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# **DISABILITY SCOPING STUDY**

**Commissioned by DFID Uganda**

**February, 2009**

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## **Final Report**

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## Abbreviations

ADD	Action on Disability and Development
AIDS	Acquired Immune Deficiency Syndrome
BBA	Blind But Able
CBR	Community-based rehabilitation
COMBRA	Community Based Rehabilitation Alliance
CSOs	Civil Society Organizations
CWDs	Children with Disabilities
DENIVA	Development Network of Indigenous Voluntary Associations
DFID	Department for International Development
DUs	District Unions
DWNRO	Disabled Women's Network and Resource Organization
ESAU	Epilepsy Support Association Uganda
FIDA	Federation of Women Lawyers Associations
GoU	Government of Uganda
IGAs	Income Generating Activities
M&E	Monitoring and Evaluation
MDGs	Millennium Development Goals
MHU	Mental Health Uganda
MFIs	Microfinance Institutions
MPs	Members of Parliament
NAADS	National Agricultural Advisory Services
NADBU	National Association of the Deaf blind in Uganda
NDP	National Development Plan
NGOs	Non Governmental Organizations
NUDIPU	National Union of Disabled Persons of Uganda
NUWODU	National Union of Women with Disabilities in Uganda
PEAP	Poverty Eradication Action Plan
PMA	Plan for Modernization of Agriculture
PMTCT	Prevention of Mother To Child Transmission of HIV
PWDs	Persons With Disabilities
SNE	Special Needs Education
SWOT	Strength Weaknesses Opportunities Threats
UBOS	Uganda Bureau Of Statistics
UDHS	Uganda Demographic and Health Survey
UN	United Nations
UNAB	Uganda National Association of the Blind
UNAD	Uganda National Association of the Deaf
UNAPD	Uganda National Action on Physical Disability
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNHS	Uganda National Household Survey
UNISE	Uganda National Institute for Special Education
UPACLED	Uganda Parents of Children with Learning Disabilities
UPE	Universal Primary Education

USAID  
USDC

United States Agency for International Development  
Uganda Society for Disabled Children

## The Consultancy Team and Acknowledgements

Dr. Raymond Lang was appointed as a Research Fellow at the Leonard Cheshire Disability and Inclusive Development Centre, based at University College, London in January, 2007. He has been working in the disability and development sector for the past fifteen years. Since joining the Centre, Dr Lang in collaboration with colleagues has been developing funding strategies and potential research projects. He has also been involved in a number of international consultancies, including the DFID-funded Disability Scoping Studies in Zimbabwe (June, 2007) and Nigeria (March, 2008), as well as attending a number of international conferences. Dr Lang is also a member of a number of advisory boards and committees, including the Leonard Cheshire Disability Editorial Advisory Board to develop future academic publications. Prior to joining the Centre, Dr Lang worked as an independent consultant with regard to disability and development, undertaking consultancies for a wide range of policy makers and practitioners working in the field. These include the Department for International Development and the United Nations Development Programme. He has direct field experience of working in Afghanistan, Bangladesh, Namibia, Nepal, India, Uganda, South Africa, Zimbabwe and the Balkan States.

Ambrose Murangira is currently the Chairman of Uganda National Association of the Deaf and a National Executive Member for the National Council for Disability and National Youth Council. He is also a consultant for REEV Consult International and Adept Consult Limited. He has been engaged in Consultancy work since 2000. He holds a Bachelors degree of Social Work and Social Administration and in the process of completing a Masters Degree in Social Sector Planning and Management at Makerere University. This course focuses on the provision of Institutional Development Services, Macro-policy analysis, and Management services all aimed at Capacity Development and Poverty reduction. He has undertaken research and consultancy mainly with regard to disability issues and has overtime generated a wealth of experience in disability issues through his active involvement in the Disability Movement in Uganda. His main objective is to provide quality and appropriate project designs, evaluative studies, and research and capacity development for people with people with disabilities in Uganda. He was active in developing "People with Disabilities District Advocacy" handbook for civil rights activists. Recently, he authored a Child-Friendly Text Book on the rights of CWDs based on the Uganda's People with Disabilities Act, 2006. He is one of the young people who participated in the writing of the World Development Report 2007 (see page 204)

The consultants would like to take this opportunity to thank all those who assisted with this consultancy and production of this report. In particular, we would like to thank Dr Joanne Bosworth, Social Development Advisor at DFID Uganda for all the support she provided to the consultancy team. A special vote of thanks should be given to Mr Barry Olouch for his unstinting work as sign language interpreter for the consultants.

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**Disclaimer**

This report has been prepared by Dr Raymond Lang and Mr Ambrose Murangira commissioned by DFID Uganda. The conclusions reached and the suggestions offered are those of the authors and do not represent the policy of DFID Uganda.

## Section One

# Executive Summary

## 1.1 Introduction

This Disability Scoping Study provides a situational analysis of people with disabilities in Uganda. The survey was commissioned by the Department for International Development (DFID) Uganda Country Office. The methodology employed within the study is fully described in the Terms of Reference for this study (Appendix 1), which included undertaking a background literature review of existing published and "grey" literature regarding disability issues in Uganda. Furthermore, a 10-day visit was undertaken between the 2<sup>nd</sup> – 13<sup>th</sup> February, 2009 to consult with key stakeholders working within the disability sector. A concerted effort was made to consult with representatives from disabled people's organisations, with two focus group discussions being held in Kampala and Gulu District. It was considered particularly important to consult with people with disabilities and their representative organisations, in order to gain a nuanced understanding of the particular issues that they encounter, in the aftermath of 20 years of sustained war and civil strife in the North. In addition, key informant interviews were conducted with officials from DFID Uganda, representatives from NGOs providing disability services, as well as representatives from mainstream human rights-based civil society institutions. The rationale behind the recommendations made within this report have been contextualised with in the current strategic objectives of DFID Uganda, as delineated in the Project Concepts Notes that DFID Uganda made available to the consultants. This study comes at a very important and opportune time, as DFID Uganda is now in the process of finalising their strategy for the next five years. Furthermore, a concerted effort has been made to ensure that these recommendations will have a strategic, long-term impact upon promoting the rights of people with disabilities within contemporary Ugandan society, and therefore facilitate their effective social inclusion within the communities in which they live.

## 1.2 Key Findings and Observations

This report attempts to provide a situational analysis of the current social economic and political status of people within Uganda, by drawing upon material gathered during key informant interviews and focus groups discussions with key stakeholders within the disability sector. In addition, reference has been made to existing international and country-specific research with regard to disability issues. The fundamental human rights of people with disabilities are explicitly recognised within the 1995 Constitution of Uganda, and in progressive rights-based legislation, (for example, the People with Disabilities Act 2006). The Ugandan Government also published its National Policy on Disability in February, 2006. Furthermore, in September 2008, the Ugandan Government ratified the UN Convention on the Rights of Persons with Disabilities. Therefore, at a prima facie level, it can be concluded that Uganda fully endorses a human rights agenda to disability policy and practice.

Notwithstanding these progressive legal instruments, it remains the case that these are honoured in the breach. The major impediment to the successful implementation of the

policies listed above, (that will facilitate the sustained social inclusion of people with disabilities in contemporary Ugandan society), is a significant "implementation gap". For example, despite the fact that the Persons with Disabilities Act was passed in 2006, to date there has been no regulations passed for its implementation. The Ministry of Gender, Labour and Social Development, (who have lead responsibility for the implementation of disability policy), has stated that these are now in the process of being finalised. However, this situation is indicative of a much broader issue, in that within Uganda there is often little appreciation of the need for good governance structures and processes. Even when the need for good governance is acknowledged, there are few incentives in the private sector for such procedures to be upheld. This is evidenced by the fact that the processes of policy formulation and implementation are totally divorced from each other, there is a lack of coordination between different Government Ministries on cross-cutting issues such as disability, and that there is a lack of robust statistical data with the reflected disability issues. This situation is further compounded by a highly decentralised form of government in Uganda, whereby the central government does not easily engage with its counterparts at the District level and below.

