not ask such an abstract question to deaf women on the grassroots because they do not understand such questions well. She instructed the author to ask rather precise questions such as, "What is your name?" and "What do you do?" Another woman with a physical disability who was also the author's assistant in her previous study facilitated many practical arrangements. She was also about to help the author as an assistant for this study. She very sadly passed away during the early stage of this research due to her disability-related complications. Without the help of these women's profound local knowledge, the author could not have interviewed many on the grassroots. Moreover, the research assistants all openly shared their personal lived experiences as women with disabilities, which supported the author's understanding on the issue to a great extent. A few more sign language interpreters helped the author in communication with Deaf/deaf persons. One of them arranged the author's visit to villages to be able to meet deaf women in their homes. They worked beyond the role of mere interpreters. Even when the author is back in Finland, she has regularly exchanged e-mails to ask for their local insights. Without them, this research would have been impossible.

3.4. Data and Analysis

Various legislative documents and policy papers, such as the Ugandan Constitution and Disability Act, and reports produced by Ugandan and Northern DPOs were reviewed. Many of the reports and writings were obtained only in Uganda, as they were not necessarily published or available on-line. Existing relevant literature on the theme of disabilities, human rights, and development was also reviewed for this study. Etic views, particularly academic and theoretical discussions, are engaged with the study. Some of the reports and literature included legal and quantitative data that complemented this study as the **secondary data**.

The main methods of the **primary data** collection include personal interviews, group interviews and observations. Emic views are focused on in the fieldwork. Such empirical data and its analysis are valuable in researching "real-world problems that have normative importance" (McCamant, 1981:534 cited in Landman, 2006:5). Personal interviews were useful and helpful in understanding lived experiences expressed in their own words, particularly when most of the interviewed persons on the grassroots were illiterate. With the help of research assistants, the author visited places where persons with disabilities are on the grassroots such as the certain area of a market place, the church for the deaf and certain area of townships. That is, the author approached the individuals as they are defined as persons with disabilities in the local context and as they themselves encompass their identity. The age of interviewees ranged between 17 and 60s. Some of them did not know their exact age, and thus the author cannot articulate an exact range. As the author was not familiar with interviewing children with disabilities, she interviewed only adults who then talked to her about their childhood as they chose to. Personal interviews ranged between 30 minutes and three hours. This is not straightforwardly comparable with other social studies because the author had a research assistant to work as a sign language interpreter to communicate with deaf women on the grassroots, and for one deaf woman, the author even had two interpreters for the process: one first from local sign language into Ugandan sign language, and then another to English.

However, there was a clear tendency that DPO staffs talked for a longer time -between one hour and three hours- than persons on the grassroots. With DPO staffs, the author conducted semi-structured interviews with certain themes to answer the key questions of this study, but left enough room for them to express their interests and issues to share with the author. With persons on the grassroots, interviews were quite open and less formal. They mainly introduced their lives, experiences and concerns that they wanted to share with the author. The majority of the time the author remained a listener in both types of interviews.

66 people participated and were personally interviewed in the **first fieldwork**, of which 14 were deaf: three Danish development workers, three research assistants, 22 Disabled People's Organisation (DPO) staff members, two sign language interpreters, six Members of Parliaments (including the Minister of disability issues), 23 people with disabilities on the ground (two men with disabilities and 21 women with disabilities), and seven others (two deaf school employees, a Kireka tailoring teacher, a Kyambogo university lecturer, an NGO staff, a personal assistant and an orthopaedist). In the Northern city of Gulu, the author had group interviews with 16 women with disabilities who were living in the internally displaced people's camps: 10 and 6 women in two camps. In addition, one of the research assistants interviewed 5 persons with disabilities living in townships. A number of key events were also observed, such as a workshop held among 11 DPO chairpersons, the Disability Stakeholders HIV/AIDS Committee meeting, a Poverty Eradication Action Plan (PEAP)³ strategy meeting, a strategy meeting for meeting the President, a partnership workshop between Ugandan DPOs and Danish DPOs, and a monitoring trip of the HIV/AIDS project of a DPO in the Northern part of Uganda.

During the **second fieldwork** in December 2008, the main aims were to participate in the event for the International Day of Persons with Disability (IDD) on 3 December, a workshop on sex education among deaf children in the Masaka District, the general assembly of Uganda National Association of the Deaf (UNAD), that of National Union of Disabled Persons of Uganda (NUDIPU), and to visit deaf women in rural villages. Except for the visit to the villages, the author moved around without any assistant, though she lived with the same woman with a physical disability. The observation had elements of participatory observation as the author marched together with or was involved in the general assemblies for managing one election as an "impartial foreigner." Due to the nature of the IDD event and the general assemblies, the author spent a lot of time with a number of persons with different disabilities and mostly talked informally with them. The author also conducted a few more focused interviews with DPOs of women with disabilities to clarify some aspects and to update information. An informal gathering over dinner with a dozen of youth with disabilities right after the general assemblies was also very informative and insightful.

The **third set of fieldwork** was conducted in April 2012 in Addis Ababa, Ethiopia and in September 2012 in New York, the United States. The main aim for this part was to accompany the missions of the United Nations Special Rapporteur pertaining to his efforts in soliciting the African Union Disability Architecture and African Disability Forum under the Architecture. The first two fieldworks concentrated on development cooperation with the focus on bottom-up

³ PEAP refers to the Poverty Eradication Action Plan in Uganda which is equivalent to the Poverty Reduction Strategy Paper (PRSP) of other countries.

approaches, while the third on international cooperation involving the African Union, the United Nations, governments of both Africa and Northern countries, the African Decade Secretariat and DPOs with a top-down approach. The policy dialogue, negotiation and information dissemination between the Special Rapporteur and different stakeholders were observed.

Throughout the study, **informal exchanges and debates** have been among the most precious materials (Pleyers, 2010:31). Due to the nature of such informal communications, it is difficult to quantify and further distinguish how many were interviewed and communicated in an exact manner.

In Uganda, Ethiopia and the United States, the author carried around a notebook and a laptop respectively and wrote down everything that she found relevant and interesting. Every evening, the author typed the written information from the notebook as well as further thoughts of the day to the computer and kept a so-called **field journal** of around five pages a day in addition to her personal dairy. (See Attachment 1 for an example of the field journal.) Daily conversation with the research assistants was mostly included in the journals. **Continuous E-mail exchanges** with research participants, mostly staffs of DPOs and the Special Rapporteur but also persons with disabilities on the grassroots, were also saved and analysed. Particularly, e-mails were heavily exchanged with Ugandan activists for one article⁴ written on the Local Government Act of 1997 of Uganda to compare with the Personal Assistant System of Finland.

The interviews were digitally recorded under the agreement and permission of the research participants and were **transcribed word-by-word** both in Uganda and Finland. Subsequently, interview transcriptions and other writings of the primary data were read carefully four times each: first to understand common themes of experiences and interplay of different factors, second to select illuminating excerpts to produce different thematic conference papers and articles to be published. For the third time, the interview transcriptions were read to structure this book. For the fourth time, after the basic structure of this book was written, when 170 pages of the draft text were ready, the transcriptions were read once again so as not to leave out important points still not included in the writing. Some interviews were read more than four times due to the importance of the themes raised in them, for instance the HIV/AIDS related issues that were one of the case studies.

Two life stories were written by Ugandan women with disabilities, one with a physical disability (Prossy Nanyinja) and the other deaf with a physical disability (Christine Lule). These stories were placed on the research blog site (Prossy on <http://disability-uganda.blogspot.com/2009/04/posting-by-ugandan-friend-prossy.html>, and Christine on <http://disability-uganda.blogspot.com/2009/03/posting-by-ugandan-friend-christine.html>) and have become the most popular postings on the blog. This is one of the experiments of participatory research approach in this study.

⁴ Kumpuvuori, J. & Katsui, H. (2009) "Achieving Human Security with Political Advocacy: Linking Ugandan and Finnish DPO Advocacy Work to Article 14 of the UN CRPD." In J. Kumpuvuori & M. Scheinin. (eds.) *The United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives*. P.208-225.

Digital pictures were also taken to record each interviewee as well as activities and events that the author felt relevant to the study. Particularly when activities and events are captured in pictures, they powerfully depict realities (Palibroda et al. 2009: 10). These pictures are utilised throughout this book to depict the lived experiences of women with disabilities and their environments today. Pictures are also a powerful means for delivering diverse messages, both positive and negative ones. McRuer (2006) introduces Garland-Thomson (2001:372) who categorised four-fold types of photographs of persons with disabilities: 1) wondrous, high and elicit, 2) sentimental, diminished or lowly positioned, 3) transgressive or freakish, and 4) realistic. Of these, Garland-Thompson argues that the realistic mode holds the most political power in a democratic order (ibid). This study aimed at applying a participatory research approach with the goal of empowering persons with disabilities in the South with the research process and findings. Therefore a number of the selected pictures in this specific book capture very diverse realities, including positive realities. For instance, even when representation and voices of women with disabilities were limited in studied general assemblies, a picture of a deaf woman standing in front and speaking in sign language was inserted. This deliberate choice was made to record the capacities of persons with disabilities. However, the author acknowledges McRuer's point that all types can potentially be deployed both in a hegemonic and counter-hegemonic mode (2006:193) and consider his question relevant: "If we are in the realm of making a particular cultural construction routine and making it seem ordinary, are we not potentially in the realm of ideology?" (ibid.180).

The collected data was analysed thematically with the **qualitative content analysis** technique. As the operationalisation of human rights-based approaches was elaborated, the principles of **empowerment, participation, non-discrimination and accountability**, with a priority on vulnerable people, were paid particular attention to as key concepts and themes. Namely, perspective of Ugandan women with disabilities, particularly that of deaf women, was central in clarifying the complex realities of international and development cooperation activities that were investigated in the study. Even though human rights discourse has been criticised for its Eurocentric and individual approaches (Kennedy, 2004:18, Uvin, 2004:17), the aforementioned principles are important in the analysis of this study. When disabilities are located only in a cultural model, disabilities are embedded in a local culture that has to be respected as such.⁵ For instance, in a comparative study on a human rights-based approach and anthropological approach to disabilities, Ameel (2010:73-4) introduces an example of persons with disabilities who are hidden at home: the former type of studies analyse it as a form of shame in families who have internalised values of a discriminating society, while the latter as diverse cultural experiences not always due to shame but often protection. Ameel (2010) argues that an anthropological approach is more comprehensive in understanding disabilities and therefore does not problematise and politicise the very fact that they are hidden at home that does not take place in the case of their siblings. Even when it is due to protection and love of the family, the locking up of persons with disabilities indicates that the environment outside of the home is extremely disabling against them. This study is a multidisciplinary study of disability studies, development studies, human rights studies and civil society studies. It thus problematises and

⁵ Mattila (2011:58) makes a very similar point in the context of child labour in India, while Merry (2005) in the context of gender inequality.

politicises the experiences of persons with disabilities that are related to asymmetrical power relations and a disabling environment by acknowledging the critiques on human rights discourse.

Hence, **the Critical discourse analysis** and its perspective (van Dijk, 1995) were also useful in the analysis of interviews and observation to elaborate on inequality in terms of power. In particular, the decision-making power of deaf women was paid attention to because it is an indispensable aspect of well-being of person with disabilities (Jenkinson, 1993; Morris, 1998; Finlay et al, 2008). This technique of explicitly critical analysis helps crystallise who holds power and reproduces it, and who has the power over whom, thereby clarifying the power structure.

This study encompasses an analysis on **different types of power**, namely 1) power to, 2) power over, 3) power with, 4) power as knowledge, and 5) power structure. The first power to refers to individual autonomy, the second to relational power that clarifies power imbalances among actors, the third to collective power among people with shared values, the forth to the production of knowledge associated with the production of power relations based on Foucault, and the fifth to the fundamental systematic forces that define the rules of power relations (cf. Frediani, 2010:180).

At the same time, the **intersectionality theory** (Knudsen, 2006:61-76) developed in feminist studies was also useful to some extent in this study, even though it was not used as the main framework. For instance, it has been applied in studies on disabilities, gender and sexuality (Thomson, 1997) and has become increasingly important in overcoming the narrow focus on “just disability” (Söder, 2009:68). Ugandan women with disabilities, especially deaf women in this study, are affected by complex inequality involving development, gender, disabilities, specific impairment, geographical location (cf. conflict) among others, all of which are impossible to enlist but intertwined to produce and reproduce different hierarchies. The intersectionality of the studied women with disabilities is paid attention to in the first two case studies by critically analysing their decision making power in order to investigate the tendency of their systematically marginalised positions. In other words, the intersectionality theory facilitates our understanding, particularly in how a power structure has been constructed.

Garland-Thomson (2011:40), a feminist disability theorist, suggests academic activism that offers counter-narratives for subjugated groups, which is the methodology of intellectual tolerance. With the data and analysis explained above, the study aimed at establishing an **empirical theory** rather than a normative one, even while dealing with human rights. That is, the author tried to explain and understand human rights-based approaches to disabilities and international and development cooperation in practice, rather than to focus only on theorising how they ought to be (cf. Landman, 2006:36).

3.5. Ethical Issues

The data collection in the form of interviews and observation of Social Sciences studies usually generates serious ethical issues to pay attention to throughout the research process before, during and after the interviews and observation are carried out (Berg, 2007). As this study also

investigated international and development cooperation activities and their effects to the well-being of persons with disabilities, particularly women with disabilities, a number of individuals participated in the study to share their experiences, information and opinions. To a large extent, the study tried to follow the usual procedure of a research by delivering an **information sheet** (Attachment 4). **An easier version of the information sheet** was also prepared (Attachment 5). It was originally planned that to begin, the information sheet be read by a research participant, and then followed by the filling in of the **Informed consent form** (Attachment 6) prior to any personal in-depth interview. As a result, some of the research participants were familiar with important ethical issues, such as confidentiality and anonymity as well as voluntary participation or withdrawal. At the same time, the author got oral permission from interviewed research participants for the use of their pictures in the research work including this book, while in public and mass events the author was introduced or introduced herself as a researcher for recording and documenting them for the research and for this, received general support. In the school for the deaf pupils that the author visited, she acquired permission to photograph the pupils from parents through the teacher she spoke with. The teacher assured the author in his e-mail later on that their parents gave the permission. Throughout this final report, visual materials, namely digital **pictures**, are inserted for the readers to visualise the writings better. For that, each picture is described rather in details so that those readers with visual impairments also could grasp the details in the picture. Many of the author's own experiences and anecdotes are also introduced together with the pictures.

This "usual procedure," however, was to a large extent challenging when the author interviewed deaf women on the grassroots, because of **severe discrimination** and their limited opportunities to acquire their mother tongue and an education. The author then had to make a compromise between ethical codes and situational common sense (Mattila, 2011:84). The author tried to orally explain their privacy and rights for the purposes of study, which was interpreted into Ugandan or local sign languages. However, she was not quite confident that they fully understood their rights. They did understand when the author asked their permission to take their pictures for the study. It was easier as the author could show her camera and asked their permission with her facial expression and gestures. Therefore, the author decided to use their pictures, but without identifying their names in this report. This issue will be discussed more in detail as one of the findings of the research in the following main text (Chapter 7).

In the Ugandan context, meeting a person for the second time makes a big difference in terms of **relationship and trust** for a researcher as an "old friend." As the Ugandan disability fraternity is small enough, the author managed to meet many research participants multiple times, especially those working in DPOs, which facilitated the relationship building with the research participants, and better enable them to trust the author and to be open with her.

In Uganda, research on Uganda requires an official **research permit** issued by the Uganda National Council for Science and Technology. The author applied for this permit, which was valid for three years, to conduct the study.

All the gathered information has been transcribed only by the author herself and kept **under strict control and access only by the author**, unless agreed otherwise (cf. postings at blog site).

During the author's previous studies, she struggled with the **ways of compensation** the research participants for sharing information with her and for spending their precious time for her and her research.⁶ A similar ethical challenge was even more evident in Uganda. Her previous research assistant in Uganda (Katsui, 2006-a&b) decided to give money for compensation because she thought this was the most appropriate way. Following her example, the author gave money to a few deaf women who came to a DPO to meet her to cover the exact costs of their transportation, and to a village-level-politician with a disability who identified deaf women in the nearby villages and made appointments for the author. She also donated money to a church in Kampala for a few times in which deaf people gathered for meeting their peers on Sunday services, regardless of their religious affiliation. For instance, a Muslim deaf woman was there in the church premise to meet other deaf friends.



Picture on the left: the church building in which Sunday mass services are held in Ugandan sign language for deaf people. The building is made of wood pieces and a tin roof. It has a ramp as there are a few deaf people with physical disabilities attending the mass. A few deaf males are standing and chatting in the entrance waiting for the mass to begin.

Picture on the right: a choir made of four deaf members singing in the Ugandan sign language during the service in front of audience. There are several colourful baskets on the table in front of them, each of which is meant for a

⁶ In the PhD study of the author, she did not want to leave any tradition of a researcher giving a big compensation of materials or money in Central Asia where foreign researchers were few then. Most of all, she feared to contribute to the reinforcement of passivity role that had already been created by society. After serious pondering upon the ethical dilemma that she wanted to compensate in some way, and she did not, by her study, want to reinforce passivity, she decided to prepare different kinds of presents to different groups of people that are not materials as such: DPO staffs received a list of information on project grants opportunities, persons with disabilities on the grassroots received some printed pictures of actively participating persons with disabilities around the world, and children with disabilities on the grassroots some stationary to encourage their education. In this way, she tried to activate different groups of people according to the needs they had expressed earlier during the first visit. However, the author is still wondering whether they were right choices, when many wanted money and material supports for their living.

different cause of donation. One basket was for a deafblind girl in her wheelchair who was stabbed by her mother-in-law and was brought here without anybody to take care of her after the mother-in-law was arrested.

In accordance with one of the author's assistant's suggestions, she gave sugar, salt, and soap to the village deaf women in return for disrupting their time to dig their garden. Otherwise, she gave different kinds of small presents which she had brought from Finland to each research participant, such as chocolates, stationeries, stuffed animals, and so forth. Among them, stuffed animals were the most popular presents that Ugandan people highly appreciated, as they always had children around them in their families, relatives or neighbours.

Dissemination efforts have been made through aforementioned ways including continuous blog postings, sharing of draft writings with research participants, conference presentations, academic article publications, Finnish DPO newsletters throughout the study period, and course teaching both in Uganda and Finland. The author was also part of the production team of a DVD, "Deaf children in developing countries" with the Finnish Federation of the Deaf to introduce lives of deaf children in Uganda. The DVD introduces the lives of three deaf children in Uganda and includes the discussion between Markku Jokinen, then the President of the World Federation of the Deaf and the author. Also, the study was introduced in the Helsinki University Faculty homepage (<http://www.helsinki.fi/valtiotieteellinen/tietoa/vuosikatsaus/tutkimus/katsui.html>) and in a news programme of the public TV channel of Finland, YLE, on April 19 2009 with simultaneous sign language interpretation.



Picture on the left: the DVD, "Deaf children in developing countries" as the Kuurojen Video Series 4/2010, which was produced by the Finnish Federation of the Deaf. The cover of the DVD has a picture of a school classroom with many deaf pupils in orange uniforms sitting side by side.

Picture on the right: the study was introduced in YLE's news on 19 April 2009. On the right, simultaneous Finnish sign language interpretation is going on as the author speaks. Many pictures that the author took in Uganda were broadcast, which was welcomed by many of her research participants when she told them so. She is sitting in her office room during the interview. On the table, the computer screen shows one of the pictures taken on 3 December, on the International Day of Persons with Disabilities, which will appear also later on in this book.

However, reaching those persons whom the author met on the grassroots to disseminate findings is extremely difficult due to a number of challenges, which will be clarified further in

the following main text. In other words, meaningful participation of DPO staffs was secured throughout the study on a voluntary basis, whereas the participation of persons with disabilities on the grassroots remained partial and mostly in the role of interviewees. One more visit to Uganda is fixed in October 2012 for disseminating the final findings to the research participants and relevant stakeholders. The author is planning to visit some deaf women on the grassroots whom she met. At the same time, her plan is to produce a **printed popular version** of this report so that those without Internet access will also get hold of a copy of the study findings. In the printed popular version, the author is to make a pamphlet type of printed material with short and precise messages and pictures. As Harrison (2011:180) presents in the context of the human rights impact assessment, there is a tension between expert-led assessment and simple, more accessible assessment. Similarly, this study alleviates this tension by producing a separate popular version for increasing accessibility (See Attachment 7).

The author has not conducted a follow-up review to individual research participants to determine if she really left without causing any **unintentional and unexpected negative consequences** that could take place in any social research (Boothroyd and Best, 2003). The author cannot deny the possibility that she may have left negative feelings with the research participants, despite her careful attention to ethical issues to her best extent.

3.6. The Author's Background, Epistemology and Positioning

In the 1980s Post-colonial feminism started to recognize the heterogeneity of Southern women instead of labelling them as a monolithic group of poor, victimized women. Then, the research setting entailed power relations between Northern researchers and the researched people in the South in favour of the former (Mattila, 2011:72). Today, research on Southern countries and people is diverse including the heterogeneity of Northern researchers, Southern researchers and Southern people who increasingly include those of middle class. For instance, many activists belonging to civil society organisations and movements are from the middle class (Pleyers, 2010). In this regards, the position of the author as a Northern person is not placing her automatically as a superior vis-à-vis Southern people who participated in the study. However, the author paid careful attention to her background to realize the potential possibilities and challenges of a research involving Southern people. Thus this sub-chapter aims to reflect on the author's background.

The author started to be engaged in disabilities at the age of 14 in Japan when she visited a Japanese institution for persons with severe disabilities. She helped with chores as a volunteer on weekends. Having visited the institution several times, she started to realize that the Japanese government and people exclude and isolate persons with disabilities. During her university years, she belonged to a circle to spend time with children with disabilities living in the university area. During her university years, the author went for a language exchange to the University of British Columbia and observed major differences in Japanese and Canadian societies towards persons with disabilities. In Japan, externally easily observable persons with disabilities were not often on streets, while she encountered many taking public transportation means in Vancouver, Canada. In her university, the author met Professor Tatsuro Kunugi who used to work at the United Nations and taught her the importance of advocacy activities of civil society organisations. During her university period, the author participated in a peace fieldtrip

to the Czech Republic, Poland and Germany to pay a visit to World War Two related sites including the Auschwitz concentration camp. She also spent one month in the Philippines to do research on Philipino women and their organisations in Manila, staying in the University of the Philippines (Katsui, 1996). The author spent one year in Finland, at the Tampere University, for her exchange because Finland as a Nordic country allocated a relatively large ratio of money to development cooperation activities including those of civil society organisations, while disability movement had been strong to be part of the formation of the welfare state. At Tampere University, the author met Farhad Hossain from Bangladesh who taught her civil society studies within development studies. The author's Bachelor's thesis compared Finnish and Japanese network non-governmental organisations in the area of development cooperation.

After the completion of the university in March 1998 and before the author started her Master's Degree in England in September 1998, she worked in an orthopaedic hospital to help rehabilitation of various patients. Many of them were persons with disabilities. She acquired the "home helper" certificate for working with elderly persons with needs, while worked as a volunteer for children with disabilities in the area where she lived. However, these volunteer experiences did not change the very situation that they were "others" (cf. Said, 1978) within Japanese society and finally linked the author to an academic discipline of disability studies for her Master's Degree. Then, the United Kingdom (UK) was one of the few countries which had disability studies as an established academic discipline. During her one year stay in England, the author worked as a volunteer once a week at a school for children with disabilities. Disability studies in the UK then interlinked very strongly with the disability movement to promote, both academically and practically, a "social model of disability." That meant the author was forced to realize her role as a person without a disability in a place where many social model adherents did not, at the time, welcome people without a disability for fear of repeating the history of their control. However, she realized that being a person without a disability is not a totally negative factor because the majority of people without a disability should be included at some stage in this movement to actually change the status quo. The author started to understand the relations between power and knowledge of Foucault from her own experiences both in the movement and against it. Her Master's thesis was on an English charity organization for persons with disabilities (Katsui, 1999). She interviewed nine persons with disabilities, three times each, using a charity organization to understand their lived experiences of using a charity. Charity organisations had then been heavily criticized for controlling the lives of persons with disabilities through the altruism of persons without a disability in disability studies by social modellists (Barnes, 1991). The findings revealed that a rigid social modellist approach was not enough to comprehend the phenomenon that many persons with disabilities continue to use services provided by charity organisations. More of a post-modernistic approach as well as contextual approach were needed.

Having completed her Master's degree in disability studies, the author came back to Finland to continue her study to pursue a PhD on development cooperation between Finnish and Central Asian organisations of persons with disabilities, combining development studies and disability studies. During her PhD period between 2000 and 2004, she also worked for one year in a Finnish private company to produce an audio programme for the Japanese elderly and persons with disabilities. When the Afghan war was provoked, visiting Central Asia became difficult as

the Ministry for Foreign Affairs of Finland recommended not visiting the area and thus the development cooperation activities were put on halt. During this period, the author was involved in two research projects: a study commissioned by KEPA, the Finnish umbrella organization for civil society organisations in the field of development cooperation (Katsui and Wamai, 2003), and a study by the Ministry for Foreign Affairs of Finland on Southern civil societies (Hakkarainen et al., 2003). The former study reviewed activities of 90 Finnish civil society organisations that were interviewed by students of development studies. The latter involved Kenya, Namibia, Nepal, Thailand, Vietnam, Mexico, and Nicaragua to investigate interplay of national and global contexts in civil society activities with Southern researchers. These experiences were indispensable for her PhD study to be located in a larger context, and for it not to essentialise and generalise persons with disabilities and their organisations as homogenous.

For her PhD study, the author selected the Threshold Association and its development cooperation activities in Central Asian countries as her case with three criteria that they conduct “1) cross-disability activities challenging social discrimination from a political model (of disability), 2) activities controlled and implemented by persons with disabilities themselves, and 3) interactive activities between Finnish and Central Asian stakeholders to learn from each other” (Katsui, 2005:25). The author travelled with the Finnish disability activists including Kalle Könkkölä to Central Asian countries three times, while she observed two seminars inviting the Central Asian counterparts to Finland. She conducted personal interviews and observation during these events, while she was a general assistant for the delegates with disabilities. She also stayed in Kazakhstan and Uzbekistan in homes of persons with disabilities and conducted her fieldwork for two and a half months. These experiences gave her a lot of insight into the lives and experiences of persons with disabilities in Finland and Central Asia, while her positioning started to shift from that of a total outsider to something different, and perhaps closer to that of an insider. From her own experiences, the author recognized that the “insider” and “outsider” binary was actually a continuum depending on place and time (Mulling, 1999 cited in Mattila, 2011:75). During her PhD period, the author went to language courses of Finnish sign language. Although sign languages are different from country and country and even within countries, learning it to some extent was helpful in Uganda when she could at least finger spell words in the alphabet.

When she was finalising her PhD thesis, she went to Washington DC with Kalle Könkkölä to participate in the World Bank conference on Disability and Inclusive Development that was mentioned in the Prologue. The author served as one of the Finnish delegates as well as a personal assistant for Könkkölä for supporting his daily routines such as taking a bath. Right after the PhD study, the author was involved in a research project, “Forging partnership?” and investigated Finnish and Japanese development cooperation activities in Vietnam with local research assistants from both Northern and Southern areas (Katsui and Hakkarainen, 2006; Hakkarainen and Katsui, 2009). Subsequently, she conducted a study on mainstreaming disabilities into Finnish and Japanese development policies based on her fieldwork in both countries (Katsui, 2008-a). Having gone through her background, as the current study is a global one in terms of context involving both North and South, her positioning as a Northern researcher implementing a research project with Ugandan researchers is a natural

consequence.⁷

When an evaluation study of the Abilis Foundation, a Finnish foundation financially supporting organisations of persons with disabilities in the global South, was commissioned, the author chose Bangladesh, Sri Lanka, Uganda and Zambia (Katsui, 2006-a&b). Uganda was included as her choice, while the others were through the wish of Abilis. As her PhD study could not successfully apply a participatory research approach (Katsui and Koistinen, 2008), she paid more attention in this evaluation study in this respect. As a result, the Ugandan research assistant was a woman with a disability. This evaluation study enriched her in understanding country specificities and contexts on the one hand. On the other hand, she learned to know some similarities in lives of persons with disabilities among the studied countries, Central Asia, Finland and Japan, even when the author had well acknowledged the importance of heterogeneity among them. During the evaluation study, she realized possible tension in the Ugandan fraternity, as is often the case in any NGO movement in any country (Murphy and Bendell, 1999). Thus during this study, from the very beginning, the author paid special attention to **her positioning as a researcher** to be open and fair to DPOs and not to be too biased to any. For instance, the late James Mwandha kindly offered the author the option to live in his house during her first visit to Uganda. However, she pondered upon this partiality and decided to turn down the very kind offer and to live with a woman with a disability instead. As a result, her position was perceived by the research participants as a foreign researcher who was neither involved nor was able to influence deeply into the local power relations and politics: not objective as such with all my epistemological background but too biased either.

On top of her conscious choices, many of her characteristics also played certain roles in a Social Science study such as this one, because they are deeply intertwined with her interactions. Perhaps the most influential of them was the author's looks: she is a young-looking, small, female "mzungu" (white foreigner). When the author introduced herself, including her university affiliation, many seemed to have understood that she was a student collecting information for her degree, even after she gave her information sheet and informed consent form. In such cases, she did not dare to raise the PhD identity because she wanted to keep her profile low. She did not want to give the impression that she knew things better than them, which is true because **they knew their lives and experiences better**. For instance, when the author was travelling to the Northern part of Uganda, Gulu and Lira with NUWODU staff for its monitoring trip for its HIV/AIDS training, she intentionally rather sat with local women with disabilities on the ground, while males and DPO staff sat on chairs.

⁷ The research project even enlarged the scope of teachers and students exchange function between Finland and Uganda by receiving further grant from Center for International Mobility.



This picture was taken in one of the internally displaced people's camps at Gulu because of the civil war. Thus the temporary houses on the back look all alike and stand one after another. On the back and right, DPO staff sit on their chairs and in front and left, local women with disabilities and the author sit on the ground.

This hierarchy which is dependent on **age and sex** is familiar to the author from her original country of Japan. Thus, in that sense, it was relatively easy for her to quickly figure out the “proper place” for herself in their culture.

People were happy to have the author visiting from Finland/Japan. In Uganda, both Finland and Japan are North, and both Finnish and Japanese people are “white.” In that sense, this characteristic seemed not to have made much difference in between. However, the author had a crucial weakness as a foreigner in not having the ability to speak the local languages and sign languages. The research assistants facilitated her communication to a great extent, but the author cannot deny the possibility of misunderstanding due to her background. At the same time, some of the research participants, particularly those on the grassroots with slightly better access to Internet such as students and local staffs of DPO in rural areas, regarded the author as a rich white person from their homogenized stereotype. They wrote to her after her trips to ask for money for various reasons, which is a common experience for many foreigners in Uganda (DSI, 2007:37). They did not talk about money when meeting face-to-face. It is also very similar to Japanese culture not to talk about money at the first meeting and/or directly. As the author was not a donor but a researcher, she did not give money to correspond with such requests because transferring money from Finland to a person without a bank account and a postal address was practically not possible in reality. Most importantly, she did not want to establish and sustain a relationship with her research participants with money. The author paid money only as salaries for her assistants, for instance, except for a few examples including donations for a deafblind female and her deaf carer living in a church, and for a deaf female who was collecting money for her wedding in the general assembly of UNAD. Dependency creation has always been on the author's mind. This position as a Northern person may have led some of the research participants to approach her not from the interests to her study but/or also to her possible monetary contribution. The truth, however, remained unclear to the author. The Northern background with different knowledge on different countries might have the possibility of predetermining findings in a certain way based on her preconceptions (Mattila, 2011:79). The preconceptions, however, also taught the author that the realities of persons with disabilities are diverse. The author was conscious of this and tried to be open to Ugandan

specificities and contexts.

Unlike other disability studies in other contexts, being **a person without a disability** was not questioned in Uganda, especially when the author was **with her female research assistant with a physical impairment** on the weekdays or with her deaf female assistant over weekends. People the author met were all very friendly and seemed happy and relaxed to talk with her in general, except for a few. This research assistant with a physical impairment was affiliated to a DPO as a member and former volunteer, and the DPO was in a competitive relationship with another DPO. Thus when the author visited the latter DPO with her assistant, she felt that she was not welcomed. From the beginning, the author asked this research assistant also to keep a low profile. But the author did not understand the consequence of having an assistant with “volunteer” experiences. Volunteer to an organization is something equivalent to or perhaps more than an intern to earn experiences as a young and inexperienced person looking for a job in the near future. However, one becomes a semi-staff in the sense that s/he represents the host organisation in different meetings and for instance gets “sitting allowances” that are paid to all participants. The author misunderstood the significance of having a volunteer experience and did not manage to minimize such negative consequences because of her ignorance of this local knowledge. Otherwise, the author quickly acquired local knowledge through interviews, literature reviews, and communication with assistants, research participants and local persons in daily life. This research assistant knew well the existing DPOs, which helped the author to visit them.

When it comes back to her academic background, the author is a Social Scientist specializing in disability studies, development studies, human rights studies and civil society studies. Thus her epistemological background surely affected the study to a great extent particularly in terms of focus, methodology, and findings as she prioritized certain theories and approaches over others. This methodology chapter and the previous chapter on conceptual, theoretical and contextual frameworks tried to reflect on the author’s epistemological background and to make it transparent.

4. Case Studies

This Chapter presents evidence-based realities of international and development cooperation activities in Uganda through the selected case studies. The focus is on the viewpoint of persons with disabilities, while a more specific focus of the first two cases on development cooperation is on women with disabilities, particularly that of deaf women, so as to understand the complex realities better. The **first case study** is on the HIV/AIDS project activities of a number of Ugandan DPOs. This project was analysed on two levels: firstly, activities to mainstream disabilities into national policy and practice against HIV/AIDS are elaborated. Secondly, the HIV/AIDS training activities of the DPOs are investigated. The **second case study** is on the general assemblies of the Uganda National Association of the Deaf (UNAD) and the National Union of Disabled Persons of Uganda (NUDIPU) in which important and relevant questions pertaining to the well-being of persons with disabilities were decided upon among representatives with disabilities around the country. The **third case study** is on international cooperation in soliciting African Union Disability Architecture. Prior to the case studies, the **life stories** of two Ugandan women with disabilities are introduced to facilitate the readers' comprehension of the realities from their viewpoints.

4.1. Life Stories of Two Ugandan Women with Disabilities

Two women with disabilities, whom the author met during her stay in Uganda, volunteered to write their life stories to share with a wider audience through this study. One is a woman with physical impairments and the other, deaf with a physical impairment. It is noteworthy to remark that they wrote the stories in their own words in their own account, which thus captures very well what it is like to be a woman with a disability in Uganda. They are both socially and economically successful women with disabilities in Uganda, as they have access to computers and Internet to start with. They are both highly educated and employed in DPOs and not the most typical women with disabilities in a Ugandan context. However, their life stories guide readers to get a sense of perspective of Ugandan women with disabilities. This will become extremely important in order to read the following case studies from that particular perspective. These stories are very powerful as they are. Hence, the author did not make any correction, even to any grammatical mistakes. The author never forget the phrase of Nanyinja, "**Living with a disability is a big challenge that I wouldn't wish even my worst enemy to become disabled.**" These life stories are short, but tell so much in between the lines about being a woman with a disability in Uganda.

4.1.1. Life Story of Prossy Nanyinja¹



Picture on the left: Prossy Nanyinja with her crutch is riding on a motorbike taxi called “boda boda”. This is one of the most popular, quick and in the author’s mind, the most dangerous method of transportation in Kampala, Uganda, due to the very heavy traffic. For instance, the greatest cause of severe injury for youth under age 20 in Uganda is traffic (46%), which is followed by falls (14%) and burns (11%) (Kobsingye, 2001 cited in Nganwa et al. 2008). The chairperson of the NUDIPU is also concerned about the increasing number of persons with physical impairments due to traffic accidents (personal interview on 31 January 2008 in Kampala). Neither the motorbike taxi driver nor Prossy wear a helmet, as is the custom here. In 2008, Nanyinja’s brother was involved in a serious traffic accident where four people were killed. He was also seriously injured. Yet, he did not receive any compensation from anyone as the driver who caused the accident died. The road is not paved and red mud implies difficulties when it rains, as she mentions in her life story.

Picture on the right: very heavy traffic in Kampala downtown area. This picture was taken at the entrance of the so-called “New Park” which is one of the huge taxi terminals. One taxi comes from the back, shops are on the right and people are passing through between them. You have to be very fast getting into a taxi. When there are many people waiting for a taxi going in the same direction, you have to compete for a ride. The author was not used to that and her assistant always shouted, “Now you quickly get on!” The author’s research assistants with physical impairments often face difficulties because they are regarded as slow customers who disrupt the driver’s aims for a quick profit. One student of Law at the Makerere University was denied access into a taxi by a taxi driver, and was told that his disability would make this taxi slow. He then mobilized his networks including the NUDIPU, the Human Rights Commission, and the Ministry among others and tried to take this case to court based on the Disability Act.

I am Nanyunja Prossy by name and I work with National Union of Disabled Persons of Uganda (NUDIPU) as an Accounts Assistant. I am a person with a physical disability who has gone through all the stages from primary, secondary and higher institutions of learning. I got this disability at the age of three, my mum told me it was one afternoon when I got a high fever, was rushed to the hospital and given an injection immediately. In a few hours the fever had cleared but the legs became very weak, since then, I’ve lived to be a person with a disability for 28 years now.

So this story is all about the challenges I have encountered as a person with disability right

¹ On 14 April 2009 her life story was uploaded to our blog: <http://disability-uganda.blogspot.com/2009/04/posting-by-ugandan-friend-prossy.html>. Her life story was also published as part of an academic article in Ngirabakunzi, E. & Katsui, H. (2009) “The Right to “Decent Work” of Persons with Disabilities: Article 27 of the Convention and the Case of Uganda” In J. Kumpuvuori & M. Scheinin. (eds.) The United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives. P.115-137.

from the age of three when I was a child and the opportunities I got on the way to where I am now. But the challenges seem not to stop or reduce because at each stage of life, they become totally different and the fact that I am to remain with the disability for as long as I am alive, I have come to terms with whatever happens anytime.

As I was growing up, my mum did her best to see me go to school. I did my primary level for seven years after which I had to go to another school for the ordinary level. That is where my problems of being a person with disability started. First, my real father disagreed with my mum, telling her that she shouldn't bother herself with me because after all, no employer would ever give a job to a person like me even if I studied hard. He then advised her to take me to a vocational school to learn tailoring. My mum cried over it but later decided to continue with her struggle of educating me with the little earnings she would get. By then they had even separated and she was working in one of the big markets in the city centre selling green vegetables.

To my own and my mum's disappointment, I was again denied admission in two boarding schools and the denial was attached with a reason that being a person with disability, she will not be able to cope with the school environment and that they didn't have special facilities for such people. This is the time when I started realising so seriously that I was different from other people, because in my former school where I did my primary, we were all disabled children, so I didn't see myself any different from others and I believed I had the potential to do what they could do. People always say that persons with disabilities are different because they are not physically able. But what is able? Because for sure they know able within a culture and not within a person. Surprising! So I ended up joining a day school, which made my attendance of classes irregular because I had to walk four kilometres everyday from home to school.



This is a typical road to connect one village to another. This particular picture was taken from a car in Gulu, the Northern area of Uganda. The traffic was like this all the way from the outskirts of Kampala, not heavy. It was only in the Kampala city centre where there was heavy traffic. Some cars carried advertisements for international agencies' names and NGOs. Others were long-distance buses. In 2008, such public transportation costs were 20€ round trip between Kampala and Gulu. The author saw many children carrying water bins. There are many "pot holes" to avoid while driving. Drivers need a lot of concentration to drive in this country.

And whenever it rained in the mornings, to me it would mean not going to school. The school buildings were all multi-storied, so I always reached my class tired because going up the stair cases everyday was not anywhere near my adventure. I studied there for one year and later

joined a boarding school.

I persevered and managed to complete my secondary levels, but with a lot of psychological torture because of the negative attitude that surrounded me from all sides. First from the school administrators, fellow schoolmates, relatives at home and the community. At home, as a child who was growing up, I was seen as an extra economic burden. I needed crutches and callipers to enable me to cope with my physical limitations, and they were very expensive. My siblings were also against me because our mum always protected me from doing any chores at home. They could not be taken to boarding schools, it always had to be me just because of my disability.

I then finished both my ordinary and advanced levels and then looked forward to joining a higher institution of learning where graduated with a Diploma in business studies. After getting my diploma, everyone started doubting whether I would be able to get a job. I remember a friend of my mum telling her that, 'nowadays employers, especially men want to first sleep with these young girls after which give them jobs. But there is no man in his right thinking capacity, who can sleep with a person with disability'. She even asked her why she bothered to waste her time and money to take me to school. It really demoralized me because I was listening to their conversation, and the fact that they were talking about me, made me listen attentively. Unfortunately I couldn't even respond to their conversation to defend myself.

As I was looking for any possible employment opportunity to come my way, I used to do handwork where I use to weave mats, table mats and table clothes from which I got money to facilitate me with transport and making photocopies of my academic transcripts so I could leave copies to wherever I went to look for a job. Fortunately, I got a job after two years of serious searching. I got to know of a job advertisement in NUDIPU through a person I studied with in primary school and that I had the qualifications required for the job. So I decided to put in my application, was short listed, did the interview and passed. I did the interview with four people, two of them were persons with disabilities and the other two were not. I came first and took up the position. It is now six years down the road and I am still working there happily. Getting a job was my turning point because it came as a surprise to everyone as many people didn't expect to see it happen.



This is the NUDIPU building. There is a ramp leading to the entrance of the building. It is accessible for wheelchair users except for the toilet. For some reason, a wheelchair was left in front of the building.

But that was not the end of my problems brought about by disability. Now they started looking at me as someone who was overgrowing and should find a man just to help me get a child who will look after me in my old age, 'after all, she has a job and getting enough money that she can use to look after her child even if the father of the child doesn't take up full responsibility'. Even up to now, am being told that crap, can you imagine even by my own mother. It really bothers me a lot when it also comes from my mother because I always saw her as a person who knew and believed that I had the potential to do and achieve whatever I wanted to do without the word disability being fronted.

Being a woman with a disability is a very big challenge here in my country. You are not expected to get married because no man will be willing to genuinely fall in love with you because of the fear of being seen with a cripple. And you are always expected to give in to any proposal of whoever comes to you because he would just be helping you to sleep with him. I remember in the year 2007, there is a man who proposed to me for more than seven months, and I remember asking him why he was insisting on me when I had already told him that I was not willing to start a relationship with him. It still sounds fresh in my ears as if it were of yesterday when that man replied me saying that because 'YOU ARE NEGLECTED'. Neglected meaning that no man can, and has ever or will ever love me. So he was just going to help me. Awful, not so? I hated myself for that.

Most times I try to put everything behind me so that I continue with my life minus what people say about me, but sometimes I lose out and end up being weak and emotionally touched. It really works me up when walking down the street and people start looking at me in a strange and inhuman way after which they start talking about you, not even minding about what you feel with their comments regarding your disability. Living with a disability is a big challenge that I wouldn't wish even my worst enemy to become disabled.

To me, the worst challenge as regards living with a disability is having to depend on other people financially. Once you are very poor and not having any income generating activity to rely on, can really complicate the life of a PWD (persons with disabilities) completely. You are looked at differently when you are a PWD with money as compared to another PWD who is in absolute poverty. Personally, I am not rich but at least what I get makes me able to cater for most of my needs. And the way my siblings and other relatives look at me now is totally different from the picture they had of me ten years back. I can even support our mother financially, which some of them cannot do.

And working with NUDIPU has helped me a lot to build my self esteem and to look at things and myself positively. First, because some of my workmates are PWDs, and secondly NUDIPU being a membership organization, all it's membership is comprised of Disabled people's organizations with different categories of disabilities. Looking at all these people in their different capacities, how they have struggled with life to sustain their families makes me proud of myself because most of them didn't even attain the education that I got.

With my earnings I've even managed to sponsor myself and go back for further studies to supplement on the Diploma that I've always had. I am now pursuing a degree in Business Administration majoring in Accounts and I am yet to complete in May month this year (thus,

becoming a full accountant). I am also paying fees to one of my sibling who is now in secondary school and always supporting my relatives financially where possible.

4.1.2. Life Story of Christine Lule²



Picture on the left: Christine Lule is standing and speaking in Ugandan Sign Language. This picture was taken after the general assembly of UNAD when deaf women with disabilities gathered to establish their own organisation aside from UNAD. It is taken in one of the classrooms of the Ntinda School for the Deaf and so the blackboard is behind her. She says, “We are marginalised triply. Disabled, women and deaf. We cannot access information. For instance, there was a case of rape of a deaf girl. And her parents got money and it was not brought to court. Parents oppress deaf girls and women. We have nowhere to run. So we need an association to respect human rights so that deaf women become women” (personal interview on 7 December 2008 in Kampala).

Picture on the right: a shopkeeper selling vegetables on the table, matooke under the table and charcoal beside the table in the author’s neighbourhood. The author often bought vegetables from her. As she did not speak English, her children sometimes helped the author in English. In Ugandan homes, there is typically no running water, electricity, and gas, particularly in rural areas. People cook food with charcoal or wood and eat it right away when cooked. In urban areas, some homes have electricity but black out is common. In both urban and rural areas, therefore, household chores require a lot of human resources. For washing clothes, you have to fetch water from a water point and wash them manually, for instance. All these household chores are usually women’s jobs. Without electricity at home, many mobile phone charging point businesses exist in the city centre.

I was born in a remote district in Uganda about 138 km from Kampala the capital of Uganda where the staple food is green banana commonly known as “Matooke” and coffee as a cash crop.

I am born to Mr. Eliphaz Lule and Mrs. Gertrude Lule. My father doubled as a self employed business man and a peasant farmer while my mother was a traditional African house wife. I am known as the first born because the actually first born died shortly after birth. My parents had 11 children but only eight survived childhood, of the eight 3 are boys the rest girls.

I was born hearing and enjoyed my childhood greatly because my parents were fond of their children. At the age of 8, I suddenly fell ill with severe vomiting; I then became unconscious

² On 26 March 2009, her life story was uploaded to our blog: <http://disability-uganda.blogspot.com/2009/03/posting-by-ugandan-friend-christine.html>

and was rushed to a hospital. The doctors discovered that I had eaten poison. After two days (I was told) I gained my conscious but could hear nothing. I had lost my sense of hearing. Imagine what a disappointment I received when on checking the doctor confirmed that am now permanently deaf. I was in hospital for four months i.e. August – December. I was almost handicapped by the illness because I could either walk on my own or feed myself. Everything was done by my mother or her sister who assisted her because she (mother) had a baby of 6 months. Well, although I was deaf I was happy that the devil had added more misery to his list of defeat.

On discharge we returned home but I no longer shared the jokes or the happiness with my siblings or friends. It took me a long time before I was completely healed. When I was fit I returned to school. To my surprise fellow student started mocking me by holding their ears (indicating that am now deaf) and laughed at me that I lost my cool and at times I resorted to fighting them or cried a lot. It was disheartening, to see the pupils I played with laughed with mocking me. To make matters worse my mother's love began to fade. She was less interested in me that I wished I had died. It was Father who came to my rescue; he comforted me and told me deafness in not the end of the road.

I hated home and started to move with my father. He took me to Uganda School for the Deaf, where a new chapter of life awaited me. At first the Deaf children resented me because I could talk. They thought I hear and only pretending (not to hear). When I mastered sign language I was transformed. I studied hard and finished my study to the school. The Head teacher transferred me to a hearing school to continue my education to a higher standard because that time there was only one deaf school in Uganda and its standard was low.



Picture on the left: deaf pupils are studying at the primary classroom at the Ntinda School for the Deaf in Kampala. The teacher, Peter, learned his sign language skill in Kenya.

Picture on the right: a building of the Kyambogo University which is the only higher education institution in Uganda where one can receive a diploma on Ugandan sign language in the Uganda National Institute of Special Education (UNISE), which was a fruit of a development cooperation project of a Nordic DPO. It is now merged into the university. This institution has been producing more than 20 graduates with a diploma in sign language every year since 2000 (Olouch, 2011). There is a ramp and stairs in the hallway. Lawrence Eron, the Dean at the Faculty of Special Needs and Rehabilitation of the University, is walking the ramp after my interview to him. The Faculty and UNAD collaborated to produce the first Ugandan sign language dictionary as a development cooperation project activity with another Nordic DPO. A report also claims that the Education Ministry of Uganda donated 5 million shillings for this (Uganda Human Rights Commission, 2009:32). The university was involved because "People respect universities a lot. When you hear that it's in the university, people pay attention a lot. So

we thought that it's better to deal with sign language in the university than doing it by ourselves" (Alex Ndeezi, personal interview on 28 January 2008 in Kampala). I asked Eron to show the dictionary, but it was neither found in the University Library nor in UNAD. He claimed that special education is not regarded as science by the government and thus only few scholarships are given to students for this discipline. The university had a good relationship with DPOs when donors were around to pay for the transportation allowance. After the withdrawal, meetings faded away, he states. The University also has a production line of white canes. Canes are sold there for a price much less than that of imported ones, according to the abovementioned report; 10,000 shillings and 110,000 shillings respectively (ibid.49). When the author visited the production line herself and interviewed the worker, the prices were 20,000 for a cane with a plastic top, 25,000 with a cow horn top and 15,000 for children's canes. A Braille printing per page costs 2000, while photocopying 50. The woman with a physical impairment (with her crutches) in the picture on the right is one of the research assistants.

I completed my studies in "0" level, and then took up CBR (Community-based rehabilitation) course and Sign language courses where I got certificates. I could not continue because in those days people despised the deaf yet had no money to go for abroad for further studies. I have accepted myself as deaf and do not look back. I first worked with World Opportunity International as administrator then with Uganda National Association of the Deaf as a sign language Instructor, and again as a Field officer under the same organisation but with the support of OXFAM before I joined Action on Disability and Development as a program coordinator (Deaf programme).

During my work I have experienced working with the most marginalized groups, deaf people without sign language skill and the poorest of the poor. I do enjoy working with them because I assist the uplifting of their standard of living and sensitize the parents and the community that deafness does not mean inability. It is the community we live in that disables us because they always refer to us as "kasiru" literally translated as "stupid." We are not stupid. The problem is communication differences, i.e. we use sign language and the community use spoken language. Some have embraced sign language and made communication easy. Others have become our interpreters. Yet there are those who are hard to change. One cannot change the world in a short time. We hope in future we will have a positive, well developed country.

4.2. Case Study 1: The Development Cooperation Project on HIV/AIDS

This sub-chapter introduces one of the selected case studies for this research in order to elaborate more in detail the decision making power of women with disabilities, particularly that of deaf women. Interviews reveal complex realities of development cooperation activities involving deaf women on the grassroots. The selected case is development cooperation project on HIV/AIDS among a number of DPOs in Uganda. The immediate objectives of the HIV/ AIDS project are; 1) to empower the disability movement in the area of HIV/AIDS, 2) to develop and promote innovative partnerships between the disability movement and mainstream HIV/AIDS prevention, care and treatment as well as Sexual and Reproductive Health service providers from government and civil society, and 3) to increase persons with disabilities' access to mainstream HIV/AIDS services (Development Research and Technology, 2008:57). Initially, it started with a development cooperation project between NUDIPU and Disabled People's Organisations Denmark (DPOD) between 2006 and 2009, which was further funded by others and extended till 2012. In this project, DPOs "test their new approaches" (Staff A of a Northern DPO, personal interview on 30.1.2008 at Kampala).

Firstly, the relationship between the HIV/AIDS epidemic and Ugandan persons with disabilities is investigated as a background. Subsequently, the project is analysed through two respective vantage points: mainstreaming and empowerment. In the end, discussions follow regarding this case study and that of the operationalisation of a human rights-based approach in the Ugandan context.

4.2.1. Background: HIV/AIDS Epidemic and Ugandan Persons with Disabilities

Sub-Saharan Africa remains the most affected region in the global AIDS epidemic. More than two thirds (68%) of all HIV-positive people live in this region where more than three quarters (76%) of all AIDS deaths in 2007 occurred. It is estimated that 1.7 million [1.4 million–2.4 million] people were newly infected with HIV in 2007, bringing to 22.5 million [20.9 million–24.3 million] the total number of people living with the virus. Unlike other regions, the majority of people living with HIV in sub-Saharan Africa (61%) are women (UNAID/WHO, 2007:15).

The estimate of the prevalence of HIV among persons with disabilities in Africa ranges from 11 percent to 60 percent due to lack of data (Couper 2002 cited in the World Bank, 2010:iv). Even though the high level meeting on HIV/AIDS at the UN in 2011 included several direct references¹ to disabilities in its "Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS," persons with disabilities are "too often" "left out" from the global response to HIV/AIDS (Chalklen, 2011).

Under the general circumstance of the Sub-Saharan Africa, aggressive sensitisation activities of the Ugandan government started in 1987 (Kanyesigye, Anguria and Mbabazi, 2007:vi). In 1992, Uganda started to record a decline in the prevalence ratio of HIV. It was the first country in Sub-Saharan Africa to have decreased the ratio, which was credited to the governmental political commitment including the active leadership of the President Museveni (Garbus and Marseille, 2003:27). In 1992, 18.3% was the estimated prevalence ratio (Uganda AIDS Commission, 2008), which decreased to 4.1% in 2003 (ibid, 11). Thus the Ugandan

¹ Direct references to disabilities were made in Articles 23, 31, 60 and 73.

“International image of success in the fight against the HIV/AIDS pandemic” prevails (Babu, 2005:2; Potts *et al.*, 2008:750).

However, the prevalence ratio started to increase and was estimated to be 6.7% in 2005 (*ibid.*, 11). Furthermore, the State Minister for the Elderly and Disability Affairs, Sulaiman Madada, claims that “people with disabilities were silently but increasingly losing lives to AIDS due to the false belief that they are sexually inactive” (Nafula & Kasozi, 2008). In March 2008, NUDIPU held the second meeting of the African Campaign on Disability and HIV/AIDS in Kampala. As a fruit of this meeting, the Kampala Declaration on Disability and HIV/AIDS was created to call for international and national attention to the realities in which persons with disabilities are disproportionately highly contaminated with HIV.



Picture on the left: the State Minister for the Elderly and Disability Affairs, Sulaiman Madada, on the right, and the author on the left.

Picture on the right: a poster of the Uganda Deaf Silent Theatre. Eight Deaf actors and actresses belonging to the UNAD perform as a theatre group. Awareness-raising on HIV/AIDS, for instance, is also done through this theatre performance. The mission statement of the pamphlet states, “We exist so that families and communities recognise it is worth the time and effort to educate their Deaf children.” This theatre group has become popular also among hearing audience, as it is also narrated orally as they perform. The theatre group went also to several primary schools for awareness-raising, where parents and neighbours also enjoyed it. The performance depends mostly on the funding of Northern donors including Northern DPOs. They perform when they get money (Silent Theatre coordinator of UNAD, personal interview on 28 January 2008 in Kampala). She shares that they have performed in Spain, Unites States, Italy, and Iran. The group has received several international awards.

For instance, 3 out of 17 women with disabilities who went for a test within the framework of HIV/AIDS training organised by NUWODU were HIV positive (NUWODU, 2007). The sample is small, but the ratio is 18%, while it is some 6% for the general population today. Another study (Mulindwa, 2003:37) reveals that none of the deaf respondents, neither males nor females, ever used condoms, while far majority of respondents with physical disabilities and blindness also have never used one before. In fact, only 31% out of 197 women with disabilities and 56% out of 174 men with disabilities know the contraceptive role of condoms (*ibid.* 60). The most common means of transmission is unprotected sex (84%) (DSI, 2007:3). Many persons with disabilities still believe that HIV/AIDS is caused by witchcraft (Uganda Disability Fraternity, 2007:2), which thus mobilises them to seek traditional healers (NUDIPU, 2010). A study reveals that 23% of studied persons with disabilities had never heard of HIV/AIDS and sexually transmitted diseases (Ugandan Disability Fraternity, 2007:5). Deaf

woman C, who is one of the actresses of the Silent Theatre Group sensitizing HIV/AIDS prevention and management, also tells:

We expect different deaf who are there to know about HIV/AIDS. We continue sensitising in schools and villages. Many are shocked to know about it. Many are getting the information. Some have even got AIDS and died. But I hope that the sensitisation will reach many. Many deaf people have died of AIDS. Parents have never counselled their children. Even with the sickness, the deaf would love one another and continue making friends. I want many other deaf to learn about AIDS (personal interview on 4 February 2008 in Kampala).

A report also establishes that out of 86 women with disabilities, “22% of the women (with disabilities) in the Kampala and Rakai Districts were reported to have been raped in their first sexual encounter” (Mulindwa, 2003:32). It continues (ibid.) that 42% of studied women with disabilities in the Kampala District (41 in number) have ever experienced forced sex, while another study in Northern area established one third of women with disabilities have experienced such violence (Human Rights Watch, 2010:10):

“Parents keep disabled children indoors or at the back of the house because they don’t want to associate with them. This is where men find them and rape them” (Parents of disabled children, Rakai District) (Cited in Mulindwa, 2003:52).

Sexual violence is too common for persons with disabilities, while negligence for children with disabilities (NUDIPU, 2010). This explains the next statistics that 49% of the first pregnancies among the studied women with disabilities in Katakwi District were not wanted, while around 30% of the last pregnancies were not wanted in three districts (ibid.55). Abortion is illegal in Uganda (ibid.) and choices for the women were limited also in this sense. Men who pregnate women with disabilities too frequently do not take care of them and their children (NUDIPU, 2010; NUDIPU, 2011:11), which was the case for a deaf woman E (personal interview on 17.2.2008 at Kampala):

I had a man. I got pregnant, I felt so bad. I was vomiting. I thought I would introduce the man to the parents. The man refused. After the man left, I was alone. He did not want to interact with any of my family or friends. I stayed in a church with three children. The man was a hearing person... They (the employers) don’t give me any money. No money. I was not paid a salary for so many months. I don’t eat once in a while. No food in the morning. No lunch. Like that. I just keep praying. I clean and wash and everything but they don’t give me any money. But I stay patient and wait that they get moralised. Even now, I have no money for porridge.

Lawyers with disabilities working at the Legal Action for Persons with Disabilities (personal interviews on 21 February 2008 in Kampala) also confirm that people come to consult with them about violence against women with disabilities. Due to poverty, women with disabilities have “sex for gain” as well:

What happens is that when they are offered sex, they never say no. They cannot say no because first of all, if a man is giving her 5000 Shillings for that, is the money provides something to eat for a day. So they end up sleeping with these men. So this is the way they

are contracting HIV/AIDS (Gender officer of UNAD, personal interview on 28 January 2008 in Kampala)

Women with disabilities are extremely vulnerable in negotiating safe sex (Mulindwa, 2003; NUDIPU, 2011:9). Alex Ndeezi, the Deaf Member of Parliament, further argues the vulnerability of deaf women:

When the men have little money to sleep with girls, they go to deaf girls because they don't have access to information, they are poor, so they are the cheapest. That is a problem. The men give little money, or men even have free sex, you know. They are HIV infected and go to these ladies. They get HIV. After using them, the men dump them and leave them. So it is very hard for the women to defend themselves because they don't have information... it's a severe situation for Ugandan deaf women (personal interview on 28 January 2008 in Kampala).

This is due to the fact that information available and accessible to women with disabilities, particularly deaf women, is limited.

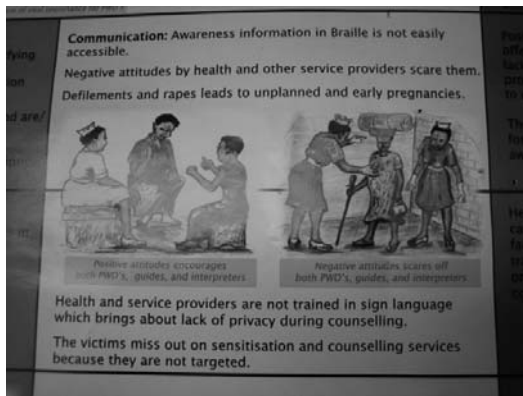
The Ministry of Health uses radio programmes in order to spread information, but deaf persons cannot hear. They use newspapers, but many deaf people cannot read and write. And the few who can read and write are not employed and so do not have salaries to pay for those newspapers (Gender officer of UNAD, personal interview on 28 January 2008 in Kampala).

Makerere University will start the first study based on a video-based sign language survey for 1000 Deaf persons in the capital city area to investigate on status of Deaf persons concerning HIV/AIDS in June 2012. Health facilities are also physically inaccessible, poor in quality and staffs are unfriendly and even force treatment against the patients' will. For instance, sign language interpreters are not available in health service centres (Kimono, 2008; Kakam, 2010). Simultaneously, deaf people face profound communication barrier without lack of education (Barriga, 2010). Thus 71% of women with disabilities and 74% of men with disabilities feel **health facilities are not accessible to persons with disabilities** (ibid.76):

"Nurses ridicule, laugh and abuse us when we emerge with reproductive health problems. They always insult us by asking questions like, 'How did you get this pregnancy, you crippled women?' "(WWDs, Rakai District) (Cited in Mulindwa, 2003:69).

"Some doctors give WWDs contraceptive methods which permanently prevent them from having children and we fear using them" (Female youths, Kampala District) (Cited in Mulindwa, 2003:70).

"I would have to crawl a long distance to get tested for HIV and sleep on the road on the way there, so I just live without knowing" (Charity, a woman with a physical disability, Amuru district) (Cited in Human Rights Watch, 2010:14).



Picture on the left: a sensitisation poster placed in a DPO. It says, "Communication: Awareness Information in Braille is not easily accessible. Negative attitudes by health and other service providers scare them. Defilements and rapes lead to unplanned and early pregnancies." Then a picture of positive and negative attitudes of health service providers: the positive nurse sits with a deaf person who has her sign language interpreter also sitting besides her, while the negative nurses try not to understand the blind woman and get rid of her. It says, "Positive attitudes encourages both PWDs, guides, and interpreters. Negative attitudes scares off both PWDs, guides, and interpreters. Health and service providers are not trained in sign language which brings about lack of privacy during counselling. The victims miss out on sensitisation and counselling services because they are not targeted."

Picture on the right: the Mulago-Mbarara Teaching Hospitals' Joint AIDS Program had a tent in the event for celebrating the International Day of Persons with Disabilities where they offered free HIV testing.

"The situation is exacerbated by the low value generally given to persons with disabilities by the community and families, leading to their health needs not being viewed as important or worth incurring medical expense for even where affordable" (Uganda Human Rights Commission, 2009:40).

"It is difficult to take care of a disabled child and we suffer a lot raising them, and yet we know they cannot contribute anything to the family wellbeing" (Parent of PwD youth, Serere District) (Cited in NUDIPU, 2011:10).

Persons with disabilities, particularly women with disabilities in the northern, civil war-affected area of Uganda are extremely vulnerable (Human Rights Watch, 2010; Ojwee, 2010), where as many as 80% of the population were displaced² (UN World Food Programme, 2004 cited in DSI, 2007:5). In 1996, internally displaced people's camps were opened to protect civilians from the civil war. Persons with disabilities are one of the most vulnerable groups in conflicts and emergency situations, and yet "often the last to be considered in almost all humanitarian response interventions" (NORAD: 2012:55). As 80% of the 1.8 millions of internally displaced people have gone back to their homes (OCHA, 2010), persons with disabilities are still left behind in the camps even when their family members have gone back homes (Nakagwa and Odeng, 2008; Lang and Murangira, 2009:43). The United Nations High Commissioner for Refugees reports that as of May 2010, there were 3,098 persons with disabilities remaining in camps –the majority of them female (Mwesigye, 2010). That is,

² Nakagwa and Odeng (2008) reveal harsh experiences of persons with disabilities during the time of the civil war. Many of them were left out at home when rebels attacked the village, because they are troublesome to take along. Deaf people did not realise the situation and were killed or physically violated even when they could have run away with others. Those who live in the camps are the "lucky ones" in a relative sense, while many others could not even reach the camps.

persons with disabilities still have need for the camps, while donor support is diminishing (OCHA, 2010). Lang and Murangira (2009:43) are concerned that the camps will become “disability ghettos.”

The author was invited to the house of Janet Owto who is a woman with a physical disability, the disability councillor at Gulu and also openly identifies her HIV positive status. She claims,

“Kampala and Gulu are so different. You can beg for money in cities, but there is no income that you can expect here in the (internally displaced people’s) camp. The only income generating activities that are offered by donors are meant for others. ... There are too many rapes here. Men visit women with disabilities at night and pregnate them. They don’t even offer money. But due to the need for sex, also for women with disabilities, when the only option is ‘sex by chance, not by choice,’ you have to accept it. ... When you (as a woman with a disability here) have four children, they are all from different fathers who do not take care of them. Only a few women with disabilities are married and even they are the third or fourth wives. ... Women with disabilities go to hospitals only when the situation is very severe” (Interview to Janet Owto on 11 February 2008 at Gulu).

Another woman with a physical disability (group interview on 11 February 2008 at Gulu) claimed inaccessible and expensive transportation is a problem for testing, even though men pregnate and leave HIV. Those houses in the camp are not secure at all in practice. The author visited one of them and it was 4-5 m2 only for the family of five including one woman with a disability. Thus often children sleep outside of the house and “get exploited,” while anybody can get into the house easily at night. Nevertheless, when condoms were distributed for free in HIV/AIDS trainings of a DPO, NUWODU, in Gulu, most women with disabilities did not take them, as they felt uncomfortable to pick them up in “public.” **Sex is too taboo a subject to talk about in public** (NUWODU Executive Director, 2008). Women with disabilities particularly find it particularly difficult to share information of HIV/AIDS with men who are “always drunk” and do not listen to them (woman with a physical disability at Koch Goma camp, group interview on 12 February 2012 at Gulu.) Another woman with a physical disability (group interview on 12 February 2012 at Gulu) even fears to talk with men, “because when you talk with a man in public, people think that I am a prostitute.” Even the third woman with a physical disability states,

Men without a disability come and sleep with women with disabilities day and night. We want to marry men without a disability because we want men to bring cassava to us. I have four children, 3 girls and 1 boy, from the same father. The problem is that husbands don’t want wives to get tested (for HIV). I also fear getting tested. If I go and am positive, I will lose my man. So I have not tested (group interview on 12 February 2012 at Gulu).

The fourth woman with a disability also fears going for testing. Out of the six women with disabilities in the group interview, only one had ever heard of the word “human rights.” Hellen Asamo, the chairperson of NUWODU and current Member of Parliament representing persons with disabilities, explains the reason why grassroots women do not know human rights. It is because politicians often claim, “I’m the one who brought you these.” This personalisation of credit as a giver confuses grassroots women and blurs their understanding on entitlement to their human rights. She sighs, “Most of them (grassroots women) down there still don’t know that kind of knowledge (on their human rights)” (personal interview on 31 January 2008 at Kampala). The chairperson of NUDIPU also argues:

The human rights violation is very serious. Yes. We are trying to sensitise and create awareness. But people's understanding is very, very slow. We talk and talk. We go on radio. We go on TV. We write papers. We organise workshops. People feel as if they have understood, but when they go back home, they do the opposite (personal interview on 31 January 2008 in Kampala).

“Consequently, disabled people experience a double burden in relation to HIV/AIDS. That is: a) increased risk of infection and, b) reduced access to prevention and care services” (DSI, 2007:4). Babu (2005) calls people with disabilities “the forgotten tribe” in this context. The findings of a global survey on HIV/AIDS and Disability show that **persons with disabilities are not included in most AIDS outreach efforts** (Groce, 2004:15). Various studies in a Ugandan context also reveal negative factors against persons with disabilities to be properly involved into HIV/AIDS-related programmes and projects (ADD, 2005; Development Research and Training, 2008:13). Those factors are negative social stigma and discrimination despite the stipulation of rights (Andersen, 2006; Kanyesigye, Anguria & Mbabazi, 2007: Development Research and Training, 2008), lack of information and accessible treatment (ADD, 2005), and “poverty, rape, non-use of condoms, lack of awareness about reproductive health issues, polygamy and wife sharing” (Mulindwa, 2003:ix). Also the misconception that persons with disabilities are sexually inactive has led to their exclusion to relevant HIV/AIDS sensitisation events (Development Research and Training, 2008:14).



Picture on the left: a group of women with disabilities keep a shop in downtown Kampala near craft village. They use their skills of tailoring and handcrafts and sell the products. Four of them are in the picture using their sewing machines in their shop. They were moving into a new premise because the landlord found a better person who promised to pay more than 300,000 per month that they paid.

Picture on the right: a group picture with tailoring class students at the Kireka Rehabilitation Centre in Kampala on 14 February 2008. There were 25 students then. Most of the students were deaf girls, while five were boys. The vocational training classes meant for youth with disabilities used to be free of charge and the government provided graduates necessary devices and material such as sewing machines, but not any longer. The course for tailoring costs 50,000 and lasts for one year (Tailoring instructor, personal communication on 14 February 2008 in Kampala). He claims that graduates cannot use the acquired skills without devices and materials. Some of the women on the left picture also gained their skills at Kireka.

And yet, women with disabilities, particularly deaf women, face more challenges due to communication barriers. The gender officer of UNAD also calls deaf people as “forgotten tribe”

because of the language barrier both in mainstream practices and in disabilities-specific activities (personal interview on 28 January 2008 in Kampala). Then Secretary of DSHAC introduced the case of a deaf woman,

I also talked with the Ugandan AIDS Association in Jinja. They told me that they have come in contact with deaf women. There were two. One of them was actually brought into the centre by her relatives, and they were blaming her that she is always falling sick and therefore they wanted to test her. This girl is deaf. She didn't understand why she was brought in by her relatives. There was no sign language interpreter. In the Ugandan AIDS Commission, or even in the TASO (The AIDS Support Organisation), before they draw your blood they have to get your consent. So they asked the relatives, "Do you have anyone who can interpreter for her?" They answered, "No, but just test her." They said, "No." They tried to look around for a sign language interpreter to communicate with her. But they failed. So they sent them out without her being tested because they needed her consent. And they told me that the biggest problem is the issue of communication, the lack of an interpreter because they don't understand sign language and the person they brought in cannot communicate with them. The failure in communication led to the unavailability of the service for that lady (Personal interview on 21 February 2008 in Kampala).

She continues and points out the **psychological difficulties** of a person with a disability to come to terms with HIV/AIDS because society already discriminates them on the basis of disabilities. Many persons with disabilities, particularly women with disabilities, are afraid to go through with the test so as "not to know of any more negative aspect in their lives." A study on Deaf pupils in primary schools also establishes similar results and a lack of knowledge on sex education in general (Senyonga et al. 2009). In this study, out of the ten female Deaf pupils based in urban primary school, all of their first sex encounters were through rape (ibid). In the same vein, several commissioned studies on HIV/AIDS and disabilities in Uganda all alarmingly concluded the vulnerable position of persons with disabilities to the HIV/AIDS epidemic (Andersen, 2006; Kanyesigye, Anguria & Mbabazi, 2007; ADD, 2005; Mulindwa, 2003). Persons with disabilities have been largely excluded from both national and international interventions against this epidemic (Evans and Atim, 2011:1438).



Picture on the left: a board hanging from the ceiling at the Ntinda school for the Deaf. It says, "Signs and symptoms of AIDS: Loss of body weight, often having coughs, feeling tired all the time, having rashes on the skin, chronic diarrhoea."

Picture on the right: another board says, "Life skills: Having high self-esteem, making good friends, resisting peer pressure, coping with stress."

4.2.2. Development Cooperation Project on HIV/AIDS: A Partnership Approach Aims at Mainstreaming Disabilities into National Response

In 2005, the frustration of each DPO led to the establishment of an ad hoc Disability Stakeholders HIV/AIDS Committee (DSHAC) among 14 stakeholder organisations interested in HIV/AIDS and disabilities. Now the membership has grown to 20 including the following organisations; Action on Disability and Development, National Union of Disabled People in Uganda, Uganda National Association of the Blind, Uganda National Association of the Deaf, Epilepsy Support Association Uganda, Mental Health Uganda, Blind But Able, National Association of the Deaf Blind in Uganda, Sense International, Community based Rehabilitation Alliance, Uganda Parents of Children with Learning Disabilities, Uganda Society for Disabled Children, National Union of Women with Disabilities of Uganda, Disabled Women Network and Resource Organisation, Uganda National Action on Physically Disability, The AIDS Support Organisation, Spinal Injuries Association Uganda, Action for Youth with Disability Uganda, Uganda Parents Association of Deafblind Children, and Legal Action for Persons with Disabilities. Almost simultaneously, the African Campaign on Disability and HIV/AIDS, led by the Secretariat of the African Decade of Persons with Disabilities and Handicap International was launched in 2007 (Evans and Atim, 2011:1439).

The Ugandan cross-disability Committee aims at jointly advocating for the mainstreaming of disabilities in national HIV/AIDS programmes (Namagulu, 2006:5), when “state welfare support is virtually non-existent” (Evans and Atim, 2011:1442). As soon as it was established, it presented a paper as “the whole disability fraternity together” in the National AIDS Conference. The paper was entitled, “The Forgotten Tribe” (Babu, 2005) and advocated for the forgotten part of the population, metaphorically depicted as a tribe on an equal basis with other mainstreamed tribes, to be included in the success of the national combat against HIV/AIDS. After the success of this paper presentation in attracting attention to disabilities, DSHAC was formally established. DSHAC has a rotational secretariat among the members.

In October 2005, DSHAC invited all the major HIV/AIDS stakeholders in Uganda to a breakfast meeting to advocate for mainstreaming disabilities into their efforts. They included the Ugandan AIDS Commission, the Uganda AIDS Information Center, AIDS Support Center, Ambassadors of Commonwealth, the European Union, and international agencies working in Northern war-torn area on HIV/AIDS among others. The impact of this meeting was immediate. For instance, the Ugandan AIDS Commission invited a disability fraternity through NUDIPU to participate in developing a National Development Strategy. As a result, disabilities are well included into the National HIV/AIDS Strategic Plan (Development Research and Technology, 2008:30; NUDIPU, 2010:10). For instance, the Ugandan government’s country progress report (2010:31) clearly mentions persons with disabilities as part of the “most-at-risk populations.” The Ugandan AIDS Commission of Civil Society Fund also allocated 400 million Ugandan shillings to advocacy and the capacity building works of the disability fraternity. TASO (The AIDS Support Organisation) also promised to ensure the mainstreaming of persons with disabilities into its activities. Today, their mainstreaming of disabilities into their activities of TASO is considered to be “significant and successful” (DSI, 2007:40; NUDIPU, 2010:10). Another international agency working in the North also started to include persons with disabilities in its efforts.



Picture on the left: one meeting of DSHAC, Disability Stakeholders HIV/AIDS Committee on 1 February 2008 at the Ugandan Society for Disabled Children. Participants from different organisations sit around a table and seriously discuss on the issue. They rotate to hold meetings in different DPOs. Drinks and transportation allowance are provided by the NUDIPU project.

Picture on the right: a meeting with the NUWODU district office staffs at Gulu on 11 February 2008. In front on the table is a computer, which was donated by the mayor of Gulu when he visited the HIV/AIDS awareness raising training organised by NUWODU. The chairperson of NUDIPU at the Gulu district also joined the meeting. It was interesting that people thanked NUDIPU for this HIV/AIDS project, not the Northern DPOs. Women with disabilities on the grassroots who attended the training did not know the existence of donors at all. The participants received 15,000 shillings each as an allowance.

The success of DSHAC is known to other countries. In February 2006, DSHAC was invited to the Distant Learning Centre of Ugandan Management Institute for a satellite session to discuss on HIV/AIDS and disabilities with Tanzanian and Ghanaian people. It was confirmed that the other countries remain “medical” while Uganda more comprehensive. Then Secretary of DSHAC claims,

*The reason why we managed to move is the way our government has directed us. The beauty of why the DSHAC is successful is a credit to our government. The fact that **HIV/AIDS is not only a medical issue but it's also political and social** means we have to bring all those three aspects in for the fight. That has brought us here. We are not only claiming the medical bit of it but also the social. And even in Uganda, we realised that providing an enabling environment for PWDs, that's social, not medical though the medical is there in how people interact with them. Until the community accepts them, you cannot improve their lives. The same goes with HIV/AIDS. You need to involve everyone, not keeping them in the hospitals.*

That is, persons with disabilities are deliberately located in an interconnected relationship with society (social) and state (political) as well as the medical dimension. As many of the actual care take place at home in Uganda and elsewhere in sub-Saharan African countries (Evans and Atim, 2011), this approach of involving the whole community is highly relevant. As **persons with disabilities are often not totally passive, many of them play different roles as members of families**, including breadwinner's roles and carers of children. At the same time, both disabilities and HIV/AIDS status stigmatise the whole family. Unlike in the North where individuals often face stigma, the interconnectedness in Uganda is an important aspect to take into account. Evans and Atim (2011:1447-8) call for “relational autonomy” in this context. They cannot be separated from this **family and community contexts**, which is an important starting point of DSHAC.



March of DSHAC on the World AIDS Day on 1 December 2006 among others. This picture was included in the DSHAC 2006 Report. The banner is identical to the following picture.



The banner says, "Inclusion of Persons with Disability in the Struggle against HIV/AIDS is a Pre-requisite to Achieving Universal Delivery of Quality HIV/AIDS Services" and carries the logo of NUDIPU on the top left, the Ugandan government crest on the top right, and 13 DPOs and stakeholder organisations' logos at the bottom. On the back of the texts and logos, there is the big red ribbon which is the awareness raising symbol for the fight against AIDS.

Then Secretary of DSHAC and the NUDIPU HIV/AIDS project officer assert that this project is applying a human rights-based approach. They call this cross-disability activity a **"partnership approach"** among different DPOs. In collaboration with DSHAC, NUDIPU the umbrella DPO initiated a development cooperation project on this issue with a Danish DPO through DANIDA funding for 2006-2009. One of the activities was media campaign in three districts (Soroti, Masaka and Gulu) in three local languages. They are the pilot districts for DSHAC activities to be "trickle-down" from the national level. This HIV/AIDS project has a so-called "Trust Fund" which is allocated to different DPOs on the basis of the individually identified needs of each group of persons with disabilities. Through 2007 to 2012, 210 million shillings per year are allocated for the use of 14 Ugandan DPOs. In this way, the diverse needs of persons with disabilities are to be covered. That is, this project has both mainstreaming activities and empowerment ones, thus a "twin-track approach." This HIV/AIDS project has attracted the attention of several more donors/funders (ex. The Global Fund) due to its relatively unique approach to partnership among DPOs.

This partnership approach has implications in terms of the operationalisation of a human rights-based approach to disabilities and development. Firstly, it is making the voice of persons with disabilities better heard, which is a positive implication.

The DSHAC is a partnership coordinating team. We have been able to share our experiences, weaknesses, challenges, but also see how together we can form a united power ahead (HIV/AIDS project officer of NUDIPU, personal interview on 1 February 2008).

He continues, "Over the last 20 years, this is the only project where all DPOs have worked together as one unit." The Ugandan disability movement has been strengthened as a result of this partnership approach (Development Research and Technology, 2008:30), as there are fewer conflicts among DPOs (Staff A of a Northern DPO, personal interview on 30 January 2008 in Kampala). DPOs are relevant in this specific context of disabilities and development because **"human rights claims are generally made most effectively by people acting together as a group"** (OHCHR, 2006:4). A human rights-based approach is often used by NGOs rather than massive organisations because of the pitfalls of this approach (Uvin, 2004:166). That is, DPOs theoretically have a great role to play when reflecting on a series of challenges of a human rights-based approach in its operationalisations in this context; 1) danger of legitimising inefficient interventions, 2) possibility of evaporation when coordinated, and 3) inequality when not coordinated (Katsui, 2008-b:19). For instance, massive organisations can claim to apply a human rights-based approach but hardly change their practices, particularly in terms of the inclusion of the most marginalised groups of people such as persons with disabilities. Moreover, when a number of massive organisations/donors/Northern countries try to coordinate their supports to a Southern country in the form of budget support or a sector-wide approach, disabilities often evaporate as themes and are too frequently not prioritised over the agenda set by those actors. Furthermore, and as a result, empowerment-focused activities are implemented to fill the gaps. However, they are stand-alone projects or programmes and do not challenge the mainstream structure and status quo of exclusion. The DSHAC challenges this very structure by implementing both empowerment-focused activities through the "Trust Fund" and also mainstreaming activities through advocacy works to the government and international agencies for including persons with disabilities into all of their responses to HIV/AIDS.

The donor community is also supportive to this initiative, as is clear from their positive funding decisions. The NUDIPU HIV/AIDS project officer discloses that it is getting difficult to get funding on an individual basis and actually all DPOs failed to receive funding when they applied separately. This "partnership approach" facilitates donors for dealing with the highly complex disability issues with one funding. Superficially, this creates a win-win situation for both DPOs and donors in the development cooperation framework.

However, the partnership sometimes falls apart or causes "a bit of tension."

It's not only the DSHAC. Basically the whole disability fraternity does face the same challenge with UNAD. They face the same with so many disability activities. They always come and say, "What about our sign language interpreters? Who is paying for their services?" But we don't have to pay for their services because if you feel it important to come to DSHAC, why do we have to pay? If you feel it's important to come, come with your interpreters and contribute, and that's it (Then Secretary of DSHAC, personal interview on 21.2.2008).

All DPOs are struggling with the payment to their personal assistants and interpreters even on the national level. “The disability fraternity in Uganda might look united from the outside. However, there are **many ‘cracks’ especially along disability categories**” (DSI, 2007:36). These internal disability politics were pointed out as one of the challenges of the project also by an external evaluator (Development Research and Training, 2008:6) as well as from inside the movement (Uganda Disability Fraternity, 2007:vii&16). This eloquently implies challenges in lower levels.

Another challenge mentioned in the same report (ibid.19) is that the project is not mainstreaming HIV/AIDS issues into other on-going activities of the NUDIPU and DPOs but remain as a “stand-alone” project, even though it is aiming at mainstreaming. Efforts have been made to acquire national responses and international agencies, but such efforts remain minimal in the activities of DPOs. Moreover, activities were often one-off, including a media campaign and dialogue meetings with stakeholders, even though **awareness-raising has to be a long-term effort** (ibid.23).

4.2.3. Empowerment Activities: How Are a Human Rights-Based Approach and Charity-Based Approach Negotiated?³

The non-discrimination principle of human rights is significant to persons with disabilities, who have been marginalised from the mainstream. When a human rights-based approach is applied, this principle finally includes persons with disabilities into the mainstream discourse, in theory. In reality, however, **properly including marginalised groups of persons with disabilities such as deaf women on the grassroots is challenging within a short timeframe**. This part analyses the training activities of Ugandan DPOs, and elaborates on the experiences of deaf women.



Picture on the left: a deaf woman with her children and her husband in a village. She has not learned any sign language and has not gone to school. She is one of those who are married to one man who is the father of all her children, although the marriage is a practical one and not official. The author met other deaf women whose

³ Acknowledgement to this part: The author would like to thank Beatrice Guzu, Alessandra Lundström Sarelin, Maija Mustaniemi-Laakso, Jonas Parby, Martin Scheinin, Sia Spiliopoulou Åkermark and Arne Torstensen for their insightful comments and input on the previous version of the article. The preliminary findings were presented in the Institute of Development Studies research seminar at the Helsinki University on 7 October 2008. The author is grateful for all the above support. However, the views expressed in this article are mine and the supporters have no responsibility for the content or any possible mistakes.

children are from different fathers and who are left behind with the children. This family drinks tea in the morning and eats once a day. They dig all day and harvest cassava, matooke, potatoes, corns, pumpkins, and sweet potatoes.

Picture on the right: a deaf woman with her two kids in front of her house in a village. She has not learned any sign language either. Her mother-in-law, however, claims to understand her well with the help of some simple gestures of their own.

A human rights-based approach 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 persons with disabilities 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 the lack of Ugandan sign language literacy of deaf people (Mukasa and Nkwangu 2007:4). This implies 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 women with disabilities is limited due to deeply rooted discrimination and disabling environment against them, while the capacity of DPOs is also limited. For instance, staff C of a Northern DPO introduced her experience on working with women with disabilities on the grassroots:

*The trainer starts explaining what money is. It's so basic, yet they don't know money and they don't know anything. And that's what we forget here in Kampala. (...) Some women in Kampala are very intellectual, and know human rights and everything, (...) I met one group in [a district], a women's group, which has been supported for like **10 years**. They also started from what money is. They worked on self-esteem and became more independent. And now they have started to say what the problem is, "When we go to local hospitals, they speak badly and deny us the right to give birth, abusing our rights." This is how it should be. Let's go and sensitise them. And that's what it becomes: a human rights issue. And that has grown from the ground. That's what [a DPO] could do, to go and advise them how to do that, and now meet them there and also give them more gender awareness because they were not aware of the male-dominating structures. They have not seen them yet. But when they mature and they come to that stage where they can start, on that level, that's when [the DPO] has to be ready for that also. And I don't think that they are ready enough today to actually guide groups of that level. It is extremely good for those who have to start and take over, but for those at that level, it's a big challenge (Staff C of a Northern DPO, personal interview on 18 February 2008 in Kampala).*

The reality of women with disabilities 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. When one deaf woman was interviewed and asked what she had learned from a training course on HIV/AIDS 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, personal interview on 17 February 2008 in Kampala).

She might have totally missed the 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 the learning of one's own human rights.** Then chairperson of the United Deaf Young Women's Group similarly expresses, "If you want to extend any service to people on the grassroots, communication is very important. First empower them with sign language skills, and then anything else follows" (personal interview on 4 February 2008 in Kampala). She introduces an example of deaf rural women in training:

Sometimes they go to the trainings with sign language interpreters (employed by project implementers), yes. But these deaf from rural areas don't even know sign language. So when the interpreters start signing, the very deaf people start laughing because they have never seen the signs.⁴

When the author visited villages to meet three deaf women with a sign language interpreter, it was the same result: none of them knew Ugandan sign language or local signs fully without education. These **preconditions for people with disabilities on the grassroots, especially those of marginalised groups, are often undermined in development cooperation activities.** The next interview statement captures this issue:

*You have to set your topic of awareness aside and begin basic sign language training first. Maybe two weeks, one week, what is this language about, first of all. So it costs a lot. Always spending and spending at the level of basic sign language training. When you are lucky to finish the training, we move on to the awareness training. It also demands more time than the training for the blind and physically disabled. The awareness needs more time because they are not yet fluent and the language is not easy to master. You keep repeating. Some of them are using lip reading while talking. **Some of them cannot understand what rights are...** We keep on teaching them the language. ... **they don't understand what it is. So you just get tired. You get tired and say, "Let me do this and carry out activities because you don't understand the word."** Sometimes you train and train, but they don't understand it. So if you want to do something with them, sign language is the first step (Deaf Member of Parliament/ Executive Director of UNAD, personal interview on 28 January 2008 in Kampala) (emphasis added).*

⁴ The same is true about persons with visual impairments in terms of Braille. As Braille typewriters and printers are very expensive, most of those with visual impairments on the grassroots have never seen them before. Thus Braille materials do not secure their accessibility to information on the grassroots. Similarly, tactile communication is also a remote idea for deaf blind people on the grassroots.



Picture on the left: the executive director of UNAD and Member of Parliament for persons with disabilities, Alex Ndeezi on the right, and the chairperson of UNAD, Ambrose Murangira on the left.

Picture on the right: NUWODU staff members at a table in the premises of the organisation at Ntinda, Kampala having a discussion. On the left, the chairperson of NUWODU, Hellen Asamo with a physical disability, and in the middle, the executive director Beatrice Guzu, who is blind. Hellen Asamo was elected as a new Member of Parliament in the 2011 election. Beatrice Guzu used to be a school teacher at Gulu. However, when the school became a battlefield of the civil war, she escaped to Kampala to depend on her brother. She chose to be safe and unemployed rather than being killed there.

Similar experiences were shared in the training activities held by the United Young Deaf Women Group and the NUWODU for their HIV/AIDS trainings. That is, they are included but yet side-lined (chairperson of NUDIPU, personal interview on 31 January 2008 in Kampala). Deeply rooted discrimination and a disabling environment against deaf people has been too big a challenge to tackle by a DPO within a single development cooperation intervention, partly because of the wide capacity gap between DPO staff at the headquarter offices and people at the grassroots level.

When taking a closer look at the capacity gap, it can also be noticed between DPO staff at the headquarter offices and those working at the district level. In February 2008, the author had a chance to observe one monitoring visit to the Northern war-torn area of Uganda, Gulu and Lira, with NUWODU which has a local branch in the area.



Picture on the left: an internally displaced people's camp at Koch Goma, Gulu, visited on 12 February 2008. Children gathered to see them as the NUWODU headquarter staff members entered the camp by car. The houses

in the background are typical ones in such camps. The houses have a straw roof on a cone-shaped mud ceiling. Some children were scared by the author's "white" look and started crying. One of the children of a woman with a disability who kindly invited the author to her house in the camp also started crying when he saw the author. The author assumed that foreigners with lighter colour skin are many in such camps but it was not the case, even though cars carrying names of international agencies and NGOs were many in the city. The women with disabilities whom the author interviewed mentioned that the positive aspects of the camp are that food was provided, clean water was available and children could go to the nearby school.

Picture on the right: NUWODU staff members are revisiting the organisation's HIV/AIDS training participants. Participant women with disabilities and the author sit on a papaya mattress on the ground. One Ugandan person who passed by greeted the author in Ugandan Sign Language. As she had picked up some vocabulary during her stay, the author greeted back and asked, "Are you deaf?" in sign language. She was a hearing person and student. The author could not ask more questions, as she was with the group, but perhaps the student was visiting the camp to help some communications with deaf inhabitants.

In general, the Gulu district has the highest number of HIV/AIDS infected persons in Uganda, followed by Kampala (Nagirinya, 2007). The war also led to a high prevalence of HIV/AIDS among persons with disabilities in this area (Baba Diri, 2006:9). About half a year prior to the follow-up visit, NUWODU conducted its HIV/AIDS training workshops for a few days to about 20 women with disabilities each in three sub-counties with the "Trust Fund" money. The sub-counties were relatively near the Gulu city centre due to security reasons. The chairperson of the Gulu district office of NUDIPU explained as follows:

When this project started (in 2006), we did not still know whether further away places were safe enough. So we started this project in the nearby places, quite close from the Gulu city centre. Thus many people are still without the knowledge of HIV/AIDS. For instance, when I visited a place 24 km away from here, there were people with disabilities who were totally ignorant of HIV issues (group interview on 11 February 2008 at Gulu).

The objective of the training was mainly to equip women with disabilities with knowledge on HIV/AIDS prevention and management. Among the 59 participants, 7 were deaf and 2 were deaf-blind. Those participants were selected by the local branch of NUWODU. This is one of the empowerment-focused specific activities rather than mainstreaming ones. The following conversation between a district staff member A (P1), headquarter staff member (P2) and the author (R) is illustrative of the gap between the staff members:

R: May I ask if your activities are taking a human rights-based approach or a charity approach?

P1: (Does not understand what the question was, thus P2 rephrased it as follows)

P2: Do you implement your activities so that the members do something like income generating activities to help themselves or do you give handouts and they are dependent on them?

P1: Human rights-based approach, yes.

...

P1: Another problem for many women with disabilities is the school fees. Could NUWODU pay for their children's school fees?

P2: NUWODU is an advocacy organisation and supports women's initiative to help themselves. For instance, we support income-generating activities so that they can pay the fee by themselves. So we are not giving out school fees.

(R: Researcher; P1: District staff A; P2: Headquarter staff/ Executive Secretary of NUWODU, group interview on 11 February 2008 at Gulu.)