The Ugandan Bureau of Statistics has produced various estimates of prevalence rates of disability, which significantly contrast with each other. The 2002 Population and Housing Census estimated that 4% of the total population, (equivalent to less than 1 million people), are considered to have a disability. However, the 2005/06 Uganda National Household Survey has estimated that 7.1% of Uganda's total population have a disability, this being equivalent to approximately to 2.1 million people. Obviously, there will be large regional variation within these estimates, particularly due to the fact that in the Northern Region, the prevalence rate of disability is likely to be far higher, due to the detrimental effects of war and civil strife.

The social and economic status of people with disabilities in Uganda is particularly precarious, with there being a high correlation between the incidence of poverty and disability. The Northern Uganda Survey of 2004 estimated that 72% of people with disabilities in the Northern Region of Uganda are living in a state of chronic poverty, with men far more likely to be poor than women. In analysing the relationship between poverty and disability, NUDIPU in their Strategic Plan 2008-2013 state:-

"Poverty and disability are impossible to disentangle. ... The causes of extreme poverty among the disabled are multiple including; the lack of access to education for most of the PWDs and those who access education most of them don't complete their education, especially girls and women. Due to lack of access to education most PWDs do not have skills and competencies required to get employment or get involved in any activities that gives them any livelihood. ... Disability and poverty can also be traced from deep rooted negative cultures, where a disabled child is looked at as a curse or more so if the child is a girl then they are denied food, education and health care among others" (NUDIPU, 2008; 9--10).

Furthermore, from the evidence gathered during the focus group discussions and the informant interviews conducted in this study, it very clear that people with disabilities encounter high-levels of social exclusion, marginalisation and discrimination. The vast

majority of children with disabilities do not attend primary schools, and even for those who do, the vast majority do not complete their primary education. This in turn leads to further exclusion, because few are able to gain sustainable long-term employment.

The most deeply entrenched levels of social exclusion, marginalisation and discrimination are faced by people with disabilities living in the Northern Region of the Uganda. Many have spent their whole lives living in IDP camps. From the focus group discussions held in Gulu District, it was clear that many people with disabilities were unable to access humanitarian aid provided by mainstream agencies. Furthermore, people with disabilities are the last to leave the IDP camps, thereby creating "disability ghettos". As the Ugandan Government is beginning to close all the camps, those with disabilities are finding it increasingly difficult to leave. This is because of the inhospitable physical environment and the government regulations that make it impossible for them to meet the criteria in order to receive grants that assist them in returning to their former homelands.

Within Uganda, there are services for people with disabilities, but these are inadequate to meet the level of demand. The Ministry of Gender, Labour and Social Development runs community-based rehabilitation programmes in 10 districts, but it is not in a position to scale up these services to cover the whole country. In principle, the Ministry of Education and Sports endorses the principles of inclusive education, yet national disabled people's organisations with the support of the President are lobbying for more special schools to be built, in the belief that such schools will provide a better education. Therefore, education policy in Uganda is in a state of hiatus and stalemate.

Clearly there are advantages and disadvantages to both approaches to education, with no one size fitting all. International evidence would suggest that, in the ideal situation, inclusive education is the best approach. If children with disabilities attend mainstream schools, this promotes social inclusion because children with disabilities interact with non-disabled children on a daily basis. Hence, from a very early age, many of the negative stereotypes with regard to disability are broken down. However, inclusive education will only work effectively if there are sufficient human and financial resources available. In the absence of such resources, children with disabilities who do attend mainstream schools are like to receive an inferior education. Merely placing children with disabilities in mainstream schools does not necessarily result in a genuinely inclusive educational environment.

Conversely, international evidence would suggest that "special schools" compound and reinforce segregation and social exclusion, with children with disabilities hardly ever interacting with their non-disabled counterparts. However, where the general educational system in the country is itself dysfunctional, (as many within the disability movement in Uganda would maintain), then it may be better for children with disabilities to attend special schools. Those within the disability movement in Uganda would maintain that if the mainstream educational system was functioning effectively, then inclusive education would indeed be the far better strategy to adopt.

Special issues, such as the need for sign language instruction compounds the forces driving social exclusion. The need for competent instruction in sign language with teachers having more than an elementary knowledge of basic sign is an example of such a complicating

factor. If the teacher at a local community school is unable to speak sign language well, then his or her ability to effectively teach a deaf child is extremely limited. In such cases, instruction at a school for the Deaf might be a more viable option.

Table 1.1 Key Facts and Statistical Data on Disability Issues in Uganda

- Total population of Uganda 29.9 million
- Average per capital income 300 USD
- 31% of population live on less than \$1 per day
- Estimates of disability prevalence rates vary
  - Uganda National Household Survey 2005/6 7.1% population disabled
  - Population and Housing Census 3.5% population disabled
- Uganda passed the Persons with Disabilities Act 2006
- Uganda ratified the UN Convention on the Rights of Persons with Disabilities September 2008
- In 2004, the Ugandan National Bureau of Statistics estimated that 72% of people with disabilities in Northern Uganda were living in a state of chronic poverty.
- There is a paucity of statistical data on disability in Uganda, particularly when disaggregated at District level.

The disability movement in Uganda is reputedly one of the most vibrant throughout Africa, and has played a key role in the promotion of disability rights throughout the continent. The National Union of Disabled People in Uganda (NUDIPU), is the national umbrella disabled people's organisation, comprising 14 national DPOs, which often cater to the needs of single impediment groups. Despite its international reputation, some people with disabilities are of the opinion that NUDIPU does not really represent the needs of all impairment groups, and does not have sufficient organisational capacity to lobby the government effectively.

Table 1.1 above provides some key facts and statistical data with respect to persons with disabilities in Uganda. A detailed analysis of the current political, social and economic status of people with disabilities is provided within Section 3 of this report.

### **1.3 SWOT Analysis of the Disability Sector**

Table 1.2 overleaf presents a SWOT analysis of the current status of the disability sector in contemporary Uganda. Uganda is indeed at a crossroads with regard to disability policy and practice. On the one hand, it has enacted progressive, forward-thinking disability legislation and has ratified the UN Convention on the Rights of Persons with Disabilities. However, the country faces significant challenges in implementing effective and efficient disability policies and services. The major critical impediment to this is the "implementation gap", characterised by a lack of appreciation of accountable and transparent governance structures, the lack of coordination between line ministries on cross-cutting issues, combined with the paucity of robust statistics in relation to disability. It will indeed be fascinating to see what happens within this sector in the future.

<b>Table 1.2 SWOT Analysis of the Disability Sector in Uganda</b>			
<b>Strengths</b>	<b>Weaknesses</b>	<b>Opportunities</b>	<b>Threats</b>
<ul style="list-style-type: none"> <li>• Uganda has passed progressive human rights-based disability legislation;</li> <li>• Uganda has ratified the UN Convention on the Rights of Persons with Disabilities;</li> <li>• The disability movement is well established in Uganda, with over 20 years of experience and has played a key strategic role throughout East Africa;</li> <li>• Political representation of people with disabilities is well established, with five MPs and over 50,000 representatives at District level and below.</li> </ul>	<ul style="list-style-type: none"> <li>• Despite progressive legislation, there are inadequate implementation modalities;</li> <li>• There is a lack of robust statistical data on disability issues, particularly at District level and below;</li> <li>• There is a lack of coordination between different line ministries on cross-cutting issues such as disability;</li> <li>• The disability movement lacks sufficient organisational capacity to effectively lobby the government;</li> <li>• There is a lack of collaboration between the disability movement and the MPs with disabilities;</li> <li>• Demand for disability services far outstrips supply.</li> <li>• People with disabilities have been excluded from the planning and development process;</li> <li>• There is currently no social assistance programmes for people with disabilities.</li> </ul>	<ul style="list-style-type: none"> <li>• The ratification of the UN Convention on the Rights of Persons with Disabilities provides the Ugandan Government with a unique opportunity to take forward a rights-based agenda to disability issues;</li> <li>• Bilateral and multilateral donor agencies are becoming increasingly aware of the systemic entrenched social inclusion, marginalisation and discrimination encountered by people with disabilities;</li> <li>• Furthermore, bilateral and multilateral donor agencies are giving priority to assisting the Ugandan Government in its quest to reform the public sector and to provide substantial assistance in rebuilding the social, political and environmental infrastructure in the Northern Region of Uganda. This has the potential to significantly improve the lives and livelihoods of people with disabilities.</li> </ul>	<ul style="list-style-type: none"> <li>• Unless there is a structural public sector reform which addresses the "implementation gap" that has been identified, then it is unlikely that people with disabilities will be able to exercise their constitutional rights</li> <li>• The severity and extent of social exclusion, marginalisation and chronic poverty is so ingrained that it will take decades for this situation to be rectified;</li> <li>• Without increased commitment and political will to implement a rights-based agenda to disability issues, it is unlikely that sufficient human and natural resources will be made available for disability service provision.</li> </ul>