Although the chairperson of NUWODU, Hellen Asamo, who is currently a Member of Parliament representing persons with disabilities assures that she respects district chairpersons and expects them to make plans “even if we look for the money” (personal interview on 31 January 2008 in Kampala), such charity-based activities are not accepted by the headquarter staff in practice. The end result, acquiring school fees for children is what the district staff focuses on, while the headquarter staff tries to teach her a more human rights-based means for them to attain the end result. This conversation clarifies the gap between the district staff, taking a charity-based approach, and the headquarter staff, a human rights-based approach. A similar conversation was also observed during the general assembly of UNAD, when a district representative complained of a lack of activities in the district by UNAD. Alex Ndeezi, the Executive Director of UNAD replied, “But (name of the district) complains without asking support from us. If you don’t take the initiative and be responsible, UNAD cannot react. You should not wait for things to happen” (on 5 December 2008 in Kampala). The chairperson of NUDIPU and William Nockrach, a Member of Parliament representing persons with disabilities, also urged the audience in his speech in the general assembly to lower the high expectation on services and materials and to start income generating activities instead (on 8 December 2008 in Kampala). The **weak capacity of district or lower branches is pointed out. It applies to all Ugandan DPOs** (DSI, 2007:25; Staff C of a Northern DPO, personal interview on 18 February 2008 in Kampala). Those branch organisations that take up challenges and pursue their own activities, framed with their own agenda, are still limited (ibid.). These intra-organisational gaps in human rights awareness cannot be easily overcome within one development cooperation project framework. NUWODU (2008:5) rightly concludes its project report by saying, “The struggle for the fight against HIV/AIDS continues.” **More time, energy and money have to be availed to build the capacity of people at different levels.**



Picture on the left: pupils of the Ntinda School for the Deaf waving hands to the author with big smile. The pupils are wearing light blue uniforms.

Picture on the right: on 19 April 2009 the public TV Channel of Finland, YLE, broadcast and introduced the study in one of its news with sign language interpretation. The picture of the TV screen was taken by the author in Gulu on 11 February 2008. The second woman from the right is Janet Owto, who is a disability councillor with a physical disability working at the district level while three others are NUWODU district office staff members. After Owto’s husband died in 2003 from HIV/AIDS-related complications, she was also tested positive in 2006. She openly identifies herself as a HIV positive person, and established her women’s group in Gulu. It was not yet

a registered organisation then but had over 40 members with disabilities who shared information and experiences on HIV/AIDS in Gulu. The author was invited to hear her experiences at her home, and she shared various challenges of women with disabilities, as mentioned in this chapter.

On top of the intra-organisational awareness gaps on human rights, the peculiar donor-recipient culture that favours the donor -known as the **development cooperation system** (Tvedt, 1998; Hoksbergen, 2005)- is also a hindrance to the operationalisation of a human rights-based approach when enough attention is not paid to persons on the grassroots, deaf women on the grassroots in particular. 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 of the issue).

These people (staff members of Northern agencies) on the ground try to say, "No, this is what it is on the ground. Let's marry the idea of yours and that of ours." But what happens is that donor says, "No, you take the one of ours."

Writing a proposal and getting it funded is one very difficult thing. And so is getting down to the real implementation. Their intention of what you want is also another. Our society is not permanent but fluid. There is no permanent factor in the 5 year plan that you stick to, not like in developed countries. Here the system keeps changing.

You might have 100 dollars and you may feel very poor when you are in Japan, but when I have 100 dollars in my village, I'm the richest man for the next month around the block. You know what I mean? That is around the world economy. The issue is still the need. These are development issues. For every step we climb, we have to climb another one. You equally need the same strength to climb. That should be the approach to disability issues and development.

One Danish report (DSI, 2007:31-2), for instance, claims, "It is worth noting that during the last 10 years, Danish DPOs have provided significant support to their Ugandan DPO counterparts. It is this funding support that has probably made the Ugandan DPOs become more visible." The author has also observed the long-term efforts of Danish DPOs⁵ as well as other Northern DPOs -mainly Nordic DPOs- in Uganda. Ugandan DPOs' staff members, however, frequently feel uneasy because of misunderstanding or lack of local knowledge of Northern staff members on the theme of disabilities and development. Many Northern DPO staff members are also aware of and pay careful attention to this. The same report points out that the relationship between Danish and Ugandan DPOs often become that of a patron and benefactor (ibid. 38). It continues, "For the Ugandan DPO it is money they want most, for the Danish DPO it is the urge to assist a sister/brother DPO. You remove the funding, it would seem the partnership also ceases. The challenge therefore is how much can the other principles of sharing and learning be promoted even beyond funding" (ibid.). The report

⁵ "Building Partnership: A Workshop on Partnerships between Ugandan and Danish DPOs" was held in Exotic Inn on 6 February 2008 and attended by 24 people. Only those Ugandan DPOs that have currently receiving funding from Danish counterparts were invited. The author wrote in the journal, "The agenda for the day was fixed by the DPOD, and (its staff) apologised for the non-participatory approach. The workshop was dominated and controlled by the Danish. But this sometimes gave the author the impression that it was not time-consuming." The workshop was only for one day and thus had to be efficient. This efficiency is going to be discussed later in Chapter 6 in relation to development cooperation systems and neoliberalism.

admits (ibid.41) that some Danish partners behave like donors instead of aimed partners. The Ugandan staff members thus often feel that they are coerced into decisions prioritising “their” ways, although they do appreciate the funding and technical advice. The Danish report ends with a section called “Project Potentials and Principles of Support” (ibid.43-47). It is important that a Northern DPO elaborates on gaps and potential, but this might also seem as if the Danish already have set a certain framework for future activities with Ugandan DPOs. Under these circumstances, a human rights-based approach is compromised, and is easily modified into a top-down type of a charity-based approach within the framework. It is pointed out in the report that ownership and commitment of the Ugandan partners easily get lost (ibid.36). This was referred to as not supporting “a sustainable approach” of “the development partners” (Mulumba, 2011:79). Sustainability of a HIV/AIDS project also depends on the availability of funds and material support from external institutions, although the challenges on HIV/AIDS are huge and long-term (Development Research and Technology, 2008:43). This external evaluation report (ibid.) introduces a voice from DSHAC:

“Two years have now gone since the project started in 2006. We have only 1 year remaining, yet very little has been implemented in our district and here you are doing an evaluation; of what? The project has just started” (Lamented one member of DSHAC).

The time and money constraints set by development cooperation are clear challenges compared with the magnitude of the problems faced by persons with disabilities on the grassroots. “This could partly explain the ‘rush’ in implementation which seems to be following an ‘activity orientation’ rather than a ‘process orientation’” (Development Research and Technology, 2008:44). Moreover, trainings were only one-off and follow-up was hardly arranged, except for the effort of Deafblind organisation (ibid.25). As a result, there is a strong tendency that a human rights-based approach disappears in the process of intervention and transforms into a charity-based approach when the intervention reaches persons with disabilities, particularly deaf women, on the grassroots.

This is not due only to the disabling environment against persons with disabilities on the grassroots. When it comes to the capacity of DPOs particularly at district levels downwards, they were often not equipped with training skills on HIV/AIDS. When current capacity is not enough, top-down intervention takes place. This underestimates the empowering effect of involving the DPOs and reinforces their powerless role. The external evaluation report (ibid.36) points out this aspect of the HIV/AIDS project of DPOs. An illustrative interview excerpt is introduced:

“On several occasions, the NUDIPU bypasses the district union structure and works with the district officers without informing us of anything. This means that we do not even learn anything from such processes. We are seen as spectators and as powerless” (Officer from Soroti district Union) (Cited in Development Research and Technology, 2008:36)

On the contrary, at some other occasion, the “Trust Fund” was allocated depending on the proposals made by each DPO despite their lack of capacity. Consequently, “nearly all funding requests were for training on the same things” “in the same way,” without elaborating details (Development Research and Technology, 2008:45). Thus, overestimating the capacity of the actors, also results in reinforcement of status quo. That is, **empowerment in this context is neither about controlling actors only with a top-down approach nor about giving all the**

power to the actors without any support. This “contradictory approach” is proved not suitable (ibid.47). In practices of development cooperation involving persons with disabilities on the grassroots, the fine line between these approaches should be found by combining a top-down approach (concentrating on good leadership) and a bottom-up approach (concentrating on ownership). These two approaches require different types of participation: partial and more meaningful participation respectively. Both require meaningful engagement.

4.3. Case Study 2: General Assemblies of UNAD and NUDIPU¹

This sub-chapter focuses on one of the practical implications of a human rights-based approach, especially that of the right to self-determination in the exercise of the general assemblies of two DPOs, the UNAD and NUDIPU, in Uganda. Article 29 of the Convention is deeply related to the case study.

Article 29: Participation in political and public life

States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake to:

(a) Ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by:

(i) Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;

(ii) Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;

(iii) Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice;

(b) Promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:

(i) Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;

(ii) Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.

The general assemblies were held in the context of DPO activities and yet, similar importance can be addressed through this Article, such as self-determination, the right to vote and participation in general. “DPOs work on a rights-based approach which means their membership will elect the leadership during regular general assemblies” (World Vision International Uganda, 2008:46). The operationalisations of these, however, are challenging as will be observed below. At the same time, this case study sheds light on the power of social conditions that have a significant impact on human behaviour concerning human rights (Woods, 2010:51). That is, human rights are not only about choice and the decision of agents, but about social situations including structures and cultures in which one is located.² This case, actually, implies a deep interconnection between Civil and Political Rights as it appears

¹ Part of this chapter was written in the following:

- Katsui, H. (2009) “The Human Rights-Based Approach to Disability in Uganda: Case Study on the General Assemblies of DPOs and the Right to Self-Determination”. The 10th Nordic Network on Disability Research Conference: Challenging Positions in Disability Research-Normativity, Knowledge and Praxis. 2-4 April 2009. Nyborg, Denmark. Conference paper published on <http://www.ndnr.no/index.php/eng/Conferences/Paperpresentations/41-paper>

² Landman (2006:52) suggests a convergence of three points of the explanatory triangle, rationalism, structuralism and culturalism that analyses structure-agency, structure-culture, and culture-agency dimensions respectively.

in the exercise of the general assemblies and Economic, Social and Cultural Rights.

The sub-chapter first introduces the event of the International Day of Persons with Disabilities (IDD) as a prologue that took place a few days before the two General Assemblies. Secondly, the General Assemblies are introduced with special attention paid to ambiguous aspects and incidents of the operationalisation of the human rights-based approach because the explanation and assessment of failures, or “negative” cases is vital in improving our understanding of social phenomena (Skocpol, 1979 cited in Landman, 2006: 138). Subsequently, the strengths of the approach are reviewed, after which the concluding part of this sub-chapter provides implications of the human rights-based approach by reflecting on the lessons learned from the case study. The following findings and arguments are largely based on the first-hand data collected during and after the conducted fieldwork and the author’s own observation with a special focus on the perspectives of deaf women. “Deaf women” are highly heterogeneous. However, their experiences in the following reveal very interesting insights into their complex realities. That is to say, other interpretations of the events from other perspectives are possible.

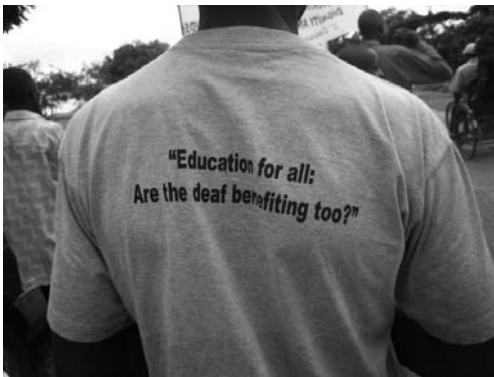
4.3.1. A National Event for Celebrating the International Day of Persons with Disabilities

The International Day of Persons with Disabilities was established by the World Programme of Action concerning Disabled Persons, adopted by the United Nations General Assembly in 1982. Since then, 3 December has been celebrated for increasing awareness on the human rights of persons with disabilities around the world.

A nation-wide International Day of Persons with Disabilities event in Uganda is held in different regions every year. In 2008³, it was organised in the West Region at Mbarara which is the hometown of the current President. The author arrived there with DPO staff on the previous night. Various accommodations were filled with persons with disabilities around the city that night. On the streets, the DPO staff members who travelled with the author hugged many colleagues as they walked. There was a lot of excitement in the air for the big event to come.

In the morning of 3 December, many including the author first marched through the downtown with banners. A convivial atmosphere dominated the march. Many DPOs prepared their own T-shirts with slogans, such as “Convention on the rights of PWDs: dignity and justice for all,” “Education for all: are the deaf benefiting, too?” and “Bringing epilepsy in Uganda out of the shadows.”

³ Following this event on 3 December 2008, the President issued a decree for more special schools to be built (Lang and Murangira, 2009:38).



Picture on the left: one example of a campaign T-shirt, which says, "Education for all: Are the deaf benefiting too?"



Picture on the right: another example of a T-shirt, "Conflicts and Humanitarian Assistance: Are Deaf People Beneficiaries or Victims?"

In addition to DPOs, pupils of the local schools for children with disabilities joined the march. People from different organisations mixed up in a short while, and all marched with a lot of joy. Everyone was an active and equal participant of the march for the "same cause." The chairperson of NUDIPU states:

*Cross-disability is something that NUDIPU takes as a priority. Being an umbrella association, we please and cater to all people with disabilities. Their needs are met without side-lining any disability because all of us are one. We differ in disability categories, but we are all persons with disabilities. So **our cause is one** (personal interview on 31 January 2008 in Kampala, emphasis added).*

In this sense, subjectivity and self-activism (cf. Pleyers, 2010:33-105) in the disability movement was manifested for the "same cause." The road was occupied by the crowd of persons and children with disabilities, while people on the streets stopped and learned to know what this day was about.



Picture on the left: Uganda National Action on Physical Disability (UNAPD) members are marching with its banner and cards. A man with crutches and a woman in her wheelchair carrying her card saying, "UNAPD Persons with Rheumatism" are moving along in the centre among the people. It was a long walk in the heat.

People helped each other and marched through the town together. The author was one of the two foreigners participating in the march. The other person was a young female NGO worker. A handful of other foreigners joined the later event in the field. They all passed by the crowd with their jeeps to enter into the field.

Picture on the right: a number of students from local schools also marched. Students are in their uniforms and queue nicely while waiting for the march to start.

The march participants gathered in a field to celebrate the day with performances of different groups of persons and children with disabilities in the presence of honourable guests such as the Minister of Gender, Labour and Social Development, the Third Prime Minister and the Minister for Information and Guidance who represented the President. Hierarchical power relations suddenly appeared in this field after the march which itself did not present a hierarchy. Superior people sat under the front tent, while others sat on both sides of it. The President was also invited but did not show up this year. By this time, the number of people increased to around 1,500. Various representatives of persons with disabilities made speeches; thereby hierarchical structures within the disability movement came to the surface. Other than Deaf people who needed to be near sign language interpreters, people sat according to the regions where they were from. The differences of disabilities were not important then except for Deaf people. Harmony among “ordinary participants” dominated for the promotion of the “same cause” -human rights of persons with disabilities- regardless of the visible hierarchy among them.

In the socialising event in the evening, persons with various disabilities gathered in one garden and enjoyed pieces of grilled bull meat donated by the Member of Parliament representing persons with disabilities in the West Region. This was the only food served during the Day -this was the only food many ate for the whole day. Many slept overnight in the venue with or without money for accommodations.⁴

The event was broadcast on one of the major national television channels, the Uganda Broadcasting Corporation, for one whole minute in the evening news the next day. “Persons with disabilities” were represented as a harmonious, if not monolithic group. This image, however, is revealed to be misleading.



Picture on the left: about 25 students with disabilities, including blind and “albino” students, are singing in front of the honourable guests. Discrimination against albino children is severe (IDA, 2011). The cameraman in front

⁴ Staff members of the DPOs get transportation allowance. For instance, officers of NUDIPU received 60,000 shillings and assistants 35,000. District councillors raise funds from their own districts. It is presumably much less than that of the DPO staffs.

wearing a vest with the logo of UBC on his back is shooting the school performance for the next day TV broadcast news which, in fact was not broadcast. When a journalist is invited for broadcasting some activity, s/he is paid a transportation allowance by the organiser. Thus visibility and publicity is something to purchase in Uganda, if not given for free on a charity basis. Behind the students, persons with disabilities sitting under three tents can be remotely observed. The number of seats was limited and many sat on the grass. Students were also mostly sitting on the grass under the sun without a tent. As the author was feeling dizzy due to the heat, dehydrated without food and drink and perhaps also jet lagged, she worried about these students who were sitting in the sun the whole time. At one point, the author started to feel so faint that she went to one of her friends' DPO tent to sit for a while. On the contrary, the honourable guests were provided with drinks and some snacks and looked quite comfortable.

Picture on the right: the same cameraman is shooting the speech of the Minister of Gender, Labour and Social Development, which was actually broadcast on TV. Next to her is the Minister of State for Disability and Elderly Affairs waiting for his turn to speak. He revealed in personal interview on 19 February 2008 that the Ministry budgeted 10 million shillings for this event. They are speaking to the honourable guests, not to the audience. The same background of tents is observed as in the previous picture. Among the honourable guests was the third deputy Prime Minister, Kirunda Kivejinja, who read the speech of President Museveni. In the speech, the President decided to establish 18 special schools for children with disabilities (Turyakira and Natweta, 2008). At some point, these honourable guests walked around the tents of DPOs showing their pamphlets, selling their products and presenting their activities, but it remained rather symbolic and took only several minutes. These people did not march with others. They had arrived later with their private cars that left them a few meters away from their seats. Even though this event took place far away from Kampala, these honourable guests paid their visit to this event. Somehow these people and Northern guests (donors) behaved in a similar manner.

4.3.2. Case Study on the General Assemblies of Ugandan DPOs⁵

A few days after the above event, the general assembly of UNAD took place, which was immediately followed by that of NUDIPU on the next day. These general assemblies as well as almost all other activities of DPOs are funded by Northern donors, namely Northern DPOs. The general assemblies of DPOs are held every five years to exercise the delegates' right to vote, to decide on representatives as well as to receive activity and financial reports and to amend the Constitutions if necessary. Based on the reports and discussions, delegates can vote for new leaders for spearheading their organisations for the forthcoming five years. The general assemblies are, therefore, the paramount examples of the operationalisation of a human rights-based approach to disabilities in Uganda: the goal is to decide their own representatives, and the means is fair and democratic voting. Individual and collective self-determination is the key word. In the end of the general assemblies, the guests of honour in the two events similarly congratulated the delegates "for exercising democratic right." The chairperson of the NUDIPU is convinced that people are given enough time to "criticise as much as possible" in these general assemblies (personal interview on 31 January 2008 in Kampala). In the process of operationalisation, however, many actions turned out to be ambiguous and sometimes even clearly undemocratic according to the author's observation, which focuses particularly on the rights of deaf women. This part presents such ambiguous aspects of the human rights-based approach of operationalisation in the particular exercises

⁵ Acknowledgement for this sub-chapter: the author appreciates the invitation of the UNAD and NUDIPU to have enabled her to participate in their general assemblies. Many Ugandan delegates as well as Northern partner DPOs took their time to share their experiences and opinions with the author. A number of them continued to provide her with further information through e-mail exchanges. The author is very grateful for their continuous support to her and her study. The author would like to thank Edson Ngirabakunzi, Deborah Iyute, Rehema Namarome, Meldah Tumukunde, Abdul Busuulwa, Christine Lule, Ambrose Murangira and Betty Kyogabirwe for their insightful comments and input on the previous versions of the article. The draft paper was presented in the 10th Nordic Network on Disability Research Conference in April 2009, and received valuable comments. However, the views expressed are mine and supporters of this research have no responsibility for the content and possible mistakes.

of the general assemblies of UNAD and NUDIPU in terms of 1) disabilities and politics, and 2) disability politics. Many warned the author beforehand that the general assemblies are very political. In her experience they were, indeed.

4.3.2.1. Disabilities and Politics: Interventions of the Members of Parliaments⁶



The then five Members of Parliament representing persons with disabilities are giving their speech in the event for the International Day for Persons with Disabilities at Mbarara. The last person on the right is hosting the event. The Ugandan national flag in the sky and the tents of the general participants are visible behind the Members of Parliament.

Uganda has a quota system for five Members of Parliament to represent people with disabilities: four Members of Parliament from four regions (Central, East, West, and North) and one woman with a disability. One is deaf and others are persons with physical disabilities. All belonged to the ruling party, the NRM. Their sign language interpreters and personal assistants are employed by the government. In the 2006 election, blind candidates also competed for the positions but lost. This, by the way, is an important piece of fact to remember for the following findings.

In the 2011 election, four out of the five Members of Parliament (Willian Nokrach, Alex Ndeezi, Safia Nalule, Hood Katuramu) were re-elected, while one new face (Hellen Grace Asamo) joined. It is noteworthy that two more women with disabilities (Margaret Baba Diri and Jessica Ababiku) were elected outside of the disability quota. Both the new Member of Parliament with the “disability ticket” (Asamo) and the other newcomer without a “disability ticket” (Ababiku) were employed at the NUDIPU prior to their career as Members of Parliament. The disability quota is applied up to the village level, which created **50,000 disability councillors all over the country** (Lang and Murangira, 2009:36). **Half of them are women with disabilities** at district and sub-county levels, while parish and village have only one councillor representing persons with disabilities. Many of the politicians at various levels have worked as leaders of DPOs and still play a big role in the disability movement. All of these indicate the **deep interrelation between disabilities and politics in Uganda**.

⁶ This particular paper concentrates on the Members of Parliament’s interventions from a critical perspective. However, the Ugandan Members of Parliament with disabilities have been playing one of the key roles in major changes in legislation, such as the Local Government Act 1997 and the Persons with Disabilities Act 2006. Their efforts and achievements in collaboration with the disability movement should not be undermined.

The NUDIPU and UNAD are not exceptions. During the last term before the concerned NUDIPU general assembly, there was one Member of Parliament with a physical disability sitting on the board of the NUDIPU. This Member of Parliament sat on the board since 1990 and was the longest serving board member. As for UNAD, the executive director and the secretary of the board are played by a Member of Parliament who is Deaf. He previously served as the chairperson of NUDIPU on the board for two terms as well. Members of Parliament representing persons with disabilities tend to have a clear connection to the disability movement as former or current DPO representatives. There is a mechanism explaining why it has been so: the Members of Parliament elections are held using the NUDIPU structure and mobilisation of persons with disabilities by NUDIPU for the elections. More precisely, Members of Parliament are elected by four delegates from each of the 56 districts, who include a woman and a deaf, a blind person and a person with a physical disability. They are in fact the same people who are the delegates to the general assemblies of NUDIPU. In this sense, the general assembly of NUDIPU resembles the elections of Members of Parliament. The similarity is that NUDIPU provides the register of the voters, whereas the difference is that the parliamentary election is administrated by the governmental electoral commission. The NUDIPU started to organise its general assemblies by the demography of the delegates since 1997, when the NUDIPU had few District Unions. The Government was going to hold the election in 1998 to elect disability councillors from the village to district levels following the Local Government Act. Thus NUDIPU, with the help of the Disabled Persons' Organisations Denmark (DPOD), quickly mobilised local persons with disabilities to represent those positions. That is, the NUDIPU structure developed hand in hand with the development of the government's local structure. Therefore, "NUDIPU is regarded as an NRM mechanism⁷ and intimidation occurs during multi-party elections" (CDRN, 2009:27).

The recognised shortcomings of using the NUDIPU structure are many. Firstly, newly recognised disabilities, other than the three major ones (deafness, blindness and physical disabilities) are not given entitlement to vote for their representatives. Robb (2012:29) points out that persons with psychosocial and intellectual disabilities are deprived of their rights to vote in this way, for example. Secondly, only 56 districts can send voters, while there are 80 districts today. Thirdly, it is said to be easy to manipulate the small number of voters. In its petition, the Legal Action for Persons with Disabilities Uganda (2012) problematises the bribery custom in the election. The Members of Parliament are given a "constituency development fund⁸" by the government, which is literally meant for the development of the constituencies they represent, namely persons with disabilities. Each Member of Parliament

⁷ In the NGO Forum meeting on 4 February 2008, the co-option of NGOs to the government was problematised as a general trend of Ugandan NGOs: "The government invites NGOs for meetings, but if they criticize the government, then they are not invited the next time and other, more supportive NGOs are invited instead. Then the government can say, 'Civil society was represented'" (Charles Lwanga Ntale).

⁸ Margaret Baba Diri, a Member of Parliament who is blind, tells in her interview how freely she can decide on to whom and how much to give money from the constituency development fund:

They think an MP is a person who solves their problems. People come and ask for their school fees, my child is sick, I need money for housing, I need money for food. They expect these things from the MPs. Actually, it is overwhelming. I have the file of requests. ... I speak very frankly. What I can give, I give them. But if I cannot, I say I cannot. If someone comes and says, "I'm sick." I can give 5000 or 10000 shillings for treatment. Maybe when someone comes and says, "My children need to go to school. They cannot buy their school uniforms," I can give 30,000 shillings. But when someone comes and asks for 100,000 shillings I say, "No, I cannot give to individuals. What I do, I give through organisations and groups like a women's group." If I get money from a development constituent fund, I pay for the group. I help groups rather than individuals. Otherwise, if you commit yourself, it becomes too much (personal interview on 19 February 2008 in Kampala).

gets ten million Ugandan shillings, which equals to 4000 Euros (James Mwandha, personal communication on 11 December 2008 in Kampala). Many anonymous interviewees and informants argued that this money is used for various election campaigns, including the election for Members of Parliament and the general assemblies of DPOs.

Already in the event for the International Day of Persons with Disabilities, those who wanted to support candidates or those who stand for positions in the forthcoming general assemblies were campaigning. “Campaigning” refers to providing material and financial input as well as a more democratic way of information and manifestation delivery. For instance, the author observed one outgoing board member of NUDIPU offering free beer to people in the evening event. At this point, the campaigns came out from the underground at last, which enabled delegates to realise who would stand for different positions. Without expensive communication devices such as a computer and a telephone, **physical contacts are the way to campaign for elections**. Before the event for the International Day of Persons with Disabilities, few knew about who were standing for positions in reality: only speculation dominated. After the event, the situation was totally different.



Picture on the left: “campaigning” activity going on by delivering free drinks to the people in the venue of the evening party on the International Day for Persons with Disabilities. People were provided with meat and bread and an enjoyable time. What they talked about there pertained mostly to the forthcoming general assemblies.

Picture on the right: delegates of UNAD gathered in the hall of the Ntinda School for the Deaf. During the day time, it was fine as in the picture, but in the evening, the hall was dark with few small lamps. It was difficult for many to communicate in sign language in the dark. Those who have their own mobile phone and are literate used the text message screen to communicate with each other in the dark. The author communicated with some in this way when she did not have any interpreter around her. During the first half of the general assembly, the author was one of the few hearing persons aside from the interpreters. One was an invited and paid guest who was a journalist. Only towards the end, hearing persons including Members of Parliament and candidates of NUDIPU general assemblies started to show up for campaigning for or against some.

In the UNAD general assembly which took place prior to the NUDIPU general assembly, the Deaf Member of Parliament was vocal as the executive director and secretary of the board of the organisation. He presented various reports and answered to raised questions. Even during the breaks, his videotaped speeches were shown in the TV screen set in front of the room. In the author’s understanding, he supported the outgoing chairperson to continue his chairpersonship. For instance, he tried to protect the chairperson and to answer the question

when some raised a question on the “corruption”⁹ of the UNAD during his public election campaign for continuing his chairpersonship, the highlight of the general assembly. The executive director first tried to answer the question. Then the audience raised their voice against him not to intervene and insisted that the chairperson himself would answer the question. So he did after all. A Member of Parliament appeared to the venue on and off, which spoke in itself that he is an ally with the executive director/the Deaf Member of Parliament for the NUDIPU general assembly. All five Members of Parliament were present towards the end of the general assembly. It was reconfirmed when this one Member of Parliament was finally introduced by the executive director that he was the honourable guest of the general assembly, and was given a space for his long speech. The speech included the following:

We support each other in the forthcoming elections. I am the board member representing [one of the four regions] in NUDIPU. And I am standing for the position. If you are from [the] region, please support me. I can bring three deaf persons to the board. Let's cooperate with each other in the NUDIPU general assembly. We have to choose a very strong board. [Name of the ED] was the chairperson of NUDIPU and now an MP. We have to change the Constitution and allow MPs to become board members. This is my appeal.

He appealed the amendment of the NUDIPU Constitution which prohibits Members of Parliament to take the board members' positions. He was elected as a Member of Parliament in 2006 when he was the board member of the NUDIPU but remained on the board against the Constitution. This alliance between the executive director and the Member of Parliament was actually part of a bigger alliance. At this stage, the author learned to know that all five Members of Parliament representing persons with disabilities were supporting the re-elected chairperson of UNAD to stand for the chairperson's position of NUDIPU.



Picture on the left: a huge, relatively accessible hall accommodated the delegates with different disabilities. The delegates sit in their chairs in smart clothes. The side, front chairs were reserved for non-delegates and guests including the author. Politicians including the Members of Parliament and Northern DPO staff members also occupied this part of the seats. The picture was taken from the seat of the author. Many carry their files with necessary documents including food tickets, the Constitution, the Activity Report, and the Financial Report. Several of them left their files unattended and got them stolen due to the food tickets, because the venue was open for anybody to come and go. Some women brought their babies and small children to the venue.

⁹ This was the terminology used by the person who posed the question. This does not necessarily determine that the UNAD is corrupted.

Picture on the right: then Member of Parliament, Julius Balyejusa, with “the President Museveni hat” busily moving around at midnight with his cane. He visited us in the hall where we sat and chatted with several Deaf delegates. It can be seen in the picture that it was dark. He is the one who beat the late James Mwandha in the election of 2006, after the introduction of the first multiparty politics, when the late Mwandha changed his political party affiliation and decided to stand as a candidate of an opposition party. His opponent, Julius Balyejusa who was an NRM candidate, was not in the disability movement by then and thus “nobody knew him,” according to informants. It seemed obvious that the late Mwandha would go through without question. However, he lost to “Mr. Nobody” (Staff member A of a Northern DPO, personal interview on 30 January 2008 in Kampala). Another candidate who stood for the Member of Parliament election without NRM affiliation says, “There was too much intimidation and harassment” against non-NRM supporters. “All the interpreters hired for me were told not to interpret for me” and “that is how I lost it” (anonymous deaf candidate, personal interview on 4 February 2008 in Kampala). “It’s a dirty game,” recalls Staff member A of a Northern DPO (personal interview on 30 January 2008 in Kampala). My research assistants recall that the late Mwandha did not offer voters “logistics” (money) and thus was considered to be “mean,” it is part of the election culture in Uganda to offer different material and financial returns for votes. Subsequently, the late Mwandha brought this case to the court and appealed that there was fraud in the election exercise. He lost this case as well. Alex Ndeezi, the Deaf Member of Parliament, stated in his speech in the general assembly of the NUDIPU that this court case disorganised the Members of Parliament for one year, and disengaged them from their constituencies (on 8 December 2008 in Kampala). Another Member of Parliament, William Nokrach, also expressed in informal conversation that they spent 25 million shillings for defending their case (personal communication on 9 December 2008 in Kampala). Mwandha stated, “Disability and politics are eating the disability movement” (personal communication on 11 December 2008 in Kampala). For the 2006 election, Hellen Asamo, the newly elected Member of Parliament in the 2011 election, considered standing for the position but did not because of loyalty and respect for the late Mwandha. She then won against Balyejusa in the 2011 election after Mwandha passed away. This is one example to prove that the multiparty politics fragmented the disability movement (Staff member B of a Northern DPO, personal interview on 15 February 2008 in Kampala), although disability politicians and activists largely still support the ruling party, the NRM.

In the NUDIPU general assembly, all Members of Parliament were very alert. They even slept in the nearby hotels to secure easy accessibility to the delegates during the time of the general assembly for influencing the “self-determination” exercise in the election. Face-to-face meetings are the crucial form of interaction with the delegates. Thus during the NUDIPU general assembly, delegates had sleepless nights. Sign language interpreters were also mobilised throughout the night for communicating with Deaf/deaf delegates (a sign language interpreter, personal communication on 9 December 2008). Candidates and their supporters were knocking on the doors of delegates’ hotel rooms all through the night campaigning for one or against another. The author stayed chatting with delegates until midnight for the two nights and saw the Members of Parliament and others going up and down. Different groups of delegates were taken away from the venue to be treated with food and drinks.

The night before the Election Day, one Member of Parliament “betrayed” the alliance and decided not to support the UNAD chairperson. He began to de-campaign him instead. Some Deaf delegates received mobile phone airtime worth up to 50,000 shillings (20 Euros) for changing their mind.¹⁰ That is equivalent to one month’s income when engaged in a petty business in the city area. The voters were promised the vice-chairperson would be Deaf if they give up the idea of supporting the UNAD chairperson for the NUDIPU chairperson’s position. A Member of Parliament and others told the author that the “betrayed” Member of Parliament changed his mind because he became afraid of losing his own position. When the

¹⁰ One female delegate with a physical disability requested the author to call attention to this undemocratic election culture in the research work. She stood for a board member’s position from one region and failed. Her competitor who won the election gave 5000 shillings to delegates for gaining their votes. She stated, “Qualification has nothing to do with the positions.” She also mentioned that the amount would increase when the competition was tight, as was observed in the election campaign for the chairperson’s position.

UNAD chairperson would become the chairperson also of the NUDIPU, he becomes too popular. As a result, the Member of Parliament might not win in the next national election in 2011, because they both compete from the same region. Moreover, the UNAD chairperson has enjoyed the strong support of the current Deaf Member of Parliament, which caused this Member of Parliament to “betray” the alliance.

With or without the influence of the Members of Parliament, the Deaf candidate lost the chairperson’s election against the blind candidate, while a Deaf woman was elected to the vice-chairperson’s position unopposed: no candidate stood against her, as if there was some underground negotiation done beforehand. Actually, several informants told the author that some candidates could not even stand for the positions for election due to the pressure of the Members of Parliament. In one region, one candidate had a personal conflict with a Member of Parliament, and thus this Member of Parliament campaigned against him. He was highly qualified and respected person among the disability community but was not re-elected. Many informants told the author that this was the most regretted result during the general assembly. In the end of the general assembly of the UNAD, one Deaf woman thanked the Members of Parliament saying, “I thank you for the MPs and all your participation. Please continue the support. We are interdependent” (on 6 December 2008 in Kampala).

A staff member of a Northern “partner” DPO stated that two Northern actors, including her own, had once “intervened” with a “very harsh letter” against the NUDIPU because of the involvement of the Members of Parliament. She said, “I’m not happy with parent-child relationship, but we have the money. So it is true that we have the power. MP should not be there. The end of the NRM and Museveni can be the end of the NUDIPU” (personal communication on 9 December 2008 in Kampala).

Despite the various interventions by the Members of Parliament, the NUDIPU general assembly decided to separate itself from the influence of the Members of Parliament and the ruling political party, the NRM. For instance, the general assembly reaffirmed that Members of Parliament should not be on the board. It also did not change the Constitution. As a result, the long-serving Member of Parliament could not continue as a board member any longer. A journalist wrote an article, “MPs Barred from the NUDIPU Board,” in one of the major newspapers, the New Vision, on 11 December 2008. The general assembly also decided to separate the NUDIPU from the national election exercise of Members of Parliament¹¹ to be more accountable as a non-partisan NGO against the criticism that the NUDIPU is a mechanism of the NRM (CDRN, 2009:27). It was celebrated among the delegates that these were clear signs of democracy, even against the hitherto powerful Members of Parliament. As has become clear, the self-determination of individuals and the collective right of the delegates was influenced by the politics in many ways.

¹¹ In the 2011 Parliamentary election, however, no change was made for the voters in practice. The same delegates voted for Members of Parliament regardless of the decision made in the general assembly.

4.3.2.2. Disability Politics: “I’m ready for the war!”



Picture on the left: Ambrose Murangira, second on the right in the back row, stood for the chairperson’s position at the NUDIPU general assembly. The others are his supporters. Some of them are wearing a campaign T-shirt with Murangira’s picture and name printed in black and white, “Ambrose ‘08.” He also delivered colour-copied fliers with his manifestation. An election campaign is expensive. In practice, therefore, only those delegates with good resources can stand for positions, which is exactly what leaves more room for more powerful people, including the Members of Parliament, to play the power game.

Picture on the right: a female guard with a big gun protecting the gate of the UNAD throughout the day and night. During the stay of the author in Uganda, one Nordic DPO was attacked by a group of robbers, while robbers killed the guard of another local office of a Northern DPO. The use of weapons is prevalent, not only in the Northern area of Uganda where the government soldiers patrol to protect people from the civil war fights, but also in Kampala city. On the way back from the International Day of Persons with Disabilities event, the car of the First Lady of Uganda passed by. Very heavily armed soldiers escorted and protected the car –so much so that it looked like war provoked. The civil war with the Lord’s Resistance Army has not been completely terminated yet, and war is still part of Uganda. Already in the late 2000s, the government arrested politicians, demonstrators and journalists for controlling them (Staff member B of a Northern DPO, personal interview on 1 February 2008 in Kampala). Moreover, in 2011 some social movements, such as the “Walk to Work” protest against the current regime concerning economic challenges, have increased the visibility of “security forces” in Kampala today. Some disability activists also participated in this demonstration. In the 2011 protest, the government security force killed nine people including one child. The protesters were all unarmed. Many more protesters were arrested. Arab Spring has not reached Uganda yet. Nevertheless the long-lasting Museveni’s presidency since 1986 potentially entails tension that could lead to a bigger social movement against him in the near future, as many young people are unemployed and yet have easy access to Internet and social media including Facebook that played a big role in the Arab Spring. For instance, one of disability activists called for participation in the “Walk to Work” campaign on Facebook. Among the Ugandan disability activists, young activists use Facebook regularly.

Politicians and internal disability politics played a significant role in the general assemblies. The UNAD is for the deaf and the NUDIPU for “**every person with a disability**,” according to their mission statements. However, different disabilities -sex, age, education level and/or geographical locations, among others- have created a certain hierarchy (cf. the Intersectionality theory): power is concentrated on certain groups of people among the persons with disabilities. This part elaborates the diversity of “persons with disabilities” and the internal politics that were manifested in the exercises of the general assemblies.

The delegates’ demography had implications on the disability politics. In the UNAD general assembly, chairpersons of seven regional associations selected 20 delegates each to participate in the general assembly. One region, the Karamoja region, has been absent in the UNAD activities due to its remoteness, insecurity and perhaps also disability politics, as it is the place with “the worst humanitarian indicators in the country” (OCHA, 2010). Thus, there were supposed to be 140 delegates from seven regions. In reality, there were 109 delegates

present. 50 of them were women, and 69 were youth under 30 years old. In the NUDIPU general assembly, 56 districts were entitled to send four delegates per district. The number of the districts still follows the older government structure, which increased to 80 districts today. At least one with a physical disability, one blind and one deaf individual and a woman have to be included among the four delegates. In addition, four UNAB delegates and four UNAD delegates were entitled to vote due to the affirmative action policy. Furthermore, 14 outgoing board members are also entitled to vote. In total, there were 243 eligible voters present, of which 113 were women. 116 were categorised as persons with physical disabilities, 59 were blind, 57 were deaf and one represented three DPOs, namely the Mental Health Uganda (MHU), the Epilepsy Support Association of Uganda (ESAU) and the Uganda Parents Association for Children with Learning Difficulties (UPACLED). That is, those with physical impairment dominate in number (Staff member B of a Northern DPO, personal interview on 15 February 2008 in Kampala). Some did not have any disability written down. 88 were youth. The delegates elected the following board members in the respective DPOs: the nine (eight in practice) UNAD board members consist of seven (six in practice) regional representatives, one youth and one woman representative, while the 13 NUDIPU board members consist of eight regional representatives (four men and four women), two blind (one man and one woman), two deaf (one man and one woman) and one youth. Two out of four executive committee members of the NUDIPU board are women (the vice-chairperson and secretary). It was overwhelming to witness that more than 100 deaf from all over Uganda gathered together for this general assembly, let alone the general assembly of the NUDIPU which mobilised the 243 delegates with one guide for each blind delegate and eight sign language interpreters for the whole deaf community.

Both general assemblies were attended by many more observers relevant to the disability movement such as other associated member DPOs, Members of Parliament, supporters of candidates, donors and also passers-by. The demography of the delegates and the board members looks superficially democratic on paper, if not carefully investigated. This part firstly elaborates the disability politics through the analysis of the delegates' demography.

First of all, the NUDIPU delegates who were entitled to vote were limited only to persons with physical disabilities, blind and deaf persons in terms of disabilities, although many more DPOs had appealed for full membership and the right to vote. On the first day, there was a demonstration of a DPO, the Uganda Parents of Children with Learning Disabilities (UPACLED), to appeal to the delegates to grant the DPO full membership to the NUDIPU. They were given three minutes for their presentation.



Picture on the left: UPACLED members are marching into the general assembly venue of the NUDIPU with their opinion cards hanging from their neck to appeal for its full membership.

Picture on the right: a girl, one of the demonstration members of the UPACLED, holding her card saying, "I am 19 years. Allow my parents to fight for my rights. UPACLED."

The Mental Health Uganda (MHU) also disseminated printed papers for appealing the same. After a heated discussion, the membership part of the Constitution was amended. Consequently all DPOs of national character were granted full membership and the entitlement to attend *annual* general assemblies. For the general assembly which is held every five years, however, it was decided to maintain status quo: only persons with physically disabilities, blind and deaf persons are entitled to vote. The annual general assemblies are a stipulated requirement in the Constitution, which have not, however, taken place so far. Donors were sceptical that the NUDIPU be able to raise funds for holding the annual general assemblies. It was also taken for granted that the districts that are not covered by the NUDIPU structure (80 minus 56 = 24 new districts) remain uncovered "due to financial constraint." The ones who hold the power of "delegate status" did not give up their advantageous positions in the general assembly in any case, perhaps due to the superficial reason of financial constraint but also due to the disability politics. That is, *voices* were heard to a limited extent, yet *votes* were not given. In between voices and votes, there lies a crucial line between mere participation and self-determination rights. Delegates with the right to vote clearly have more power over those who do not have the right to vote. **Representative participation is one form of democracy, which is, however, used as a means to reinforce the power of powerful ones in this specific context.** The "dominance of some categories at the expense of others" and "discrimination within the disability fraternity" were illuminated in the general assemblies but actually, an observed weakness in the disability fraternity in general (Ugandan Disability Fraternity, 2007:16-7). Resistance to change from the side of the powerful ones was a clear sign of efforts to maintain the power structure of undemocracy. Backlash discourse (Jung, 2011:270) was clearly present.

Secondly, many of the UNAD delegates were illiterate. The secret ballots for writing down the names of the candidates they vote for did not work out in practice. This is due to the profound discrimination against deaf people in Uganda, as the illiteracy rate among Ugandan deaf people is as high as 95% (Development Research and Technology, 2008:53). Some suggested roman numbers, such as "1" "2" and "3" but the idea was turned down because it was still too difficult for many. Consequently, in the UNAD general assembly, it was agreed that the delegates were to draw strokes on the secret ballots, such as "I" "II" and "III" instead of writing names. In the Central region's election, however, all delegates could write their names. This indicates rural-urban gaps in literacy among deaf/Deaf people in Uganda. In one election, one drew an "X" on her ballot for the election for a deaf women representative and the vote was disqualified. Towards the very end of the elections, one woman voiced her concern, "On the ballots, many of us don't know what are written there." These examples illustrate a **huge diversity among the delegates** and imply that some were not able to follow what took place in the general assembly at all.



This is the election scene to decide on the board member representing deaf women. Four candidates are standing, showing their backs. A piece of paper is taped to each candidate's back with her number, such as "I," "II" and so on written on it. Four is also only represented in strokes, "IIII" instead of "IV".

The deaf people's education level is extremely low. Many of them even did not follow the discussions of the UNAD general assembly at all because they did not know the sign language. This was officially pointed out as a challenge. Nevertheless, the general assembly of the UNAD went on with the use of the Ugandan sign language. At this point, many were left out. The selection of the 20 delegates each from a region is made by the chairpersons of the regions themselves. The delegates from the same region elect the forthcoming representative of the region. Naturally, the chairpersons choose those who are supportive and seem "weak" to increase the likelihood he/she is re-elected (anonymous deaf delegate, personal interview on 7 December 2008 in Kampala). At the same time, multiple voices assured the author that the outgoing regional chairpersons deliberately choose lowly educated persons because they are easier to convince and they avoid potential oppositions, as the social network analysis explains (Woods, 2010:63). When the author socialised with the delegates during the days and nights, she realised that **many more women were both illiterate and did not have the literacy of sign language than were men**. Naturally or coincidentally, four out of the six regional representatives' positions were elected unopposed. This silently supports the aforementioned argument of the rather sophisticated manipulation of the powerful ones over other delegates. One position is meant for a woman representative. Aside from that, there was only one woman elected to the board.¹² Therefore, two women and six men were elected to the board of UNAD. It was particularly interesting to observe the questions and answers raised during the general assembly prior to the election. A deaf woman raised the following questions and the Executive Director of the UNAD, who is also the Member of Parliament, answered:

Q (woman): Seven regions are not represented. One is left out. Karamoja is left out.¹³ This is a big gap. We also have to have gender balance. Four regional models are better.

¹² This female board member of the UNAD resigned from the board, as she applied for a job to work as a staff member at the UNAD. However, the board, which includes the Executive Director as the secretary of the board, decided to employ the other candidate for the job. The one who got the job is the wife of the Executive Director. Hence, as of 2012, there is only one female board member at the UNAD.

¹³ The chairperson of the UNAD claims to have good explanations why they were not there. There was a heated discussion on whether an invitation letter to the UNAD general assembly was sent to Karamoja at all. The truth remains unclear, at least to the author as an observer.

I'm ready to fight for the gender balance. Many countries talk "Uganda is doing well." But we are oppressing women. We are at the bottom regarding women. (applause)

...

Q (the same woman): Six regions are here but one forgotten. I know that the invitation letter was not sent there. This is a hidden agenda. The GA should be made by seven regions. The Constitution says that we elect seven regions, and so we have to follow that. Karamoja deaf should be included. It's discrimination against them. There is no democracy here.

ED: Now tea is ready. Let's go for a tea.

...

Q (the same woman): There is no Karamoja delegates!

ED: It's time for tea. Closed!

This same tactic was used several times to stop strategic discussions, including the time when the chairperson was presenting the activity report.¹⁴ He started his presentation by following the written material. He explained what the UNAD had achieved. Then, he came upon the section on challenges in the printed materials. But he said, "The dinner is ready." And the chairperson's presentation was terminated there without going into the challenges. For those who are illiterate, they did not know that there was the section on challenges which raised crucial issues for the delegates to discuss. The challenges included, "Deaf prefer cash handouts rather than accessing services or training to empower them. Sometimes they cannot participate in activities due to lack of money for transport to meeting venues" and "Some regional associations are not active at all, e.g. Karamoja has no functional executive committee." These statements imply that **the activities have not accommodated deaf people who are vulnerable and poor**, and thus it would have been important for these issues to be discussed. The more educated and more powerful delegates used undemocratic methods to avoid certain discussions, which went unnoticed by many delegates. In this case, the power and knowledge relation of Foucault was relevant in this specific social situation.

Another tactic used to end a discussion when the chair of the session agrees with an idea raised by one delegate is to ask the audience, "Who supports the idea? Seconded by whom?" One more is needed then to finish the conversation by declaring, "The idea was seconded by A." This was very widely used in both of the general assemblies in favour of the powerful. It did not necessarily represent the majority voices, which made deaf delegates particularly vulnerable in the NUDIPU general assembly. Both persons with physical disabilities and blind delegates could raise the voice and appealed, "Yes!" or "No!" when asked "Do you agree?" However, **deaf delegates' "voices" in sign language were disregarded on too many occasions** because the sign language interpreter responsible for the voice of the deaf audience can serve one at a time and because others do not understand the signs of the deaf expressing their opinions.

Something similar was also observed among deaf delegates in terms of **power relationships**. When nominations were called for some position, "vocal" people started to show the sign "close!" to express that the nomination should be closed after their supporting candidate had been nominated. Even when there were another nomination hands up, sometimes they were not visible among the people who repeatedly show "close!" signs standing up. It was observed

¹⁴ The chairperson of the UNAD disagrees with this.

that at least one candidate who raised a hand for nomination but could not be nominated due to the “vocal” signs of “close!” among the deaf delegates.

Another challenge in the NUDIPU general assembly, specifically for the deaf, was the way the election took place with the secret ballots. As was mentioned, many deaf delegates had the great disadvantage of not being able to write down the names of the candidates. Each blind delegate had a guide of one’s own, while the deaf did not have such a personal assistant. In the very beginning of the general assembly, one deaf delegate publicly announced the challenge of the deaf delegates in the election process. It was recorded but literally ignored in terms of succeeding action in practice. The deaf delegates got frustrated as the general assembly proceeded. When a blind delegate made the next statement on the first day, the “war” between deaf and blind was re-confirmed:

The guides for blind people and sign language interpreters are totally different. Because we don’t have eyes, we are vulnerable in movement. For instance, we cannot go to toilet alone. We cannot eat alone. The difficulties of ours are bigger. For you, deaf people, if some learns to know your language, you can communicate. The magnitude of our needs is totally different.

When resources are limited, the rights of persons with different disabilities collide. All rights should be equally important. Nevertheless, in practice priorities are made that frequently infringe on the rights of ones whose priorities are low.

On the second day when the election took place, one of the deaf delegates told the author, “I’m ready for the war!”¹⁵ There was one deaf person contesting the chairperson’s position in the NUDIPU general assembly. The other candidate was the outgoing chairperson who is blind. He was elected in the last general assembly by taking advantage of the alliances: then deaf and blind people were allies and tried to go against those with physical disabilities who are dominant in number (female deaf delegate, personal interview on 7 December 2008 in Kampala). In-group and out-group bias was actively utilised (cf. Woods, 2010:67). A blind person stood for the Member of Parliament election in 2006 and lost it. During the election, the alliance between the deaf and blind is said to have fallen apart. The deaf and blind were supposed to support each other’s candidates and not to set an opposition to each other’s candidates. However, a blind candidate stood against the Deaf Member of Parliament to be re-elected, which resulted in a situation where the delegates did not support each other. The commitment/consistency bias was broken down (cf. Woods, 2010:66). As a result of the collapse of the alliance, the blind candidate did not go through in the national election. This was remembered bitterly in the NUDIPU general assembly two years later, as some explained in detail. In this regard, “disabilities and politics” and “disability politics” overlap. Others speculated that the UNAD general assembly just took place and the deaf delegates were still divided: those who supported one candidate for the chairperson’s position of the UNAD are not supportive yet of the new UNAD chairperson for the NUDIPU chairpersonship. When a meeting was held among the chairpersons of 11 nation-wide DPOs on 29 January 2008, Hellen Asamo, the chairperson of the NUWODU and current Member of Parliament proclaimed, “We are chairpersons as well as politicians.”

¹⁵ It is not only metaphoric in the sense that these general assemblies employ armed soldiers for controlling heated situations. In the UNAD general assembly, the soldiers did not intervene as things went smoothly. In the NUDIPU general assembly, soldiers once stepped into the crowd of delegates who rushed to vote.

Throughout the general assemblies, **female delegates remained largely silent**. The author made a marking in her journal whenever females spoke up. According to the count, only 10-15% of the speakers were women in both general assemblies. Uganda is highly male-dominant (Ministry of Finance, 2008: 53-78; DSI, 2007:2), which was reflected in the general assembly exercise. That is, the **local power structure affects** the operationalisation of the human rights-based approach in the general assembly practices. At the same time, the social conditions powerfully impacted the delegates' self-determination behaviours.



A deaf female delegate on the right is speaking to the delegates in Ugandan sign language in the NUDIPU general assembly. Her speech is simultaneously interpreted by the interpreter on the left with a microphone. It is supported by the deaf delegates on the right side of the crowd raising their hands up which is "applause".

In the end, 10 out of 13 board members' posts were taken over by the same people in the NUDIPU general assembly. One of the re-elected board members was particularly contested due to the Constitution article that prohibits serving the same position for the third term. The appeal from the audience continued to be ignored, and so one blind person went to the front and forcefully grabbed the microphone and raised this issue to the audience, despite of the fact that he was not appointed to speak. This, however, was solved through a very strange interpretation of the Constitution: "The Constitution was amended in this general assembly, and thus the content of the Constitution is valid only from today onwards." That means the clause to prohibit long-serving in a position cannot be applied to anybody, because the Constitution is amended in every general assembly. The board members have been highly criticised for their decision making power over various issues. This issue was particularly explicated in the NUDIPU organisational assessment report (CDRN, 2008), which was presented by a consultant during the general assembly. Many of the findings, however, were not discussed in the general assembly, with or without intention. The delegates were not given a copy of the report which the author managed to obtain, and so the information, including the following, did not reach them: the chairperson of the NUDIPU received 2876 Euros in 2008 including an "untaxed monthly allowance of 450,000 UGX, 70,000 UGX worth of airtime per month, and 50,000 UGX travel and subsistence for each board and sub-committee meeting." The too-expensive and too-powerful board was considered "not justifiable" in the report (CDRN, 2008:31-32). Another report similarly asserts that the **NUDIPU board**

members are “too powerful and out of reach of the membership” (DSI, 2007:40). Staff member C of a Northern DPO (personal interview on 18 February 2008 in Kampala) points out the same. This staff member analyses that it is similar to the general Ugandan context - politics included- where one inherits and keeps some position, or gets it because s/he is rich enough to pay to gain support. Consequently, the distance between the NUDIPU and DPOs is “ever increasing” and “many DPOs have lost confidence in the NUDIPU which should have been a unifying factor. They no longer identify with it as such.” (DSI, 2007:36). It further explains the relationship between **power and money** in Ugandan organisations as follows: “Because of poverty the motive behind forming a new organisation might be to create a source to a steady personal income rather than to address a specific issue. A position on the board of directors in an organisation gives allowances on which one can keep a family. Poverty among leaders and activists in the disability movement therefore can confuse the picture of the drive and the motivation behind activities and it sometimes create organisational power struggles, which is not so known in Denmark” (ibid.37).¹⁶ Thus **Economic, Social, and Cultural Rights including education and economic empowerment are deeply involved in operationalising Civil and Political Rights** in a proper manner.

Another anonymous informant told the author that the amendment ideas of the Constitution were also manipulated in favour of those who wanted to reinforce the status quo (personal communication on 11 December 2008 in Kampala). District Unions documented and submitted their ideas of the Constitutional amendment to be discussed in the general assembly of the NUDIPU, which were handled in regional workshops. However, in the board meeting just before the NUDIPU general assembly, it was decided that the discussion would take place in the actual general assembly itself. And yet, the discussion did not properly take place with the presentations of those amendment ideas from the District Unions. In such a sophisticated manner of using **knowledge as power**, certain decisions were made in favour of those who are powerful (cf. social network analysis of Woods, 2010:63).

In the opening of the general assembly of the NUDIPU, one representative of the Northern “partner” DPO made a speech and urged the delegates to democratic decision making:

[W]e as DPOs have the same responsibility to act democratically and transparently. We have to practice what we preach. Unfortunately, we too often see that leaders stay on and on, and that leadership development for the younger generations is not a priority, that women are not encouraged to take on leading roles. There are too many examples of moneys are being used to uphold structures as they have always been, rather than using them to create a change, and to give more disabled people the opportunity to become empowered, demand their own rights and live an independent life.

This precautionary speech, however, was not well taken into consideration in the exercises of the general assemblies in both DPOs. The present and previous sub-chapters elaborated on the main social fabrics that had great impact on the delegates’ self-determination rights and behaviour around it.

¹⁶ The report continues to assert that this centralised power structure applies to each DPO. “The DPOs have increasingly become entities of the leaders (Board of Directors) who set their terms of reference and manipulate their membership. As a result, many organisations lack transparency in their operations.” (ibid.41)

4.3.3. The Strengths of the Human Rights-Based Approach in the general assemblies of Ugandan DPOs

The previous parts concentrated on the ambiguous and undemocratic ways of the operationalisation of the human rights-based approach. This study, however, is not aimed at criticising the two DPOs that kindly invited the author to their general assemblies. On the contrary, the aim is to learn from the good practices and challenges in the operationalisation practices of DPOs in Uganda. This part focuses on the strengths of the human rights-based approach in the practice of DPO general assemblies in Uganda. In the specific context of the general assemblies of Ugandan DPOs, the following strengths of the approach were observed around the concept of empowerment. A report (NORAD, 2012:24) used the theory of change for its analysis and established that individual and organisational empowerment around peer support is the main theory among actors.

The general assemblies are very expensive as they mobilise such a significant number of delegates to one venue and accommodate them in accessible hotels. They are financially supported by various Northern partners and donors.¹⁷ One Northern “partner” DPO staff member explains that not many donors are willing to fund general assemblies because “these are typically costs that don't lead to direct changes in the lives of the target group, and which therefore most probably are less sexy to fund in a time where development agencies experience a high pressure on delivering concrete and measurable results in people's lives from their funding.” Despite that, this Northern DPO has supported the general assemblies and anticipates continuing to give support for the forthcoming general assemblies. She argues,

Although GAs don't guarantee for a democratic and transparent organization, we perceive that holding GAs according to your own constitution is an indication of that the organization is striving towards democracy, and a sound organizational culture. [Name of this Northern DPO] is a DPO itself, and it would be very awkward for [the name of this Northern DPO] to deny our sister organizations to spend some of the funding on the governing bodies of the organization, when we know how important they are (personal communication by e-mail on 6 February 2009).

This statement coincides with that of another Northern DPO staff member that also supported the general assemblies,

One of [name of this Northern DPO]'s aim is to build the capacity of her partners, particularly DPOs. Capacity building takes different forms. One key indicator that we put forward to measure success of the capacity building programme is presence of democratic and representative DPOs. A GA is one way that PWDs are able to demonstrate democratic and effective governance. A GA is a high level policy making body which if handled well and with maturity the people elected as office bearers become cornerstones in the implementation of the activities of the organisation. That is why [the name of this Northern DPO] supports GAs of DPOs (personal communication by e-mail on 6 February 2009).

¹⁷ Ugandan DPOs often call their Northern counterparts “donors” or “parents” by placing themselves lower in the hierarchy, while Northern ones call the Ugandan counterparts “partners” and “sisters” to stress the horizontal relationship between them (woman with a disability, personal communication on 8 December 2008 in Kampala).

The third Northern DPO staff member also made a very similar statement (personal communication via e-mail on 26 February 2009). That is, the general assemblies are regarded as integral parts of organisational activities towards the good and democratic governance of DPOs, if implemented well. **Self-determination exercised in the general assemblies is the sign of democratic capacity, which is not charity but an entitlement.** Persons with disabilities who are too frequently and disproportionately at the bottom of the social stratification gain decision-making power for their own DPOs, as non-disabled peers do in their NGOs and elsewhere. Thus ownership and the participation of persons with disabilities in the form of general assembly activities in their DPOs is **a part of mainstreaming.** A deaf woman A expresses how proud she is now:

If I move with the deaf, I feel so confident. I don't feel ashamed because I share the same thing and I'm not the only one. In the beginning, I was so afraid in the community of hearing people. I was one of the few deaf. Now I feel very proud because I'm not the only deaf and there are a lot of them here (personal interview on 4 February 2008 in Kampala).

In the general assembly of the UNAD, a deaf woman from a rural area came to the front only to say, "I'm here for the first time. I feel honoured. Deaf in rural areas don't even have food" (on 5 December 2008 in Kampala). Another also states that it is significant for those who do not speak sign language because they can learn from others there and then (personal communication on 7 December 2008 in Kampala). At one point, a man also came to the front and imitated others with his own gestures. It did not make sense to anybody but he received warm applause by the UNAD general assembly audience nevertheless. The chairperson of the UNAD commented during his presentation, "It's a good sign that people started to pose questions. People became active. The general assembly of 5 years ago was not like this. All agreed with everything. It is good" (on 5 December 2008 in Kampala). Hellen Asamo, current Member of Parliament representing persons with disabilities (personal interview on 31 January 2008 in Kampala) has been the chairperson of the NUWODU for the third time and served as a board member of the NUDIPU for three terms. Through these experiences in the disability movement, she says, "I think that the truth is that **I got empowered through being disabled.** I can now penetrate any organisation and stand there, be elected as any other person." She has been empowered so much that she is now confident to represent any other position elsewhere. Margaret Baba Diri, a blind woman and a Member of Parliament, also recalls her initial engagement with the disability movement as very empowering: "First of all, I was encouraged because there were so many blind, deaf, and they all looked so smart. I was impressed that I was not the only one. So I became very active in the disability movement" (personal interview on 19 February 2008 in Kampala). She was one of the first five Members of Parliament representing persons with disabilities elected in 1996, and elected as a Member of Parliament in the mainstream election in 2006 and 2011. She continues,

I thank people with disabilities. They are the ones who built my capacity. When I lost my sight, I lost all hope completely. I thought that was the end of my life. I thought sight was everything. When I lost my sight, I could not see my children, I could not do anything for myself. I said that was the end. But when I turn to the disability movement, I build my capacity through all the programmes of NUDIPU and I am exposed to many things.

Alex Ndeezi, the Deaf Member of Parliament representing persons with disabilities acknowledges his role as a **role model** for other deaf people (personal interview on 28

January 2008 in Kampala). He often morally supports and encourages other Deaf/deaf people by showing his own example. A study of OHCHR (2011) found out that the participation of persons with disabilities in political and public life has been still restricted on a global scale, particularly for persons with psychosocial and intellectual disabilities and in terms of physical accessibility and communication barriers of the election exercises. General assemblies are pilot cases to be operationalised in other political rights as well. Thus they are of importance to accumulate good practices and learn lessons from to be implemented elsewhere.

Another expressed strength is the attempt towards **solidarity** at different levels. For instance, the Northern partners express their solidarity by calling the Ugandan DPOs “sister organisations” and “partners.” This solidarity highly motivates the Northern DPOs to financially and morally support the general assemblies as well as other activities because they also use part of their budget for upholding such regular assemblies for collect decision making. Similarly, the general assemblies promoted solidarity among the delegates by frequently referring to them as “**brothers**” and “**sisters**” who share similar experiences -and thus the identity of persons with disabilities- to attain the “same goal” of human rights. Many speakers stressed that the delegates own the DPOs and that they are “family.” For instance, the chairperson of the NUDIPU stated, “What is the NUDIPU? We are from the villages to the national level. NUDIPU is you and me. It’s our home” (on 8 December 2008 in Kampala). The deliberate choice of these solidarity-oriented words was partly to take control over the situation where the dissolution and dispute among the delegates was manifested in the election activities, but also to strengthen the disability movement. In-group and out-group bias was utilised for furthering cooperation and group identity (Woods, 2010:67-8). These “participation forums” contribute to produce collective identity (Barnes et al., 2006:201). Ownership and togetherness were experienced in the general assemblies (female deaf delegate to both general assemblies, personal communication by e-mail on 2 March 2009). In this sense, **the general assemblies are part of the “process” of constructing an action system** (Melucci 1996:70 cited in Barnes et al., 2006:201). Hellen Asamo describes how she prioritises her constituencies over anything else, even when Judith Heumann who was then the advisor for the World Bank visited Uganda:

Can you imagine that by that time Judith was the World Bank representative? Judith decided to come to NUWODU, and we were having the general assembly. So people were saying, ‘Chairperson, Judith is waiting for you.’ But I told them, ‘Judith is flying away. But these people are with me. This is the vote. Judith does not have a vote. She is asked to wait. Let me settle these people’ (personal interview on 31 January 2008 in Kampala).

General assemblies directly connect leaders on top to members on the bottom, which is paramount in elections and campaigns. This process forces leaders to carefully listen to the constituencies and leads to democratic decision making when it goes well.



The outgoing chairperson of UNAD was re-elected. He is in the middle, in a blue shirt, with his hands up. He enjoys his victory with his supporters in the general assembly of UNAD.

The turn up rate is very high. This shows the high commitment of the delegates to the general assemblies.¹⁸ The fact that persons with disabilities were eloquently making different appeals and negotiating their own rights was an empowering process. **This political space for exercising their right to vote made the delegates realise their power** both in good and bad ways: the realisation of rights to make decisions and the realisation of power to pull a string for gaining money. In any case, each delegate was treated as an important voter and a decision maker throughout the general assemblies. It was the delegates' entitlement to judge the accountability of the office bearers in the form of elections (male with physical impairment, personal communication by e-mail on 26 February 2009). The right to vote was equally distributed to each delegate despite the power gaps, not only among the delegates but also in relation to semi-external actors such as the Members of Parliament. The elected board members are responsible for the steering of the DPOs as office bearers, without which DPOs would collapse (female deaf delegate to one general assembly, personal communication by e-mail on 27 February 2009). The delegates' participation in the general assemblies facilitated to disconnect the stereotypical image that persons with disabilities are passive. Female candidates, in particular, were more visible than ever before. For instance, the first female contestant in its history stood for the chairperson's position in the UNAD's general assembly (male deaf delegate to both general assemblies, personal communication by e-mail on 6 March 2009). The general assemblies provided the space for operationalising their rights. In other words, the **delegates were both individually and collectively empowered through the general assembly exercises**, at least to some extent. The decision made in the NUDIPU general assembly to become independent from Members of Parliament and the NRM, against pressure, proved the realisation of their own decision-making power, including collective power, with other persons with disabilities.

¹⁸ Some ironically pointed out that the turn up rate is so good because they are paid a high transportation cost. For instance, for those from Lira, 60,000 shillings were paid, while those from Gulu received 90,000 shillings at the NUDIPU general assembly. This subsistence culture introduced in the development cooperation activities has been highly criticised for demoralising and discouraging voluntary participation. A report describes this as even "grotesque" as follows: "Poverty has killed the culture of voluntarism in Uganda and people expect to be paid an allowance when they attend meetings. Allowances are often the only income for many people in DPOs. The allowance system is very complex (transport, sitting, subsistence, lunch allowance etc.) and can reach grotesque levels" (DSI, 2007:37). Moreover, food served at the general assemblies is also something that people in villages would eat only for Christmas (a sign language interpreter, personal communication on 9 December 2008 in Kampala).

4.4. Case Study 3: Establishment of the African Union Disability Architecture¹

The third and last case study is on a top-down approach of international cooperation in the field of disabilities in Africa, which is different from the first two cases that are both development cooperation activities based in the Ugandan context. The third case is not a time-framed project or programme but a process. More precisely, the third case is on the creation of the African Union Disability Architecture (AUDA) which has been on-going at the level of the African Union (AU) together with international agencies including the United Nations (UN), particularly the Division for Social Policy and Development at the Department of Economic and Social Affairs, the UN Special Rapporteur on Disability of the Commission for Social Development, the African Decade Secretariat, the governments of Finland and the United States, and civil society organizations among others. The author accompanied the UN Special Rapporteur on his missions to Addis Ababa in April and to New York in September 2012 to observe how dialogue, policy negotiation and information dissemination take place at this level of international cooperation and to interrogate the third track.

4.4.1. United Nations Special Rapporteur on Disability

The United Nations Standard Rules for the Equalisation of Opportunities of Persons with Disabilities, the so-called Standard Rules, were adopted in 1993 following the United Nations International Year of Disabled Persons in 1981 and the Decade of Disabled Persons between 1983 and 1992. The Standard Rules represent “a strong moral and political commitment of Governments to take action to attain equalization of opportunities for persons with disabilities” (United Nations, 2007), and established monitoring mechanisms including appointment of a Special Rapporteur. The Secretary-General of the United Nations appointed the first Special Rapporteur, Bengt Lindqvist from Sweden in 1994. The Swedish government financially supported him and his activities. His mandate was renewed two times. He served as the Special Rapporteur until 2002. The second Special Rapporteur, Sheikh Hessa Khalifa bin Ahmed al-Thani of Qatar, was appointed in 2003 and served until 2009. The Qatar government financially supported her.

During the process of appointment of the third Special Rapporteur, Kalle Könkkölä of Finland was one of the 44 candidates. The selection process remained unclear as to whether governmental financial promise, strategic geographical politics, disability politics and/or gender politics would affect it, as was the case for the previous Special Rapporteurs. Chalklen was nominated to this position by the previous South African government. Consequently, unlike the previous two Special Rapporteurs, he had to start from raising funds for his activities, as his current government could not financially support him and his activities. The Finnish government was one of the first to have financially supported him, as it has earmarked possible support to Könkkölä in its budget.

4.4.2. African Union Disability Architecture

The new AUDA, African Union Disability Architecture, will seek to promote equality as enshrined in the “International Disability Architecture,” which consists of the CRPD and other international human rights and development instruments, including Millennium Development Goals² and other internationally agreed upon Development Goals (Ito, 2012-a & b). AUDA will be a multi-stakeholder partnership including African governments, the African Decade Secretariat, and the African Rehabilitation Institute (ARI) among others. The ARI was

¹ Acknowledgement: The UN Special Rapporteur, Shuaib Chalklen, kindly read a draft of this sub-chapter and made his valuable comments on it to improve the text. The author is very grateful for his support.

² The Millennium Development Goals, however, have largely excluded persons with disabilities.

established in 1981, on the International Year of Disabled Persons of UN, as an inter-governmental institute on disabilities in Africa. The ARI has not been functioning for a long time. The African Union made a decision to revitalize the ARI with a wider mandate for facilitating the process of the AUDA (EX.CL/Dec.684(XX)). The ARI was first established as a rehabilitation- and prevention-centered institute that would promote coordinated actions, measures and programmes among the African countries (Organisation of African Unity, undated).



Picture on the left: one of the meetings for soliciting the AUDA among stakeholders. The meeting was held in the AU Clinic boardroom on 18 April 2012. From the left, Olawale I. Maiyegun (Director for Social Affairs Department at AU), Johan L. Strijdom (Head of Social Welfare, Vulnerable Groups, Drug Control and Crime Prevention at AU), Dube's assistant, Kudakwashe Dube (Chief Executive Officer of the African Decade Secretariat), Shuaib Chalklen (the UN Special Rapporteur), and Ariam Gebremariam (African Decade Secretariat Regional Officer at Addis Ababa). Both Dube and Chalklen are from South Africa.

Picture on the right: the UN Special Rapporteur visited the UN Economic Commission for Africa (ECA) and met a Population Affairs Officer, Hassan Musa Yousif. The ECA does not have any focal point or a staff whose mandate is to promote human rights of persons with disabilities. The ECA has one staff member, Yousif, who is personally interested in disabilities and works for them on a part-time basis along with his own mandate. Considering the population ratio of persons with disabilities, 15% of the total population, as revealed in the World Report on Disability (WHO and World Bank, 2011), it is disproportionate not to have staff specifically dedicated to disabilities.

In April 2012, the UN Special Rapporteur visited the African Union and held a meeting for sharing information on the AUDA, followed by the previous meeting in February. The AU officials presented their plan and forthcoming events for soliciting the AUDA on their side, which had three components: 1) legal, 2) programmatic and 3) institutional components. Firstly, the AU is drafting a legal policy document which could be an African Disability Protocol to be adopted by the member states. The idea came in 2003, and a working group was formed to develop a protocol on the protection and promotion of the rights of persons with disabilities (Resolution ACHPR/Res.143 (XXXXV) 09, adopted during the 45th ordinary session of the African Commission on Human and Peoples' Rights, 13-27 2009, Banjul, Gambia) (Mureriwa, 2011:3). The draft version, "the Accra Draft," was formulated but was insufficient without the involvement of DPOs in the process of making the draft particularly in terms of watering down the implementation enforcement mechanism (ibid.3-5). **After vigorous advocacy work by African DPOs, the process has become participatory. Constant reminder and dialogue are needed for meaningful participation of persons with disabilities and DPOs.**

This legal framework enables member states to promote the human rights of persons with disabilities in cooperation with each other with periodic reporting obligation. Secondly, the AU is planning output-oriented programmes to be implemented. Thirdly, the AU institutionalises and revitalises the ARI as one of the key actors for the inter-governmental and international efforts. The AUDA framework in these three components will be ready by spring 2013. Several meetings have been set both among disability experts and relevant Ministers on social affairs and development among the member states. Dr. Strijdom stated, "The political will is very strong for this initiative. Money is also there." The momentum created after the CRPD has attracted attention of both the AU officials and donor communities including the UN, and Finnish and American governments to financially, technically and morally support this process. This will be elaborated further in the following.

4.4.3. African Decade of Persons with Disabilities

Following the UN Decade of Disabled Persons between 1983-1992, the first African Decade of Persons with Disabilities started in 1999 and ended in 2009. The first Continental Plan of Action states in its introduction, **"The UN Decade of Disabled Persons had its successes and failures...its successes which were more pronounced in the northern hemisphere than elsewhere."** This was the primary reason why the Asia and Pacific Decade of Disabled Persons (1993-2002), the Arab Decade of Disabled Persons (2003-2012), and the African Decade were begun. Both the Asia and Pacific Decade, and the African Decade are extended for another decade. The responsibility for organizing the Decade was given to the African Rehabilitation Institute (ARI), an inter-governmental institute under the African Union for the first decade. The Continental Plan of Action (African Union, 2002) makes a special note referring to the lack of financial support provided by the African governments for this Decade for the first few years. This Decade did not attract much attention of donors either, and therefore not much fruit was borne in terms of an implementation of the Action Plan.

The Secretariat of the African Decade of Persons with Disabilities (SADPD) opened its office in Cape Town in 2004. This decision was made during the Disability African Regional Consultative Conference held in May 2003 in Johannesburg. The task of setting up the Secretariat was initiated by continental DPOs such as the Pan African Federation of the Disabled (PAFOD), the African Union of the Blind (AFUB) with the mandate and support of the African Union, and the South African government (SADPD, 2010-a&b). The present UN Special Rapporteur, Shuaib Chalklen, was the first Chief Executive Officer of the Secretariat for the African Decade between 2003-2006. Chalklen was dispatched by the South African government.

The current Chief Executive Officer, Kudakwashe Dube, was also present in the aforementioned meeting at the African Union in April 2012. Dube presented updates on the preparation process of the Continental Plan of Action for the second Decade that started in 2009. The Plan of Action was discussed in the working group meeting among African DPOs and relevant governmental and international actors in June 2012 in Addis Ababa, Ethiopia. The US Embassy among others financially supported the travel costs of the DPOs. In the meeting at the African Union in April, Dube promised the AU officials to submit a budget and then decide, based on the budget, and donated money, how many people could participate in the working group meeting in June. This is superficially logical. However, if a human rights-based approach is operationalized fully, the order should be the other way around: first relevant participants are identified and money should be properly allocated to accommodate their costs. This example identifies the **importance of proper and meaningful involvement of DPOs into the process, rather than the slippery practice of token DPO involvement**

based on the reality of resource constraint.

The regional officer of the Secretariat based in Addis Ababa, Ariam Gebremariam, has advocated for mainstreaming disabilities in the African Union with her own capacity. The African Union Peace and Security Department and the Secretariat of African Decade East Africa Regional Office officially signed a memorandum of understanding on 6 June 2011 to implement a disability inclusive peace and security project (Gebremariam, 2011). Gebremariam organized a workshop on 17 April 2012 at Addis Ababa in collaboration with Northern bilateral donors. As a result of this workshop, there will be a Nordic workshop on this theme in Stockholm in the autumn of 2012. This seemingly very successful initiative, however, has been constrained by the staff members of the Social Development Council of the African Union who claim, "Disability is our thing, not for Peace and Security." Disabilities are crosscutting issues, while to date they have predominantly been assumed to be part of welfare and social development. This example eloquently indicates the **challenges of mainstreaming disabilities as a matter of human rights beyond the classic realm of social development**, even at this high level where a human rights-based approach is (supposed to be) one of the norms.

4.4.4. Trans-Atlantic Initiative

The strong global activists' solidarity and friendship between Judy Heumann of United States and Kalle Könkkölä of Finland led to the "Trans-Atlantic Process" of the two governments for supporting the mainstreaming of disabilities in the African continent. They had long discussed this possibility and then turned to their respective governments for support (Voipio, 2012). In 2012, both governments decided to allocate a significant amount of money for this initiative. The Finnish government will kick-start this "process" to build the capacity of the African stakeholders to mainstream disabilities, while the American government concentrates its activities on four or five African countries (plans as of April 2012). From the Finnish side, one million Euros is already budgeted by the Minister Hautala for the operationalizing of a human rights-based approach, which has become central to the present Finnish development policy.

The UN Special Rapporteur urged both parties not to duplicate activities but to coordinate to maximize outcomes. When it comes to **a top-down approach at this level, the biggest challenge is perhaps coordination**. International agencies such as the AU and the UN ECA are required to listen to member states. They must also coordinate to achieve collective consensus on both policy and action. Northern governments are similarly required accountability to the taxpayers. As the actors are many, coordination among them becomes key.

At the same time, the representation of persons with disabilities could easily be ignored when actors are many. For instance, when Kalle Könkkölä met in Helsinki with Timo Voipio of the Finnish Ministry for Foreign Affairs and Leo Olasvirta, the Finnish Ambassador in Ethiopia, on 3 April 2012, Könkkölä reminded them to employ an African expert *with a disability* for the Finnish initiative (Katsui, 2012). **Constant dialogue, policy negotiation and information dissemination among actors, including the DPOs, are more than needed for keeping the relevance of international activities on track**. As only limited number of people shares the essential information on different actors in the field of disabilities and international cooperation at this high level, activities could easily be duplicated without coordination. For instance, many of the aforementioned stakeholders expressed ignorance on all or part of the forthcoming international cooperation activities of other actors when the Special Rapporteur explained what the other international cooperation activities in the field of disabilities in

Africa are in the near future. During this trip to Addis Ababa, therefore, the Special Rapporteur played an indispensable role in disseminating and sharing existing information to relevant stakeholders to promote coordination, and to eventually respect, protect and fulfil the human rights of persons with disabilities in Africa in practice.

In May 2012, the United States invited relevant actors including Könkkölä and Voipio to Washington to the "U.S. Leadership Conference on International Disability Rights" and reconfirmed cooperation in this area. In the 5th Conference of State Parties to the CRPD at the UN headquarter in New York in September 2012, representatives of the both governments including Könkkölä and Heumann, as well as the Rapporteur had meetings to discuss on the AUDA. Right after that, Heumann came to Finland in the end of September prior to the November meeting in the AU among the Social Ministers when the United States and Finland plan to hold a side-event on disabilities. During her stay in Finland, Heumann met the Finnish President and the Finnish Foreign Minister and discussed on the way forward to promote disability rights particularly in Africa in partnership with the Finnish government. Coordination between donors has always been a huge challenge in international cooperation. In this regard, both governments are making significant efforts in becoming pioneers. One of the further challenges would be to ensure ownership of African stakeholders in this process.



Picture on the left: the UN Special Rapporteur met the Finnish Ambassador, Leo Olasvirta, for exchanging information on the AUDA and the Trans-Atlantic Initiative.



Picture on the right: the UN Special Rapporteur met the Deputy Chief of Mission to the African Union of the Embassy of the United States, Peter W. Lord.

4.4.5. African Disability Forum

It is a top priority of the UN Special Rapporteur to establish an African Disability Forum (ADF), as noted in his reports to the 49th and 50th sessions of the Commission for Social Development. The Forum will contribute to the global goal of full participation and equality of persons with disabilities particularly in Africa, guided by the CRPD and African Human Rights instruments and the global development commitments (Ito, 2012-a). This forum will be an "independent actor" under the AUDA, although its status and membership are still open, while division of works between the ARI and ADF is also unclear. Although this is an initiative of the Special Rapporteur, he cannot make the decision by himself: the AU and potential members of the Forum including Continental DPOs decides on that. **Democratic decision-making at this high level is time-consuming when involving a number of international actors.**



Picture on the left: the UN Special Rapporteur also made appointments to meet two Ethiopian DPOs, the Ethiopian Centre for Disability and Development (ECDD) and the Federation of National Association of Persons with Disabilities, of which the latter cancelled the meeting for an unknown reason. A blind Member of Parliament also cancelled the meeting. There are a dozen of Members of Parliament with disabilities in Ethiopia without having any disability quota, while ECDD staff members confessed not to have met them before. The Ministry of Labour and Social Affairs, Members of Parliament with disabilities and DPOs are all independent from each other, unlike Uganda in which they work hand in hand for the human rights of persons with disabilities. This brief comparison enabled us to understand how active and developed the Ugandan disability movement is, particularly in the political sphere. Above is the picture taken at the ECDD with the staff members. The staff shared their experiences in working for persons with disabilities in this country where the notorious “NGO Law” of 2009 (the Proclamation to Provide for the Registration and Regulation of Charities and Societies) restricts NGOs from receiving more than 10% of the budget for human rights and advocacy activities. As a result, many DPOs cannot use “human rights” terminologies for their activities and concentrate more on capacity-building activities such as income generating activities and service provisions. The Law also restricts NGOs from spending more than 30% of their money for administrative costs: more than 70% of the money is to be used directly for activities. DPOs, however, gained the government support in allocating the salaries of staff with disabilities to be counted as activity costs instead of administrative costs. The UN Special Rapporteur urged the ECDD staff not to be satisfied with this exception by internalising and taking restrictions of the government on NGOs for granted. He used the analogy of apartheid in South Africa in which people internalised the discriminative ideology under the regime.

Picture on the right: the UN Special Rapporteur visited the Ministry of Labour and Social Affairs of the Ethiopian government and met Abebech Asfaw, the Director for Social Welfare Promotion Directorate. He listened to the challenges to implementing the CRPD in Ethiopian practices: funding and capacity. He then introduced some existing sources of possible funding. When the author raised the question on the exception given to DPOs in the framework of the NGO Law, as described above, the officials were not aware of this information. The officials were also concerned about how to formulate a required report for the CRPD which is due in 2012. The Special Rapporteur promised to send information on the guideline. These two examples indicate that disabilities have not been the priority for the Ministry, as they have not kept themselves up-to-date with the latest development and information in this field. In the end, he recommended that the Ministry staff and the local DPOs meet to discuss and decide on a few priority areas to work on in the near future, as “you are not expected to implement everything (of the CRPD) at the same time.” Priority-making is the key for successful planning and the operationalisation of the CRPD, as positive measures in legal terms are not expected to take place immediately but progressively, while reasonable accommodation is immediate and inherent. However, making disabilities a priority in general is a big challenge even before that.

In the April meeting at Addis Ababa, the UN Special Rapporteur brought the concept paper of the ADF to the AU staffs and discussed on forthcoming activities under the ADF. He assured the author in personal communication that it was important for the procedure to go through the AU, and not to bypass it with such a continental agenda. When he established the African

Decade Secretariat as the dispatched officer by the government of South Africa, he did not go through this process of consulting with the AU. For getting institutional support from the AU for a continental agenda, this meeting was of importance. The UN Special Rapporteur explained, "It is important to start the Forum slowly and surely not to make mistakes." He has "learned the lesson." Due to the meaning attached to the dialogue, the meeting was rather formal.

The Special Rapporteur presented some outcomes the Forum aims for when it is established. The first is a publication on disabilities in Africa. The second activity is trainings for DPOs and government officials. The third is research on different themes. The Forum will thus focus on information dissemination in general among African stakeholders and beyond by starting with only limited number of selected activities with the intention to expand its mandate and scope in the future.

As the Rapporteur has been seeking for consensus on the ADF, the concept paper has been commented by many actors including the AU, UN DESA, American and Finnish stakeholders, and the Secretariat of the African Decade. In September 2012, the Rapporteur held many meetings with the stakeholders to find possible consensus during the period of the 5th Conference of State Parties to the Convention of the Rights of Persons with Disabilities. Their ideas, inputs and expectations have complicated the establishment process: some stress inter-governmental aspect to satisfy the member states of the AU, while other suggests the Forum to be a short-term project without any new structure. Such information dissemination, dialogues and negotiation are unavoidable, as opinions of relevant stakeholders have to be exhausted for establishing an activity at the African Continental level as this one. However, such discussions could also be driven by own interests of individuals or interests of different agencies that they represent for. Disabilities are diverse, development partners have rather complicated relationships among themselves, and personal feelings are also involved when it comes to issues around disabilities. The Rapporteur has not been successful in raising fund for this Forum activity yet as of September 2012. Nevertheless, it could become even more complicated when money is found, for doing some simple activities for increasing capacity of disability stakeholders in Africa.

4.4.6. Co-relation between Personal Capacity and Environment

On 22 May, the Special Rapporteur received an invitation letter from the African Union to attend the "Technical Expert Consultation for the Finalization of the Draft Continental Plan of Action on the African Decade of Persons with Disabilities (2010-2019) and Agreement on the AU Disability Architecture (AUDA), Addis Ababa, Ethiopia, on 20-21 June." This is a follow-up meeting after the April meeting. He then immediately turned to the author to travel to Addis Ababa again as his assistant, as he knew the research interests and was going to conduct research together with the author on Africa, including Ethiopia from December 2012 onwards. This was a great opportunity for the author, and she accepted the kind offer to be able to travel with him and observe the series of important meetings for soliciting African Union Disability Architecture. On 25 May, the UN accepted to pay for the trip of the author to Ethiopia and any forthcoming trips with the Special Rapporteur as his assistant. The author was asked to send her passport copy, information of her bank account, contact information such as postal address, telephone number, and e-mail address to the United Nations.

Then on 7 June, only ten days before the actual trip to Ethiopia, an e-mail was sent both to the Special Rapporteur and to the author from a social affair officer of the United Nations

Secretariat for the Convention on the Rights of Persons with Disabilities stating, “We were informed that the United Nations can not authorise Hisayo [the author]’s travel. Since the tickets must be issued as of today, *please confirm if you can travel alone for this mission to Addis?*” The Special Rapporteur is a wheelchair user, and he “cannot go there alone” (personal e-mail communication with the Special Rapporteur on 7 June 2012). They are supposed to be the advocate for the human rights of persons with disabilities in the United Nations, as they are the Secretariat of the Convention. Yet, their immediate reaction to this was to ask the Special Rapporteur to travel without his personal assistant. This example speaks of many things. **Even at this level where a human rights-based approach is the norm, it is not automatic to assume the human rights of persons with disabilities are realised in practice.** If “experts” sometimes fail in meeting the rights of persons with disabilities, it is not too difficult to imagine how other actors continue to reproduce inequality with or without intention to do so. Having acknowledged the important roles played by the Secretariat for the human rights of persons with disabilities, this particular incident was a typical example of a disabling environment that does not materialise the human rights of a person with a disability, even when s/he has been empowered and has acquired good capacities.

However, **environment is fluid and could change, in particular through dialogue, negotiation and information dissemination.** In August 2012, the Special Rapporteur once again informed the United Nations of his intent to take the author as his assistant to the fifth Conference of State Parties to the Convention on the Rights of Persons with Disabilities to be held in the United Nations at New York in September. After some constructive dialogue, the United Nations approved to authorise the author’s travel as his assistant. Such dialogue, negotiation and struggles for the realizing of one’s own rights require a lot of energy for the persons with disabilities to transform their living environment from disabling to enabling. It is often too energy-consuming for persons with disabilities to keep on making extra efforts to attain their rights, even when they have been empowered and their capacity is high. As securing the human rights of persons with disabilities is not common sense yet, the continuous reminder to -and dialogue with- duty-bearers is necessary for rights-holders in different contexts. Hence, the **empowerment and capacity-building of persons with disabilities and their organisations are equally indispensable as those of duty-bearers.** This correlation between environment and personal capacity will be theorised further in the next Chapter 5.

4.5. Preliminary Findings from the Case Studies

As described above, the human rights-based approaches exercised in the HIV/AIDS project, the general assemblies of Ugandan DPOs, and the mission of the UN Special Rapporteur to Ethiopia have left some important implications for making the approaches more useful and usable in their operationalisation. In short, the existing power structure and environment matter: they deeply affect self-determination and behaviour even where equal rights are entitled to each person with a disability under the principles of equality and non-discrimination. This part elaborates on power with reference to 1) power to, 2) power over, 3) power with, 4) power as knowledge and 5) power structure (Frediani, 2010:180).

Empowerment of persons with disabilities has been linked to self-determination (Jenkinson, 1993; Finlay et al, 2008). When elaborated the demography of the participants and how they “self-determine” various matters in the case studies contexts, it became clear that operationalising self-determination rights cannot be taken for granted. Firstly, who is “self”? In this specific context, persons with disabilities are at stake, even though in the UNAD general assembly, several non-deaf delegates were present, whereas stakeholders of the African Union Disability Architecture are not necessarily all persons with disabilities while the Special Rapporteur is. Then secondly, which persons with disabilities are making decisions? Who has the power to decide for whom? On many occasions in the Ugandan context, the decisions made at different levels are not based on the voluntary decisions of the agents but rather, they are socially, culturally and structurally affected by power. It is evident that those who are better integrated into social networks are more likely to be recruited to social movements, and that among the ‘core group’ of such movements is found a high percentage of people from ‘mid to high’ social positions (Pleyers, 2010; Della Porta and Diani, 1999 cited in Barnes, et.al. 2006:196). For instance, DPO staffs are highly educated persons with disabilities. When it comes to the delegates of the NUDIPU general assembly, they were the elected ones in their district general assemblies who met the set criteria: at least one woman, one deaf, one blind and one person with a physical disability. In the UNAD general assembly, some delegates were invited to facilitate the re-election of the same people easier and thus were illiterate, for instance. However, they were also somewhat “powerful” as they have a direct connection to the most powerful persons with disabilities who selected them as the regional delegates. When it comes to the more international level, as was exemplified in case study three, only representatives with disabilities such as the UN Special Rapporteur and the Chief Executive Officer of the African Decade Secretariat participated in meetings, while only representatives such as Judy Heumann and Kalle Könkkölä do in respective Northern countries. At this level, only representative democracy is exercised in decision making, which is significant for the lives of African persons with disabilities. At one stage, the author observed that the UN and African Union had the ability to exercise power over the UN Special Rapporteur. That is, even when persons with disabilities have been empowered, the environment and structure can undermine decisions made by them.

The case studies explicate the importance of solidarity among stakeholders in the field of disabilities, both in a local context as in Uganda and in an international context such as the African Union and the United Nations. Solidarity is characterised as a collective identity, an awareness of equality (or a problematisation of inequality) and the ability to articulate priorities of disadvantaged people (Katsui, 2009-a:22). That is, solidarity entails both internal and external power gaps among different actors as a natural matter of fact. The HIV/AIDS case clarified inequality between persons with and without disabilities in the national response to HIV/AIDS, which connected all the DPOs participating in this project. Similarly,

the external inequality disproportionately experienced by African persons with disabilities led to various African Continent-wide activities, including the African Union Disability Architecture, an African Disability Forum, the African Decade, and so forth. The general assemblies brought about the collective identity as persons with disabilities who generally face severe discrimination against them, which was reassured,¹ while the general assemblies themselves illuminated the diversity among “persons with disabilities.” The HIV/AIDS project also brought to light capacity gaps among persons with disabilities. Internal inequality was treated in different manners in the cases: in the HIV/AIDS case, internal inequality was problematised in a development cooperation system centred towards efficiency, and led to decision making in a top-down manner, whereas in the general assemblies it was not problematised by the majority as such –even to the point that the whole issue of internal inequality was ignored when raised by the minority (the deaf) as a topic needing to be addressed. The existing internal inequality and power structure tended to be taken for granted in favour of the powerful ones, with or without intention, in both of the Ugandan-based cases. When it comes to the top-down approach at the international level investigated in the third case study, only representative persons with disabilities pave the way for other African-wide DPOs to be able to attend forthcoming meetings more in a participatory manner. At this level of dialogue and policy negotiation, local DPOs are not expected to play a role except to advocate, so as to encourage their own government to become accountable for its policies and actions. Solidarity, therefore, is more among actors both with and without disabilities at this level beyond the global and local disability movements.

The last characteristic of solidarity, the ability to articulate priorities of disadvantaged people, therefore, was paid little attention to due to the development cooperation system in the HIV/AIDS project, the power struggle of individuals in the general assemblies, and the nature of the general agreement among state actors in the African Union case. That is, to some extent both of the two Ugandan-based cases have disempowered and further marginalised already marginalised groups of people in the disability movement, while reinforcing the status quo in favour of the powerful. This phenomenon has already been observed long ago in the history of social movements. Van Houten and Jacobs (2005:648) claim,

When a social movement wants to gain power, a stronger organisation is needed and the organisation must grow. This demands a more bureaucratic form of leadership and some degree of specialisation and division of labour. Ordinary members no longer understand their leaders and vice versa. The social movement has been transformed into an oligarchy, ruled only by a few people.