## **1.4 Recommendations**

This report makes 14 key recommendations to enable DFID Uganda to make a strategic, focused impact on promoting the rights and social inclusion of people with disabilities in Uganda, that fall within the broader strategic priorities of the organisation. In section 4 of this report, a rationale and justification of each of these recommendations is provided. The recommendations have been clustered in alignment with the proposed strategic priorities that DFID Uganda has identified as being key within their next five year strategy. Furthermore, they have been written in recognition of the fact that DFID Uganda is not going to fund a new specifically designated disability programme per se, but will endeavour to incorporate a disability component into their future core programmes.

### **Accountability/Direct Budget Support**

1. That DFID Uganda identifies partners and mechanisms to undertake a baseline survey to determine the prevalence rates of children with disabilities in 2 Districts;
2. That DFID Uganda identifies partners (MoES) and mechanisms to pilot inclusive education programmes in 2 Districts;
3. That DFID Uganda, through its direct budget support, encourages the Government of Uganda to develop a national inclusive education policy, in alignment with the UN Convention.
4. That DFID Uganda support the Uganda Bureau of Statistics and the National Council for Disability to develop input, output and outcome indicators that effectively monitor the extent to which disability has been mainstreamed and included in public services;
5. DFID Uganda funds disability awareness training to senior civil servants in all line Ministries and District authorities in the next 5 years

### **Northern Uganda**

6. That DFID Uganda considers providing assistance to people with disabilities to return to their homelands;
7. That DFID Uganda undertakes a comprehensive needs assessment of the assistance needed by people with disabilities in the North;
8. That DFID Uganda actively consults and engages with DPOs and other people with disabilities during this needs assessment.

### **Social Assistance**

9. That DFID Uganda implements its cash transfer programme for people with disabilities in all six Districts;
10. That the monitoring and evaluation frameworks developed for this programme explicitly assess the extent to which people with disabilities have been included, and the impact on the lives of PWDs.
11. That DFID Uganda encourages the Government of Uganda to include cash transfer schemes under gender and social protection thematic area within the National Development Plan (NDP);

12. That DFID Uganda encourages the Government of Uganda to investigate developing other forms of social protection for people with disabilities as part of a national social protection framework and action plan.

**General Recommendations**

13. That DFID Uganda hosts a seminar for other bilateral and multilateral donor agencies to disseminate the findings and recommendations of this Disability Scoping Study;
14. That if DFID Uganda is serious about mainstreaming disability throughout its core programmes, then consideration be given to a specific allocation of financial resources for disability in each of its core programmes;
15. That DFID Uganda gives some consideration to how include people with disabilities in their road construction programme,

## Section Two Methodology

The methodology employed in this Disability Scoping Study was agreed between the consultants and officials at DFID Uganda Country Office. This study complements previous disability scoping studies that have been conducted in Zimbabwe (June, 2006) and Nigeria (March, 2007). The overall objective of this study was to provide a situation analysis of the political, economic and social status of disability in Uganda, as well as providing strategic recommendations on how DFID Uganda can mainstream disability within their core programmes. Furthermore, this study comes at a very opportune time, as DFID Uganda is currently developing its strategic plan for the five years.

It was originally intended that a comprehensive literature review of all relevant documents regarding disability issues in Uganda would be undertaken and constitute a separate section of this report. This would comprise a review of academic articles, as well as reports and other forms of "grey" literature produced by disabled people's organisations (DPOs), and other civil society institutions working within the disability sector in Uganda. In addition, DFID Uganda made available unpublished concept notes regarding their future strategy and priorities for the next five years. These documents have proved invaluable, and have provided the context and foundation upon which the majority of recommendations made within this report have been made. Where possible, a concerted effort had been made to make strategic recommendations that are in alignment with existing and future DFID priorities, with a view to ensure that disability issues and people with disabilities are effectively mainstreamed within DFID Uganda's core activities. However, in contrast to the majority of developing countries, there has already been a great deal of research undertaken in the field of disability in Uganda. Therefore, within this report, reference to the secondary published literature has been incorporated into Section Three of the report, which by so doing embellishes the rich material that was gathered during the focus group discussions and key informant interviews conducted as part of the fieldwork. A comprehensive bibliography of existing literature dealing with disability issues is provided at the end of this report.

The consultants undertook a two week field visit within Uganda, (2<sup>nd</sup> – 13<sup>th</sup> February, 2009) to gain some understanding of the issues encountered by people with disabilities in Uganda. A concerted effort was made to engage with the leaders of the disability movement. To that end, two focus group discussions were held with DPOs in Kampala and Gulu District. A list of all those who participated in the focus group discussions is found in Appendix II. Within each of the focus groups, the following issues were discussed:-

- What are the main challenges faced by DPOs?
- How have DPOs been lobbying the Ugandan Government and how effective has this lobbying been?
- How have DPOs being worked in collaboration with other NGOs and INGOs and how effectively?
- What needs to change to make the lives of Ugandan persons with disabilities better?

The rationale for undertaking focus group discussions in both Kampala and Gulu District was to provide a comparative analysis between the experiences of people with disabilities living in a war-affected region and those living in comparatively more stable environments. There is compelling anecdotal evidence to suggest that previous studies of the living conditions and barriers that militate against the social inclusion of people with disabilities in Uganda have primarily focused on those living in Kampala. Therefore, it has been argued that these studies do not reflect the additional and perhaps contrasting life experiences and barriers to social inclusion of people with disabilities who have encountered as a result of war and civil strife. The Uganda Bureau for Statistics (2002) has estimated that Northern Uganda has the highest prevalence rate (4.4%) of disability within a whole country. The 2005-06 Uganda National Household Survey estimates there are many more disabled children in Northern and Eastern Uganda than elsewhere. Furthermore, anecdotal evidence would suggest national disabled people's organisations, who are primarily based in Kampala, do not reflect the needs and aspirations of people with disabilities living in such areas. Consequently, disabled people's organisations based in Northern Uganda have been questioning the validity of previous research undertaken in this field. Therefore, by undertaking such a comparative analysis, this study highlights the policy implications, for DFID, the Ugandan Government and other bilateral and multilateral donor agencies, in developing genuinely inclusive policies and operational modalities, which take into account the potentially differing needs of people with disabilities living in conflict-affected and comparatively stable environments. During the focus group discussions in Gulu District, participants were encouraged to discuss their experiences of living within a conflict-affected environment. As will be demonstrated below, people with disabilities living in the Northern Region of Uganda encounter the most severe and deeply embedded forms of social exclusion, deprivation and marginalization, often manifested by psychological trauma and high levels of stress.

The consultants also undertook a series of key informant interviews with key stakeholders who are working within the disability sector in Uganda. These included officials from DFID Uganda, mainstream generic civil society institutions promoting human rights, government officials from the Ministry Gender, Labour and Social Development, the Ministry of Finance, Planning and Economic Development, the Office of the Prime Minister, the Ministry of Education and Sports, the Ministry of Works and Transport, and Parliament of Uganda. In addition interviews were held with NGOs and INGOs specifically providing services to people with disabilities, including World Vision and Leonard Cheshire Disability. Interviews were also conducted with senior officials at UNICEF, The World Bank, International Republican Institute and USAID. We also interviewed academicians at Kyambogo University, the only University offering special needs education in Uganda. A comprehensive list of key informant interviews is provided in Appendix III.