This is known as “‘The Law of Michels’, the Iron Law of Oligarchisation” (Michels, 1911 cited in van Houten and Jacobs, 2005). Representation is not straightforward when its negative side significantly affects the collective goals to be achieved. The top-down approaches, partially taken by the HIV/AIDS project and the African Union case study, are aimed to empower Ugandan and African persons with disabilities in the long run by slowly changing the institutional and social structures where these persons live. The process is slow and often its impact is invisible for the persons with disabilities on the grassroots. As a result,

¹ The essentialisation of individual identity fixed only as persons with disabilities is problematic because the delegates change their identity depending on time, place and occasion: sometime they feel their identity as women, fathers, members of ethnic groups and so forth. Such identity could be more important than the identity as persons with disabilities depending on different contexts. This identity question is discussed in Chapter 2 and elsewhere (cf. Katsui, 2008-b).

representation has the potential to increase the distance between participants and non-participants (Barnes et al. 2006:205), which has to be kept in mind, even when longer-term impacts are targeted. Increased transparency of the representatives might be necessary to account for their meaningful activities not necessarily on the grassroots level but at higher levels such as governmental and continental levels.

Furthermore, a group of the most powerful persons with disabilities, namely the Members of Parliament, had a lot of influence over the decision making process, particularly in the second case study on general assemblies. The Members of Parliament have much better access to various information and resources, thus power as knowledge, which contributed to the power gap with the delegates and ended up in the influence: some coercive and other simply convincing political campaign. One woman with a physical disability said, "Many people were taken away by special hires and boda boda from the hotel to somewhere. They are treated with beer and money in nice bars and restaurants where they cannot afford. When many are from villages and come to Kampala for the first time and treated like that, they think those are Gods. They vote for anybody." (Personal communication on 8 December 2008.) A Deaf woman contestant who lost in an election of the UNAD general assembly tells, "The level of education of deaf is low and so it's easy to convince deaf by rich and influential persons like them. When you are poor, you believe in the powerful." (Personal interview on 6 December 2008 in Kampala.) According to the theory of decision making, when options are not clear to the decision makers due to lack of information, for instance, the decision makers are particularly vulnerable to the influence of others (Jenkinson, 1993:367). Social network analysis reveals the same (Woods, 2010:63-4), while another social psychology theory of social proof also affects decisions (ibid.59). As a result, power over others and power as knowledge become relevant. Groce and Bakshi (2009:3) claims that "Article 24 (of the Convention) itself refers to 'youth and adults', and Article 21 re-affirms the freedom of expression, opinion, and access to information, while Article 29 refers to the right to participation in political and public life. The ability to exercise these rights is directly related to the mastery of literacy skills." Thus, those who were illiterate, including the majority of deaf women, became vulnerable in this context due to the power structure based on power as knowledge. Landman (2006:10) also claims in more general contexts that the "full protection of the right to vote is largely meaningless in societies that do not have adequate health, education, and social welfare provision, since high rates of illiteracy and poverty may mean the *de facto* disenfranchisement of large sectors of the population." Under this condition, especially when the candidates and their supporters involved money, voluntary decision making becomes challenging when many of the delegates are poor due to often severely disabling environments and their impairments. In other words, there is the phenomenon of colliding rights: already powerful ones want to protect their individual positions in the name of the "right to participation in political and public life" as in the Article 29 of the Convention (power over), while others would like to raise gender equality, the non-discrimination of persons with different impairments as collective rights of representation (power to and power with). Consequently, **priorities tend to be made in favour of already powerful, vocal and/or visible people too often reflecting the existing power structure** at various levels. This internal dynamics of a social situation are important to understand because the existing power structure is not deconstructed without special attention, as there is often a mechanism to reinforce it from the side of more powerful actors.

When it comes to policy dialogue and negotiation at the level of the African Union by the UN Special Rapporteur, many persons with disabilities are not equipped with knowledge at this level. His mandate and capacity as the Special Rapporteur require him to act as one of the

representatives of the global disability movement to mainstream disabilities into policies and practices at high levels. He, however, does not forget to stay in touch with DPOs and listen to their experiences and challenges, and remains connected to the grassroots levels as was introduced in the previous sub-chapter. He concentrates on Africa because of his human rights-based approach that prioritises the most marginalised groups, while the two former Special Rapporteurs did not pay such attention to Africa. Thus a top-down approach is also highly connected to the concept of solidarity.

The positive aspect is that the studied DPOs are well aware of this marginalisation of the marginalised people and have been working on it to fill the gaps towards their empowerment in different contexts. At present, the self-determination principle of human rights as a group right of persons with disabilities more or less started to be achieved, while self-determination as an individual right is not achieved for the many persons with disabilities on the grassroots who are marginalised even within the disability movement. Empowerment approach with a focus on the individual, however, has been criticised as Eurocentric. For instance, van Houten and Jacobs (2005:644) argue that the conceptualisation of citizenship reflects the Western view of human beings as being autonomous and self-reliant and is often understood around the concepts including “(political) decision-making, deliberation and argumentation,” and “the free and critical mind (ibid.).” In Uganda, individuals are part of bigger units such as families, clans, (geographical, social and cultural) communities and so forth. Hence, it is self-evident that the local power structure matters. The concepts of empowerment **and well-being, therefore, need also to pay attention to the differences and dynamics of different stakeholders in these contexts**, while equality discourse tends to undermine differences (ibid.645). “Contextual variables” need to be taken into account (Jenkinson, 1993) rather than contextual universalism. That is to say, the empowerment effect cannot be limited to the official venue of the general assemblies, for instance. The empowerment effect takes place also in different localities or families where the delegates are from, after they have participated in the general assemblies. The immediate material impact comes from the transportation costs paid by the DPOs for the delegates to participate in the general assemblies. It is an overlooked truth that it costs much more for many persons with disabilities to travel the same distance compared with peers without disabilities, because some public transport vehicles charge even three times the fee for wheelchair users, for instance (Ministry of Finance, 2008:104). Nevertheless, the amount paid as transportation compensation was significant for any delegate. This financial impact might lead to the empowerment of the families of the delegates as a whole, which might lead to the better treatment of the person with disabilities by family members. Empowerment effects and well-being outside of the official venue are perhaps more important to elaborate on in future research, taking into account the local power dynamics among different stakeholders.

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

5. Evidence-Based Realities of Human Rights-Based Approaches to Disabilities and International and Development Cooperation¹

This Chapter tries to theorise human rights-based approaches to disabilities and international and development cooperation in practice based on the findings presented in the previous chapters. It first revisits the theoretical dichotomy between a human rights-based approach and a charity-based approach. In reflecting on the lived experiences of persons with disabilities, particularly those of women with disabilities, human rights-based approaches are understood through the concept of participation, namely, different forms of participation. The power to participate and the power of the more powerful over the less powerful actors are investigated. This first sub-chapter concludes that a human rights-based approach that is operationalised due to a power and treatment gap between different actors, or the inequality of some actor, often in reality starts from the level of passive participation when persons with disabilities on the grassroots are to be involved. This is more often characterised as a charity-based approach. Although human rights have been a “discursive process, not a static set of prescriptive values” that were “formed in the process of struggle and debates” (Meekosha and Soldatic, 2011:1387), when operationalised, they are located in this very context of power gaps. Hence, the two approaches are actually intertwined rather than dichotomously coexistent. The second sub-chapter analyses the reasons behind solidarity for these approaches and elaborates on the conditions where the approaches are actually operationalised. Subsequently, the theoretically negative charity-based approach is focused on to investigate its positive elements found in Uganda regarding charity. The third sub-chapter ponders the twin-track approach, namely empowerment and mainstreaming, in conjunction with the relational approach of disabilities to understand and theorise the well-being concept towards a collective well-being beyond an individual one. The final sub-chapter places all these arguments into a more realistic, evidence-based empirical theory of the human rights-based approach operationalised in practice today, and introduces it in a visual chart.

5.1. Participation in Practice

The self-determination of rights-holders, namely persons with disabilities in this case, is one of the most important concepts in a human rights-based approach, without which, in theory, the approach would frequently not function and reach a set goal of human rights. Theoretically, as the juxtaposition of a charity-based approach and a human rights-based approach clarifies below, rights-holders are active subjects.

¹ Acknowledgement: this chapter was presented in the Finnish Disability Studies Conference on 8 June 2012 in Turku, Finland, and received positive and insightful comments. The author would like to thank the audience for the valuable input.

	Goal	Individuals	Responsibilities based on
Charity-Based Approach	Filling the gaps of (often material) needs	Objects of charity, “beneficiaries”	Discretion of givers, no obligations
Human Rights-Based Approach	Fulfilling aimed human rights in a human rights-sensitive manner particularly for the most marginalised people	Subjects as rights-holders as well as duty-bearers in different contexts	National and international law-oriented obligations and accountability for fulfilling the rights of individuals

Inspired by (Lundström-Sarelin and Mustaniemi-Laakso 2007; OHCHR, 2010:10) and created by the author.

However, the above case studies and their elaboration revealed that **“persons with disabilities” are diverse and individuals are playing different roles in the framework of international and development cooperation activities**. The participation of “persons with disabilities,” rather than self-determination, is superficially secured for both HIV/AIDS project activities and the general assemblies: in these cases, the representative persons with disabilities make decisions and exercise self-determination, which thus could be illustrated as the full participation of persons with disabilities. When the realities were elaborated more closely, it was found that only certain persons with disabilities actually fully and/or meaningfully participated, while many other persons with disabilities were left behind as passive participants or non-participants. For instance, deaf women and women with disabilities on the grassroots in the HIV/AIDS project remained passive participants, if included at all. Only “accessible” women with disabilities were included in the training activities, while “the most marginalised” women with disabilities, ones living in remote places where security challenges had not been cleared due to the civil war, were not targeted. Even district representatives with disabilities did not perceive their activities as a human rights-based and rather wished for material and financial support-based activities that are typical charity-based approaches. Staff C of a Northern DPO (personal interview on 18 February 2008 in Kampala) also supports this argument:

The people (with disabilities) on the ground, they are extremely poor and they have to do something about that first. We have to meet them first and empower them economically before we can talk about women’s emancipation, liberalisation and human rights issues. You have to bring these women (with disabilities) to a certain level.

This is echoed by the observation of the acting chairperson of National Council for Disability:

*“We are trying to do what you told us.” But some place, I think it was *** (name of a district), the Human Rights Commission was telling them, “We want to work with people with disabilities in human rights awareness as part of our major work. But we must confess that we have never seen disabled people coming to us to request any programme or any activity to engage in. It’s only people like you who come from Kampala who come here.” ... So there is a challenge. There are opportunities there, but people are not utilising them (personal interview on 4 February 2008 in Kampala).*

At this stage, the Staff C implies a top-down approach to reach and empower them first before further human rights-based activities. She expressed that it took 10 years of support before a group of women with disabilities on the grassroots could finally start talking about human rights. Hellen Asamo, the chairperson of NUWODU and a Member of Parliament representing persons with disabilities, also uses an analogy of war in this context:

“Put her to this job!” I fight very tough for women (with disabilities) so that they can get jobs. It’s really a war. It’s a successful war (personal interview on 31 January 2008 in Kampala).

Only those staff at the national representative level spoke using human rights terminology and located their activities in a human rights-based approach. Alex Ndeezi, the Deaf Member of Parliament and Executive Director of UNAD, hopes for the future that:

Capacity building of deaf people [is important] so that they can advocate for their human rights. When you go to the village level, they wait for someone like Ambrose (the chairperson) or Alex to come and tell them about certain issues. They are always waiting for Alex or Ambrose. They only wait for us. We need to empower them to look for things by themselves, to go into the grassroots, and not wait for the national organisation to come and visit them (personal interview on 28 January 2008 in Kampala).

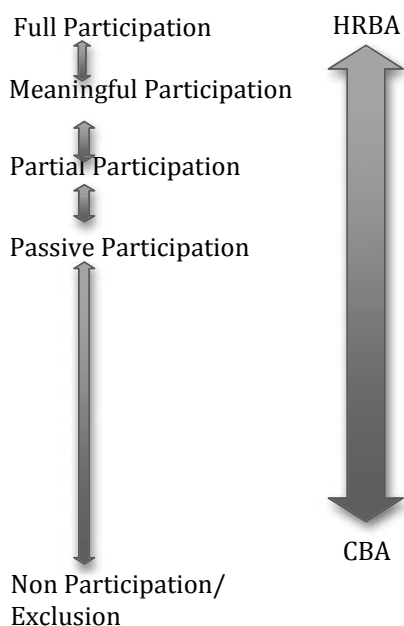
In practice, therefore, **self-determination as an important concept of a human rights-based approach was transformed into diverse levels of “participation,” which thus co-opts the existing power structures and even reinforces the status quo** (Frediani, 2010:174), as a charity-based approach notoriously does. In practice, this finding of little attention paid to the non-discrimination principle was also valid among Norwegian actors in the field of disabilities and development (NORAD, 2012:77). The report argues that the explicit action of inclusion is necessary to apply human rights-based approaches (ibid.78).

When it comes to the general assembly of NUDIPU, the national umbrella organisation, voices of diverse persons with disabilities, in terms of different impairments, were heard. However, votes were not given -except for one single vote for three other DPOs- neither in the concerned general assembly nor in the future. Only those with physical disabilities, “deaf” and “blind” were represented as entire “persons with disabilities.” Internal disability politics and politics in disabilities played significant roles in reinforcing existing power structure within the disability fraternity. In the UNAD general assembly, hierarchy even among “deaf” persons led to decision making that left those deaf persons with less capacities behind, while one region was not represented in the general assembly at all. Particularly deaf women who are neither sign language literate nor literate in writing and reading were largely passive participants. As for the case of international cooperation involving the African Union, many stakeholders, including donors and the African Union, frequently have an upper hand at making strategic decisions, while full participation of persons with disabilities tends not to be prioritised, let alone participation of the most marginalised women with disabilities.

The findings from the case studies, therefore, mean that persons with disabilities are not automatically playing the rights-holders’ role, namely by exercising self-determination power. Many of them remain passive and are only included, or in some cases even excluded, by representative persons with disabilities. In their study on post-conflict Sierra Leone, Santos-

Zingale and McColl (2006:253) similarly claim, “NGOs cannot expect the poorest of the poor to manage on their own without assistance in a country which does not even have services for the general population.” In this regard, a human rights-based approach and a charity-based approach are not totally as different as they appear in theoretical juxtaposition, but are different edges of the same spectrum. Heidi Hautala, the Finnish Minister of International Cooperation, made a keynote speech in the conference on “Equal before the Law” on 6 March 2012 in Helsinki, and asserted the importance of human rights-based approaches. She further claimed, **“Bottom-up and top-down approaches are complementary.”** She stated, “The rule of law should be everyone’s best friend.” That implies everyone should be included and grow into rights-holders, while the government, institutions or DPOs in different contexts pave the road for them to fully participate and exercise self-determination rights. McRuer (2006:101) also asserts that the feminist notion of interdependence that is the mutual cooperation between essentially independent persons is actually not true and suggests, “Interdependence begins with dependence.” The European Commission Report (2010:29) similarly reveals that many NGOs with charity and medical approaches have increasingly “embraced a comprehensive rights-based approach.” Hence, evidence has been accumulated to prove that they are not totally separate approaches but an interplaying continuum. In the same vein, starting from the reality that is seemingly far from human rights-based approaches and thus “it may go against our personal belief” (Santos-Zingale and McColl, 2006:256) and Northern “norms and values” (ibid.243) is sometimes unavoidable for eventually attaining human rights objectives including non-discrimination.

The graph below illustrates evidence-based knowledge on a human rights-based approach and a charity-based approach in terms of the participation of persons with disabilities.



The gradation of participation of each individual implies how much power one holds: only powerful actors among persons with disabilities tend to exercise meaningful and full participation and to have the choice of participation or non-participation, while many remain

as partial, passive or non-participants without a choice. It is beyond the binary of powerful and powerless, as is often the case for describing persons without a disability and persons with disabilities, but much more diverse even among persons with disabilities. Michael Foucault's power and knowledge theory is relevant both externally and internally. Knowledge, shared, hidden or controlled with or without intention, by the power of more powerful actors is often considered "truth" regardless of its validity. Externally persons with disabilities tend to be left out from HIV/AIDS-related international and national programmes and discourses, whereas internally those on the grassroots, particularly deaf women, tend to be marginalised even in the disabilities-specific development cooperation activities of Ugandan DPOs. Internally, power was often materialised in the division between **votes and voices** in the general assemblies and top-down modalities for women with disabilities on the grassroots in the HIV/AIDS project. Clear power gaps were observed in the case studies among persons with disabilities, particularly when those on the grassroots are involved. **Persons with disabilities are both rights-holders AND duty-bearers: they are also responsible for respecting, protecting and fulfilling others' human rights.** Many of them in the general assemblies, however, forgot that they were also duty-bearers and asserted on their behalf only.² In this very regard, the capacity of persons with disabilities, even that of those who were playing powerful roles in decision making has not reached the aimed level of equality yet in reality. Consequently, this under-capacity jeopardised the participation of many others. That is, a similar hierarchy of power in society was reproduced within the disability fraternity. One of the characteristics of a human rights-based approach is that it recognises structural causes for the deteriorating well-being of persons with disabilities, and it is operationalised in that specific context of power inequality. Due to this very reason, it is not straightforward to operationalise it in practice. The legal pluralism theory³ is informative for understanding "the role of diverse normative regimes not (legally) connected to the State and conceiving them in a language and vocabulary that does not presuppose the State as the standard case" (MacDonald, 1998:13). Similarly, **a human rights-based approach is often investigated in the context where a charity-based approach or other approaches are predominant.** Hence, a social science study as is this one is required to understand and explain a human rights-based approach in such a context.

5.2. Solidarity Connects the Two Approaches

Despite the differences among persons with disabilities and between countries, solidarity often plays an important role in connecting them; especially those with the same or similar disabilities (see the deaf people's case in Saito, 2007:108). Solidarity is an interesting concept

² Safia Nalule, the Member of Parliament representing women with disabilities argues that the government is to fulfil the rights of persons with disabilities. She adds,

We have a role to play as beneficiaries because rights are not given. Although they are inevitable, you cannot just sit there and expect that people will give you the rights. You have to rise up and demand it. If someone is not observing your rights, they you have to challenge them in court. But also we disabled people have the obligation as leaders to make these rights known to disabled people. ... Even me, I cannot say that I know each one and everything. ... Nobody should take away your rights. As much as that is clear, if everybody actually knows that, people would not be abusing the rights of others (personal interview on 15 February 2008 in Kampala)

³ A feminist researcher, Griffiths (2001:120) recommends pluralism that "is grounded in the reality of people's lives" for a human rights discourse, rather than universalism, essentialism or relativism. Similarly, MacDonald (1998:3) refers to legal pluralism as "a radically heterogeneous concept. The plurality is not just of citizens; it is a plurality of legal orders as well-each operative within the same social space and each one of which exists independently of the others. ... Conversely, to understand the role that State law actually plays in a given social field, it is necessary to understand the character and operation of multiple regimes of unofficial law in the same field."

to explore in the discussion between human rights-based and charity-based approaches, as solidarity rights⁴ include rights to development and are the most progressive rights (Landman, 2006:9). 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, the author would rephrase the following, based on the case study findings, as characteristics of **solidarity: a collective identity, an awareness of equality (or a problematisation of inequality) and the ability to articulate priorities of the disadvantaged people.**

Solidarity coupled with other strong motivations leads to concrete action by the advantaged people for and/or with the disadvantaged people towards equality. Within the case study settings, solidarity was exercised when there were ‘advantage gaps’ between actors, such as between deaf women on the grassroots and the Deaf leaders of DPOs, between the Ugandan and Northern DPOs, and between persons with disabilities in African grassroots and the Special Rapporteur. Staff C of a Northern DPO explains how she started to be involved into development cooperation activities:

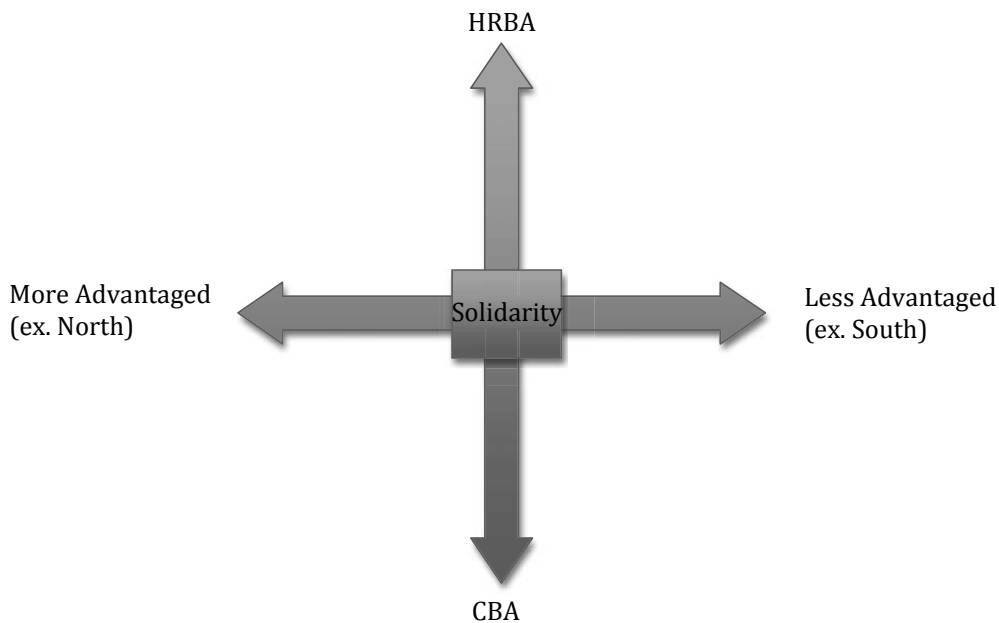
Slowly and slowly as I matured and gained more acceptance of my own disability, I started to look out in the world. I think it is a very classic development when you get settled with your own things, you get more ready to focus on other things. And that followed the general development of the disability movement in (my country). It actually started to look out more and became more active in international development cooperation (personal interview on 18 February 2008 in Kampala).

Expressions used, such as “our sisters and brothers” (NUDIPU chairperson, 2008) when a Ugandan DPO describes their constituency, and “sister organisations” (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 hitherto excluded people based on a good intention. Staff C of a Northern DPO (personal interview on 18 February 2008 in Kampala) explains that the disability movement in Uganda is an exceptional experiment in solidarity in otherwise a very hierarchical “feudal society.”

You could say that in the whole of Uganda, this disability movement is a big experiment. It's conflicting with the basic ways of organising things in Uganda because we are organising across tribal, family and clan issues, everything. And normally, we are trying to organise Ugandans in a horizontal way where the Ugandan system is organised in vertical lines. So it's a very crazy experiment. And only it goes because we have this solidarity of disability among us, due to something which is more than a tribe, more than anything. Yeah. Solidarity. Because otherwise, you don't meet the word solidarity in the Ugandan context, it is patronising. If you have something, then of course it's charity. You'll give something to those in your family who are under you vertically.

⁴ Landman (2006:9-10) explains that solidarity rights include the rights to public goods such as development and the environment. Solidarity rights seek to guarantee that all individuals and groups have the right to share in the benefits of the earth's natural resources, as well as those goods and products that are made through processes of economic growth, expansion and innovation. Many of these rights are transnational in that they make claims against wealthy nations to redistribute wealth to poor nations, cancel or reduce international debt obligations, pay compensation for past imperial and colonial adventures, reduce environmental degradation, and help promote policies for sustainable development.

In her explanation, there is a fine line between a “horizontal” way of organising (human rights-based approach) and a vertical way (charity). They are very close to each other, divided only by “something.” Disabilities, however, go beyond the existing power structure and enable solidarity to function also in a horizontal manner in Uganda, which is otherwise based on a “feudal,” vertical system. In theory, therefore, **solidarity as a motivation for action and as a starting point can lead to both charity-based (CBA) and human rights-based approaches (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 that connects both approaches in this context.



The precondition for solidarity in developmental activities is often a power gap in terms of personal or organisational capacity and the environment, which cannot be changed over a short period of time. For instance, it took 10 years for a Northern DPO to sensitise a group of women with disabilities on the grassroots to start talking about their rights (Staff member C of a Northern DPO, personal interview on 18 February 2008 in Kampala), while a single intervention of a DPO can hardly change this structural demography among them. Thus, solidarity-oriented action is first exercised under this power structure, ideally to the most disadvantaged ones. Empowerment and capacity building of disadvantaged people, therefore, are some of the first activities that frequently take shape in giving, such as service provision, material delivery and various trainings. This top-down approach in the framework of DPO activities is applied to maximise the benefits of the disadvantaged people in a given situation, so as to first fill any necessary preconditions for further activities utilising a human rights-based approach. At the same time, patterns of societal behaviour in which persons with disabilities play 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, which will be investigated further shortly in Chapter 6. Thus, **DPOs end up operationalising a charity-based approach in practice, due to the very circumstances of many persons with disabilities on the**

grassroots pertaining to their under-capacity and a disabling environment. In this way, the stakeholders' choices are made, with reason, between the charity-based and human rights-based approaches.

The empirical theory, based on the lived experiences of persons with disabilities involved in this study is, therefore, that when those three characteristics of solidarity, coupled also with resource availability in some cases, are shared between people from different advantage backgrounds, then activities more likely result in a human rights-based approach. For instance, Danish development workers and Ugandan DPO staff members share a similar understanding, including a collective identity, equality awareness and the prioritisation of disadvantaged people. Amongst them, a human rights-based approach was regarded as natural and important. On the other hand, when those three characteristics are maintained only by the more advantaged group of people but not by the less advantaged ones, the result tends to be a charity-based approach. For instance, the deaf women on the grassroots and the Ugandan DPO staff did not share those values amongst themselves and as a result, their activities resulted in a more charity-based approach despite the intention of applying a human rights-based approach. This theory provides practical implications to understanding under which circumstance a human rights-based approach can be operationalised in practice.

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 disabilities. Shakespeare (2006:3) claims, "[R]ights alone are not sufficient to promote the well-being of disabled people, and that charity - defined broadly as love and solidarity - must also play an important part." At the end of this sub-chapter, we shall contemplate **the role of the charity-based approach as a cutting edge for the analysis of the human rights-based approach to disabilities and international and development cooperation.**

When this debate is transferred to a Southern context, **charity becomes an indispensable aspect of realities of many persons with disabilities on the grassroots** because they are recognised as "the vulnerable among the poor" (Wilkinson-Maposa et al., 2005:42). Conducted interviews in the study clarified that the neighbours, friends and family members of persons with disabilities -even though they are poor themselves- give support to persons with disabilities simply because they are part of their community. That is, they are not excluded as non-participants but included as passive participants under a charity-based approach. On the one hand, this reality frequently perpetuates the continuing of many persons with disabilities on the grassroots to play the passive role of objects in international and 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, and yet as a community culture, quite sustainable even though help can be sporadic. This philanthropy community culture is not regarded as problematic for Ugandans. Moreover, the above case study analysis implies the possibility that a human rights-based approach has to start at the level where persons with disabilities 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, a charity-based approach

cannot be undermined as a solely negative intervention approach without taking into consideration the specific context in which collective well-being is more valued than the individual one. Shakespeare (2006:165) also asserts, “disability rights are not incompatible with charity.” Therefore, **the analysis of human rights-based approaches to disabilities and international and development cooperation should, rather, pay more attention to the negotiation of these approaches.**

5.3. Empowerment, Mainstreaming and Well-being

The evidence-based knowledge accumulated by hearing the lived experiences of persons with disabilities in Uganda reveals that a charity-based approach is not totally evil, let alone the top-down approach of the case study on international cooperation on the continental level. Even passive participation in a charity-based approach is much better than non-participation in the form of exclusion and could improve the well-being of persons with disabilities to some extent. **Without certain prerequisites such as food, mother tongue literacy and assistive devices among others, persons with disabilities hardly feel the sense of empowerment to identify themselves as rights-holders.** Alex Ndeezi, the Deaf Member of Parliament, argues, “The most important thing is information. Information is power, but for the deaf people, it is the problem. They don’t have access to information and so they are not getting human rights because information is power. It cannot be developed without information” (personal interview on 28 January 2008 in Kampala). That is one of the first steps for persons with disabilities on the grassroots, particularly for more disadvantaged groups of them such as women, children and elderly with disabilities on the grassroots. Empowering activities are often disabilities-specific top-down provisions, particularly when the persons with disabilities on the grassroots have not played active roles in social situations within their own communities and families. For instance, HIV/AIDS training for deaf women actually started with sign language training in order for them to gain the mother tongue literacy needed for understanding the following advocacy part of the training. DPO staff members identified their needs and implemented the training in this way, which is thus technically close to a charity-based approach in terms of decision making power and the passive role of the deaf women on the grassroots. Nevertheless, by learning basic terminology such as “matooke” “skirt” and “shirt” in the training, the deaf women experienced positive changes in their lives for being able to express themselves in their language. This is a fundamental prerequisite of a human rights-based approach, although dealt with via a top-down approach. That is to say, even a top-down approach could sometimes be linked to a human rights-based approach, unlike the hitherto theory focusing only on the self-determination of rights-holders as active and autonomous subjects.

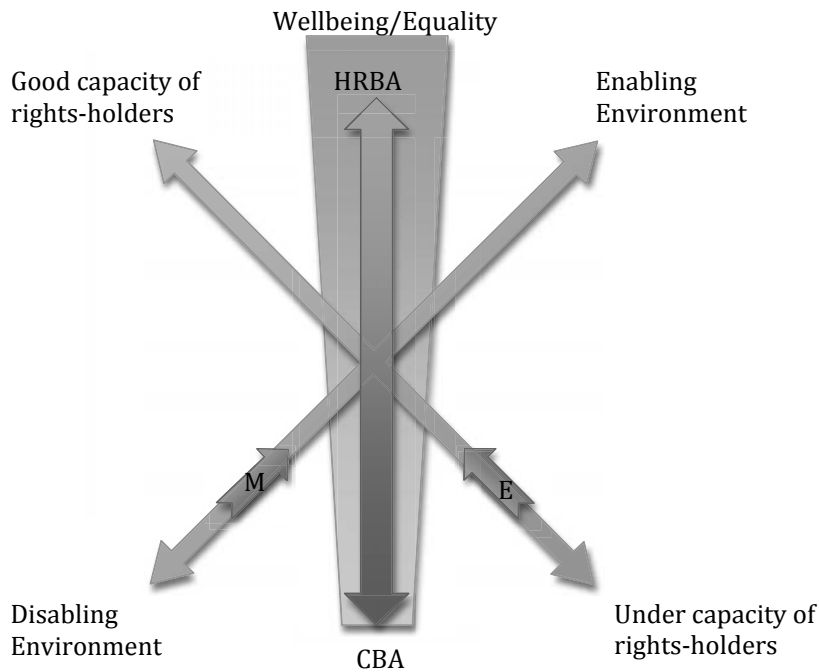
When it comes to general assemblies, delegates and non-delegates practiced the political negotiation of power as citizens in the specific contexts. They assure that they are not isolated from each other but also have decision-making power when granted a delegate status. Collective identity is formed by meeting peers with disabilities. Through the process, persons with disabilities on the grassroots can deconstruct the stigma, self-blaming and the negative images acquired from witchcraft that the community tends to have coerced them to internalise. That is to say empowerment, thus, takes place also by passive participation due to the severely disabling environment in which they tend to live. The fact that a majority of deaf women do not acquire a mother tongue eloquently demonstrates the reality of such severely disabling environments. In the case studies, the collective well-being of their families and communities, however, is often not directly targeted with this approach. In this sense, a human rights-based approach -and particularly the empowerment part of it- has been similar

to the approach of “women in development” where only women were focused on and targeted to be empowered without considering the aspect of gender. “Gender and development” approach implies the necessity of moving from “persons with disabilities in development” to **“disabilities and development.”**

Conversely, an **enabling environment** is therefore indispensable for the well-being and eventual equality of persons with disabilities. The “environment” could involve different contexts such as family, community, DPO activity, school, work place and state. The environment can also be at a global level such as international and development cooperation, international trade, and global social movements, to name a few. In many cases, persons with disabilities themselves change their hats and become duty-bearers as responsible agents to respect, protect and fulfil rights of other people with or without disabilities. Even when the environment is not easily deconstructed in the form of societal change, such as climate involving heavy rain and snow, equal opportunities are to be secured with reasonable accommodation stipulated in the new Convention. The widely accepted twin-track approach, thus, claims the importance of both the empowerment of individual persons with disabilities and their organisations for increasing their capacities, and that of mainstreaming. Mainstreaming means, in practice that families send children with disabilities to school on an equal basis with siblings without a disability, and schools seriously take into consideration the reasonable accommodation principle to accommodate the different needs of children with disabilities. **Persons with disabilities, therefore, become empowered through mainstreaming and vice versa. Both empowerment and mainstreaming mutually benefit from each other -for the well-being of persons with disabilities and for collective well-being- in the efforts to achieve equality.**

A relational approach to disabilities, mentioned in the Chapter 2, is important for explaining the complex nature of disabilities. Even when a person with a disability increases capacity and is willing to participate, s/he still cannot fully participate if the surrounding environment is disabling. For instance, without skilled teachers, many deaf children drop out of schools, and persons with psychosocial or intellectual disabilities and parents of children with disabilities were not allowed to vote even in the disabilities-specific context such as the general assembly of NUDIPU. Shakespeare (2006:34) similarly states that impairments are often exacerbated by social arrangements. Conversely, even when the environment is ready, a person with a disability cannot still fully participate without proper support if s/he is not empowered enough. For instance, disability councillors at a lower level cannot negotiate their concerns into the mainstreaming agenda even though they are mainstreamed into local politics, and deaf women cannot raise their voices to be heard in the general assembly of UNAD, even when they are represented as delegates. Even the Special Rapporteur has difficulties to make his voices heard in different mainstream agencies. Barrier removal is not an end in itself. It is a means to an end (Shakespeare, 2006:50). That is, a **theoretically articulated human rights-based approach is only possible when the capacity of the individuals and their organisations are equipped and the environmental context is an enabling one in which human rights are respected, protected and fulfilled with reasonable accommodation.** In practice, therefore, a human rights-based approach is often operationalised in conjunction with a top-down approach with the intention of moving in the direction of the goals of the human rights-based approach: the well-being of persons with disabilities, collective well-being, and eventually, equality. **A human rights-based approach (HRBA) is not the only modality.** Various modalities, including empowerment (E), mainstreaming (M) and even the theoretically negative charity-based approach (CBA), among others, co-exist to change the

well-being of persons with disabilities and their communities for the better -towards the ultimate goal of equality- as has been exemplified in the case studies.



Improving individual situations is complex and “should be based on evidence, not ideology” (Shakespeare, 2006:62) of individuals, families, communities and specific contexts. Woods (2010:51) also claims, “For the last sixty years, scholars and practitioners of international human rights have paid insufficient attention to the ground level social contexts in which human rights norms are imbued with or deprived of social meaning. During the same time period, social science insights have shown that social conditions can have a significant impact on human behaviour.” His argument is extremely relevant to this study of social science on the human rights of persons with disabilities in Uganda. The case studies explicated that capacities and enabling or disabling environments on the ground, as well as personal characteristics, are too often a prerequisite for fully operationalising human rights-based approaches in the way the theory presumes.

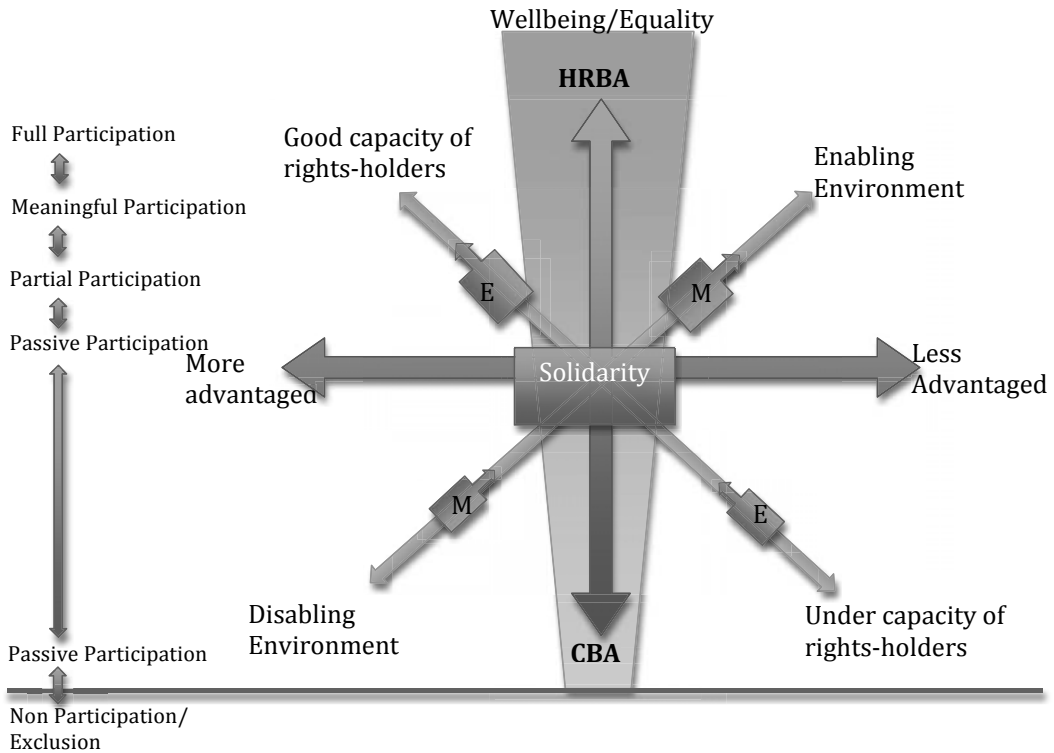
5.4. Evidence-Based Realities and an Empirical Theory of a Human Rights-Based Approach to Disabilities and International and Development Cooperation

The evidence accumulated in this study reveals that a human rights-based approach is rather theoretical, and not yet fully operational in the practice of disabilities and development pertaining to international and development cooperation. This is due both to a lack of capacity in persons with disabilities and DPOs, and lack of an enabling environment. Many persons with disabilities, particularly women with disabilities, remain passive participants even when

involved in an activity based on human rights-based approaches. However, due to the very fact that there are power and advantage gaps, solidarity often serves as the bridge which connects more advantageous people with less advantageous ones for the well-being of the latter. It can take place through more participation (a human rights-based approach) or without -or with much less- participation (a charity-based approach). Neither of the approaches has to date, however, secured self-determination and reconcile participation instead. Even in a human rights-based approach, participation levels differ, reflecting the local power structure, including disability politics and mainstream culture and the selected modalities of the more advantaged people with more capacities. The process of empowerment and mainstreaming, respectively, might be slower when the person's own capacities and environmental capacities are limited, while such intervention tends to make significant impacts when the capacities of rights-holders and their environment are better. For instance, Members of Parliament representing persons with disabilities have made national level impact on mainstreaming disabilities into Ugandan governmental policy and to some extent also practice (ex. The Universal primary education policy). On the other hand, disability councillors at the district level downwards are struggling with making their voices heard. The token involvement of under-capacitated individuals implies that it is easier to create visible outcome when interventions are aimed at those who have better capacities in a more enabling environment. This knowledge, however, should not be used to undermine the significantly greater needs of those with less capacity, because in principle a human rights-based approach is to be targeted for the most marginalised groups of people. **Interventions to these very people who have the least capacity due to a disabling environment require a much longer time period and more resources for positive impacts to be observed.** The outcome might be difficult to quantify, for instance, when a deaf woman meets other deaf women in training but still they cannot communicate well without having any common systematically learned language, and does not learn the content of the training implemented by a DPO. When it comes to "persons with complex dependency needs," as was pointed out by the European Disability Forum (2007), the outcomes of any intervention could be more difficult to quantify, while the recipients tend to remain passive objects of the interventions. Neoliberal optimism is "misplaced," particularly when it comes to persons with intellectual disabilities (Swenson, 2008:626) and psychosocial disabilities. This, however, does not by any means indicate that the persons' well-being is lower as a result of their capacity (particularly as capacity pertains to self-determination) as better well-being and equality are the goals of *intervention* in this empirical theory. Moreover, the **decision not to participate is not equal to non-participation in the form of exclusion.** The following is an empirical theory of a human rights-based approach to disabilities and international and development cooperation. It is not an empirical theory to disabilities in general outside of the intervention context, unless proved to be applicable in other contexts.

A human rights-based approach (HRBA) to disabilities and international and development cooperation is often under pressure to lean towards a top-down type of approach or a charity-based approach (CBA) due to disabling environments and consequently, the under-capacity of persons with disabilities. Materiality, defined as the "actual historical, social and economic conditions that influence disabled people's lives, conditions further mediated by race, ethnic, gender, class and sexual politics" (Erevelles, 2011:119) is relevant. Therefore, the various interventions based on empowerment (E) and mainstreaming (M) activities try to improve realities respectively and interactively. The positive impacts of interventions to the well-being of persons with disabilities can be observed more easily when the persons are more

empowered and the environment more enabling. An empirical theory of a human rights-based approach is simplified, but captured in the following:



As the above picture shows, **the line between a charity-based approach and a human rights-based approach is vague** in the sense that in both approaches, persons with disabilities can play passive roles in terms of participation. Perhaps the difference is that in a charity-based approach, the persons' needs are met in a sporadic manner decided by the givers, while in a human rights-based approach, needs are met as a matter of human rights and thus as sustainable and legally stipulated rights. For instance, in a charity-based approach a necessary assistive device would be given to a recipient when a giver decides to deliver a limited number of standardised models of the device only in the capital city area. In a human rights-based approach, however, the assistive device is secured to be given to anybody who needs it, regardless of geographical proximity or distance to the capital city and it would be tailor-made to meet the specific needs of the person. In the former case, one might miss out on the information that some organisation received such devices. One may also not have enough money to go get the device from a certain spot without accessible transportation means. In the latter case, information and devices are available, accessible and affordable. Nevertheless, even if sporadic, a charity-based device provision would improve the well-being of some persons with disabilities and their families when institutional services are non-existent. In this regard, charity as such cannot be undermined because it also serves to fill the gaps.

Persons with disabilities are both rights-holders and duty-bearers in different contexts, though the primary duty-bearers are the states as referred to in the Convention. For instance, the persons with disabilities could be duty-bearers as parents of their children for their rights

to education. In this context, they are part of an enabling or disabling environment for their children, who are rights-holders. One important finding missing from the above picture - particularly on the basis of the third case study on the international cooperation facilitated by the UN Special Rapporteur- is dialogue, negotiation and information dissemination (the third track) among different stakeholders so that mainstreaming disabilities becomes common practice for everyone. Without this, an enabling environment is difficult to achieve. This part will be mentioned further in the following Chapter 6. As the picture depicts, human rights-based approaches try to improve both the individual and collective well-being of persons with disabilities and their families, with the ultimate goal of equality.

6. A Human Rights-Based Approach to Disabilities and Development in a Global Context: Politicising the Global Context

“There are no neutral agendas, there is no pre-discursive embodiment and there are no politics-free zones where stakeholders can unite in terms of absolute good” (Oinas and Jungar, 2008:255). However, a human rights-based approach aims at universal norms and is thus criticised for the absence of public scrutiny to discuss why and how. It is also criticised for undermining the agencies’ own identification of values (Frediani, 2010:182-3). He rephrases that “approaches to development can explicitly incorporate this reflexivity of their (the agencies’) role in the process of moving from rhetoric into transformation, without being coerced, manipulated, and co-opted into preconceived goals” (ibid.185). Values based on local context and individuals are often undermined and even overruled by universal norms. In other words, although human rights have been a “discursive process, not a static set of prescriptive values” that were “formed in the process of struggle and debates” (Meekosha and Soldatic, 2011:1387), a human rights-based approach tends to depoliticise itself. Thus it needs critical self-reflection to examine whether the approach really fits the reality where it is used. When many modalities are identified in development and disability discourse, such as empowerment, mainstreaming and community-based rehabilitation (European Commission, 2010:48; NORAD, 2012) to name a few, a human rights-based approach needs to be continuously questioned on its validity in a specific context. The context which has been missing is the global one, as is often the case in the analysis on disabilities and development (ex. NORAD, 2011:22⁵), to which now we are turning.

6.1. Neoliberalism as a Form of Globalisation: the Evil Force against Persons with Disabilities

When a human rights-based approach, exemplified in the American with Disabilities Act (ADA) of 1990, is implemented in the United States into a growing economy (before the financial crisis), the unemployment rate of working age persons with disabilities remains around 70%, while that of persons without a disability continues to decrease (Russel, 2002:117). Russel further uses the example of the Civil Rights Act of 1964 and points out that “black unemployment remains twice (8%) that of the official national rate (4.2%)” (ibid.121). Even under current “welfare” capitalism, the ADA has not succeeded to address and remedy systematic economic substratum already pointed out in Marx’s theory of absolute impoverishment (Mandel, 1962 cited in Russel, 2002). She points out that “methodological individualism” (ibid.122) depoliticises an economy that accepts “unemployment as an integral part of the normal capitalist system” (Kalecki, 1971 cited in Russel, 2002:125). The work ethic of capitalism and industrialism in the late nineteenth and early twentieth century which concentrates on efficiency is part of a social model approach used to explain disabilities (Chappell, 1998; McRuer, 2006:88). McRuer (ibid.) asserts that a shift took place in the emergence of the identity of the able-bodied worker, and as a result that of disabled bodies. Disability identities have emerged in multiple public locations over the course of the twentieth century, from the League of the Physically Handicapped in the 1930s to the Deaf President Now action at Gallaudet University more recently (ibid.89-90). At the same time, in the early decades of the twentieth century in the United States, for instance, persons and children with disabilities were institutionalised (ibid.92). In Uganda, this took place during

⁵ NORAD (2012:22) shows a chart of theory of change in the field of disabilities and development. However, it neglects to reveal any global context.

the 1960s when the government constructed institutions for rehabilitating persons with disabilities (James Mwandha, personal interviews on 25 January 2008 in Kampala). Even today, many parents of children with disabilities “dump them” in boarding schools for children with disabilities and “go away thinking everything is done” (Chairperson of NUDIPU, personal interview on 31 January 2008 in Kampala). Conversely, children with disabilities in mainstream schools experience negative attitudes:

They (the teachers) go with those (pupils) who are quick. So those with intellectual disabilities are left behind. They are called, “musil,” meaning stupid. They don’t take care of their concerns. They move with those who are speedy, those who are able-bodied and those who are intellectually sound. And those who are slow either in terms of intellectuality or disability, either they are blind or deaf, they don’t mind. So there are very many challenges (Chairperson of NUDIPU, personal interview on 31 January 2008 in Kampala).



Picture on the left: Susan, a Deaf girl, and Benjamin, a son of a father with a physical impairment, are cutting a big cake for celebrating their graduation from Makerere University on 1 February 2008. They are cousins. They are dressed in a gown and wear a black hat with red strings. They are about to cut the cake on the table in front of them. A field had several tents to accommodate guests. Food and drinks were served. Guests went to congratulate their achievements and hug, while sliding money into the hood of the gowns. Only privileged ones hold a party for their graduation. As Susan went to the Ntinda School for the Deaf, there were a number of Deaf friends of hers attending this party. In her speech, Susan said, “Sign language looks different and people feel that we are special. But as I talk, they also know what I speak through the sign language interpreter. They might look different but they also have feelings and they are also the same people. Disability is not inability. Please understand that we are the same people.”

Picture on the right: the Kireka Rehabilitation Centre premise which shows signs of different organisations, such as the Uganda Foundation for the Blind, Sense International East Africa, and UNAB (Uganda National Association of Blind). Since the 1960s until recently, this institution/vocational training centre was free of charge and gave skills to persons with disabilities for income generating activities. Today, the services are provided only for a fee. For instance, an information and communication technology (ICT) course costs 455,000 shillings for 2-6 months, according to a blind ICT instructor (personal interview on 14 February 2008 in Kampala). Accommodation is free. He explained that the tailoring course is mostly for deaf girls but also girls with other disabilities, while carpentry is for boys. ICT is only for the blind. He advertises the course in a radio programme meant for persons with disabilities, because radio is the most appropriate means for blind people, he claims.

Today, the implications of unemployment are “good” for the economy: to discipline labour, to keep competition high and workers’ wages down, and to control inflation, thereby protect class privilege (Russel, 2002). She criticises the pure economist for rationalising unemployment as “voluntary” without addressing the economic system or social relations that create it (ibid.126). Similar trade-off takes place between equality and market efficiency

in capitalism. "Reasonable accommodation" is often watered down because employers' right to property weighs more than the right to work of persons with disabilities. In this context, Russel (2002:128) calls disabilities historical social creations of capitalism.

[When 'rights-bearing persons'] lack the power and resources to properly 'compete,' rights can do nothing but reinforce the status quo, as those left powerless can do nothing [but] make sporadic and/or symbolic claims. (Young & Quibell, 2000: 757 Cited in Russel, 2002:122).

Along with the same vein, persons with disabilities in Australia have to go through a "neoliberal workfare programme" to gain access to needed services and the "disability support pension" (Soldatic and Meekosha, 2011). They claim that this statutory-citizen relationship and structure are embedded in neoliberalism.

When it comes to the realities of Southern countries in relation to neoliberalism, the Member of Parliament representing women with disabilities, Safia Nalule, states:

As much as we are fighting for the human rights and dignity and whatever, you cannot be a dignified person when you are begging, for example, when you are sleeping in somebody's house, when you are a totally dependent (personal interview on 15 February 2008 in Kampala).

Her statement powerfully tells of the **paradoxical context in which the human rights discourse is located**. A human rights-based approach is to be implemented "out there, in this separate place called the Third World, but it does not require any critique of the global system and our place in it" (Uvin, 2002:9) and thus, it tends to depoliticize Northern realities including the global structure. This criticism is related to the world-systems analysis which was developed by Immanuel Wallerstein in 1970s and 1980s. The analysis tries to investigate social change in the world systems and history, and explains the situations of periphery and semi-periphery countries in relation to the situations of counterpart core countries. Development "business" has depoliticised this historical background. It is often the relationship between the (Southern) state and the citizens which is under scrutiny, while global phenomenon and patterns often remain unanalysed. Moreover, the well-being of individuals is paid attention to in relationship with community at its best. The collective approach, rather than the individual approach, tends also to be marginalized which is problematic particularly in Southern contexts (Meekosha and Soldatic, 2011:1387) in which disabilities are often family concerns (Grech, 2011:94). The "free autonomous individual" is often associated with neoliberal views in itself (Söder, 2009:78). This was also pointed out in the aforementioned United States' case (Russel, 2002). At the same time, the **well-being of individuals is not much located in a global structure**. For instance, even while the Nordic countries use human rights-based approaches as an essential part of their development policy today, Sweden, for instance, increased its export of weapons, amounting to a total of 13,9 billion Swedish krona (1,6 billion Euros) in 2011. This includes exports to conflict areas (Kauhanen, 2012). A peace organization heavily criticises such exportation, to Saudi Arabia, for example, as it is one of the world's "most brutal dictator" countries (ibid.). Although the Swedish government tries to put pressure on the weapon companies, it cannot control them. Similarly, neoliberal globalisation hardly becomes part and parcel of a human rights discourse on disabilities and development -consider the impact of Chinese companies in Africa. Mashaie (2012) goes so far as to assert that Chinese investment does not have democracy and human rights conditionality built into its economic-centred cooperation. He claims that

Northern countries have to learn from Chinese flexibility. Concerns about the missing global context are increasingly attracting attention also in international events on disabilities and development. For instance in a UN event, a representative from the NGO Committee for Social Development stresses global social justice through redistribution and a balance between social and economic investment by establishing a progressive financial transaction tax, reallocating 2% of the military budget to social development, eliminating subsidies, and allowing Southern countries to control their own markets (United Nations Economic and Social Commission, 2012). Another mention was also made of a Bolivian alternative of well-being, “*vivir bien*” not only in climate change discourse but development discourse in general.

Ontoformativity is a concept in “understanding social dynamics in bodies as a form of global social embodiment” (Connell, 2011:1371) and social process on a world scale, as it focuses on the power to create social realities on bodies through historical time (ibid.; Soldatic and Meekosha, 2012:251). McRuer (2006:57) similarly argues, “On me, not in me,” which refers to “ways of seeing, questions about when and where looking inside the body works in tandem with the relations of looking shaped by global movements for social and economic justice and when and where looking inside the body works against those relations.” McRuer (2006:41-2) names this the Crip theory and asserts, “Crip experiences and epistemologies should be central to our efforts to counter neoliberalism and access alternative ways of being.” Meekosha and Soldatic (ibid.1392) then continue that this ontoformativity sheds light on impairment not as “natural” but “artificial,” also in relation to imperialism and colonialism. They call imperialism and colonialism the “root causes of global impairment” and thereby open the debate on redistributive justice. Neoliberalism and its competition and profit-centred ideology have affected disability services by “pushing for privatisation, encouraging for-profit services, emphasising competition, and imposing indirect controls in the name of accountability” (Connell, 2011:1375). More directly, capitalism has shaped the understanding of disabilities as “impaired productivity” or “exclusion from the labour market” (ibid). When employment has become norm, only the right to decent work is promoted (ex. ILO, 1996-2008). However, for persons with severe disabilities, the right *not* to work is a highly relevant topic for discussion (Ngirabakunzi and Katsui, 2009:133-136).

Not only has the shipment of blood and organs from the South to the North, but also the beauty industry has driven the “global rich” to body perfection and thereby left others with a counter image (Connell, 2011:1376). Meekosha and Soldatic (2011:1387-8) argue that global neoliberalism has driven many persons with disabilities into lowly paid jobs as their “duties,” while global climate change and ecological catastrophe have forced many to become disabled. In Botswana and South Africa, many workers became disabled due to insecure work in mines to make profits for wealthier people (Ingstad, 1997 cited in Benedict and Eide, 2011:6). Grech (2011:89) further enlists hitherto missing aspects in North-centered disability studies: the experience of colonialism, the development of post-colonial contexts and identities, the impacts of neoliberal globalisation and neocolonialism, poverty, micro-politics, communities, linkages to historical and global metropolitan power centres, and the negotiation of hybrid identities and settings in local/global intersections.⁶ Neoliberalism has marginalised and isolated persons with disabilities, while the “colonial humanitarian model” also brought (re)institutionalisation, thereby destroying traditional ways of caring for persons with disabilities within communities (Miles, 2003; Ingstad, 2001 cited in Grech, 2011:95). Whyte and Ingstad (1995) claim that the informal economy may provide a greater probability of work for persons with disabilities, especially when the family is the basic unit of production,

⁶ Of which poverty and disability have attracted attention of disability studies (ex. Benedict and Eide, 2011).

working conditions are flexible and tasks are varied (e.g. handicrafts) (Grech, 2011:95). Nevertheless, McRuer (2006:193) points out the perpetual (and disciplining) possibility of co-optation to hegemony and normalcy. His criticism is valid to the claims of Whyte and Ingstad as they make the suggestion only in the framework of neoliberalism focusing primarily on employment and personal efficiency. **The past, present and future of neoliberalism as a form of globalisation, therefore, have been constantly reconsolidated in disability studies, both in local and global contexts** (cf. McRuer, 2006:17 and 201-8).

6.2. Ugandan Disabilities in a Global Context

Annual growth rate of the population in Uganda is as high as 3,4%. Life expectancy at birth is as low as 45,7 years. 38,8% of the population is under the national poverty line (UN Uganda, 2005:iii). About 78% of the population lives in rural areas (WHO, 2009-b), most of whom are engaged in agricultural work. An urban-rural polarisation is taking place: the Ugandan National Household Survey of 2003 reveals that 54% of the people in the Western region live in absolute poverty, while 28% in Central region which includes Kampala. The Northern region was devastated by the civil war which lasted for more than 20 years and remains the poorest. There 61% of the population live under the poverty line (WHO, 2009-b). Persons with disabilities who are deprived of their human rights in multiple ways are disproportionately overrepresented among the poor population in Uganda. These are neither natural nor ontological facts to take for granted but creations of the present global context, to which we are turning in this sub-chapter.

Uganda became independent from Britain in 1962. The chairperson of the NUDIPU thinks that the passivity of persons with disabilities on the grassroots partly arose from the period of colonisation when charity-based approaches were introduced and predominant:

A lot has to be done because many of our members who are persons with disabilities, they think that things have to be done for them. This is because during the colonial days when the British were still here and in the days that followed, PWDs were taken more as a case for charity than individuals with rights. Things were given as a favour instead of thinking that it's a must. They have to. They are supposed to be part of the system. Many of the people down there still think so [of disabilities as charity issues] (personal interview on 31 January 2008 in Kampala).

Until the regime of the current president Museveni since 1986, upheaval of both internal and external politics, including the military dictatorship of the infamous Idi Amin took place. Even after Museveni's regime, civil war in Northern part of Uganda continues with the Lord Resistant Army, which has led to increased number of persons with disabilities in this area, including landmine survivors, and those with physical and hearing disabilities among others. Since 1987, Museveni's regime actively followed the structural adjustment programmes (SAPs) recommended by the World Bank and the International Monetary Fund in favour of market forces and the private sector. As many other countries that followed the SAP, Uganda was not an exception in entering into economic stagnation and debt accumulation. People in the formal sector became unemployed, which led to further development of the informal sector to alleviate large-scale poverty in Uganda (Ssonko, 2007:188). Ssonko points out that the low level of production and the poor quality of products in the majority of cases may not stand up to the competition arising out of the liberalisation programme that permits the importation of cheaper but better quality goods (ibid.190). The major negative impacts of the SAPs are increased poverty among people and the polarisation of wealth (ibid.194). Many persons with disabilities have been disadvantaged by this process.

Under these circumstances, Sulaiman Madada, the State Minister for the Elderly and the Disabled explains why the Ugandan government has enacted a number of proactive legal frameworks, including the Constitution, and gave credit to both the democratic government and strong advocacy and lobbying of the disability movement:

The current government went to fight for the rights of the people. It is a people-based government. And it has listened to each circle of society. That way, because of the opportunities to listen to people, we realised that with affirmative action to originally disadvantaged groups, we would have development that would not care [for them otherwise]. Particularly when looking at the international trend, the globalisation, liberalisation and capitalism, it's the stronger ones that benefit in the open economy. So we need what we call a special programme in order for us to bring out those people who are originally marginalised. And therefore, this particular Minister of Gender, Labour and Social Development is here to ensure that the marginalised groups of people in society are brought forward in the development arena. (Personal interview on 19 February 2008 in Kampala.)

Nevertheless, staff member A of a Northern DPO criticises that the political representation is only a “cheap solution” compared with proper service provisions to persons with disabilities (personal interview on 30 January 2008 in Kampala). He recalls the vice chairperson of the ruling party saying, “We gave you the representation. What more do you want?” thereby depoliticizing disability issues as a whole. That is, the representation is supposed to go against globalisation and capitalism but the solution is also embedded into capitalism in this way.

In 1996 the Uganda Debt Network, a civil society network, was established under the Jubilee 2000 for the total cancellation of debt. In 1998, Uganda was one of the first countries to benefit from debt relief from the Highly Indebted Poor Countries Initiative. Uganda produced the Poverty Reduction Strategy Paper as known as the Poverty Eradication Action Plan in 1999 and received the second debt relief in 2000. The Ugandan government set up the Poverty Action Fund as a form of budget support⁷ from donors, thereby savings from the debt relief are allocated for directly reducing poverty (WHO, 2009-a). Consequently, the budget for primary health care increased by 50% and water and sanitation 40%, though cases of corruption exist (Freer, 2002). In 2005, pilfering of some government ministers led to suspension by the Global Fund (Kelly and Ford, 2009). GDP growth of 2010/2011 is 6,3%, and real GDP growth per capita is around four percent in the 2000s. “Uganda’s growth over the years has remained well above Sub-Saharan Africa average” (World Bank, 2011). Today, the World Bank, African Development Fund, the United States and the United Kingdom are the four biggest donors of development aid to Uganda (Kelly and Ford, 2009). Even the Minister for the Elderly and the Disabled admits, “The country is not financially sound. So when you begin with portioning this money to many demands and conflicting needs, you find competition for this resource” (personal interview on 19 February 2008 in Kampala). Donor dependency of Ugandan government is 55.9% in 2009. Uganda is one of the top 20 donor dependent countries in the world (ActionAid, 2011). Persons with disabilities have not been prioritised, neither by donors nor the government, which will be elaborated further in the

⁷ Budget support is one of the responses to aid effectiveness and coordination among donors. However, this method of support has shifted the decision making power to higher levels, thereby making support more inaccessible to marginalised groups of people (Wood et al., 2011:47 cited in NORAD, 2012:60). Consequently, Norway stopped this modality in 2011 and started a more sector-focused modality in its support in Uganda (NORAD, 2012:60).

following sub-chapter.

International events have affected the disability movement in Uganda. The Fourth World Conference on Women in Beijing in 1995 affected the Ugandan disability movement. Some women with disabilities participated in the Conference, and subsequently established a network DPO of women with disabilities (Safia Nalule, the Member of Parliament representing women with disabilities, personal interview on 15 February 2008 in Kampala). Similarly, a regional workshop at Harare in 1998 participated by a group of women with disabilities led to the establishment of another DPO of women with disabilities (Staff member C of a Northern DPO, personal interview on 18 February 2008 in Kampala). The gender sensitive proponents have been pressuring the Northern DPO also to apply a similar approach back in the North. (ibid.) The South African Treatment Action Campaign (TAC) that was established on the International Human Rights Day, 9 December 1998, succeeded in making generic antiretroviral medicines available to 47 countries in Sub-Saharan Africa in 2003. Multinational pharmaceutical companies agreed upon it. HIV/AIDS issues involve both local and global aspects (McRuer, 2006:54) also in Uganda. Also, in November 2007 when the 53 Commonwealth Heads of Government Meeting (CHOGM) was held in Kampala, the disability movement held the first ever Disability Conference in the Commonwealth. It accepted a Memorandum⁸ which included the sentence that all Commonwealth countries “develop disability policies and programmes to cater for the concerns of persons with disabilities (PWDs) in line with article 32 of the UN Convention on International Development Cooperation.” Subsequently, in 2008, the Commonwealth Disabled People’s Forum was newly established and the late James Mwandha was elected as the chairperson. The UN Convention also affected the making of the Disability Act of Uganda. Alex Ndeezi, the Deaf Member of Parliament recalls, “We identified issues from the UN Convention and drafted it” (personal interview on 28 January 2008 in Kampala). These are only a few examples of deep inter-linkages of Uganda with globalisation in the field of disabilities.

When it comes to the level of individuals with disabilities, neoliberalism has been dominantly affecting everybody. For instance, lawyers with disabilities working at Legal Action for Persons with Disabilities (personal interviews on 21 February 2008 in Kampala) do not get salaries, as donors tend to pay for the direct costs of activities but not salaries. Other lawyers with disabilities prefer to work in law companies rather than in DPOs. The same criticism against donors not paying for human resources was raised even by a staff member C of a Northern DPO (personal interview on 18 February 2008): “They (donors) are not so good in supporting secretariat structure but we need a strong secretariat to do the fund raising.” Similarly, a “brain drain” has been occurring among those educated medical staff members who could serve persons with disabilities. As soon as they are trained, they move into South Africa and those in South Africa, to the United Kingdom (Staff member A of a Northern DPO, personal interview on 30 January 2008 in Kampala). Neoliberalism, therefore, has been both directly and indirectly driving attention away from persons with disabilities.

As for experiences of persons with disabilities more on the grassroots, without such a good education, an interviewee (deaf woman F, personal interview on 10 February 2008 in Kampala) expressed word-by-word as follows with her limited sign language literacy:

In (19)87, I started this job. I go there. At 6 pm, I finish my work. After that, I go back home.

⁸ A Memorandum of the CHOGM is found on <http://wecando.wordpress.com/2007/11/22/memorandum-commonwealth-disabled-peoples-conference-2007/> Visited on 14 March 2012.

One day when I went back home, there were people knocking the house down with big stones. There are rich people who can buy land without us noticing. When I went back, my house was demolished. All the buildings which were in the place were demolished. That was in 94. ... My parents died in 91. All my sisters and brothers died. I'm the only one still alive. Right now I have 5 boys and 1 girl. I have 4 other children but they died. I stay in a very small house. I sponsor my children to go to school, one child goes to school. Very little money. I don't buy clothes. I just wash and keep them clean. In 06, my husband passed away. ... All the houses were destroyed. I try to get another house. We live in a very, very small house.

The inhabitants of one area suddenly lost their houses because of "rich people," which she could do nothing about. Not only poverty, but also lack of a social network including extended family members forced her to a position of vulnerability in the community. As she did not understand some of the simple questions that the author asked, the research assistant who is Deaf added her information from time to time. Here is a fragment of a conversation between the deaf woman F, the research assistant (RA) and the author (R):

R: Do you participate in any activity of UNAD? (This question was not understood.)

RA: Sometimes she does not understand and repeat the question I ask. What I know is that currently she does not attend any activity. But UNAD used to organise the end of year party in Kampala and those who can afford to come to UNAD came there. Drinks were free of charge and they talked. So those who could come came there. But she is a very busy woman washing clothes (for her work). So she does not have much time to go and participate in UNAD activities. That's why her sign language skills are limited and mainly speaks with local signs because she didn't have opportunities to sign to interact. Being a responsible mother of a big family, she didn't have much time to interact with others. That's at least what I can know about her lifestyle and background information of her.

F: I don't go to different places. I wake up in the morning, dress up, and go wash babies' clothes. I don't go up and down. I don't have rumors. I just stay at home. When the work is done, I come home and sleep. Rumors and fighting, no I don't do that. At 5⁹ pm, I go back and eat whatever. But I don't do anything else.

Her life as the female head of her household is centred around work to cater for her children. This has restricted her time of socialising and has limited her opportunities to learn her mother tongue of sign language in a proper way. That is why the author had difficulties in communicating with her. Capitalism has caught her up to make her ends meet. The chairperson of the UNAD shares a similar story of his mother: "I owe so much to my mum because she pushed so hard for me to be here. My dad lost his job due to SAPs. So mum is our breadwinner at home" (personal interview on 28 January 2008 in Kampala). In parallel with that, some others are benefiting from the neoliberal economy: "In the past, persons with disabilities were beggars. But now they are earning their own living. So we have many positive changes, though challenges are still there. There is an issue of poverty" (Alex Ndeezi, personal interview on 28 January 2008 in Kampala).

A Member of Parliament representing women with disabilities, Safia Nalule (personal

⁹ She mixed up 5 and 6 in other places, too, when she was telling about her final education. She said primary 5 sometimes, and later primary 6. This implies that counting might be difficult for her due to lack of educational opportunities.

interview on 15 February 2008 in Kampala), faced the discriminative attitude of the government when she was young and looking for a job in the Ministry after completing her university degree. All the others from the same course were employed in the Ministry, while a “secretary” refused her by saying that she would not manage the job and did not allow her to meet “any top people.” She was very disappointed by this refusal. Her father then asked his friend who was a headmaster of a secondary school to employ her as a teacher. So she was a teacher for a while. When teachers went on a strike against the low salary, she also joined. The headmaster said, “Even this one joined the strike.” She recalls, “He even did not call me by my name.” After continuous disappointing experiences and “negative attitudes” in the labour market, she felt, “I must go out and join other disabled people to work for my own people. I should go to a place where I belong.” And she finally decided to work in a DPO. Her experiences also highlight the importance of education, work, efficiency, able-bodiedness and power in the Ugandan context. Consequently, her identity as a person with a disability was formed through the struggle in the labour market.

Disparity between urban and rural areas is extensive. The Executive Director of NUDIPU (personal interview on 31 January 2008 in Kampala) explains that productive ability in agriculture in rural areas and employment/begging in urban areas for livelihoods are different, though both are deeply related to capitalism. A person’s worth and usefulness tend to be measured by such productivity. Individuals are more pronounced in urban areas than in rural areas where persons with disabilities are part of families. He connects the lifestyle of urban persons with that of “developed countries.” He then presents an example of a sign language interpreter:

When we are planning (some activity), we include disability compensation to cover the elements of guides and also sign language interpreters. In villages, it could be free when you bring your family member, but in town, this is a service when you go to a seminar or a conference, this person is paid. But it is much money. It’s around 30,000 (shillings), which is big. 30-40,000¹⁰ shillings, it’s around 20 dollars. So a person cannot afford it. But like in rural areas, they can use local interpreters¹¹ because I know that the signs are not universal.

He asserts that people need to appreciate the challenges and not to “look at deaf people as burdens who are very expensive.” As a result of neoliberalism, sign language interpretation has become a service that you have to purchase for a very high price. Deaf woman A also mentions, “Official interpreters want to be paid. But we cannot use interpreters because we don’t have jobs. So the alternative is to pick a family member. Then you can understand a bit” (personal interview on 4 February 2008 in Kampala). In some sense, deaf persons are further marginalised because interpretation service is not affordable. Similarly, assistive devices are on sale in a shop. “Orthotech and Physical Rehabilitation International” was the only such shop in Kampala. An orthopaedic doctor working in this shop explains that the other shop went bankrupt (personal interview on 14 February 2008 in Kampala). For instance, one of the author’s assistants bought her callipers for the price of 300€ from this shop. The consultation

¹⁰ According to Ambrose Murangira, the Chairperson of UNAD, it is 50,000 shillings today (personal communication by e-mail on 15 March 2012.)

¹¹ The families the author met in villages did not learn to speak any proper sign language but communicated only with simple gestures. Thus, using family members as interpreters is to some extent unrealistic. But in rural areas, the only people who understand family-based gestures are the family members. In that sense, the interpreter’s role cannot be played but simple communication has to be relied on from family members.

fee is 15,000 shillings. Even if services and devices are expensive, around 300 patients visit the doctor per month with their own money. This is a totally private business, which establishes a big disparity between rich and poor persons with disabilities. These examples indicate that **society connects persons with disabilities not only to unproductivity but also to expensive burdens, according to neoliberalistic ideology.**

The definition given to the term “persons with disabilities” that includes within it only persons with physical, visual and hearing disabilities for the purpose of the delegations of the general assembly could be due to a lack of accessible and affordable medical services for most persons with disabilities. As a result, they began with the most objectively obvious categories.

In parallel with that, **consumerism** has been accelerated among persons with disabilities with more income. For instance, many activists have Nokia mobile phones, while others much cheaper Chinese ones.¹² Development of information and communication technology (ICT) has become a national strategy for development, as the fully-fledged Ministry was established in 2006. However, the digital gap between urban and rural areas is significant due to the affordability of ICTs. (Chairperson of UNAD, personal interview on 28 January 2008 in Kampala; Obot, 2010). The chairperson of UNAD tells that “those who use technology are Kampala dwellers” and for instance, the price of an internet connection per minute is cheaper in Kampala than in Gulu and Lira in the North. The often commoditized consumption and its patterns among the middle class Africans assimilate those of Northern counties, which include but are not limited to one’s own house, own vehicle, flat-screen TV, private schooling for children, foreign brand commodities, supermarket, and fast food (Ämmälä, 2010-b). This African-wide tendency is applicable also to Ugandans, but particularly to the middle-class population in Uganda.

6.3. Neoliberalism and the Development Cooperation System



Picture on the left: “Building Partnership: a workshop on partnerships between Ugandan and Danish DPOs” held in the Exotic Inn on 6 February 2008. Development partners gathered to strategise their activities for forging partnership. 24 people participated the workshop. One Danish person stated, “With the money involvement, we are not equal.”

After the general assembly of UNAD, the Deaf/deaf delegates danced and enjoyed the late night party. The Members of Parliament served foods and drinks. Not only the delegates but other members also joined this part of the general assembly. A DJ was present to play very loud music.

¹² The author had a Chinese phone which costs 20 Euros.

The development cooperation system, a social system, is not neutral either. The system has a peculiar donor-recipient culture that favours the donor (Tvedt, 1998; Hoksbergen, 2005). This was not always the case in the conducted observations and interviews (HIV/AIDS project officer at NUDIPU, personal interview on 1 February 2008 in Kampala; James Mwandha, personal interview on 25 January 2008 in Kampala; Hellen Asamo, personal interview on 31 January 2008 in Kampala; Alex Ndeezi, personal interview on 28 January 2008 in Kampala). It is (re)politicised in a human rights-based approach (Frediani, 2010:182). Many NGOs and DPOs working in Uganda in the field of disabilities get their funding from Northern governments, which vividly articulates that development cooperation is highly interlinked to global patterns and trends. For instance, the global financial crisis in 2008 led to a “reduction of the activities by most non-governmental organisations” (ADD, 2009; NORAD, 2012:80).¹³ This sub-chapter interrogates this realm of the development cooperation system from the viewpoint of the influence of efficiency-driven neoliberalism.

The starting point of development cooperation activities is often to show solidarity, by the more advantaged (ex. Northern DPOs) to the less advantaged (ex. Southern DPOs). For instance, a staff member of one Nordic DPO that financially supported the general assembly of NUDIPU states:

Realising that many DPO's in the South do not have the tradition, knowledge or experience with democratic practices, (my Northern DPO) has given support technically and financially to partner organisations to develop democratic practices and exercise these practices (staff member A of a Northern DPO, personal e-mail exchange on 26 February 2009).

Northern staff members sometimes start from very basic things, as was cited in case study 2:

The trainer starts explaining what money is. It's so basic, they don't know money and they don't know anything. And that's what we forget here in Kampala (Staff member C of a Northern DPO, personal interview on 18 February 2008 in Kampala).

That is, capitalism as well as neoliberalism enters into the lives of persons with disabilities on the grassroots also through development cooperation activities.

Many Northern modalities in general are criticised as being “old-fashioned,” still the dependency theory has prevailed. Is it generalisable in the Ugandan context? First of all, the development cooperation system requires **accountability and positive (tangible) outcomes** from intervention (Landman, 2006:126). The Paris Declaration (2005) mentions it as one of the five areas to improve the quality of aid, while the Accra Agenda for Action (2008) set as one of the three areas for improvement. Moreover the Busan Partnership for Effective Development Co-operation (2011) further reiterated its importance. Staff member B of a Northern DPO (personal interview on 15 February 2008 in Kampala) also struggles with the demand of the development agency of his own country which “always likes clear output data like numbers and figures and stuff like that.” In general, accountability is multiple both upward and downward (Edwards and Hulme, 1998) or mutual (Yakel, 2001). In a development cooperation system with hierarchy among actors, recipients are required to be upwardly accountable to donors, while downward accountability is rarely demanded

¹³ The reports did not mention how much the support has decreased.

(Townsend and Townsend, 2004; Johnson, 2001; Edwards and Hulme, 1998; INTRAC, 1998). Staff member A of a Northern DPO mentions such conditionality and restrictions of the country development agency with an example of questions on terrorism and corruption in the contract form to be filled by a Southern partner: "It is a paragraph, but it can look sometimes offensive, when you are suspecting corruption in the organisation because they are formulated in a very offensive language. It can be a root for mistrust... it sends a signal that I don't trust the organisation" (personal interview on 30 January 2008 in Kampala). Similarly, Southern actors are under invisible pressure to report positive results in this system (Tvedt, 1998; Edwards and Hulme, 1998). Alex Ndeezi recalls the reporting to a Northern DPO to be "very, very strict" (personal interview on 28 January 2008 in Kampala). Activities targeting persons with disabilities on the grassroots might not attract the attention of many Southern and Northern or international/multilateral agencies. This is not only due to their ignorance pertaining to persons with disabilities, but also due to the complexity of disabilities and the difficulties of producing quantifiable positive outcomes at the grassroots level, especially when the persons with disabilities have not acquired any mother tongue to express their opinion properly, for instance. Grech (2011:96) makes the same point about the **"unattractiveness" of persons with disabilities for donors** in the context of inclusive education in the South, and claims that "development is not for everybody."

If an intervention cannot prove its positive outcome in the development cooperation system, it is likely to be terminated as irrelevant, inefficient and/or unproductive. The utilitarianism and efficiency inherent in neoliberalism were transferred and rooted deeply into the development cooperation system. Alternatively, when activities take place "long enough," they are terminated as well. The realities of the case studies clarify that the development cooperation systems apply a neoliberalistic approach towards efficiency. Leaders and staff members make decisions eventually, although they try to decentralise them in the HIV/AIDS project and in the negotiation process on the African Union level. Even the delegates make national decisions rather than engage the population with disabilities en masse to thoroughly discuss and attain consensus in the general assemblies. Staff member B of a Northern DPO (personal interview on 15 February 2008 in Kampala) explains the **speed with which you have to move** within this system through an example of meeting deadlines for project proposals that sometimes come on short notice. As a result, only representatives work on such things to save time. He shares his experiences of working with Ugandan DPO staff:

Working dynamics here are sometimes different depending on whom you are working with... In that one (project) I feel myself pushing all the time. ... For the first month, I found myself doing a lot of follow-up and follow-up, trying to make sure that people are doing things in time. Meeting a deadline is always a problem, a big problem. That was a bit annoying but on the other hand, I saw them growing. ... Everything was delayed and delayed. And I said, "No, that's not an excuse. You still have to continue activities." I spent a lot of time clearing this mess. Well, not a mess, but those misunderstandings. Then people are keeping up to promises what they said they would do. I spent a lot of time with them. I also pressure them from time to time with text message reminders. ... I am a very fast person and I expect others to work as the same level as me -that is the challenge. You cannot expect the same output from each person (Staff member B of a Northern DPO, personal interview on 15 February 2008 in Kampala).

He thus ends up "doing so much what I am not supposed to do." Efficiency pressures the DPOs of both sides to work fast and among only the representatives on many occasions. Quick and

positive results are needed in a short term. For that, Northern DPOs send development workers to Uganda. Based on her own experiences, staff member C of a Northern DPO (personal interview on 18 February 2008) also claims that it requires more than 10 years of commitment from donors to create sustainable positive changes towards the well-being of persons with disabilities on the grassroots, while the system requires efficient, positive results quickly. Thus, she continues, "If you are sent by a development worker, you do what you are pressured to do."

That's where the negative part comes, when you are too busy in a short term contract and you have some output you have to fulfil. Then you become too focused on those and it makes you sort of deaf to those organisations and their needs. That could be a negative thing. ... They are recruited from (my country) and sent here. And the (Ugandan) partners don't have much say (Staff member C of a Northern DPO, personal interview on 18 February 2008 in Kampala).

The system overlooks the realities and contexts specific to persons with disabilities and their organisations in Uganda. It is also highlighted in the way a development worker is sent from a Northern country to Uganda:

Now the chief of (an impairment-specific DPO in my country) is visiting (a Ugandan corresponding DPO) and they would talk and say, "Would it not be a good idea to have a development worker?" Then they would answer, "Yes, yes." And Ugandan organisations say so because they need some human resources and manpower in the secretariat and somebody to fundraise, and that's what we are not very good in. We should not go and fill the gap in the Ugandan organisations. It may create some conflicts that the reasons why the Ugandan partners say, "Yes, yes" is different from the task for the development workers why they are recruited for. There is a problem (Staff member C of a Northern DPO, personal interview on 18 February 2008 in Kampala).

The chairperson of NUDIPU introduces an analogy of marriage between NUDIPU and the Northern funders:

Persons with disabilities in Uganda may think this is best for us, but (a staff member of a Northern DPO) can easily come and say, "No, that's not the way you have to go." But that's not what we want. Ok? So that's a bit, some kind of weakness, which we have lived with. We have lived with it because in marriage, you have to sometimes bend. ... At times, we have really insisted and said no. But at times, we were pushed to walls because you don't want to break the marriage. Sometimes you keep quiet and accept and say, "Yes," which is not good (personal interview on 31 January 2008 in Kampala).

He then introduces a concrete example where one Northern DPO decided to change the executive director of NUDIPU, even if this person was "of our interest" (ibid.) On the other edge of the spectrum, however, staff member B of a Northern DPO (personal interview on 15 February 2008 in Kampala) cautions against a long-lasting relationship with its Ugandan counterpart organisation as both of them "get tired of each other" and "personal conflicts" escalate to the level that they hinder development cooperation activities. He was sent from his country to Uganda because of this fatigue between the two parties. Although according to him, "Any aids are huge for them that are small and weak," maintaining the Northern staff in Kampala involves a lot of **costs** including salaries, "a big office, big car and all that." Staff

member A also states, “It (the money from this Northern country to DPOs in Uganda) even looks big. But some of them go to my salary and then administration in (my country) and even administration here, board meetings and whatever. It’s not reaching the grassroots” (personal interview on 30 January 2008 in Kampala). The author’s observation of the monitoring trip of the HIV/AIDS training in Gulu also indicates a mechanism for the high costs in Uganda: 500,000 shillings for the petrol, more than 100,000 shillings in allowance per day for three staff members from Kampala, 15,000-20,000 shilling allowance for 15 or so local staff members, and so forth. Similarly, in a regular workshop of the NGO Forum in Uganda entitled, “NGO Sector Consolidation, Diversity or Rationalization: Exploring the Synergy between National Umbrella NGO Networks for Greater Collective Impact” one of the presenters, Charles Lwanga Ntale (on 4 February 2008 at Hotel Protea) stated, “NGO workers have rich cars, laptop computers, they do not represent constituencies, and depend on donors. All NGOs are top heavy.” NGO management is criticised for “becoming a balloon that flies away from members.” He also criticised the general assemblies for being a site for votes only, no longer one for activities. Staff member B thus stresses to always question one’s relevance in the context. As a result, there is an increasing disparity between the development cooperation system and the realities of persons with disabilities on the grassroots.

While it is wrong to generalise the Northern actors as a monolithic group, some tendencies and patterns can be observed. One of these is that Northern and international actors do not tend to commit themselves to persons with disabilities in the South as obligations, and thus for a long period of time. Donor support to Southern DPOs are very few (NORAD, 2012:80), while some of the donors that support Southern DPOs choose the priorities on their own. For instance, a Danish report includes areas of potential future support already articulated in detail (DSI, 2007:43-47). This has been long observed and criticised. As Hofstede (1991:218) argues, “Donors tend to allocate money according to the (psychological) needs of the donor countries.” In other words, **donor countries allocate money according to their own evolving values and priority areas**. On the one hand, the chairperson of NUDIPU explicitly stated in the general assembly that it has changed its strategies from project to programme and also thematically, “In order to meet donor requirements.” He continued, “Donors’ priorities drive us, which is a problem” (on 8 December 2008 in Kampala). On the other hand on the donor side, for instance each newly elected government formulates a new development policy with new agenda in Finland: 2007 Finnish development policy programme highlighted environmental and climate change (Ministry for Foreign Affairs of Finland, 2007), while 2012 Finnish development policy action plan human rights-based approach among others (Ministry for Foreign Affairs of Finland, 2012). The Northern actors could even withdraw the whole development cooperation activities away from a Southern country when it contradicts Northern values and priorities. Sweden withdrew from Nicaragua due to various reasons, including concerns about the country’s authoritarian inclinations, human rights concerns pertaining to the banning of abortion as illegal (Schulz, 2007:3) and it threatens to withdraw from Uganda due to the Anti-Homosexuality Bill (Wambi, 2009). These methods of withdrawal express similarity to the conditionality of human rights in development support included in the second category of interplay between human rights and development (Uvin, 2004). When it comes to development cooperation in the field of disabilities in Uganda, Northern support phase-out is “the biggest threat that we are facing” (Chairperson of NUDIPU, personal interview on 31 January 2008 in Kampala). Withdrawal cannot be negotiated, “Because that is their decision. What we have to do is to identify new friends” (ibid.) Therefore, even when Northern actors claim that they highlight human rights and equality in their development cooperation activities, what is available and accessible for

persons with disabilities on the grassroots is few and sporadic, if not at all. Alex Ndeezi, the Executive Director of UNAD and the Deaf Member of Parliament, expressed to the audience in the general assembly of UNAD, "There are 700,000 deaf people in Uganda according to the Ugandan Bureau of Statistics. You as leaders need to know this number. We cannot save them all" (on 5 December 2008 in Kampala). Staff member A of a Northern DPO explains the positioning of NGOs, "With development cooperation we have provided as NGOs or DPOs, it's not expected from our budget that we can reach everybody. ... With NGO support, we can only look at them as pilot. We can test things out. We can test interventions, somehow create good examples that can be taken over by the huge donors like bilateral donors and powerful NGOs" (personal interview on 30 January 2008 in Kampala). Interestingly, the state is not considered the primary duty-bearer in this statement, but the actors of the development cooperation system are. Hence, in terms of responsibility, not all but many of the Northern actors are, in reality, closer to the charity-based approaches of "Discretion of givers" and "No obligations" under this system.

The disability movement is trapped in the system also in terms also of the donors' modalities of support. A staff member of a Nordic "partner" DPO that financially supported the studied general assembly of NUDIPU says:

In general the support from (my DPO) has been quite flexible, so the funding tends to end up in areas which no other financial source is willing to fund. Which very often are administration, monitoring, and costs related to the governing bodies of the organisations. These are typically costs that don't lead to direct changes in the lives of the target group, and which therefore most probably are less sexy to fund in a time where development agencies experience a high pressure on delivering concrete and measurable results in people's lives from their funding (A staff member of one Nordic "partner" DPO, personal e-mail exchange on 6 February 2009).

Research also supports the argument that few donors support the DPOs' administrative costs, when few donors support DPOs in the South in general (NORAD, 2012:80). DPOs therefore constantly need to compete for donor support. Umbrella DPOs, in particular, are in competition with other DPOs (ibid.41), when the umbrella DPOs have to deal with "general" issues applicable to all DPOs, while other DPOs pay more attention to different specific needs of their constituencies (Safia Nalule, personal interview on 15 February 2008 in Kampala). Even when one tries to establish a DPO, s/he meets very strong resistance from existing DPOs due to competition (anonymous, personal interview on 4 February 2008 in Kampala). This competitive environment of neoliberalism, in combination with disabilities-specific aspects of diversity in the needs of groups of persons with different disabilities¹⁴ often causes fragmentation of the disability movement as a result (ibid.41). Neoliberalistic ideology is paramount in a description used by the NORAD report when it claims some funds are "well-invested" due to a positive result (ibid.41).

The staff member of the Nordic "partner" DPO says:

¹⁴ The aforementioned Nalule also claims that being a person with a physical disability, she cannot fully understand the concerns of persons with psychosocial disabilities. The same point was made by Shakespeare (2006:195).

First and foremost, I think having the GA every five years does not promote a stronger democracy in the organisation, it gives the professional and top people in the organisation too much power (personal e-mail exchange on 6 February 2009).

Staff member B of a Northern DPO (personal interview on 15 February 2008 in Kampala) also observes some leader's personal interests on money only. This leader was nevertheless re-elected in the general assembly. Even though the representation is highly ambiguous, **representative democracy** in the form of organisational and movement management has been largely perpetuated as a power structure in today's development cooperation system also in Uganda, regardless of whether it is democratic or not. The present United Nations Secretary General, Ban Ki-moon, stated at the Davos World Economic Forum in 2009 that, "Our times demand a new definition of leadership - global leadership. They demand a new constellation of international cooperation - governments, civil society and the private sector, working together for a collective global good." After introducing this quote, the United Nations homepage introduced its partnership with NGOs and Civil Society Organisations (CSOs) as representatives of "civil society" (United Nations, undated). The Ugandan DPOs among them have become increasingly instrumental in working with different actors, including multilateral and bilateral institutions and governments (Lang and Murangira, 2009:18). Thus in general, the development cooperation system has a mechanism -and even a motivation- not to deal with persons with disabilities on the grassroots. Under the circumstance, Northern DPOs and disability organisations and their counterparts from the South, namely Southern DPOs, are often the only ones that include persons with disabilities on the grassroots in their activities. That is to say, generalising development cooperation activities solely as negative as a whole is too superficial and simplistic for understanding the diverse activities among them within the system.

When representation of the country is at stake, persons with disabilities are too often not involved in the representative delegates. Consequently, the development cooperation activities of the bilateral and multilateral levels are so beyond the reach of persons with disabilities that they cannot affect the decisions and budgets. Donors are not sensitive to having disability issues included into the agenda:

Most of the time when, for example, bilateral negotiations were taking place, it was in the high, high level, in those structures where we don't have our representatives, you see. For me, I realised this is the case when I was still in the council in Kampala city. For example, the World Bank would come, then negotiate a project with the Kampala City council. Of course the people who negotiate are those ones in the executive and high technical staff. So us disabled people are not part of the negotiations. So they would come up with, for example a project like constructing a structure, and when the project is presented to the council, disabled people are not included and access is not there and so on and so forth. When the negotiation is already done, and the budget is already done, here we complain about things when almost nothing can be changed. You see? (Safia Nalule, the Member of Parliament representing women with disabilities, personal interview on 15 February 2008 in Kampala)

This power structure of the global development system based on neoliberalism has a great effect on the well-being of persons with disabilities in Uganda by excluding them too often from the development discourse at different levels. For instance, the HIV/AIDS project has been trying to train TASO workers in accommodating disabilities-specific needs

and including persons with disabilities into their activities. However, “Our money is so small compared to what they get from the UN and all those other people. So they tend to sort of put us down in the priority list” (Staff B of a Northern DPO, personal interview on 15 February 2008 in Kampala). Thus, as long as big and influential actors are ignorant about disabilities, disabilities-focused activities are too easily watered down even when DPOs implement activities through a “partnership approach” with local mainstream actors. When approached, other actors in the mainstream are “positive” but in practice, they say, “Sorry, we have already made our strategy plans. We already made this and it was confirmed by the donor, so we cannot change” (Human Rights Officer at NUDIPU, personal interview on 4 February 2008 in Kampala). When donors including Northern NGOs are approached, they say, “We cannot mainstream them because we lack resources” (ibid.). They think “everything is expensive and special things” (ibid.). The human rights officer of NUDIPU asserts, “The donors have to promote a human rights-based approach. ... But currently donors are silent about it” (personal interview on 4 February 2008 in Kampala). She continues to assert that a disabilities inclusive activity is often “just one-off thing” (ibid.). Many actors “pretend to be human rights advocates” but “they themselves are not aware of what they are supposed to do for persons with disabilities” (Staff member B of a Northern DPO, personal interview on 15 February 2008 in Kampala). Landman (2006:2) argues, “Foreign aid, developmental assistance and programmes and actions by the ‘international community’... may be made in haste or at the service of ideological and political agendas, which in the end may have the perverse effect of undermining the promotion and protection of human rights.” Another Ugandan activist asserts that donors have to articulate disabilities as one of the key areas in their policies (Human Rights Officer at NUDIPU, personal interview on 4 February 2008 in Kampala). Consequently, “In most cases, we find ourselves in the jungle standing alone” (Chairperson of NUDIPU, personal interview on 31 January 2008 in Kampala).

When it comes back to the development cooperation activities, they are **not comprehensive but sporadic**¹⁵, even though extraterritorial obligation is stipulated in Article 32 of the new United Nations Convention on the Rights of Persons with Disabilities. For instance, the case study of the HIV/AIDS project implemented pilot activities only in three districts out of 80 existing districts in Uganda, although HIV/AIDS is also prevalent elsewhere. Similarly, a community-based rehabilitation programme of the government started in 1992 and was supported financially by the Norwegian Association of the Disabled until 2008 covered 10 districts only (Lang and Murangira, 2009:33). However, mainstreaming examples also started to accumulate. In 2008, World Vision International Uganda and NUDIPU created a manual for mainstreaming disabilities.¹⁶ However, good practices are still largely missing in mainstreaming disabilities into all levels of development.

A duplication and concentration of Northern interventions also take place, as the Paris Declaration on Aid Effectiveness calls for harmonisation and coordination among donors. A report of Norwegian development cooperation activities finds that even the coordination of Norwegian actors in a single Southern country has not been achieved so far (NORAD, 2012:66). In the Northern area of Uganda which has been affected by the civil war, the existence of many international agencies and NGOs made the prices high. For instance, one

¹⁵ For instance, Senyonga et al. (2009) claim that the efforts by the UNAD on sex education for deaf children are sporadic.