This study has also utilized the "Stepping Stool" to inclusion, originally designed by Philippa Thomas, (Social Development Advisor at DFID Zimbabwe), as an analytical tool to assess the relative strengths of the respective roles played by the State, service providers and DPOs with regard to the inclusion of people with disabilities within a given society. This model assumes that each of these components must be in equilibrium and interact with each other in mutually supportive and reinforcing ways, otherwise the Stepping Stool to Inclusion will be unbalanced or the legs may splay outwards causing the stool to collapse. The strength of

each component or 'leg' in a country can be assessed by finding the answers to few simple questions. Then the Stepping Stool to Inclusion can be drawn to visually represent the basic status of disability issues within a country.

Finally, this study developed a Strengths, Weaknesses, Opportunities and Threats (SWOT) analysis of the contemporary position of the disability sector in Uganda. Such an analysis provides an instructive insight and basis for making specific, strategic recommendations to DFID Uganda in supporting people with disabilities and their representative organisations in taking forward a rights-based agenda to disability issues, but which nevertheless takes into account the political realities and operational modalities to which DFID Uganda must adhere.

## Section Three

# Key Findings and Observations

### 3.1 Global Trends regarding Disability and Development

It is important, at the beginning of this study, to make some reference to global trends and developments regarding disability in developing countries, and the dynamics of international disability politics. People with disabilities comprise approximately 10% of the world's population, 75% of whom live in developing countries, and constitute one of the poorest, marginalised and socially excluded groups in any society (DFID, 2005, Barron & Amerena ed. 2007). People with disabilities, irrespective of where they live, are statistically more likely to be unemployed, illiterate, to have less formal education, and have less access to developed support networks and social capital than their able-bodied counterparts. Consequently, disability is both a cause and a consequence of poverty (Yeo, 2005).

Development agencies and practitioners are increasingly recognising disability as a key issue, inexorably linked to poverty, in the extension of human rights and citizenship. In 2002, James Wolfensohn, former President of the World Bank, stated that unless disability issues were addressed, the UN Millennium Development Goal targets would not be met. Furthermore, the United Nations, in collaboration with civil society institutions, has successfully negotiated a convention regarding disability rights, ratified at the 61<sup>st</sup> Session of the General Assembly in December, 2007. At the time of writing this report, 137 States have signed the Convention, with 81 States signing the Optional Protocol. Furthermore, 49 States have ratified the UN Convention, with 28 States ratifying the Optional Protocol. The Government of Uganda ratified the UN Convention on the 25<sup>th</sup> September, 2008. The Convention is of historic importance, for it is the first international legally-binding instrument that will hold signatory states to account to ensure that appropriate, robust policies and effective implementation architectures are developed to guarantee that the rights and dignities of people with disabilities are upheld. Such developments will facilitate the social inclusion of people with disabilities within their respective countries.

Notwithstanding the high profile given to disability and development issues, there remains scant consensus on what are the most appropriate, sustainable strategies and operational modalities that should be employed for effective interventions within the disability sector. In 2000, DFID published its issues paper on disability and development, advocating a "twin-track approach" whereby DFID would fund projects specifically targeted at people with disabilities, as well as encouraging mainstream development projects to incorporate a disability component into generic development programmes (DFID, 2000). Since its publication, more emphasis has been placed on mainstreaming, in the belief that including people with disabilities in generic development activities will ultimately result in building more inclusive, sustainable societies (Voluntary Services Overseas, 2006). Nevertheless, development agencies are struggling to develop effective, sustainable operational modalities for mainstreaming disability issues into generic development programmes. This can be partially explained by the contention that surrounds what is precisely meant by "mainstreaming". In 2007, DFID published its "How To Note" on disability that provides

practical guidance to DFID country offices and other development practitioners on how to mainstream disability into their core activities (DFID 2007).

The past 40 years have witnessed, throughout developed and developing countries, the emergence of an international disability movement. Disabled People's Organisations (DPOs) now constitute a critical and essential component of civil society. The *raison d'être* of DPOs is to advocate for the advancement and enforcement of rights of people with disabilities, in the belief that, at its foundation, disability is a human rights issue. Typically, DPOs are run and managed by people with disabilities. During the past decade, DPOs have become increasingly instrumental in working with national governments, as well as the bilateral and multilateral institutions, in developing policies and operational modalities for the effective social inclusion of people with disabilities in the societies in which they live.

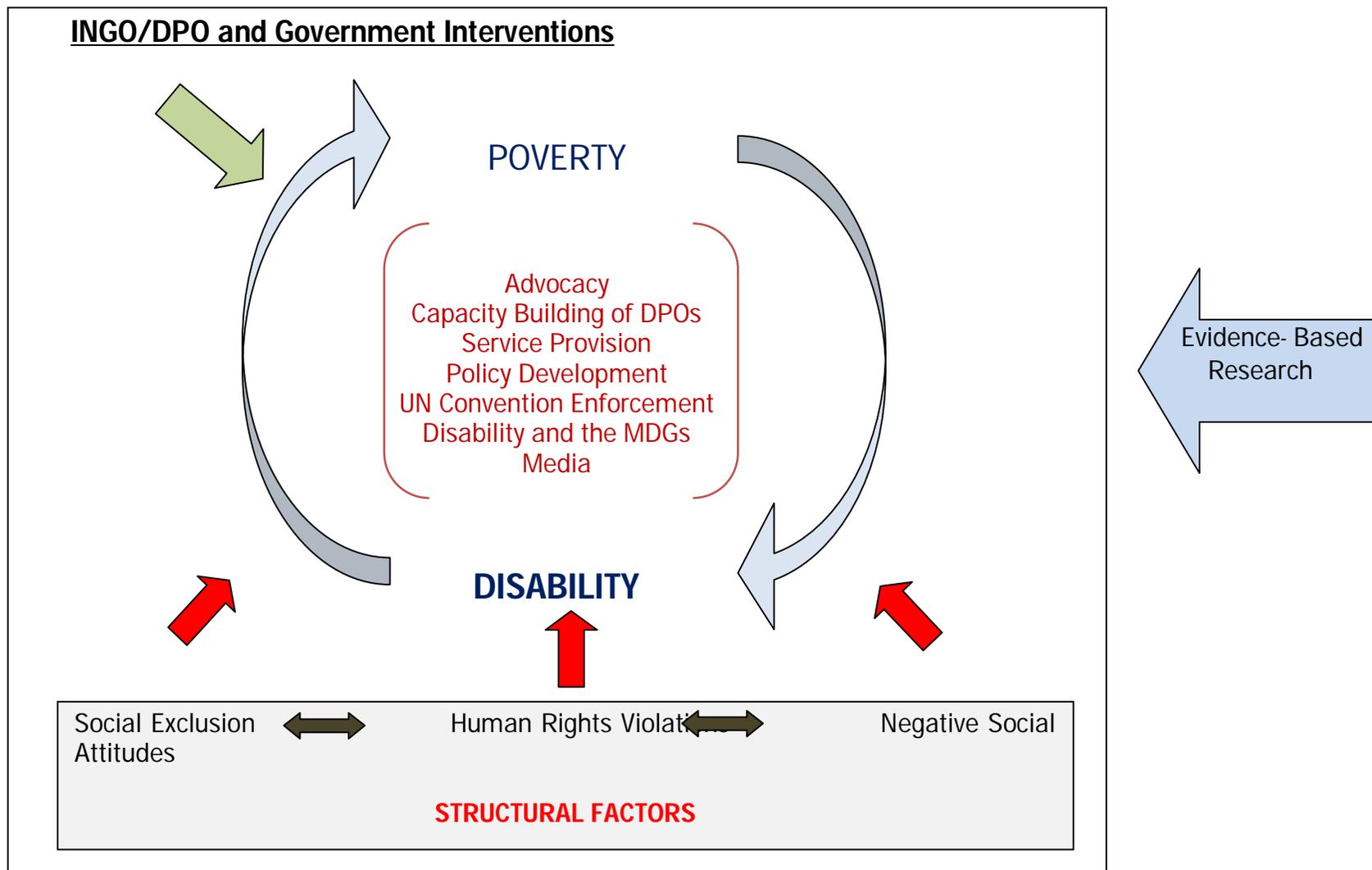
The ideological foundation of the international disability movement is the social model of disability. This maintains that disability arises from the attitudinal, physical and institutional barriers that systematically exclude people with disabilities from fully participating in society. Therefore, rather than focusing on the physical and/or psychological limitations of individuals, the emphasis of the analysis now focuses upon empowerment, social inclusion, choice and human rights. Furthermore, the clarion call of the movement is "Nothing About Us Without Us", which emphatically emphasises that disability policies and practices should not be developed and implemented without the non-tokenistic involvement of people with disabilities and their democratically elected organisations. The tenets of the social model of disability have become the ideological hegemony of disability policy-making and practice in the 21<sup>st</sup> century.