¹⁶ World Vision International Uganda. (2008) Including Disability in Development: Awareness Raising Training Manual -a practical guide for development workers on inclusion of persons with disabilities. On <http://ochaonline.un.org/OchaLinkClick.aspx?link=ocha&docId=1318358> Visited on 20 March 2012.

local deaf woman claims, “The price of everything is going up in the North due to Sudanese refugees who get cash allowance from the United Nations High Commissioner for Refugees. They buy anything with very high price, and thus locals suffer from high prices now. For instance, sugar cane is 1000 shillings when Sudanese brought the price up. It was 100 shillings before” (personal communication on 13 February 2008). This is one of the examples of **unintended impacts** of development cooperation and humanitarian aid. One deaf women’s group started a micro credit scheme with financial support of a Northern NGO, but that complicated the relationship between the group and members because money is involved and it must be collected (Chairperson of United Young Deaf Women, personal interview on 10 February 2008 in Kampala). She also sometimes has difficulties with members’ husbands who think that activities of the group “spoil” their wives and as a result, they do not allow the women to join. Some family relationships got worse when Deaf woman G participated in some activities of the group (Deaf woman G, personal interview on 10 February 2008 in Kampala). Another example of unintended impact is the very expensive sitting allowance for anyone to attend a meeting. On the one hand, donors are not willing to pay salaries and administrative costs but only the direct costs of activities. On the other hand, donors have left a culture of giving out sitting allowances to participants of meetings. UN agencies, the government¹⁷, NGOs and DPOs have all domesticated this habit (Staff member C of a Northern DPO, personal interview on 18 February 2008 in Kampala):

In a developing country like Uganda where people are extremely poor, people cannot be strictly volunteers as we are used to in a developed part of the world where we have the social security net. I have the disability grant. Nobody has that here. So it's a survival of the fittest. So that's why if you are a volunteer, you have to give them and cover their transport and their lunch. But it's true and it's a hard thing to tackle. We should take care in the up country in the fields, it also spoils people if people come and join associations to get money for the meetings. ... I also hear that there is a culture which might be gender-related that for a woman to leave the home and join a course, she has to come back with something. That is another side of coin. Money in cash, then you are allowed to leave the home.

The executive director of NUWODU asserts that allowances are indispensable for persons with disabilities to participate in associational activities and meetings:

It's not much when you think that they are PWDs and they often need extra transport for the distance which could be easy for others to walk but not so for them. There are unexpected incidents where you might need extra money to reach the meeting because our taxis are not trustworthy. Some bus comes only once a day and some might need to stay overnight to take the next bus. So for those reasons, there are more than the usual costs (personal communication on 13 February 2008 at Lira).

Nevertheless, staff member B of a Northern DPO (personal interview on 15 February 2008 in Kampala) points out that the allowance habit has created a “dependency syndrome.” He admits the diversity among the disability activists in Uganda, while confirms:

¹⁷ Staff member B of a Northern DPO (personal interview on 15 February 2008) says the government allowances are much bigger and around 200,000 shillings (100€) per meeting. He felt complicated receiving this money knowing half of the money comes from donors and the other half from domestic tax payers in terms of the national budget.

It has definitely killed a lot of dynamic in terms of people having their own initiatives and hosting meetings over time, not expecting someone to come and fund from outside. That's the very bad side of development aid, especially in this country. It created some bad dynamics in terms of expectations and all of that. I don't know how you can deal with it, but it's become so much part of the process.

He explains about the direct damage of this allowance culture to the Ugandan disability movement that “the board members of different organisations are interested in attending as many meetings as possible” for the allowance. On another occasion he says there are too many meetings and too little action. That is, getting the allowance becomes a personal priority over the activities. Hellen Asamo, a Member of Parliament representing persons with disabilities, also supports the argument:

You should not keep us reminding all the time about cash. That's why some of us were saying (in the chairpersons' meeting among 11 DPOs) that we used to come and sit without money. You carry your water and pay 500 shillings for your taxi and come back. But it (the sitting allowance) was brought with the development (personal interview on 31 January 2008 in Kampala).

Obviously, many activists still work hard in their activities, while this monetary incentive to rather spend time and energy on meetings is an observable aspect in the Ugandan disability movement today.

While staff member C (personal interview on 18 February 2008 in Kampala) claims, “I did a lot first years with Ugandans. We formed all those DPOs, **, ** and ** (names of DPOs),” the number of established DPOs is one of the indicators of development in this area (Staff member B, personal interview on 15 February 2008 in Kampala). Several impairment-specific Ugandan DPOs were established under the influence of corresponding Northern sister DPOs. The presence or absence of external funds is also an important indicator for judging the success of the DPO:

*Probably only 3-4 districts (District DPOs) have access to funding from **, from ** (names of funders) and from other funds. But other than that, some districts are very poor and they are not doing very well (Staff member B of a Northern DPO, personal interview on 15 February 2008 in Kampala).*

Today, from establishment to evaluation, perhaps too many aspects of the Ugandan disability movement are linked to the development cooperation system and neoliberalism, as has become clear from this sub-chapter. Having discussed the negative and controversial aspects of a development cooperation system based on neoliberalism, many of the inter-personal relationships are very good between Northern and Ugandan DPOs. Without the Northern interventions, persons with disabilities would have been left even more behind national development, because the **DPOs are too often the only actors reaching these persons with disabilities** as beneficiaries and participants of a number of activities. As discussed earlier, even a passive form of inclusion is a step towards a human rights-based approach. The Ugandan disability movement is very young¹⁸ and its originally human rights-based advocacy and activities have been overshadowed by the longer-lasting development

¹⁸ The Chairperson of NUDIPU states, “We feel we have just started our work” (personal interview on 31 January 2008 in Kampala).

cooperation system. If the development cooperation system does not change radically¹⁹, development cooperation activities will continue to exclude particularly persons with disabilities on the grassroots, due to the hitherto systematic mechanism of exclusion at different levels even within DPO activities. This is a consequence of the efficiency-based logic of neoliberalism, among others.

6.4. Globalisation also as Possibilities

Depoliticising the global structure is too naïve, whereas generalising globalisation as pure evil is also too simplistic and misleading. Touraine (2010:xi) argues, “A general consensus emerged that a globalisation which could also have positive dimensions should not be rejected and analysis and action should be focused on proposals and strategies to fight the negative form of capitalism.” Hence, we now turn to possibilities of the globalisation.

Ämmälä (2012-a) introduces the prevalence of mobile phones in Africa: even 63% of the population in Africa used mobile phones in 2011 already, although disaggregated data in different countries are not introduced and thus inequality among and within different African countries is unclear. Many Deaf people in urban areas of Uganda also use mobile phones - particularly the text message function- to communicate with Deaf fellows, which has introduced many possibilities. This phenomenon of using a wide range of new technologies as communication tools has been observed simultaneously also among Deaf people in many Northern countries (ex. Australia in Power and Power, 2007 and Germany in Power and Power, 2007). New technologies always entail further marginalisation possibilities, particularly among elderly people and others who are not keen on learning new technology as well as those who cannot afford it. It is a relevant theme to investigate as many deaf remain illiterate and thus, such technology is out of reach in many senses. However, the globalisation has reached some persons with disabilities, as this mobile phone example shows.

Not only the globalisation of new technology itself, but also international and local firms have increasingly paid attention to **corporate social responsibility** which aims at positive impacts, not only limited to employees but also to wider stakeholders. However the modalities are diverse and not necessarily leading to positive impacts. For instance in Uganda, DPOs started to seek partnership with external donors as well as domestic private companies for sustainability. “This is very new” (Staff member B of a Northern DPO, private interview on 15 February 2008 in Kampala). The case study HIV/AIDS project is partly funded by the “Global Fund to Fight AIDS, Tuberculosis and Malaria” that was established in Geneva, Switzerland, in 2002. Bill Gates of Microsoft was one of the first to have donated money for this fund.²⁰ When it comes to local Ugandan initiative, Crane Bank and Entebbe Handling Services have employed more than 10 persons with disabilities (Ngirabakunzi and Katsui, 2009:117). The Persons with Disabilities Act (2006) Article 13 stipulates the employment of

¹⁹ Professor Juhani Koponen of the Institute of Development Studies at Helsinki University expressed his vision to change the development cooperation system radically from donors’ altruistic aid to entitlement of Southern countries to receive aid as their rights, and the resources should be collected more like a tax (Rudanko, 2008).

²⁰ “As of January 2011, pledges from the public sector of US\$ 28.3 billion represent 95 percent of all pledges to the Global Fund since its inception in 2002. Pledges from the private sector and from innovative financing initiatives constitute the remaining 5 percent (or US\$ 1.6 billion). For 2002 up to 2015, 54 donor governments have pledged US\$ 28.3 billion and paid in US\$ 17.2 billion. Of all public sector contributions in 2009, 97.5 percent was paid in by 19 OECD Development Assistance Committee members. The remaining 2.5 percent was provided collectively by ten additional donor governments” (The Global Fund to Fight HIV, Tuberculosis and Malaria, 2012).

persons with disabilities and stipulates tax exemptions to employers when the quota is filled, though the quota is not numerically articulated (ibid.). From this fact, it is difficult to understand the nature of corporate social responsibility, whether it was based purely on philanthropy, shared values, risk management or corporate profit induced by the tax exemption. However, it is true that many Ugandan DPOs started to ask for financial support and/or partnership from private companies for their activities, while pressuring them to employ persons with disabilities.

Social enterprises and social entrepreneurship thus have increasingly attracted attention, too. Social entrepreneurship refers to innovative activity with a social objective in either the for-profit sector, in the corporate social entrepreneurship, or in the non-profit sector (Chell, Nicolopoulou and Karatas-Özkan, 2010:485). Entrepreneurial innovativeness for the goal of social well-being or to solve a “social problem” is one of the characteristics of social entrepreneurship. The financial profit is also meant to be reinvested into the community. The term social enterprise refers to an organisation in which this activity manifests itself (ibid.486). Going further into the discussion on social enterprises is beyond the scope of this study, but it is noteworthy that not only non-governmental organisations in the form of development cooperation activities, but more business-oriented organisations and companies are emerging to pay needed attention to people who have been affected negatively within the existing global structure. Social enterprises face similar questions as human rights-based approaches wrestles with: whether their activities are relevant; how they should be defined; whether they depoliticise the global disparity of equality; in which Southern contexts are they effective; whether they are seeking collective well-being or the individual one; how not to further marginalise already marginalised groups of people and so forth.

6.5. “Experience Is the Tool to Another Side”- Lessons to Learn from the Alter-Globalisation Movement

The aforementioned transformation has taken place through the **influence of the alter-globalisation movement**. Geoffrey Pleyers, the author of “Alter-Globalisation: Becoming Actors in the Global Age (2010)” presented in one of the keynote speeches at the Citizenship Transformation in a Global World Conference at Helsinki on 10 February 2012 that “Experience is the core of movement. Experience is the tool to another side.” His book ends by stating, “It is possible for states, the civil society, local communities and citizens to become actors in the global age” (Pleyers, 2010:263). Disability rights as well as human rights have been part of the alter-globalisation movement in the global context, even though they are not mentioned even once in Pleyers’ book as an active and influential participant group. Pleyers’ book could have been enriched by interrogating more on disability movement. His choice of excluding an analysis on disabilities within the alter-globalisation movement naturalises able-bodiedness and thus reinforces embodied normalcy in the global movement discourse. This theme will be revisited shortly.

Pleyers (2010) categorises the movement activists into two groups: those of the way of subjectivity (ibid.33-105) and those of reason (ibid.107-178). The former group focuses on autonomous experiences free of global neoliberalism and seeks participatory democracy. Such values are implemented in these activists’ daily life, including their movement and organisations, local communities and neighbourhoods in innovative and convivial ways through learning by trial and error. He (2010:96) states, “People who are excluded or marginalised often have little experience and few theoretical arguments but the experience they have is profound. It is on this basis that they build innovative movements in way of subjectivity.” The limitation of this group is its extensive focus on self-activism, which leaves

global engagement behind and helps to reproduce the very system that they are originally against (ibid.101).

The latter are mostly intellectuals and experts who use their specialised expertise and knowledge on certain issues to construct and present rational alternatives against neoliberalism with relevance and feasibility. They tend to privilege efficiency over participation and institutionalise the movement through top-down decision making to become a counter power for regulating the economy. Here, Foucault's power of knowledge is exercised. The mobilisation of international experts at the global level gives legitimacy to their arguments, but is contradictory in its internal democracy due to the reinforcement of the power of technocracy in the movement. These intellectuals' and experts' rationality and democracy are highly criticised and debated within the movement. The Iron Law of Oligarchy (Michels, 1966) takes place, while a classic phenomenon in the evolution of the social movement is materialised. That is, the activists become politicians themselves (Klandermans, Roefs and Olivier, 1998 cited in Pleyers, 2010:248). Thus dichotomisation between leaders and members is the risk for fragmentation. These two groups have been negotiating their concepts of social change within the same movement. This could bring about "cross-fertilisation" by maximising both positive sides with multiple alternatives. Each group must find its model (ibid.220). Multiple alternatives are needed to create a world in which many worlds fit (ibid.218). In this sense, even a small person and a local organisation can become a global actor (ibid.263).

Pleyers' sociological analysis on the alter-globalisation movement is useful to understanding the Ugandan disability movement today in a global context. Firstly, a big disparity exists between the leaders and "ordinary people" and even the "ordinary delegates." Their relationship resembles that of the alter-globalisation movement between the activists of the way of reason and those of subjectivity in terms of their participation and decision making. At present, participation is largely compromised in the general elections, where the Internet and other communication means that have played a big role in the alter-globalisation movement have not yet reached the majority of persons with disabilities in Uganda. Such means, however, have decreased collective identity, solidarity and activism in the alter-globalisation movement (McDonald, 2006; Aguiton and Cardon, 2007; Ion, 1997 cited in Pleyers, 2010:235). The face-to-face gathering at the event to celebrate the International Day of Persons with Disabilities and the general assemblies were festive and convivial for exchanging ideas and local practices. It was based strongly on the individuals' own experiences for those of the way of subjectivity. On the other hand, those are the places for leaders to present their (top-down) decisions, appeal to government officials and society in general also through media, and to reinforce their power over the movement to a large extent. The leaders who became Members of Parliaments, in particular, are controversial actors in terms of their autonomy and power over the disability movement, while they have facilitated nation-wide changes in Ugandan legal and political spheres. Thus, **without conscious efforts in cross-fertilisation, the movement has the potential high risk of dichotomisation and absorption**, as has been already observed to some extent. Staff member B of a Northern DPO (personal interview on 15 February 2008 in Kampala) observes that those who are good in advocacy work to high-level people have a weakness for working with people on the grassroots.

The Ugandan disability movement has not yet spent much energy on global issues such as climate change and the indigenous movement. It has concentrated its efforts on disabilities-

specific issues, including the new United Nations Convention. Even when an event takes place in Uganda, raising enough funds for travel costs and securing “fair” accessibility “for all” are big challenges for persons with disabilities.²¹ “Expansion of social movements along existing interpersonal networks excludes those who don’t belong” (Tilly, 2004:152 cited in Pleyers, 2010:142). Disabilities, particularly those in Southern contexts, are largely left behind in the alter-globalisation movement and its analysis, which is also implied by Pleyers’ book as it does not mention disabilities even once. McRuer (2006:42-48) points out that the Fourth World Social Forum of the alter-globalisation movement in January 2004 in Mumbai was different from the past and not harmonious, because persons with disabilities could not physically access the venue and were not included into the panel, and Deaf people were not provided with sign language interpreters. Disability activists raised these points vocally in the press conference. Apologies from the organisers were regarded as “a merely symbolic or token gesture” and did not satisfy the disability activists. At the same time, some World Bank officials were excluded for legitimising the voices and communities of the activists and told to speak elsewhere. The “open meeting place” and discourse promised in the World Social Forum superficially looks flexible to diversity, but in actuality the persons with disabilities are only subordinates to able-bodied people. In this way, the “system of compulsory able-bodiedness” prevails and repeats itself (ibid. 2). For instance, due to the repetition of history, a demonstration of women with disabilities was once again organised in India and a hundred of female wheelchair users staged a protest on the eve of International Women’s Day in 2012 (The Hindu, 2012).

In parallel with that, the alter-globalisation movement is institutionally largely supported by middle-class people with university degrees, because what they tackle is neoliberalism, and the subject is “quite complicated” (Pleyers, 2010:132). **The disability movement in the North also follows a similar trend in that many leaders are from privileged socio-economic contexts** (Shakespeare, 2006:75). This is hence another reason why many Ugandan persons with disabilities on the grassroots are out of reach of such a global movement. For instance, a study reveals that lowly educated people do not know about the existence of NGOs/DPOs (Kiribaki et al, 2008:16). Some form of representative democracy is needed to articulate problems, strategies, activities, implementations, evaluations and so forth, particularly when an overwhelming part of the population with disabilities is still illiterate and lacks resources and opportunities for communication. Without such representative democracy, whole issues could be easily depoliticised as taken-for-granted facts and as personal curses, witchcraft and the like.

The Ugandan leaders in the disability movement resemble the alter-globalisation activists of the way of reason in the sense that they do not necessarily internalise the values in their own lives. The author observed that some leaders of the Ugandan disability movement exercise top-down decision making not only in their movement and in organisational practices but also at home. Many of them employ maids, usually young girls from rural areas, for little money.²² Also their drivers²³ are treated badly in the sense that they work very long hours.

²¹ This issue was discussed on the basis of the experiences in the following:

- Katsui, H. & Kumpuvuori, J. (2009-a) “Vammaissopimuksen fraasi ‘samalla tavalla muiden kanssa’ käytäntöön Ugandassa.” Kynnys Mielipidelehti No.4 2009. (In Finnish.)
- Katsui, H. & Kumpuvuori, J. (2009-c) “Others.” On <http://disability-uganda.blogspot.com/2009/11/others.html> (In English.)

²² One of the research assistants had a maid at home. She paid her 20,000 shillings (10€) per month. She told the author, “It’s so cheap to hire a maid in Uganda.” The author’s next door neighbour family also had a maid who

Some of them are conscious about such a paradox and dare not to have any maid at home but these leaders remain a minority. This is an area of potential tension in the future of the Ugandan disability movement that should quickly be made note of in light of older social movements²⁴ as well as Crip theory (McRuer, 2006).

The Ugandan disability movement has not yet found its place in such a global movement, and as a result, finding its place in the international disability movement becomes important. Through conscious discourse using human rights terminologies from the beginning of the creation of the movement, some Ugandan disability leaders have become influential at a global level. Development cooperation activities and its system have affected the Ugandan disability movement to a great extent also through financially and morally enabling Ugandan leaders to travel abroad for attending international meetings (James Mwandha, former Member of Parliament representing persons with disabilities, personal interview on 25 January 2008 in Kampala). Nordic DPOs are visible in the disability movement today (NORAD, 2012:80), as almost all impairment-specific Ugandan DPOs get funding and other resources from their “sister” organisations in Denmark (DSI, 2006) and in Norway (NORAD, 2012:59). Some Ugandan DPOs have managed to diversify their source of funds, while others depend solely on Danish and Norwegian “sister” organisations. One Executive Director of a DPO first expressed that the relationship with its partner Northern DPO is good and based on a participatory approach. He then shared about a meeting among the DPO staff when a staff member of a Northern DPO joined in: “Before he (the Northern DPO staff member) came, the meeting was going on very well. But then when he came in, he just disorganised the whole process.” He carefully told the author of their vertical relationship particularly in terms of money:

Sometimes there could be some confrontation in terms of budgetary use. For us, what is right could be this, and the donor might say it's that. So we have to sit around a table. But they have the upper hand in determining what may not be such a priority for the membership and what would be funded.

He stresses that there are different kinds of donors and “their approaches are very different.” Much top-down decision making has been made at different levels, and will continue to be made in development cooperation systems which are located in power structures.

However, it is also true that **Northern DPOs and NGOs are too often the only ones approaching persons with disabilities with their activities, when the development cooperation system itself has the mechanism to exclude them in its search for efficiency.** Implications of any single approach in the development cooperation system as of today are obviously mixed. Nevertheless under the current global, national and local circumstances in which **Northern DPOs and NGOs** are one of the few actors, except for

was paid 30,000 per month. Another research assistant calls this “exploitation” as employers take advantage of the ignorance of rural girls for not knowing the standard salary in Kampala.

²³ One Ugandan disability activist suggested to the author that she could employ a driver for 10,000 shillings per day. The author chose to get around using public transportation means.

²⁴ Learning from other social movements is not always meaningful for disability movement, as disablism is, “in many ways more complex than sexism, racism and homophobia” particularly when impairments, even in the “absence of social barriers or oppression” are still “limiting or difficult” and “not neutral” (Shakespeare, 2006:41). Mintz (2011) examines the book of Kleege (1999), *Sight Unseen*, introduces blindness as a “skill” and dismantles the disciplines of normality. Thus, not all persons with disabilities conceptualise their impairments as negative either. In this very regard, learning from other social movements alone is not enough.

families and neighbours who are reaching **persons with disabilities**, even sporadic and patchy **development cooperation matters**. The experience of being even a passive participant in such activities matters, when many persons with disabilities and their families on the grassroots tend to have gone through personal experiences of exclusion and discrimination at various levels. However, modalities are expected to change from individual towards more collective well-being, as demonstrated by the feminist movement in the South which has shifted from the “women in development” to the “gender and development” approach. One implication from the lessons learned from the alter-globalisation movement is that “the absence of a universal alternative and general models does not refer to a deficient of the movement but constitutes an intrinsic and constitutive feature of alter-globalisation” (Pleyers, 2010:218). As disablism and its influences are observed at multiple levels, solutions also have to be numerous. A human rights-based approach has begun to dominate disability discourse today. However, its operationalisation has still been limited and experiences of this approach are only beginning to accumulate. Learning by trial and error is the only way to move forward for successful and innovative models that fit to the specific context of Uganda. For that, participation even in a passive form as recipients of prerequisite services and devices matters. **Although not the only one, development cooperation through a human rights-based approach is one of the many tools to improving well-being towards the ultimate goal of equality.**

The Executive Director of NUDIPU, person without a disability (personal interview on 31 January 2008 in Kampala) states, “The new approach is inclusion. When it comes to inclusion, it has to be dual.” A reciprocal approach between more advantaged and less advantaged people in every step, in different contexts, is insightful in breaking the seeming dichotomies at different levels, as has already taken place in many levels among different people. Rights-holders are also duty-bearers and responsibilities and duties follow hand in hand with rights. Disability studies have paid less attention on partnership or alliance (Shakespeare, 2006:187). For instance, in the discourse on human rights, disabilities and development, the role of persons without a disability is often undermined (ibid.185-197). “Just because someone is disabled does not mean they have an automatic insight into the lives of other disabled people” (ibid.195), as has become clear from the case studies and from the heterogeneity among persons with disabilities. “Supporting positive social relationships between disabled and non-disabled people and recognising the beneficial roles of solidarity and mutuality are both vital to the flourishing of disabled people” (ibid.199). Likewise, supporting positive relationships between persons with disabilities on the grassroots and those working at DPOs, Ugandan DPOs and Northern ones, the Ugandan disability movement and the government, the African disability movement and the global structure, and recognising the beneficial roles of solidarity and mutuality are vital to the well-being of persons with disabilities in Uganda both individually and collectively, for working towards the ultimate goal of equality. Such dialogues and negotiations, instead of finger-pointing and dichotomy between different stakeholders, become an important and pragmatic strategy for attaining equality.



Picture on the left: a Ugandan Craft shop of an NGO in Kampala selling products made by around 100 marginalised women, including women with disabilities and women living with HIV. A number of colourful handcrafted baskets are on display. The managing director is a woman with a disability. The author bought many souvenirs from this shop. The products are also exported to Northern countries. That is, they are customers but not donors. Each product carries a note with the producer's names and brief information such as "a woman living with HIV" which encouraged the author to purchase the products specifically made by women with disabilities. Some of the producers of crafts who are women with disabilities are also invited to different events, such as an International Day on Persons with Disabilities (IDD) so that they can sell their products in the event. For instance, NUWODU invited some women with disabilities to an IDD event and offered a transportation allowance to cover their costs.

Picture on the right: when the author visited the craft shop, there was one woman with a disability keeping the shop and producing the crafts. She told the author when a product costs 2,500 shillings, she gets 1,500 for herself (personal interview on 14 February 2008). She says, "I enjoy the work very much because I can provide my children. I have three children and I pay for their school fees. ... I enjoy my work because I can be somebody when I can pay for my children."

7. Is a Participatory Research Approach a Burden for Southern Researched People?¹

This chapter reflects on the participatory research approach applied in this study. Even though it was not the only approach used in this study, it was a very important part of the study. The theory and practice of the participatory research approach is explained in the Methodology chapter (Chapter 3). The participatory research approach process also raised one of the key questions to elaborate in this study: How can research empower the participants, the researched people, through their participation in the research process? What are the possibilities and challenges of participatory research on disabilities and development? This chapter attempts to answer these questions. As the research participants are not a monolithic group of people, it is natural to have diverse responses in terms of their participation in the research work. This is in line with the empirical theory of human rights-based approaches *in practice* (Chapter 5). Thus, how the author carried out this research is, to some extent, legitimized in this specific context. Nevertheless, this diversity should not be normalized and depoliticised as it exists now, rather, the participatory research approach needs continuous and further attention to point towards a more equal society so that heterogeneity among persons with disabilities, particularly that pertaining to power, is alleviated. This chapter firstly introduces the ideal model cases in which the research participants expressed their empowerment through the research process. Subsequently, the challenges faced regarding disagreements, accessibility and self-determination are elaborated, followed by the lessons learned in the research process. In the end, the author connects the research experiences with DPO activities to illuminate the challenges of operationalising a human rights-based approach in practice. Without the experiential knowledge on the participatory research approach, the author would not have deeply understood the power structures -or power in general, in this specific context- as she has articulated in the previous chapter (Chapter 4). In this regard too, this approach was significant for this study.

7.1. Ideal Model Cases

Ideally, this participatory research approach would empower the research participants through *proper engagement* with the research process to create evidence-based knowledge together with the researcher. One of the positive examples is Prossy Nanyinja who voluntarily shared her life story, which is included in Chapter 4. The author wrote to her an e-mail after receiving her life story:

Prossy, I was really positively surprised how good you are in writing it!! I can never bring out the challenges of persons with disabilities in Uganda in the way you powerfully did with your experiences. Thank you for sharing it with me. I'm very grateful.

She then replied back to me:

Thanks a lot Hisayo, you really inspire me. I didn't think of that story as having any meaning to anyone, but you have made me think of it in a positive way now. I am now

¹ Part of the writing was presented in the following:

- Katsui, H. (2009-a) "Is the Participatory Research Approach a Burden for the Researched People?" Finnish Society for Development Research Conference: Knowledge, Development and Academic Partnership. On 12 February 2009. Helsinki, Finland.

adding you to my list, because you have always been my only inspiration which keeps me going. I like your attitude, thanks a lot dear.

One of the research assistants also expressed as follows:

This method is very effective when conducting a research. It enables the researcher to get to see and learn of the real life situation on ground. You get to learn directly from the primary target group. It actually empowers the primary target group with research skills if they are involved directly in the assignment. I, for one participated as a research assistant in the research by Hisayo Katsui and I'm now skilled in conducting research ever since that experience (Posted on the Facebook group site, "Human Rights, Disability and Development" on 7 February 2012).

Staff member C of a Northern DPO (personal interview on 18 February 2008 in Kampala) also appreciated the research:

You become too much a part of it, so you also don't see it... you lose the ability to look from the outside, which is healthy. Those women in the village, they don't have the consciousness because it's the first time when they get the ability to look from outside. Otherwise you have been soaked into the everyday village life and simply don't look out whatever. That could be the risk of staying here so long. So that's good that people like you come and ask questions. It gives the theory and practice to interact. So you don't forget about using theories as well. I think that might be the biggest danger. It's not only for me but also for (the Ugandan counterpart DPO). We need time to reflect and develop theories on what we are doing. And it sometimes takes outsiders to push it... We don't know well what we are doing. We don't get that academic, theoretic part of our own works.

"Proper engagement," however, is tricky in Ugandan practice especially with deaf women on the grassroots. The challenges of the research approach can be summarised as follows: 1) disagreements with the research participants, 2) accessibility, and 3) self-determination, as will be discussed below.

7.2. Disagreements with the Research Participants

The study started by involving national DPOs. It is easy to communicate with the management staff members of DPOs as they have good communication skills and they are located in offices equipped with communication devices. The DPO staff members were actively involved in this study. Many readily made comments on the draft papers via e-mails throughout the study and continuously contributed to the research process. Also, they participated in the form of interviews while the author was in Uganda. **The participatory research approach was rather fruitful in validating the research results with their lived, local knowledge.**

It became difficult to cooperate when staff members, amidst offering information and complementing the author's knowledge gaps, would offer her **counter arguments**, especially due to the different perspectives during the general assemblies of DPOs observed in December 2008. They were highly political and divisive exercises where different parties had different opinions and experiences, and there were many "truths." The author decided to make her observations from the perspective of deaf women, which was criticized by one DPO staff member. The author's critical observation from the specific perspective was accused as a "wrong interpretation" due to the highly political nature of the observed events. Many e-mails

were exchanged between the DPO staff member and the author to clarify the differences in their arguments, which led to a common understanding on some points. However, they could not reach consensus on other interpretations. As the author's arguments are based on her observation –and these observations were cross-checked by her interviews with key informants- she did not change her writing even though the staff was not satisfied with some parts of her writing. His dissatisfaction lay mainly on the author's criticism of the undemocratic practices of the general assembly management of the very DPO that staff member belongs to. Consequently, the author made footnotes to mention the places which were opposed as “not true” by the DPO staff member, as was agreed upon with him. He then gave the author permission to present it in an international conference. It was a very stressful process to reach this point. This is a challenge embedded in this participatory research approach. The diversity of “persons with disabilities” means, in many cases, different viewpoints in practice. Therefore, it is indispensable to go through these kinds of “clashes” with a participatory research approach. **When opinions are many and they are equally valued, researchers must make the decision to choose legitimate ones with good reasons.** They must also choose arguments that support the primary cause of the research to create a social theory rather than the secondary cause of political intervention (cf. Shakespeare, 2006:33). That is, the very final decision making power is held by the researcher, not the participants, even though power relationship between them is carefully taken into account in the process of decision making. This is an actual **dilemma** of an approach that seeks proper engagement.

7.3. Accessibility

When it comes to persons with disabilities, particularly deaf women on the grassroots, their conditions are totally different from those of the aforementioned DPO staff members. As was expected, deaf women on the grassroots do not have an access to a computer, phone, or postal address. That means visiting these persons one by one is the only way to communicate with them, even when the persons with disabilities are scattered in communities (Development Research and Technology, 2008:43). This is not the biggest challenge, except in that meeting them is time, energy and money-consuming.



Picture on the left: Laura Kanushu Opori and Miriam Kiconco, staff members of a DPO, the Legal Action for Persons with Disabilities Uganda with the author. They are highly educated, smart women with disabilities based in Kampala. Kanushu officially got married to a person without a disability in summer 2008, which is still rare in Uganda. Her wedding was broadcast on TV. Both Kanushu and Kiconco have university degrees in law, and are lawyers. They have a daily access to the Internet.

Picture on the right: The author is sitting with women with disabilities who went through the NUWODU HIV/AIDS training in the Northern area of Uganda. When the author arrived at the internally displaced people's camps, local NUWODU staff members went to visit different people one by one to call the training participants to gather for this meeting. Thus some could not join this monitoring meeting because they were away. Physically visiting one by one is often the only way to reach people in Uganda, except in urban cities where some people have their mobile phones. Even in DPOs in Kampala which have facilities with computers and Internet access, people tend to meet for discussions instead of holding virtual meetings. "These meetings and conferences (of DPOs) take a lot of resources that could otherwise be better spent on other issues" (DSI, 2007:37). Nevertheless, the author believes that it is important to meet people face to face in the Ugandan context.

The biggest challenge is that the author cannot communicate with many because she does not have any common language with deaf women on the grassroots, even with the presence of a sign language interpreter who handles both Ugandan sign language and the local one. Interviewees sometimes use local signs rather than the standardised Ugandan sign language, and **even more commonly "gestures (home signs)"** rather than local signs. When the author visited deaf women in their homes deep in the villages, these women used only home signs that are understandable, to some extent, only by their family members. All of the three deaf women in the villages had never been to school because of the communication barrier. Due to this **communication barrier**, in two families these women's family members answered all the questions. The family members of the third deaf woman were all small children and so the author failed to get much information from this family except for the observations she made. One of the mothers appreciated the deaf woman's good work in their garden, while another mother called her deaf daughter "kasiru (=stupid)" all the time, even though the assistant reminded her not to do so. All deaf women, including their family members, are occupied with their daily household chores and the digging of their gardens. Under the circumstance, deaf women hardly have an access to information in general, much less the process and findings of this research work.



The author is sitting on the floor with a deaf woman in her house in a village. Her mother-in-law is on her right, and her mother is on her left. The man of the deaf woman disappeared and it is a female-head household. Her mother-in-law appreciates the hard work of the deaf woman in their garden and communicates with her with simple gestures. This is due to the Ugandan women's quality in the local context. Several elderly Ugandan men asked the author whether she could dig. This obviously is an important quality in a woman in a Ugandan context, as most of them rely on agricultural business or at least on self-sufficiency for daily nutrition. The Ugandan Ministry of Finance, Planning and Economic Development (2008:21) claims that people with hearing impairments "can dig and do what others do" and thus are "almost as competitive as non-disabled people" in terms of employment. This deaf woman can dig and thus is much more useful and productive than the author in Uganda. The mother-in-law asked the author to write that they look for places to sell their handmade mats. Another aspect to make note of when looking at this picture is that the male sign language interpreter took this

picture from the “male side” of the room where he sat with the village-level male disability councillor and a male driver on chairs. These males are not captured in this picture. Nevertheless, this picture reminds the author of such hierarchical gender-based experiences in a Ugandan village.

7.4. Self-Determination

Participation is diverse. In this study, the decision not to participate in the research was also considered important because that is also the exercise of decision making power (Katsui and Koistinen, 2008). Participation should not be imposed but voluntarily decided. However, **self-determination is badly jeopardised when trying to engage deaf women on the grassroots**. For those persons with disabilities who are literate or sign language literate (either in the use of local signs or Ugandan sign language), the author could introduce her study and the conditions for the interviewees or research participants in the form of an information sheet and an informed consent form either orally or in writing. However, the author failed to present these and to go through the procedure before her interviews with deaf women not only in the villages, but also those on the grassroots in Kampala City. The women did not have the vocabulary of “human rights” to start with. Many of the concepts used in the study are not included in their daily vocabulary. The author failed to explain the meaning of key concepts such as participation and development cooperation. Therefore, in those cases where they did not have literacy and sign language skills, the author tried to communicate with them without going through such formality. In these cases the conversation topics were dominated by what the women were interested in sharing with the author. In the villages, the family members welcomed the author without the consent of the deaf women, as a disability councillor of the village level visited them to inform them about the coming of the author to their places the following day. The disability councillor made the agreement with the deaf women’s families only due to the practical challenge of the communication barrier. That is, the self-determination of one of the most vulnerable groups of people, the deaf women in the villages, was unfortunately infringed upon in this study.

This is one of the unsolved dilemmas in this study: the dilemma between the academic goals to reach the women to hear their experiences on the grassroots, and the empowerment of persons with disabilities through this research. **A study of this kind cannot dramatically change the realities of the involved persons with disabilities particularly when the discrimination against these persons has been as severe as it was in terms of their capacities and environments**. Realistic goal has to be set, which was acknowledged for this study (Katsui and Koistinen, 2008). Nevertheless, if the study included only those who could explicitly express their opinions and decisions it would have excluded many others who are more marginalised in reality, such as these deaf women in the villages and those on the grassroots in Kampala and Northern part of Uganda. Reaching those on the grassroots was essential for this study, to be able to understand part of the complexities of international and development cooperation activities relevant to them. For instance, the author now knows from her own experiences how challenging it is to mobilise persons with disabilities on the grassroots to any associational activities of DPOs. She reached only three deaf women in one day in the villages. This academic goal of including the experiences and perspectives of deaf women on the grassroots, however, was partially against the ethical perspective of ensuring their voluntary participation, even though excluding their experiences and perspectives is not only unethical but also academically unfruitful. The inclusion of only DPOs at the management level would have made the analysis extremely superficial in reflecting on the realities and experiences of a vast majority of persons with disabilities on the grassroots. Hence, between the two unethical choices, the author chose the one in which she met these deaf women in the villages even though she could not ensure their willingness to participate in the study.

This is an analogy of the deaf woman cited in the HIV/AIDS case study who was brought to the test for an HIV infection and was denied because personal informed consent from the deaf woman was impossible without proper communication means. It is correct, to a certain extent, to go through the procedure for securing voluntary decisions on the one hand. On the other hand, she would then never be tested without having any means to communicate if she is not only illiterate but also sign language illiterate, which is most probably the case for her as well as many other deaf women on the grassroots. In fact, many other examples were introduced which are analogous to that of choosing a charity-based approach even though the Ugandan DPOs and Northern counterparts try to apply a human rights-based approach in their activities involving persons with disabilities on the grassroots. In such cases, the top-down decision making of others, similar to a charity-based approach, is not necessarily totally evil. The sterilisation of a woman with a disability without her consent through top-down decision-making is a violation of rights (Open Society Institute, 2011). However, when the eventual goal is a better quality of life of the person with a disability, a top-down approach is perhaps the only way at this stage where a deaf woman does not have any means to express her opinion without education, literacy and sign language literacy. In this very regard, the academic and theoretical discussion on a human rights-based approach versus a charity-based approach is surely relevant in any research on disabilities and development regarding its methodology.

7.5. Lessons Learned from the Study: Which “Persons with Disabilities” Are Included?

Due to the tendency of the disabling environment against deaf people, particularly deaf women, many of these deaf people on the grassroots have not acquired any mother tongue at all. Therefore, accessibility to and the self-determination of the deaf people remained big challenges for the purpose of applying the participatory research approach of this study to these persons. As a natural consequence, therefore, the relevance of this study to deaf women on the grassroots is highly questionable, even though the DPO management staff is in constant dialogue with the author throughout the study. Is this study relevant to “persons with disabilities”? The answer is perhaps yes as the study investigates their experiences under human rights-based approaches to international and development cooperation. Is this study process relevant to “persons with disabilities”? The answer is yes to a limited extent only to those DPO staff members. Are the findings of this study relevant to “persons with disabilities”? The answer is most probably yes, but they are not accessible to many. In other words, only a limited number of “persons with disabilities” might find this study relevant as a whole, as of now, before they are more empowered.

Experiential knowledge indicates that the **diversity of “persons with disabilities” is a huge challenge to overcome in any intervention meant for/with “persons with disabilities.”** The most vulnerable groups of people in the “persons with disabilities” category are easily left out due to the challenges stemming from the tendency of profound discrimination against them, and also due to the limited resources in intervention to accommodate their needs. The study is in the framework of a four-year-project, which turned out to be six years due to the author’s maternity leave for two years. The resources of the study are also limited: human resource is limited; time is limited; money was not granted as much as budgeted for accommodating various costs, particularly related to reasonable accommodation.² Most of all,

² Our advocacy of the project team led to a policy change of a North-South-South project of Center for International Mobility that the research team has received some funding for exchange of lecturers and students between African universities and Åbo Akademi University in Finland. In the first granted project, reasonable

this is a research project with the secondary aim of empowering the research participants - not an international and/or development cooperation project as such, which primarily aims to empowerment them. Priority is set high on the academic findings. As a result this study, for instance, cannot give sign language education to the deaf women, equip them with accessibility to different communication devices and then ask for their more proper engagement to the research, for instance, which would have been ideal.

When DPOs are included in the whole research process, it is considered a “success” and “emancipatory” in disability research today (ex. Albert, 2005:29-31). On the one hand, the diversity of “persons with disabilities,” however, cannot be covered only by the active involvement of DPOs and their staff members, as has been clarified above. On the other hand, all existing persons with disabilities cannot be included into a research study of this kind. That is, the author has the power to decide which “persons with disabilities” are included in the research activities concerned and in what way, as much as they decide on that by themselves with or without their intention. The researcher makes a realistic and practical choice under the circumstance, sometimes against the principles of human rights such as equality and non-discrimination. The specific **perspective of deaf women in this research clarified the challenge of operationalising this approach to disabilities in Ugandan practices**. If the excluded persons want to participate and they cannot due to the challenges of accessibility, self-determination, and/or resource availability, that is problematic in theory and principle.

Then, another question is: “Is a participatory research approach a burden for Southern research participants?” If they are not willing to be part of this research, and they are not included, that would be their choice, or would it? The previous studies (Katsui and Koistinen, 2008) revealed the unwillingness of the research participants to participate in the research process such as data collection, analysis and writing: DPOs are overloaded with their own works while persons with disabilities on the grassroots also have their hands full with their own daily chores and work (Kamanyi, 2008:57). There is a **high possibility that this kind of a research approach is a burden for many** of them. At the same time, there is also another possibility that they are not exposed to research work and thus they do not consider them relevant. They are not familiar with such research and say they are not interested in it. In Northern contexts, this knowledge gap is filled by a series of procedures of informed consent, especially in the beginning but also throughout the research process. In the Ugandan context, informed consent was difficult to those on the grassroots to start with. Consequently, this study applied the participatory approach only at a superficial level, involving more actively the willing representatives of “persons with disabilities” who have more possibilities to affect the research, while including those on the grassroots mostly as interviewees. If participation depends on willingness, the more powerful participants might benefit to a greater extent because of their advantageous positions in terms of capacity and environment. This **voluntary decision-making poses a dilemma** in a human rights-based approach which is based on voluntary decision-making, and which tries to prioritise the most marginalised groups of people who might not exercise the power to make decisions, with or without their intention. This is the space where a more top-down approach enters into the picture.

accommodation was not granted and thus extra money used to accommodate for our project members were ignored. The Center now grants additional money for reasonable accommodation.

7.6. Relevance of External Impetus in a Human Rights-Based Approach to Deaf Women in Uganda

Experiences of trying to apply this research approach into Ugandan realities of persons with disabilities enabled us to understand part of the challenges faced by the Ugandan DPOs in their efforts to engage their constituencies on the grassroots into their activities. The series of constraints of this research are also similar to the ones of DPOs. As this study is also strangled by the project cycle and related constraints, the experiences of this study in using the participatory approach and the lessons learned have some implications to international and development cooperation activities involving persons with disabilities in general.

The author had to enter into realities with the tendency of deep discrimination against the persons whom she studied. A single research of this kind cannot dramatically change realities, as the root causes of a disabling environment are many and intertwined. For instance, for deaf persons, mastering a language is not a simple task. They have to be mobilised, their family must be convinced, their absence from home should be compensated in one way or another and most of all, they themselves have to be motivated to voluntarily study the language. Groce and Bakshi (2009:4) similarly claims that “(g)iven the competing demands of making a living, raising families and fulfilling other adult responsibilities, school-based education for them, at this point, is unrealistic” and concludes that **“breaking the links between poverty and disabilities will be extremely difficult, if not impossible.”** Furthermore, the number of “persons with disabilities” is significant. Consequently, (equal) participation in both DPO activities and research in any form becomes a huge challenge for persons with disabilities, particularly for those on the grassroots. In this way, many international and development cooperation activities become irrelevant to deaf people when mastering a language is one of the prerequisites. **Without making changes, deaf persons on the grassroots in Uganda will hardly benefit from the continuous input of development agencies or any academic study of this kind.**

The author went to the villages to meet deaf women through her own decision so that her study would be enriched by the information of their lives. They never asked her to come without knowing her and her study. It was the author who took the initiative. She does not know whether they benefited from her visit except for the gifts she brought as a token of her gratitude for sharing their experiences and time with her; one package of salt and sugar, a bar of soap and a symbolic Japanese present.³ With her modest experiences in Uganda, she started to understand that the top-down approach of DPOs, which is theoretically opposite of a human rights-based approach, is necessary to first identify and mobilise the targeted population who are one of the most marginalised groups of people. This explains part of the mechanism in which human rights-based approach projects transform into a charity-based approach when they reach deaf women on the grassroots (Katsui, 2009-b). One of the motivations of activities, solidarity, is not enough for a project to operationalise a human rights-based approach without collective identity, awareness of equality (or problematisation of inequality), the ability to articulate the priorities of more marginalized people and enough

³ In her previous study in Central Asia, the author dared not to give any such presents because she did not want to leave any “charity-like” memory associated with her visit. Instead, she gave them pictures of active persons with disabilities in Northern countries to persons with disabilities, and a list of contact information of grant giving agencies to DPOs. This time, the assistants gave the author the idea to give those items to the village dwelling deaf women because they need those and would appreciate those the most. The author is still struggling to find what she should do for those who help her with her research, except for writing and informing about them to a wider audience as a researcher.

resources. A human rights-based approach assumes many preconditions. For instance, every person is assumed to have his/her own decision making power, space and language to express it. To operationalise a human rights-based approach in practice, the necessary prerequisites should be elaborated further. **External impetus or outside intervention is needed, in a way that respects human rights.** That is to say, a purely bottom-up human rights-based approach is hardly existent when involving deaf women on the grassroots if their realities are what they are as of now. External impetus similar to that of a charity-based approach is actually an indispensable part of a human rights-based approach, especially at the very initial stages. It is needed to locate the deaf women on the grassroots and to identify their needs by more knowledgeable DPO staff members, who can then involve them into organisational activities for human rights or the better well-being of their families -towards the ultimate goal of equality. Participation does not necessarily start from the bottom in reality, but in the long run can transform into proper engagement and meaningful participation if a human rights-based approach is taken seriously into account.

8. Concluding Remarks

This chapter concludes this book by presenting the main findings and answering the set key questions. Subsequently, the validity of the study is assessed, which then is followed by areas of future research. Merry (2005:255) argues that “it is increasingly important to recognise that the social science knowledge that is produced in the global North is shaping activism around the world, whether or not its terms and categories have been adequately translated.” Although the author deeply acknowledges that the realistic impact of a study of this kind is very modest, it is nevertheless imperative to self-reflect on the study to investigate the aforementioned themes.

8.1. Main Findings of the Study

The objective of this study was to investigate human rights-based approaches of international and development cooperation towards the equality of persons with disabilities in Uganda. The study focused on the lived-experiences of Ugandan women with disabilities, particularly that of Ugandan deaf women on the grassroots. The key questions were:

- 1) How do different stakeholders perceive “Human Rights” in the framework of international and development cooperation activities? How are the perception gaps reflected to the international and development cooperation modality and practices?
- 2) How can persons with disabilities play a significant role in making a human rights-based approach into the fourth category of Uvin (2004) by working primarily in the third category?
- 3) What are the practical implications of a human rights-based approach?
- 4) How can research empower its researched people through their participation in the research process? What are the possibilities and challenges of participatory research on disabilities and development?

The following were established as the main findings to answer the above key questions.

Finding One: Disabilities as Human Rights Issues Are NOT Norms yet.