The relationship between disability, poverty and international cooperation is complex, but it is crucial to understand these relational dynamics if bilateral and multilateral agencies are to be in a position to make a long-term, sustainable impact on improving the lives of people with disabilities, by developing appropriate policies and implementing well-grounded, strategic interventions in low-income countries. While it is often said that people with disabilities constitute one of the poorest groupings in any society, the evidence for this is predominantly anecdotal. What is clear is that a mutually self-reinforcing cycle exists between poverty and disability, with each being a cause and consequence of the other. However, the dynamics of this relationship remains ill-defined and under-researched. What is known is that people with disabilities invariably encounter discrimination when accessing loans from mainstream micro-finance institutions (Marsland et al 2008), and that in the majority of developing countries, no social protection programmes exist for people with disabilities (Mitra, 2008).

The diagram overleaf attempts, in a very simple manner, to provide an analysis of these dynamics, and how they can be effectively tackled. At the heart of the model is a mutually self-reinforcing negative cycle between poverty and disability. Hence, if one is poor, there is a greater likelihood of being disabled, due to the fact that those who are poor often live in physical and environmental conditions, (such as inadequate sanitary conditions and lack of access to health care provision), that will result in disability and the onset of impairments. Similarly, a disabled person has a greater statistical probability of being poor than their able-bodied counterparts, because of lack of access to education and employment opportunities.

This mutually self-reinforcing negative cycle is driven and fuelled by underlining structural factors, the most prominent of which are social exclusion, negative social attitudes and human rights violations. Furthermore, in many low-income countries, there is a paucity of appropriate, sustainable services that are affordable and that facilitate the effective social inclusion of people with disabilities. In many instances, if not for the activities undertaken by international NGOs, many people with disabilities would not receive any services whatsoever.

**DISABILITY, POVERTY AND DEVELOPMENT COOPERATION**  
**A Conceptual Framework**



### **3.2 The Role of DFID Uganda**

DFID Uganda is one of the major bilateral donor agencies providing overseas development assistance within the country. This Disability Scoping Study comes at a very opportune and important time, as the DFID Uganda Country Office is now in the process of developing its strategy for the next five years. Concept notes for each of the major programmes that DFID Uganda is now developing were made available to the consultants of this study, and these provide the basis for the strategic recommendations that are made later within this report. It is also assumed that the current level of expenditure by DFID Uganda will continue as currently planned for the foreseeable future. This is heavily contingent upon the global economic crisis not having a significant impact upon bilateral and multilateral donor assistance in Uganda. However, it is fully acknowledged by the consultants that this is a significant assumption to make in the current economic climate. This is already beginning to have a negative impact.

Therefore, it is assumed that DFID Uganda will continue to provide direct budget support to the Government of Uganda, with this constituting approximately 50% of its total spending. Under its accountability programme, DFID Uganda is committed to assisting the Ugandan Government to "*achieve a responsive and accountable public sector that delivers value for money services in a timely and effective manner*" (DFID Uganda 2009a: 1).

In addition, DFID Uganda will develop and implement specific programmes to support the reconstruction of the Northern Region; institute a social protection programme in collaboration with the Ministry of Gender, Labour and Social Development and the Ministry of Finance, Planning and Economic Development; as well as improving the physical infrastructure, (particularly in relation to roads and transport).

#### **TABLE 3.1: Development Challenges in Uganda**

Source, DFID Fact sheet on Uganda, (updated September, 2008)

- Total population: 29.9m
- Average life expectancy is 50 years
- Average per capita income 300 USD
- Approximately 435 per 100,000 women die in childbirth
- 6.4% of people aged 15-49 years are affected by HIV/AIDs
- 68% of the population has access to clean water
- 31% of the population live below the national poverty line (less than \$1 per day)

### **3.3 Disability Statistics in Uganda**

There is a real paucity of robust statistical data with regard to disability issues in Uganda. However, the Uganda Bureau of Statistics has undertaken some preliminary work in this field. One of the inherent problems in collecting such data, which is common in many developing countries, is that there is no universally agreed definition of what constitutes "disability" and "disablement". The following tables elaborate some of the details that can be extrapolated from the data collected to date. Thus, it can be seen that the prevalence

rate in the latter study is approximately double that of the former, which compounds the difficulties in planning and targeting of disability services, particularly at the local level.

<b>Table 3.2: Prevalence Rates of People with Disabilities in Uganda</b>				
Sources: The 2002 Population and Housing Census and the 2005/05 Uganda National Household Survey 2005/06				
	Uganda National Household Survey 2005/06		Population and Housing Census 2002	
	Frequency	Percent	Frequency	Percent
Disabled	2,093,011	7.1	838,000	3.5
Not Disabled	27,394,102	92.9	23,003,000	96.5
Total	29,487,113	100	23,841,000	100

It is also insightful to compare differing prevalence rates disaggregated by different categories of impairment between surveys, which is outlined in Table 3.3 below.

<b>Table 3.3: Prevalence Rates of People with Disabilities in Uganda Disaggregated by Category of Impairment</b>		
Sources: The 2002 Population and Housing Census and the 2005/05 Uganda Demographic and Health Survey		
Category of Impairment	Uganda Demographic and Health Survey 2005/06 (Percent)	Population and Housing Census 2002 (Percent)
Seeing	35.17	22
Mobility Problems	24.46	34
Hearing	20.43	15
Taking Part in Social Activities	6.63	8
Psychological, Emotional Communication	4.33	8
Other	3.97	4
Personal Care	1.97	5
Learning	1.64	1
<b>TOTAL</b>	<b>100.0</b>	<b>100</b>

Table 3.4 below disaggregates the percentages of those with disabilities by age. It should be noted that approximately 45% of people with disabilities are aged under 30.

<b>Table 3.4: Selected Characteristics of PWDs by age group</b>	
Source: The 2005/05 Uganda National Household Survey	
Age group	Percent
0-17 (Children)	31.4
18-30 (Youth)	14.4
31-59	26.4
60+ (Older persons)	27.8
<b>Total</b>	<b>100.0</b>

The Ugandan Bureau of Statistics has undertaken some analysis of disability rates at regional level. The 2002 Population and Housing Census estimated a national disability prevalence rate that was 1.1% higher than that estimated in 1991 Census. The increase was attributed to improvements in the methods of data collection used. Furthermore, the 2002 Population and Housing Census found that Northern Uganda had the highest incidence of disability (4.4%), the Western region had the lowest (2.9%), Eastern region had 3.6% while the Central region had 3.1%.

### **3.4 The Ugandan Policy Context with Regard to Disability Issues**

The policy context in which disability issues are framed within Uganda is complex, and to some extent contradictory. On the one hand, the Ugandan Government has passed forward-looking, progressive antidiscrimination disability legislation, (as exemplified by the Persons with Disabilities Act 2006 and the National Council for Disability Act 2004), which will be described in greater detail below. Furthermore, disability rights are explicitly recognised within the 1995 Constitution. Article 32 explicitly outlaws discrimination on the basis of race, gender and disability. Article 34 recognises the right of all children to benefit from universal primary education. In addition, Article 16 explicitly recognises the rights of persons with disability which states that the "Society and the State shall recognise the right of persons with disability to respect and human dignity". Other mainstream domestic legislation also recognises disability rights. These include The Local Government Act 2001, The Children Statute 1996; The Uganda Communications Act 1998; The Land Act 1998; The Uganda Traffic and Road Safety Act 1998; The Universities and Tertiary Institutions Act 2001; The Equal Opportunities Act 2008; Education (Pre-primary, Primary, Post-Primary) Act 2008. The Ugandan Government has ratified the UN Convention on the Rights of Persons with Disabilities on 25 September, 2008. Thus, from a constitutional perspective, the human rights of all people with disabilities living in Uganda are enshrined in national legislation and internationally legally binding instruments.

It should also be noted that within the Ugandan Parliament, there are five MPs who have a disability and might have been more instrumental in spearheading the legislation delineated above. At the local government level, there are approximately 50,000 local council councillors representing PWDs, these being elected at every council level. Furthermore, all are people with disabilities themselves. However, it is unclear to what extent these councillors are collaborating with the disabled movement and what training they have received. Nevertheless, this is a potentially an invaluable resource for implementing a rights-based agenda to disability at the local level.

Notwithstanding these laudable constitutional provisions, it is nevertheless the case that the major challenge to the effective enforcement of disability rights is a significant "implementation gap" in the policy-making process, this being manifested in a multiplicity of ways. At the crux of this implementation gap is poor governance structures and processes that affect not only disability legislation, but constitute a significant impediment to the development of social and economic policy in general. From the key informant interviews undertaken for this study, it was abundantly clear that the legislative process is divorced and separated from the implementation of such legislation. A prime example of this is that

although the Persons with Disabilities Act was enacted in 2006, to date there has been no regulations published to enforce this legislation. An interview with the Commissioner for Disability Issues confirmed that these regulations were still in the process of being drafted. The Ministry of Gender, Labour and Social Development pointed out that the process of developing the guidelines is almost complete, and that it has been delayed because of technicalities involved (i.e. the need to append a 'schedule' for measurements etc). MGLSD told the consultants that DPOs are consulted during the process of formulating the policies and guidelines. However, the National NGO forum was of the opinion that the government usually consults NGOs/CSOs/DPOs only during the final stage of policy formulation or planning, and as a result minimal inputs are incorporated. For example, all the DPOs interviewed except NUDIPU have never participated in the planning, implementation, monitoring of the Poverty Eradication Action Plan (PEAP) which is overall planning framework for guiding public action on development/poverty reduction. As a result the needs of different categories of PWDs are not included. It was also noted that gaps do exist between regulations and policies. This is a common problem in many developing countries.

Another complicating factor is that Uganda has a very decentralised form of government, which results in the central government having little effective control on how national legislation is enacted at the local level. This is further compromised by weak accountability structures. Again, this feeds the implementation gap described above.

This situation is further compounded by the absence of robust and accurate statistical data with respect to disability issues, this being particularly at the case District and local government levels. In the absence of such data, it is extremely difficult for people with disabilities and other civil society institutions working within the disability sector to hold their government to account for the promotion and enforcement of the disability rights, thereby creating a significant "democratic deficit" in the governance infrastructure that has been instituted within Uganda.

### **3.4.1 Disability Specific Policies and Legislation**

This section of the paper provides a synopsis of disability-specific policies and legislation currently existing within Uganda. As previously noted, the Ugandan Parliament has already passed progressive, human rights-based legislation in this field. The Government published its National Policy on Disability in February, 2006. Its strategic objective is "promoting equal opportunities and enhanced empowerment, participation and protection of rights of persons with disabilities irrespective of gender, age and type of disability" (Ministry of Gender, Labour and Social Development, 2006:1). This policy paper delineates the major concerns faced by people with disabilities being poverty, education and skills, employment, conflicts and emergencies, health, HIV/AIDs and accessibility.

The policy also recognises the imperative of adopting a rights-based approach with respect to "programming by seeking to minimise stigmatisation and discrimination". It also recognises the fact that disabled people's organisations must play a vital role in the planning, implementing, monitoring and evaluation of disability programmes. It further recognises that disability is by definition a multi-sectoral and cross-cutting issue. Therefore, the policy states that "every stakeholder should undertake the responsibility of

mainstreaming disability concerns in the respective sectoral plans" (Ministry of Gender, Labour and Social Development, 2006:13-14). Interestingly, the policy recognises the necessity for good governance as a prerequisite for the implementation of effective inclusive disability policy and programmes. However, as already been highlighted above, one of the major impediments to effective policy-making in Uganda is the absence of a robust implementation architecture.

In addition, the Ugandan Parliament enacted the Persons with Disabilities Act (2006), which attempts to provide the legal basis for the implementation of the National Policy on Disability described above. According to the preamble of this Act, its objective is to "provide a comprehensive legal protection for persons with disabilities in accordance with Article 32 and 35 of the Constitution; to make provision for the elimination of all forms of discrimination against persons with disabilities towards equalisation of opportunity and for related matters". Moreover, within the Act, many substantive rights are recognised for people with disabilities including the rights to privacy, family life, participation in public and cultural life, access to social services, and access to public services and so forth. However, at the time of writing, there are no regulations that have been drafted or agreed to ensure that the principles and tenet of this act are indeed implemented, despite the fact that this Act received Assent on 24 May, 2006.

Commenting on the inadequacy of existing disability legislation, the National Union of Disabled Persons in Uganda (NUDIPU) candidly state that:

*"The Persons with Disabilities Act, 2006, provide a comprehensive legal protection for the disability in accordance with Article 32 and 35 of the Constitution, which aims at including all forms of discrimination against people with disabilities as well as ensuring equal opportunities for people with disabilities. This Act provides a good basis for the actors in the disability fraternity to promote a human rights approach in their work. The law can also be used by the disability fraternity to undertake public litigation as recourse for promoting and protecting the rights of people with disabilities. Although the law looks comprehensive in addressing disability issues, it has not been translated into concrete programmes for people with disabilities. There are huge gaps that still require robust advocacy and network at implementation level which NUDIPU seeks to address. These gaps are in the area of popularising and disseminating the laws and policies, resources to implement these laws and policies where NUDIPU has an advocacy role to play in influencing budgetary allocations"* (NUDIPU, 2008: 11).

The National Council for Disability (NCD) Act 2002 was enacted by Parliament to promote the rights of persons with disabilities as delineated in existing international conventions and legal instruments and the 1995 Constitution. The overall strategic goal of the NCD is to promote equalization of opportunities for people with disabilities through empowerment, participation and monitoring of services, which again is underpinned by the principles of human rights.

Section 5 of the National Council for Disability Act 2003 outlines the aims and objectives of the Council as being:-

- To promote the implementation and equalization of opportunities for persons with disabilities;
- To monitor and evaluate the impact of policies and programmes designed for equality and full participation of people with disabilities;
- To advocate for and promote effective service delivery and collaboration between service providers and persons with disabilities; and
- To advocate for the enactment of laws and the reviewing of existing laws with a view to complying with the equalization of opportunities as stipulated in the United Nations Standard Rules on the Equalisation of Opportunities for persons with disabilities, the Constitution and other laws and international legal instruments.

Section 6 of the Act delineating the functions of the Council as:-

- To act as a body at a national level through which the needs, problems, concerns, potentials and abilities of people with disabilities can be communicated to the government and its agencies for action;
- To monitor and evaluate the extent to which government, NGOs and the private sector include and meet the needs of people with disabilities in their planning and service delivery;
- To act as a co-ordinating body between government departments, other service providers and people with disabilities
- To solicit for and acquire funds and other resources from government and donors for use in the performance of the council's functions;
- To advocate for the promotion of and encourage activities undertaken by institutions, organizations and individuals for the promotion and development of programmes and projects designed to improve the lives and situations of people with disabilities;
- To carry out or commission surveys and investigations in matters or incidents relating to violation of rights of persons with disabilities, non-compliance with programmes, policies or laws relating to disabilities; and take appropriate action in relation thereto or refer the matter to the relevant authority;
- To hold annual general meetings of representative from lower councils for people with disabilities for the purposes of reviewing the council's performance and also plan for the subsequent year;
- To consider and recommend ways and means of controlling the unnecessary increase of disability in Uganda;
- To assist the Electoral Commission to ensure the conducting of free and fair elections of representatives of people with disabilities to Parliament and Local Government Councils;
- To identify and give guidelines to organizations working for people with disabilities; and
- To perform any other functions relating to the above as the Minister may determine.