Even when international and national laws stipulate it, mainstream international and development cooperation too frequently do not regard disabilities as human rights issues. As a result, mainstream development actors exclude persons with disabilities from their discourse and practices, even policies, and thereby have not only been reinforcing the status quo but also enlarging the gaps between persons with disabilities and peers without a disability. For instance, the Ugandan governmental and international campaign and activities on HIV/AIDS had long excluded persons with disabilities despite the fact that the “virus did not discriminate them,” whereas disabilities as themes evaporate in the process of coordination among donors (NORAD, 2012:60). Some of these actors have started to conceptualise disabilities as human rights issues only recently. Even if some individuals of the mainstream actors comprehend the relevance of including persons with disabilities into their discourse and practices, they do not give it priority through the allocation of resources and thus the impacts remain minimal at diverse levels.

Disabilities as crosscutting human rights issues are still not a reality even among stakeholders directly relevant to disabilities and persons with disabilities. For instance,

disabilities are too often a separate issue under the Ministries/Commission of Welfare, Social Development or the like, even though they are relevant crosscutting human rights issues in all units. Even in Uganda where political representation has been developed, the state Minister responsible for disabilities also has the mandate not only for disabilities but also for elderly people. Moreover, the Ministry is one of the poorest ones in terms of resources. A fully-fledged focal point with the allocation of enough resources is still rare as of today, despite the significant number of persons with disabilities, 15% of the population globally. In reality, **DPOs often become the actual focal point.** Consequently, DPOs both in the North and South carry the great responsibility for respecting, protecting and fulfilling the human rights of persons with disabilities, which conversely exemplifies the lack of understanding of disabilities as human rights issues among the general public.

When it comes to persons with disabilities on the grassroots, particularly deaf women, many have never heard of the word, “human rights.” That is, human rights as a concept is far from their realities. Intersectionality and ontoformativity theories revealed that deaf women on the grassroots often experience negative impacts on their bodies with regard to male dominance (Chapter 4), compulsory able-bodiedness (throughout this book), and neoliberalism (Chapter 6) among others, all of which are intertwined to create both a disabling environment and the under-capacity of many persons with disabilities. On the one hand, these mechanisms too frequently force persons with disabilities on the grassroots to play the passive role of objects in international and development cooperation activities, even when many of them play meaningful roles within their families and communities. On the other hand, development cooperation activities are also pressured by the neoliberalistic ideology of efficiency and management, and thereby tend to systematically deprive persons with disabilities on the grassroots of strategic decision making power without enough consideration on the prerequisites for meaningful participation.

Despite many improvements in political representation and legal frameworks in Uganda, evidence indicates that disabilities are too often not regarded as human rights issues but rather, are approached in a charity-based manner in which givers make decisions on what, to whom, when and how much to give. The Ugandan disability movement has been rigorously advocating that disabilities are to be mainstreamed as part and parcel of development which, however, has faced a lot of both internal and external challenges. Internal challenges became paramount in the general assembly exercises. These internal challenges include disabilities and politics, disability politics, and the major poverty experienced by persons with disabilities, among others. External challenges include the insufficient implementation of laws, a discriminating and disabling society, the ignorance of mainstream actors including donors, the development cooperation system that often ignores the prerequisites (ex. mother tongue) necessary for activities and so forth.

At present, only the Northern and Ugandan DPOs’ staff members at the managerial level have internalised human rights into their discourse, as found in the case studies on development cooperation. That is, the understanding of a human rights-based approach among stakeholders has not been fully operationalised, as became evident in the case study on international cooperation involving the African Union. It is an important piece of information that the Ugandan DPOs and activists have used human rights-based approaches since their establishment in the 1980s. Thus they were not coerced to use the approaches by their Northern partners. Human rights norms, however, largely do not have social meaning (cf. Woods, 2010). That is, the activities of the Ugandan DPOs often end up incorporating a

charity-based approach despite their intentions to operationalise a human rights-based approach in their practices. Consequently, too often activities transform into a charity-based approach when they reach persons with disabilities on the grassroots. At times, both approaches co-exist in an activity at different levels. **Under the circumstances in which disabilities are not considered a human rights issue, the modalities are greatly affected and tend to end up demonstrating charity-based approaches in current practices.**

The **perspective of deaf women on the grassroots** enabled us to better comprehend heterogeneity and inequality among persons with disabilities in Uganda. It also facilitated an increased understanding of the diversity also among Northern actors, including or excluding deaf women on the grassroots in their activities. At the same time, this specific perspective and a deeper understanding of their realities provided us with fundamental knowledge for imagining how it would be for individuals with other types of disabilities in different age groups and in different settings, such as children with intellectual disabilities in rural areas or blind youth in school settings.

The experiences gathered through operationalising the United Nations Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) are informative. It was not until the 1990s that the violation of women globally started to be perceived as a human rights violation (Merry, 2006:982). As socio-legal studies of law within nation-states indicate, compliance depends largely on individual consciousness and commitment, not policing and force. Most people, most of the time, conform to laws because they are part of the taken-for-granted world they inhabit, not because they calculate the relative costs of violation and compliance (Ewich and Silbey, 1998 cited in Merry, 2006:979). **Disability stakeholders are to create a convergence of different approaches -including the human rights-based approach- to complement each other and to increase the possibilities for operationalisation,** as has been the case for CEDAW.

Finding Two: Self-Determination Is NOT Self-Evident

In theory, a human rights-based approach presumes the self-determination of rights holders to claim their rights (objectives) in a human rights-based manner (means). For that, both the good capacity of persons with disabilities and an enabling environment are indispensable, while persons with severe disabilities require proper support for their well-being. The case studies proved **huge heterogeneity among different persons with disabilities:** some enjoy their rights, such as the Members of Parliament and DPO staff, while the majority of others, particularly those on the grassroots, do not to the same extent; many persons with disabilities in the North enjoy their fundamental rights, while most in the South do not. Thus the gaps often lead to **solidarity as a motivation for the more advantaged people to do something for and/or with less advantaged ones.** The modalities of activities are not predetermined by such solidarity, but often take the form of empowerment of the less advantaged people (the third category of Uvin, 2004). The relational approach to disabilities points out the importance of both individual and environmental aspects for improving the well-being of persons with disabilities both individually and collectively. Thus both empowerment-centred and mainstreaming activities are focused (the twin-track approach).

When it comes to empowerment-centred, disabilities-specific activities, all case studies posed the question whether the self-determination concept was useful in the specific contexts. At present, the self-determination of persons with disabilities is not as self-evident as the human rights-based approach assumes in theory. Different levels of participation are more useful

concepts for comprehending the complex realities of international and development cooperation activities, and for analysing the different levels of decision making power (Chapter 5). Focusing on the participation levels brings to light both the diversity of persons with disabilities and realities of human rights-based approaches in Uganda. The self-determination of persons with disabilities is too frequently watered down in international and development cooperation activities and replaced by the representation or consultation of a limited number of persons with disabilities, or alternatively by one-off activity at best. They are not sustainable and human rights-based. Securing sustainable support at all levels with good enough resources as an obligation of duty-bearers, namely the government and donors, is an ideal scenario which is equivalent to the fourth category of Uvin (2004). However, international and development cooperation activities often remain in the third category of Uvin, disabilities-specific “add on.” All cases imply **mutually positive effects between empowerment and mainstreaming** when any one of them is conducted. At present, however, the needs of many persons with disabilities and their families on the grassroots are huge. They are prerequisites that must be met before the persons are able to exercise their self-determination rights. More sustainable and systematic supports are needed to meet their needs. At this stage, a top-down approach is actually useful in including hitherto excluded groups into the mainstream discourse and practice. Top-down activities could gradually shift to human rights-based activities for more sustainable, positive social change. **Self-determination, in other words, does not necessarily take place without prerequisites** as of now, should no changes be made to practices at all levels and in different contexts including families, schools, work places, transportation means, attitudes of community, governmental support, international and development cooperation system, globalisation system and so forth. That is, **continuous and constructive dialogue, negotiations and information dissemination as the third track are necessary among all actors**, not only externally between the disability movement and mainstream actors but also internally among the actors within the movement. This will be mentioned further in detail in the following Finding Three.

Finding Three: Practical Implications of a Human Rights-Based Approach to Disabilities and International and Development Cooperation

Having analysed the case studies in conjunction with existing relevant theories, and having established the evidence-based empirical theory of a human rights-based approach to disabilities and international and development cooperation (Chapter 5), the practical implications are elaborated so that a human rights-based approach is challenged in its negative consequences and operationalised better to fit the realities of persons with disabilities in Africa, particularly in Uganda, including those on the grassroots.

First of all, a human rights-based approach in international and development cooperation discourse, even though not necessarily fully operational yet in practice, is hence important for including persons with disabilities as **equal members of society** into mainstream discourse and practice **as a natural matter of fact**. The transformative potential of a human rights-based approach has to do with practical implications, due to the number of challenging tendencies against persons with disabilities on the grassroots in Uganda. Persons with disabilities as active actors with decision making power present **a clear paradigm shift** from passive objects of care, charity and the like. Lack of reciprocity, however, is not a negative factor in determining that an activity is disempowering, when “the rewards are not reciprocation and mutual support but the satisfaction of making someone else happier and more included, and playing a socially valued role” (Shakespeare, 2006:179). That is, activities can begin from the premise of a lack of reciprocity -and even remain there- in the sense that

some continue to play a passive role, because disabilities are “not neutral” for many (ibid.43), particularly for “persons with complex dependency needs” (European Disability Forum, 2007). This argument makes sense when **a human rights-based approach is a continuum to a charity-based approach in practice**, as was proven and theorised above.

The second implication is on a possible negative consequence of a human rights-based approach if enough attention is not paid to dialogue, negotiation and information dissemination among stakeholders. On the one hand, a human rights-based approach is an effective and powerful lobbying tool for making changes in policy. On the other hand, however, “The human rights route is a cul-de-sac,” because it often leads to the “politics of dichotomies: either-or; good-bad; us-them,” as Oinas and Jungar (2008:250) point out in another context of South African HIV activism. Binaries and dichotomies are too often not enough when “collaboration and dialogue” are undermined and political choices become “moral questions” and polarised (ibid.251). **Implementation, in particular remains a challenge even after a positive decision is made.** Oinas and Jungar (2008:253) assert that it is alarming when activists resort to a rights discourse and lack fair political debate towards democratic practices, in particular as they pertain to the role of civil society. Such activism often militarises language, thereby a campaign becomes a “battle” (Friedman and Mottiar 2006: 27 Cited in Oinas and Junar, 2008:253). Instead of winning over duty bearers such as the government, working with them is the key for successful change both in policy and its implementation in practice. Human rights discourse tends to reduce the alternatives by “finger pointing at the bad guys” (ibid.256). Instead, various actors and modalities need to be called for to deconstruct the massive mechanism against persons with disabilities. In the context of mainstreaming gender, Skotnes (2011) also stresses that frank discussions among stakeholders are important for mainstreaming to be transformative beyond rhetoric. She continues, “It is not enough to talk about rights that all agree with. One must take time and have resources to document reality and solutions. We must be able to tell why and how.” Thus the third track of “disability in policy dialogue, country negotiations and multilateral cooperation and information dissemination” (European Commission, 2010:122), recommended by the Finnish Ministry for Foreign Affairs is of great relevance, as was exemplified in the third case study on international cooperation. The Finnish government promotes policy dialogue as a strategy to diplomacy, but this study further recommends **dialogue, negotiation and information dissemination both externally and internally among different actors in general, including the ones on the grassroots, so that the equality of persons with disabilities becomes common sense for everyone.**

The third practical implication is the fact that **transformation takes place as a result of a long-term commitment with a lot of resources**, unlike hitherto sporadic activities with limited time and money. The mechanisms against persons with disabilities are many and huge. These mechanisms include global scale neoliberalism with its ideology (Chapter 6). A single international and development cooperation activity of any kind can NOT deconstruct the mechanisms and construct enabling environments. That is to say that a disabilities-friendly modality of international and development cooperation is required to change dramatically by going beyond the neoliberalistic ideology within it. Short-term interventions otherwise continue to exclude the most marginalised groups of people, even when the activities are targeted to persons with disabilities because positive, quantifiable impacts to them are much more limited compared to those who are already more advantageous among them, due to their better capacity and more enabling environments. The focus on deaf women on the grassroots explicitly supports this argument, as thorough sign language education and

training for them -prior to any international and development cooperation- has been too limited, when the vast majority of deaf women on the grassroots have never been to school. It is, therefore, not fair to measure the impact in the same scale as with others when their capacities and environments are significantly different from that of their peers. Positive measures and reasonable accommodation are necessary, preferably in the form of affirmative action as the Ugandan examples show.

The fourth implication is the continuation and co-existence of charity-based and human rights-based approaches, as verified in the case studies. This reality implies that **a new intervention in the form of development and international cooperation, applying a human rights-based approach, could also be linked more directly to existing charities and/or vertical relationships rather than merely creating a separate new experiment as an “add on.”** Similarly, Woods (2010:99) argues that human rights norms could be linked to other existing norms, such as religious ones, for creating rights-positive situations. Charity-based approaches have a great potential to transform into human rights-based approaches. The central focus is on rights-positive behaviours on the ground “where they matter most” rather than on human rights values as such (ibid.82 &104-5). More concretely in this study context, the development cooperation system should allow such flexibility that both Northern and Southern DPOs could become partners of on-going and existing mainstream programmes, projects and activities even when the planning, budget allocation and/or implementation have been already predetermined without them. Those DPOs can provide their local disability-specific knowledge and insight to transform on-going mainstream activities into more human rights-based means and goals inclusive of persons with disabilities. Otherwise, mainstream interventions continue to enlarge gaps. Thus delaying set timetables and allocating additional resources to on-going activities, in order for them to include persons with disabilities properly, are small adjustments compared with the negative consequences that mainstream interventions further create for the lives of persons with disabilities. Alternatively, DPOs should be at least consulted at the beginning of any activity if consulting with them is not made a focal point. Where including persons with disabilities is not common practice yet, “multiple regulatory regimes” such as “morality, financial incentives, fear, shame,¹ inter alia” (Woods, 2010:108) could at least be thoroughly analysed and considered to take disability rights seriously into account in all general activities in society, in international and development cooperation in particular. The conditionality of human rights is highly controversial (Uvin’s second category). It must be kept in mind, however, that measures including dichotomisation and polarisation (cf. Oinas and Jungar, 2008) are not the only means, as human rights-based approaches are operationalised in many different ways and co-exist with charity-based and other approaches. Hence, operationalisation of human rights-based approaches in conjunction with other existing approaches, modalities and activities becomes important.

Finding Four: The Participatory Research Approach Is a Burden for Many Southern Researched People

As has become clear from the above, a human rights-based approach is required to go beyond the existing system centred by efficiency and neoliberalistic ideology. This lesson applies also

¹ Kim (2011:97) claims that the external pressure of the North causes shame on Southern countries, as it undermines local activism and also leaves the public perception that human rights is a Northern agenda. In the study context, not only Northern but also Southern DPOs could pressure other mainstream international and development cooperation stakeholders with various suitable strategies so that they would begin to internalise inclusive development.

to a study concerning persons with disabilities in an academic world. That is, a participatory research approach is ideally feasible in a long-term framework with the fully-fledged commitment of academic actors and the researched persons with disabilities so that a sustainable, positive consequence would be realised for many research participants. In reality, therefore, within the short-term framework given in a research project such as this one, only a limited number of already rather empowered persons with disabilities would be emancipated to a limited extent, as was described in Chapter 7. This reflects the existing local power relationships and structures to a great extent, as the different levels of participation were observed in the case studies. Similarly, participation in a study also depends on personal capacities as well as on enabling/disabling environments, among others. Thus it is a natural matter of fact that not all participate in the same way, as persons with disabilities are not monolithic. Even when two persons with similar capacities and environments are invited, one would be willing to join, while the other would not, due to their different personalities. Such ambiguity always persists. Thus, expecting that all the participants gain the same benefits from this research approach does not reflect their realities and diversity well enough. **Each person's capacities, personalities and environments need to be taken into account so that this ideologically formulated research approach is not imposed on the realities and practices of everyone in the same way.** This is an important lesson learned from this study.

The positive experience of this approach, nevertheless, is the fact that very diverse lived experiences could be collected and analysed using participants' local knowledge and through academic theories. As a result, the findings are largely based on these live accounts of disabilities. This was of indispensable value to gaining understanding of the participants' realities for the key concepts in this study. Having benefited from the research approach, it is high time to bring the findings back to the people who kindly participated in this study. This study prepares a popular version with visual materials, namely pictures, and delivers the results to the participants in October 2012 when the author revisits Uganda. At the same time, this manuscript will be available for free on-line at the research blog site (<http://disability-uganda.blogspot.fi/>) and at the home page of VIKE (the Centre for Human Rights of Persons with Disabilities, <http://www.kynnys.fi/vike.html>). The knowledge that was acquired through the participants will hopefully reach them through efforts in the near future.

8.2. Validity of the Study

Every study in Development Studies has its own limitations (Koponen, 2011). Thus what is important is to admit limitations and "manage inconsistency" (Fforden, 2010:202). This part is thus for the validity of the study.

Internal validity questions if the research accurately examines the set questions (Murray, 2004). As is clear from the above, this study accurately answered the set questions on the basis of the collected data, namely the lived experiences of persons with disabilities in Uganda. The particular focus was on deaf women and women with disabilities on the grassroots. The previous study of the author on Central Asian countries focused largely on persons with disabilities and failed to encompass those with psychosocial and intellectual disabilities, which was regretted (Katsui, 2005:185). Thus this study deliberately chose the perspectives and experiences of deaf women on the grassroots so that their views come to the forefront to help comprehend the complex realities of international and development cooperation. The concentration on deaf women as one of the most marginalised groups among persons with disabilities facilitated to deepen the understanding about their lives and

realities. It also succeeded in implying some practical pitfalls of a human rights-based approach for other marginalised groups among persons with disabilities. For instance, the allocation of a sign language interpreter is not a remedy for deaf women on the grassroots when they do not have sign language literacy, while Braille materials are similarly not the solution for blind persons on the grassroots when they have not had the chance to learn Braille. Other similar patterns, drawn from the findings based on the experiences of deaf women on the grassroots can also be applied to other marginalised groups of persons with disabilities.

Not only one research assistant, but four of them worked for this study to cross-check the validity. Also, DPOs and the research team members have ensured validity throughout the study and on this text as well. At one point, the author thought about the possible limitation of working only with Ugandan female assistants with disabilities for the study. However, the research project team members are all males with disabilities and the majority of their assistants are also males with disabilities. Their input has been cross-examined with the findings of this study to validate the study from their perspectives. This combination of gender perspectives as well as a gender-neutral perspective was important in identifying the existing gaps of experiences between males and females with disabilities in contemporary Uganda. Similarly, other research project studies carried out by the primary team members include a legal study based on both legal and empirical data, and a human rights study with quantitative data. This study also included both legal and quantitative data, especially from the secondary data to support arguments, but to a much lesser extent compared to their studies. Thus, all the studies were planned to be complementary from the beginning.

The research participants not only depended on highly educated DPO staff members but also on those participants on the grassroots who were not selected by DPO staff in favour of them, but who were independently sought out. Both Northern and Southern DPO staff members were mostly males and females with disabilities except for a few persons without a disability. Merry (2005:251) argues in her research context on the violation of the rights of women that NGOs and activists approach knowledge and documentation in a different manner compared with academics. “A successful NGO is one that builds an issue that has a name, evokes sympathy, defines a villain, and compels a form of action” while academics “focus on shades of grey, on context and structure” (ibid.). Her observation implies that interviewing only NGO staff could bring biased knowledge to the realities and/or phenomenon that are under scrutiny because their objectives are different from those of academics. This is not necessarily true in this study context particularly in terms of the conducted interviews, as many of the DPO staff members did not treat the author as a donor but as a researcher. In any case, this study included not only DPOs but also other relevant stakeholders, including the State Minister responsible for persons with disabilities, sign language interpreters, a schoolteacher and a staff of the school for Deaf pupils, an orthopaedic doctor, and a Deaf priest among others who were also informative and assisted in grasping complex realities. Personal interviews with persons with disabilities on the grassroots mainly involved deaf women and women with disabilities, while informal conversations and communications during the celebration event of the International Day for Persons with Disabilities and two general assemblies were with persons with diverse disabilities. Such informal conversations and communications enriched the study to a great extent, and served to expand the vantage point of the author so as to encompass diverse experiences even when focusing primarily on women with disabilities on the grassroots as a cutting edge perspective. Obviously, this study could not meet every single person with a disability in Uganda but nevertheless, managed to select

research participants in a balanced and academically valuable manner to investigate the set themes and objectives.

External validity questions the transferability of the study findings of a qualitative study as this one into different contexts. A single-country study on human rights explicitly or implicitly suggests that the generated hypothesis ought to be tested in a larger selection of countries (Lijphart, 1971:692 cited in Landman, 2006:69). The research project members as well as interested Ugandan DPOs commented and confirmed the validity from their points of view. They claim this study to be externally valid in the Ugandan context in general, outside of the specific case study contexts. The study was careful about not generalising the findings to external contexts other than the studied ones. However, it turned out that the findings are transferable outside of the specific case study context, most probably due to the universality of disabilities as “not neutral” (cf. Shakespeare, 2006:43) rather than to the universalism of human rights as such.

The findings have been largely connected to existing relevant theories in different contexts. In this regard, this study carries some tentative inference to a wider context based on empirical findings. When it comes to a much wider context in other Southern countries, the author’s own previous studies on Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan and Uzbekistan (Katsui, 2005) and Bangladesh, Sri Lanka, Uganda and Zambia (Katsui, 2006-a&b) also support the findings, particularly the empirical theory of a human rights-based approach to disabilities and international cooperation. Towards the end of this study, the author was preparing for the forthcoming study on good practices of international cooperation in the field of disabilities in Africa, which includes Ethiopia, Kenya, Malawi, Uganda and Zambia as case countries. Communication with the Special Rapporteur who leads the forthcoming research project and relevant literature review on these countries also largely supported the findings in their country contexts (ex. ENDAN/CCM, 2010). Moreover, the board members of the Abilis Foundation, which is an NGO funded by the Finnish Ministry for Foreign Affairs and funds activities of persons with disabilities and their organisations in the global South, has confirmed that the findings in this study are valid based on their extensive experiences. The Foundation has accepted the empirical theory in its policy paper on its human rights-based approach. The Foundation has 270 projects in 48 Southern countries as of January 2012 and thus this validates the study’s generalisability. However, in the author’s opinion, such inference remains an inference and it is not transferable per se until thoroughly tested in different contexts.

Room for improvement in this study could be in the following. Firstly, the duration of the study could have been much longer as this study dealt with such complex themes as disabilities, human rights and international and development cooperation. One visit to Uganda in March 2010 was cancelled due to the maternity leave. The author also left the research for two whole years for her leave in 2010 and 2011. Her trip to Uganda in 2012 will be also shorter than the previous ones due to her changed family situation. This possible shortcoming was compensated for by the deep and active involvement of her research assistants, research project team mates, DPOs and some of the researched persons with disabilities on a regular basis. As the new UN Convention has entered into force, disability movements have become more dynamic than ever before in a global context. In this regard, if the study could spanned more time, it could have witnessed a number of on-going experiments in the field of disabilities world wide: the trial of the UN Special Rapporteur to establish the African Disability Forum; the high level meeting set in September 2013 at the

United Nations on “disability and development”; global advocacy to include disabilities into the post-MDGs; and the achievements of the second African Decade of Persons with Disabilities terminating in 2019. These are all highly relevant to the Ugandan disability movement.

Secondly the agenda, pre-set together with Ugandan DPOs on human rights-based approaches in their international and development cooperation continues to be relevant for the DPOs today, while deaf women on the grassroots are more concerned with where to get financial support for the school fees for their children or where to sell their handcraft products for a living. Even though their experiences and perspectives are central in the analysis of this study, the pre-set agenda with the Ugandan DPOs was not what many of the research participants on the grassroots were interested in. In the end, the findings cannot meet their needs of finding the school fees or market information. Even though it is beyond the scope of this particular study to meet their needs, it is still worthwhile to stop and consider whether their agenda could become central in an academic research work. This matter is tied to the discussion on areas of further research in the following section.

Thirdly, any study on disabilities focusing on one group often leads to negative feelings among other groups that are excluded as a result. Samuels (2011:49) cites Butler and makes a similar argument regarding the positioning of disabilities in the framework of feminist studies: any analysis which foregrounds one vector of power over another will doubtless become vulnerable to criticisms that it not only ignores or devalues the others, but that its own constructions depend on the exclusion of the others in order to proceed. As was discussed above, this study carefully approached persons with diverse disabilities during the course of the study not to be biased in such a way, and to comprehend their positions in the whole disability movement dynamics. Thus, the primary focus on deaf women and women with disabilities did not mean an exclusion of other groups of people. Nevertheless, one Deaf male told the author, “Deaf men have limited opportunities because development cooperation activities are for women, women and women. As men, we have fewer opportunities” (Personal interview on 6 December 2008 in Kampala). He actually criticised women-centred development cooperation activities in this interview. Nevertheless, his nuanced statement could be well directed to this study. The author should have made it more explicit that the primary focus on women does not exclude men, as she also interviewed and informally communicated with many men.

8.3. Areas of Further Research

One immediate unexplored area for future research, stemming from this study, is the concept of well-being. There is a gap in existing literature on this specific theme. Well-being research has been largely quantitative (White, 2010:165). “To understand the lived experiences of people with disabilities, more qualitative research is required. Measures of the lived experience of disabilities need to be coupled with measurements of the well-being and quality of life of people with disabilities” (WHO and the World Bank, 2011: 46-7). This study touched upon this concept in the human rights-based approach framework and analysis, and also on the self-determination concept, in part, but not as its primary focus. Should individual and collective well-being become the central theme of a study, it would definitely raise the agenda that persons with disabilities on the grassroots are most interested in, such as how to acquire money for school fees and market-related information. This is an important area to be further investigated in future research.

Other possible future research concerns international cooperation beyond development cooperation, particularly on policy negotiation as the third track (cf. twin-track approach to disabilities). Now that the new UN Convention included international cooperation (Article 32) as a stand-alone provision, its theoretical significance is great. However, its role is yet to be widely recognised and more research is needed (United Nations Human Rights Council, 2010). South-South, multilateral and international cooperation are all inter-linked with local contexts and global aspects, and are important areas to examine further. For instance, how would the formation of an African Disability Forum affect policy negotiations in African countries? Could the Forum make a good example of the third track? These are interesting questions to explore.

The third area is on global theories of disabilities. Now that country-based theories -based on lived evidences- have started to accumulate, more global theories involving the global South, in particular, are needed. Meekosha and Soldatic (2011) similarly discuss the needs to focus on Southern disabilities in a global context. Is it the compulsory able-bodiedness, explored by McRuer (2006) in his book, which connects the global phenomenon of discrimination against persons with disabilities around the world? Why are persons with disabilities not considered “just one expression of the diversity of the human race” (World Vision International Uganda, 2008:39)? Pleyer (2010:263) asserts “it is possible for states, the civil society, local communities and citizens to become actors in the global age.” But could they also change the world in favour of persons with disabilities? Now that the momentum is given for the international disability movements to drive their agenda with the support of the new UN Convention, academic work also needs to globalise its scope to comprehend and further its theories globally.

Epilogue

In September 2012, I was eating dinner with Judy Heumann, Charlotte McClain-Nhlapo, Kalle Könkkölä, Timo Voipio, Shuaib Chalklen among others in New York. All of us were participating in the 5th Conference of State Parties to the Convention of the Rights of Persons with Disabilities. The main agenda of the Conference was to find ways together and individually in increasing visibility of disabilities in the high level meeting on “disability and development” in September 2013 among the member states of the United Nations and in the post-Millennium Development Goals. Over the dinner, we discussed upon the African Union Disability Architecture, as all were stakeholders. Many things have changed, while others remained unchanged since last time when I had a similar dinner with Heumann and Könkkölä in Washington in 2004.

When finalising this manuscript, the Finnish government approved its new development policy programme with a very strong focus on a human rights-based approach to development. The Finnish Minister for International Development Heidi Hautala (2012:6) calls the present Finnish development policy a “human rights-based development policy.” The approach had been already popular but it became even more prominent after the introduction of the policy. In a seminar on 21 May 2012 at the Helsinki University, Harri Englund of the University of Cambridge provocatively named this phenomenon “human rights fundamentalism,” in his presentation entitled, “Human Rights + Development Policy in Africa = ?” By this he meant that human rights activists and practitioners are increasingly becoming intolerant to alternative ideas and means. He pointed out that the concerned people’s voices are not heard under this approach when activists’ and practitioners’ voices are louder. He stressed that the human rights-based approach is “very productive” and yet, it is “another buzz word,” “only one alternative,” and then: “not a final solution at all.”

Listening to the voices of the concerned people is not simple, as this book explicated: voices are not one but many; historically produced and reproduced ways could contradict with rights; prerequisites for expressing voices could be lacking; neoliberalism which seeks efficiency affects everybody. These are only a few of the challenges. However, it is difficult and thus is important for me as an academic in this field to work on an empirical theory. I sincerely hope that this piece has contributed to it.

Attachment 1. An Example of the Field Journal

One journal was chosen at random. For the privacy of individuals, all names and relevant identifiable information was replaced by **.

Journal of one day in February 2008.

- By the way, yesterday I heard from ** that Makerere University lecturers went on strike again due to the delay of pensions and salaries.

Listening to a Sensitisation Radio Programme when (my assistant) was interviewed

- It was 2 times every month on Fridays at 9-10 a.m. on Radio Maria (a religious channel, which is for Central Region). The NUWODU got airtime for free. Otherwise when one wants to sensitise, then you have to buy airtime.
- I recorded the programme.
- The station is a Catholic one and so the content was too often too religious for my ears. But otherwise, it was an interesting interview.
- One was on education opportunities of girls with disabilities and the other was on domestic violence.

Raining Day

- When it rains, it gets very slippery because of the type of mud here. It is really true that rain is a troublesome thing for those with physical disabilities.

Visit to the Ntinda School for the Deaf

- During my previous visit to the school, the secretary ** suggested I visit the school on this day, and so I did.
- I was introduced at the P-1 class. ** (teacher) is the teacher who has a degree in special education in Kenya.
- There were 10 children, 6 girls and 4 boys. One girl is an orphan.
- There was one girl who was not in a uniform, who is new here.
- The age varies because parents do not necessarily take children to school right away due to the low expectation on their deaf children.
- Children were learning how to count with SL and write 1 to 10.
- The education is all in SL.
- Students are from all over the country, also from Rwanda, "because this is an old school which is famous for providing good education for deaf children."
- There are not many places available and there is a waiting list of children. When a child is diagnosed as deaf, the Mulago Hospital sends them to this school. On every Wednesday, parents with deaf children visit the school to be sensitized. I asked whether that limits the families only to the Kampala area because not many parents can come to this school every Wednesday from far away. Then he said, "That is true. But some also come from far." Some even wait for 2 years to get into the school. ** (teacher) admits that it is "economically burdensome" to have a deaf child.
- ** (teacher) thinks that the society still thinks that deaf are stupid, "kasiru," but they are not.
- They follow the same curriculum as mainstream schools.
- The school provides a mattress and blankets (though according to my observation, the blankets were different from each other and some had a new one on the bed. So I

understood that they brought those with them when the term started). **(teacher) stressed, “This is the cheapest boarding school” because of donors. He said the tuition fee is 70,000 shillings per term, and that includes the cost of food. (But I looked through the students’ files offered by him during the exercise period and it said 137,500 shillings. Everybody tries to impress me like that! All information has to be at least double-checked and cross-checked with other stakeholders on the validity.)

During the break

- All go to the dining room and had a cup of porridge.
- I took pictures in the room.

After the break, I still joined the same class

- During the exercise, I continued reading the students’ files. It’s a bit difficult because I feel that they are confidential information, including the cause of deafness, the number of wives, occurrence of abortion or miscarriage prior to the birth of the child. So I did not make any note of names nor such identifiable information in my notes, but picked up interesting information as follows.
- **(teacher) said that stationeries are provided by some international schools, but it is not the case because each file and term report asked the parents to bring various things such as 15 exercise books (notebooks), 1 set of colouring pens, 2 rubbers, 1 packet of razor blades, 6 pencils, 2 brooms, and so on.
- The school produces an annual report. I found it in one of the files for 2007. This is meant for donors and parents. It said; 198 pupils, 25 teaching employees and 15 non-teaching employees. Most classes are composed of around 15 students. Two classes per grade.
- CBM of Germany is the major donor. Many others fund the school.
- There was also an agreement form to be signed by the parents. They have to promise that the tuition fee would be paid on time, always in the beginning of the term. Otherwise the placement would be given to others in the waiting list. It was sort of threatening! But on the other hand, the term report on their academic and life achievement often demands parents to pay the tuition fee. So I guess they tend to delay the payment.
- The number of wives is often 1 or 2. There are children without fathers, too. Mothers are often housewives.
- A record of one student who was in a mainstream school before. The school fee for that school was 100,000 shillings plus stationeries. Thus the deaf school is much more expensive.
- Aside from academic achievement, there are mentions of health (he can brush teeth now), physical coordination (whether he can move around alone), play with other children, concentration and imagination, concept of numbers, and general remarks. Many of the comments were positive and encouraging. “He is a good boy” or “promising.” I thought it’s good that those daily skills are also supervised.
- Holidays during the last year were: 17 August -17 September, 13 April-22 May, 6 December- 4 February. Thus they have 3 terms a year.
- **(teacher) had 15 students in the class last year.
- It seems that during the first year, 1-5 signs are too much for some.
- Learning signs: drawing→ signs→ writing. Such as ball, house, flower, pencil, chair
- I gave pens from Finland. They were very happy to have them. I took pictures when they thanked me with applause.

Visit of the dormitory room

- I visited the dormitory of bigger girls (They divide them into smaller and bigger ones and girls and boys. So there are 4 dormitories). There was a dormitory staff member who explained to me that there are 42 girls. They all sleep in the same room with double deck beds.
- The 3 toilets have holes on the floor.
- There are 3 showers.
- Washing space of clothes was also attached there.
- 3 are deafblind and they stay in the room across from the dormitory staff so the staff member is able "to give more special attention."

Visit of the knitting and sawing room

- There was ** (Tel: 0782 *****) who used to be a student in this school and now is employed as a teacher of knitting and sawing. There were works of students sold there for 3000-15,000 shillings.
- She is also deaf.
- Her work was also on sale. I bought a black scarf from her at the price of 30,000 shillings. She was so happy and thanked me many times.
- She also asked me to introduce more donors who can buy their products.

Meeting with **

- He is at the final year at Makerere University. He also did some research on disabilities, so he promised to give it to me. We exchanged phone numbers: 0782 *****
- He is also an OB and deaf. He was there as Makerere went on strike.
- Many more people came and introduced themselves to me.

(My assistant) interviewed **, the secretary, who has been there 13 years.

- There is a menstruation teaching for girls.
- Tuition fees are as follows: 150,000 shillings for lower classes (nursery-P-3), and 162,500 shillings for upper classes (P-4-P-7).
- Human rights is taught in the general assembly meetings but also NGOs like UNAD come and speak about it.
- Knitting, weaving, carpentry, cooking, tailoring and crafts are extra-curriculum activities.
- The results of this school in the "Primary Leaving Exam" (the exam one has to go through for completing the primary level and to continue to secondary level) show that they perform poorly. There are 6 grades in the exam, starting from the best being 1 and fail being 6. There was none for division 1, only 2 received the grade 2, one person the grade 3, 4 persons the grade 4 and 26 received the U-grade, which is the last group that barely passed the exam. (My assistant) said that compared with mainstream schools, this result shows that the performance is very poor in general. U is supposed to be very bad, according to her. Also, one student failed.
- When holiday starts, parents pick the students up. When holidays end, then parents bring them to the school.
- There were a few mothers visiting the school. They were in smart clothes and looked like that they were from relatively rich families.

- Though there are children without fathers, funders are financially supporting some pupils, too.

Lunch at the Ntinda Centre

- The restaurant where we often ate did not prepare food for lunch. So we went to another one for the first time. It was good.
- When going into a taxi to the next destination, one asked me, "What happened to her legs?" by pointing to (my assistant) from the back and whispering only to me. I thought it is wrong that he asked me that, so I answered him, "That is none of your business!" Did I need to answer in a better way?

Meetings at the UNAD

- There was poster advertising a course for Sign Language for 3 months. The registration cost is 5000 shillings, and tuition fee is 150,000.
- There was a rehearsal stage for the Silent Theatre. During February and June this year, they plan to visit different schools to perform. But that depends when the money is transferred to them.

Meeting with Alex Ndeezi, the Deaf Member of Parliament

- He was very comprehensive in answering in a very structured manner.
- Good to know that "the whole activities are HRBA," he said. But the problem is the fact that it is time and energy consuming to involve deaf people into activities of HRBA, because they have to begin from teaching the basics of sign language, or even from identifying where they are.
- Ntinda at Kampala and Ngora at Kumi are the two old deaf schools, and now 15 more new schools (integrated?) exist in Uganda.

Meeting with **

- She was very informative on deaf women's issues as she is herself deaf. But her stories were very cruel, such as rape of a 6-year-old deaf girl. It was very difficult to listen to.

Meeting with **, sign language interpreter

- ** (0774*****) interpreted between English and sign language for me. She was paid 20,000 shillings, but it was not necessary, she said. She is a free-lancer. She is a graduate of Kyambogo University which has a good reputation of producing sign language interpreters lately. First, the tuition was free and the school was supported by the government. But now it costs 400,000 shillings for the first semester and then 300,000 shillings for other semesters for 2 years. Then the pupils get diplomas. In her class, there were 8 students, and around 20 in the next year.

The following are:

Attachment 2. Terms and Conditions for the Research Assistant

Attachment 3. Certificate for Completing the Research Assistant's Job

Attachment 4. Information Sheet

Attachment 5. Easier Version of the Information Sheet

Attachment 6. Informed Consent Form

Attachment 7. Popular Version



INSTITUTE FOR HUMAN RIGHTS
ÅBO AKADEMI UNIVERSITY

Terms and Conditions for the Research Assistant Job

Project Title: Human Rights-Based Approach to Development Cooperation:
A Case Study of Disabled Women's Rights to Development in Uganda

Researcher: **Hisayo Katsui** (Senior Researcher, Ph.D.)

Institute for Human Rights, Åbo Akademi University, Finland
Phone: +358-40-7236680, E-mail: hisayo.katsui@helsinki.fi

The salary is _____ for the agreed work.

This amount includes my own insurance responsibility and social security in case something happens during the engagement. For that purpose, 10% more salary is added.

If there are any direct expenses such as transportation because of this study, they are paid against receipts in principle. If you have to stay overnight outside of Kampala, food and accommodation are paid by the researcher. When the fieldwork is in Kampala or outside of Kampala but within the distance of a day-trip, you are responsible for your own accommodation and food.

The salary is provided to you after you complete your job, if not agreed otherwise.

You are responsible for paying any necessary tax out of the salary according to the law of your country.

You are also responsible for covering possible insurance for your sudden sickness and accidents during the engagement to this job.

Main assignments are the following:

- Making appointments for necessary meetings,
- Arranging the meetings including transportation means,
- Arranging other more practical matters when necessary,
- Providing local knowledge and expertise to help the researcher during her stay including the analysis of data,
- Conducting follow-up minor data collection, if needed, even after the researcher has left Uganda,
- And other minor works that might come up during the engaged period.

If you agree with the terms and conditions for this job, please fill the next page and return it to the researcher.



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Agreement on My Assignments

Hereby I, (name) _____, agree to the working terms and conditions.

The salary is _____ all together for the agreed work.

In case I fail to complete this study for some reason, I will not get full salary.

Date

Signature



INSTITUTE FOR HUMAN RIGHTS
ÅBO AKADEMI UNIVERSITY

Certificate for Completing the Research Assistant's Job

For _____

Hereby, I, Hisayo Katsui, certify that _____ has successfully completed her job as my research assistant for the research project, "Human Rights-Based Approach to Development Cooperation: A Case Study of Disabled Women's Rights to Development in Uganda."

The assignment was conducted during the end of 2008 and the beginning of 2009.

Her assignments included:

- Arrangement of important meetings for the researcher,
- Providing local knowledge and expertise to help the researcher with the analysis of data,
- Conducting follow-up data collection after the researcher has left Uganda.

I am satisfied with her work and would warmly recommend her for similar or more demanding jobs in the future.

Hisayo Katsui

Date _____

Senior Researcher, Ph.D.
Institute for Human Rights,
Åbo Akademi University, Finland
Phone: +358-40-7236680,
E-mail: hisayo.katsui@helsinki.fi



INSTITUTE FOR HUMAN RIGHTS
ÅBO AKADEMI UNIVERSITY

Information Sheet

Project Title: Human Rights-Based Approach to Development Cooperation:
A Case Study of Disabled Women's Rights to Development in Uganda

Researcher: **Hisayo Katsui** (Senior Researcher, Ph.D.)
Institute for Human Rights, Åbo Akademi University, Finland
Phone: +358-40-7236680, E-mail: hisayo.katsui@helsinki.fi

I am a Japanese researcher in Finland studying the lives of persons with disabilities particularly in the framework of development or international cooperation activities in Uganda. My special focus is on women with disabilities and deaf women among them.

The purpose of the study is **firstly** to focus on the perception of "human rights" among different stakeholders in the framework of selected development or international cooperation projects of/for people with disabilities. The researcher analyses how the perception gaps and/or consistency are reflected in the cooperation modality and practices.

Secondly, ownership of disabled women is analysed to understand how persons with disabilities themselves are involved in making their society non-discriminating in the framework of the development or international cooperation projects. Empowerment through self-determination is central in this part. How the perception develops during the course of development intervention is another central question.

The **third** part will discuss the rights to the development of women with disabilities in the South on the basis of the findings from the case study in Uganda. The research aims at making practical implications towards a disabilities-sensitive modality in development or international cooperation, particularly to the marginalised group of women with disabilities even among persons with disabilities.

I believe that this study will be useful not only to those interested academics but also to all stakeholders involved in development or international cooperation activities.

I wonder if you would be willing to take part in my study for attaining those purposes. Your participation will primarily be in the form of interviews and observations. Additionally, if you could join me in different stages of the research process, that will be more than appreciated. During these interviews, questions will be asked and recorded. At the same time, I will observe any relevant events and meetings. I might take pictures upon agreement. These records or written data will not be shared with anybody, but the final report with no names will be available at the end of the study if you or your organisation would like to have a copy.

If you agree with participating in my research, would you please fill in the attached informed consent form? If you have any questions, please do not hesitate to contact me.

Sincerely Yours,
Hisayo Katsui



INSTITUTE FOR HUMAN RIGHTS
ÅBO AKADEMI UNIVERSITY

Information Sheet

Project Title: Human Rights-Based Approach to Development Cooperation:
A Case Study of Disabled Women's Rights to Development in Uganda

Researcher: **Hisayo Katsui** (Senior Researcher, Ph.D.)

Institute for Human Rights, Åbo Akademi University, Finland
Phone: +256-775381761(Uganda), +358-40-7236680 (Finland)
E-mail: hisayo.katsui@helsinki.fi

I am a Japanese researcher in Finland studying the lives of persons with disabilities particularly in the framework of development or international cooperation activities in Uganda. My special focus is on women with disabilities and deaf women among them.

I hope to be able to formulate the research process with you.

The preliminary purpose of the study is firstly to focus on the **perception of "human rights"** among different people. Secondly, **ownership and self-determination of women with disabilities**, including deaf women, is analysed in selected development cooperation activities. The third part will focus on the **operational values of human rights-based approaches** and try to reach practical implications. The fourth objective is to try to apply a **participatory research approach** to develop this method.

I believe that this study will be useful not only to interested academics but also to people involved in development or international cooperation activities including persons with disabilities themselves.

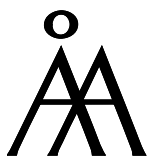
I wonder if you would be willing to take part in my study for attaining those purposes.

Your participation will primarily be in the form of **interviews and observations**. Additionally, if you could join me in different stages of the research process, that will be more than appreciated. During these interviews, questions will be asked and recorded. At the same time, I will observe any relevant events and meetings. I might **take pictures upon agreement**. These records or written data will not be shared with anybody, but the final report will be available at the end of the study if you or your organisation would like to have a copy.

Would you like to participate in this research **with or without your name** to be identified?

If you have any questions, **please do not hesitate to contact me**. If you can, please visit our research project website (<http://disability-uganda.blogspot.com/>) and my homepage (<http://blogs.helsinki.fi/katsui>) for more information.

Sincerely Yours,
Hisayo Katsui



INSTITUTE FOR HUMAN RIGHTS
ÅBO AKADEMI UNIVERSITY

Informed Consent Form

Project Title: Human Rights-Based Approach to Development Cooperation:
A Case Study of Disabled Women's Rights to Development in Uganda

Researcher: **Hisayo Katsui** (Senior Researcher, Ph.D.)

Institute for Human Rights, Åbo Akademi University, Finland
Phone: +358-40-7236680, E-mail: hisayo.katsui@helsinki.fi

I would like to agree to participate in the above named project.

I understand the nature of the project and how I participate in the project.

I understand that the information may be published, but my name will **not** be disclosed. Taken pictures might be included in the publications but will not be associated with my interview statements so that my privacy is secured.

I understand that I am free to deny any answer to specific questions during the interviews.

I also understand that I am free to withdraw my consent and terminate my participation at any time.

I have been given the opportunity to ask whatever questions I desire, and all such questions have been answered to my satisfaction.

Participant _____

Researcher _____

Date _____

Name (please PRINT) _____

Address _____

Telephone (if any) _____

E-mail address (if any) _____

(to be folded up in the middle)
Freedom of Speech



Political Representation



Policy Dialogue and Negotiation



**Both Top-Down and
Bottom-Up Approaches Are
Needed**

**Capacity Building of Persons
with Disabilities
And Enabling Environments
Are Both Important**

***Understanding Family & Inclusive
Local and Global Community***



Education and Information for All



***Accessibility, Assistive Devices,
Prevention, & Medical Treatment***



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Establishing a Family



Good Leadership in Organisations



Grassroots Activities



Decent Work



Advocating for Human Rights



Peer Support



**Dialogue, Negotiation and
Information Dissemination
Are the Keys
For Promoting
Human Rights**

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