Notwithstanding the ostensible wide-ranging power of the NCD, it is apparent that it is not being able to function in an effective manner, this being the result of a multiplicity of complex and interrelated factors. Anecdotal evidence would suggest that the relationship

between the NCD and the disability movement in Uganda has been tense and to some extent counter-productive. This is because national disabled people's organisations have perceived the NCD as being a threat, in as far as taking over functions that have traditionally been undertaken by the former. Furthermore, the NCD has been dysfunctional, evidenced by the fact that the Executive Secretary of the Council was not appointed until August, 2008. In addition, the NCD has yet to submit its first report to Parliament, despite the fact that it is mandated to submit such reports every three years. Therefore, it is fair to conclude that the NCD lacks the sufficient organisational capacity to conduct its affairs in an efficient and effective manner. However, insufficient funding can be perceived as a major problem facing NCD. The table below illustrates the trend of support from the government to National Council for Disability in comparison with others;

Trends in government support to National Council for Disability in comparison with government support to other councils (wages and non-wage) in millions shillings

<b>Table 3.5 Expenditure of The National Council for Disability 2004/05 - 2007</b>								
<b>Council</b>	<b>FY 2004/05</b>	<b>Council Share</b>	<b>FY 2005/06</b>	<b>Council Share</b>	<b>FY 2006/07</b>	<b>Council Share</b>	<b>FY 2007/08</b>	<b>Council Share</b>
National Council for Children	230.01	33%	219.80	35%	208.80	41%	208.80	41%
<b>National Council for Disability</b>	<b>117.80</b>	<b>17%</b>	<b>102.00</b>	<b>16%</b>	<b>96.00</b>	<b>19%</b>	<b>96.00</b>	<b>19%</b>
National Council for Women	184.20	26%	160.00	25%	101.00	20%	109.70	21%
National Youth Council	168.80	24%	149.40	24%	98.40	20%	98.40	19%
<b>Total support</b>	<b>700.81</b>	<b>100.00%</b>	<b>631.20</b>	<b>100.00%</b>	<b>504.20</b>	<b>100.00%</b>	<b>512.90</b>	<b>100.00%</b>

Source: Authors

### **3.4.2 Education Policy**

At this juncture, it is important to make some pertinent observations with regard to the current status of education policy in Uganda. This particular issue was highlighted by many of the key informants and participants in the focus group discussions as being one of the major areas in need of substantial attention. As has already been noted, the Ugandan Government has ratified the UN Convention on the Rights of Persons with Disabilities, which in Article 24 (Education) explicitly endorses the principles of inclusive education. Article 24 states that "with a view to realising this right without discrimination and on basis of equal opportunity, State Parties shall ensure an inclusive education system at all levels and

lifelong learning". Furthermore, as previously noted, the 2006 National Policy on Disability explicitly makes reference to Uganda's universal primary education policy, which declares that all children have a right to receive such an indication.

Despite these laudable and progressive education policies, it was abundantly clear that Uganda is in no position to implement inclusive education in any sustainable manner at the current time. Indeed, at the last International Disability Day, (held on the 3rd December, 2008), at an event attended by the President of Uganda, leaders of the disabled people's organisations lobbied for the extension and building of more special schools, in the belief that children with disabilities receive a far better education in such environments than in mainstream schools. Subsequently, the President issued a Decree sent to the Ministry of Education and Sports to build more special schools. Therefore, Uganda's education policy with respect to disability is in a state of hiatus and confusion. On the one hand, the Government is committed to the principle of inclusive education, (evidenced by the ratification of the UN Convention and the adoption of a universal primary education policy). On the other hand, it is clear that some people with disabilities and their representative organisations are pressing for more special schools to be built.

International evidence would suggest that an inclusive education approach, in the ideal scenario is the best strategy. If children are educated alongside their non-disabled peers, then many of the negative stereotypes and social attitudes are broken down. However, if mainstream for children with disabilities is to be more than just tokenistic, then adequate human and financial resources need to be provided. Inclusive education is far more than just placing children within a "normal classroom", but demands that teachers receive training on how to work with children with disabilities, that brings out their best educational achievements.

However, given that the mainstream educational system is currently inefficient, and taking a pragmatic approach, many people with disabilities in the Ugandan disability movement have been advocating for the building of more special schools. This is because they believe that, in the current system, children with disabilities will receive a far better education, and stand a far greater likelihood of securing long-term employment if they receive education in special schools. Notwithstanding this pragmatic approach, it has to be acknowledged that, historically, special schools only provide education to a very small number of children with disabilities, are extremely expensive to run, and seriously militates against the social inclusion of people with disabilities. In the long term, if the mainstream education system can be improved, the disability movement would indeed advocate for more children to be educated within mainstream schools.

From the key informant interviews undertaken a study, it was obvious that there are many institutional and attitudinal barriers that militate and hamper children with disabilities completing even primary education. For example, the Dean of the Special Needs Education faculty at Kyambogo University identified a number of complex factors that preclude children with disabilities completing their education. Firstly, especially in rural areas, the physical environment of many schools and the public transportation infrastructure result in many children with disabilities being unable to attend. Secondly, even if such children do enrol, there is no guarantee that they will complete primary schooling. Parents of children

with disabilities often are unwilling to pay the necessary school fees. In addition, as children with disabilities progress through primary schools, they are increasingly teased by their non-disabled peers. A further factor that seriously militates against children with disabilities graduating from primary education is that the whole education system in Uganda is exam-focused and that it becomes too competitive for many children with disabilities to survive in such an environment. Finally, it should be noted that there is a chronic shortage of trained special needs education teachers within Uganda, which again compounds the difficulty in implementing any viable and sustainable inclusive education policy within the country.

Tables 3.6 and 3.7 below compare the number of children with disabilities who actually attend with those who have the potential to do so. There are several important points to note. First, the number of children with disabilities actually attending school is very small, approximately 183,000 throughout the whole country. Secondly, for all impairment group there is a significant and progressive trend of children with disabilities dropping out of school as they move from one year to the next. Finally, there is a very large variation between those attending primary education and those who have the ability to do so. These statistics reinforce the necessity of addressing those systemic barriers that militate against children with attending schools outlined above.

<b>Table 3.6: Number of Children attending Primary School by Class 2007</b>								
Source: Educational Statistical Abstract 2007								
<b>Disability</b>	<b>Primary one</b>	<b>Primary two</b>	<b>Primary three</b>	<b>Primary four</b>	<b>Primary five</b>	<b>Primary six</b>	<b>Primary seven</b>	<b>Total</b>
Autism	1,574	1,176	1,215	918	870	716	440	<b>6,909</b>
Hearing Impaired	11,567	8,702	9,859	8,645	6,711	4,993	2,902	<b>53,379</b>
Mentally impaired	12,280	7,511	6,681	5,886	4,797	3,512	2,152	<b>42,819</b>
Multiple handicaps	1,297	884	783	672	607	456	280	<b>4,979</b>
Physically impaired	6,105	4,648	5,209	5,089	4,615	3,615	2,266	<b>31,547</b>
Visually impaired	7,017	6,045	7,105	7,312	6,757	5,607	3,602	<b>43,445</b>
<b>Total disabled children</b>	<b>39,840</b>	<b>28,966</b>	<b>30,852</b>	<b>28,522</b>	<b>24,357</b>	<b>18,899</b>	<b>11,642</b>	<b>183,078</b>
<b>Percent</b>	<b>21.8%</b>	<b>15.8%</b>	<b>16.9%</b>	<b>15.6%</b>	<b>13.3%</b>	<b>10.3%</b>	<b>6.4%</b>	<b>100.0%</b>

**Table 3.7: Distribution of Children with Disabilities with the Ability to Attend School**

Source: Uganda National Household Survey 2005/06

Disability type	Affected all the time	Affected sometimes	Not Affected	Not Available	Total
Visual impairment	59.8	22.0	3.1	15.2	100.0
Mobility problem	47.2	36.3	6.4	10.1	100.0
Hearing impaired	34.6	40.9	14.8	9.8	100.0
Difficulty in taking part in social activities	12.0	62.0	21.2	4.8	100.0
Psychological emotional	22.1	44.5	17.8	15.6	100.0
Communication difficulties	36.3	18.0	32.5	13.3	100.0
Difficulty in personal care	22.6	39.1	31.1	7.2	100.0
Other difficulties	28.6	40.3	21.6	9.5	100.0
Learning difficulties	20.1	55.7	18.4	5.8	100.0
<b>Total</b>	<b>41.2</b>	<b>34.4</b>	<b>12.9</b>	<b>11.5</b>	<b>100.0</b>

This situation is further compounded in Northern Uganda, where many children with disabilities have spent their entire lives living in IDP camps, where levels of chronic poverty is at its highest and where education provision is poor irrespective of whether one has a disability or not.

### 3.4.3 Transportation

It was apparent to the consultants that the public transportation system in Uganda was totally inaccessible to people with disabilities. Within Kampala none of the buses and taxi had been adapted to enable people with disabilities to freely move around the city. In addition, the public roads infrastructure is virtually inaccessible, with many streets not having lighting, sidewalks & etc. In rural areas, transport via bus, mini-bus or other rural public transport systems are even less accessible. From the focus group discussions it was also revealed that people with disabilities were charged extra when taking taxis because they were deemed to take up more room. The consultants do not have sufficient expertise in making specific recommendations in this area. However, it is suggested that DFID Uganda contacts the International Forum for Rural Transport and Development <http://www.ifrtd.org/new/index.htm> which specializes in this area.

## 3.5 The Disability Movement in Uganda

Historically, Uganda has been that the forefront of the disability movement in Africa, and has one of the most vibrant disability movements in the whole continent. The national umbrella disabled people's organisation is the National Union of Disabled Persons in Uganda (UNDIPU). Founded in 1987, NUDIPU's mandate is to promote a human rights agenda to

disability issues within the country. Its mission is to provide "A united voice for people with disabilities for the full realisation of their rights and inclusive development through support and advocacy" (NUDIPU 2008:21). Within its strategic plan covering 2008-2013, NUDIPU identifies key strategic areas for its future work, these being economic empowerment; disability and human rights; disability and HIV/AIDs; networking and coordination; and gender and youth mainstreaming. The organisation also attempts to base its work on the achievement of the Millennium Development Goals. This is somewhat problematic, because the MDGs do not currently directly address disability issues, although at the global level, there are initiatives being discussed that will modify the MDGs so that disability is explicitly included.

As a national umbrella organisation, NUDIPU attempts to represent the needs of all impairment groups, including those with physical, sensory, hearing and intellectual impairments. Currently it has an operational presence in 56 Districts, with its membership being comprised of the following organisations.

1. Action on Disability and Development (ADD);
2. National Association of the Deaf Blind in Uganda (NADBU);
3. Blind But Able (BBA);
4. Community Based Rehabilitation Alliance (COMBRA);
5. Uganda National Association of the Blind (UNAB);
6. Uganda National Action on Physical Disability (UNAPD);
7. National Union of Women with Disabilities of Uganda (NUWODU);
8. Mental Health Uganda (MHU);
9. Epilepsy Support Association Uganda (ESAU);
10. Uganda Parents of Children with Learning Disabilities (UPACLED);
11. Disabled Women's Network and Resource Organization (DWNRO);
12. Uganda Society for Disabled Children (USDC);
13. Sense international;
14. Uganda National Association of the Deaf (UNAD)

During the past six years, NUDIPU has been influential in lobbying the Government of Uganda, particularly with the Ministry of Gender, Labour and Social Development in developing a rights-based approach to disability issues. It provided advice during the legislative process for the enactment of the Persons with Disabilities Act 2006, as well as lobbying for affirmative action with regard to access to universities. NUDIPU has also been instrumental in ensuring that disability issues are included in the National Strategic Plan for HIV/AIDs 2007-2012. Over the course of the past six years, NUDIPU has made strategic alliances with a number of governmental and civil society institutions. These include the Ministry of Labour, Gender and Social Development; the Ministry of Health; CARE International and World Vision.

In addition, NUDIPU has been active internationally within the East African region. For example, it has provided advice to disabled people's organisations in Sudan, Somalia, Rwanda and the Democratic Republic of Congo, who have experienced the ravages of war and civil strife. In November 2007, it was also instrumental in ensuring that disability rights were highlighted at the Commonwealth Heads of State Meeting held in Kampala.

In describing the role that NUDIPU plays in the political process, Alex Ndeezi, (who is a MP with a disability) has commented:-

*"NUDIPU is not a political party or organisation, but in order to play its human rights and advocacy roles, NUDIPU must relate to the political environment, since disability issues do not exist in isolation of the political environment. There is a political element to almost all disability issues. So we are primarily disability activists who must relate to the political environment by ensuring our issues are high on the agenda of all politicians irrespective of their party or political affiliations. If participation in mainstream politics helps people with disabilities to advance the original goals of NUDIPU, then there is nothing like goal displacement, one would probably say that NUDIPU is has realised its goal of seeking active involvement in decision making and influence" (Ndeezi 2004: 30).*

Within its strategic plan, published in September 2008, NUDIPU has developed the following strategic objectives which are outlined in Table 3.8 below. Despite the laudable achievements of NUDIPU that are described above, some other national disabled people's organisations question whether the organisation actually represents the needs of all impairment groups - for example, those with hearing and visual impairments. Thus, there are real questions regarding representation. Anecdotal evidence would also suggest that the governance structures and internal organisational capacity of NUDIPU are at an insufficient level in order to implement its strategic objectives in a coherent, efficient and effective manner. This is particularly the case at the regional and District level and below, where many disabled people's organisations are of the opinion that their particular needs are not represented at the national level. This was very evident during the field visit undertaken by the consultants to Gulu District. Organisations based in Kampala have not been able to adequately represent the needs and aspirations of people with disabilities who are recovering from the detrimental effects of war and civil strife, and who have spent the vast majority of their lives living in IDP camps. While acknowledging that the circumstances apply to all those who have lived in IDP camps, it nevertheless remains the case that people with disabilities are invariably among the last to leave. Therefore, it can be said that IDP camps can become "disability ghettos".

However, it has to be acknowledged that NUDIPU recognises that it has some major weaknesses and challenges that need to be addressed, which are listed in their SWOT analysis in their strategic plan. These include the fact that many of their member organisations lack generic skills in strategic planning and resource management; that NUDIPU is totally dependent on donor funding; that the organisation does not have sufficient capacity to provide support to member organisations working at District level and below, and that there is a lack of clarity regarding membership criteria (NUDIPU, 2008:19).

**Table 3.8 NUDIPIU STRATEGIC OBJECTIVES**

Source: NUDIPIU Strategic Plan 2008-2013

**Programme Area 1: ECONOMIC EMPOWERMENT**

**Strategic Objective 1:** An enabling environment in which PWDs can realize their potential and participate in development created by 2013.

**Strategic Objective 2:** PWD Capacity of PWDs to engage in income generating activities strengthened by 2013

**Strategic Objective 3:** To uplift the social and economic wellbeing of PWDs among the internally displaced people in the war affected areas in Northern Uganda by 2013

**Programme Area 2: DISABILITY AND HUMAN RIGHTS**

**Strategic Objective 1:** Violation of rights of PWDs among communities and social service providers in government and private sector reduced by 2013

**Strategic Objective 2:** Knowledge on rights and responsibilities among PWDs increased by 2013.

**Strategic Objective 3:** Responsiveness of service provider institutions to PWD needs strengthened by 2013

**Program area 3: DISABILITY AND HIV/AIDS**

**Strategic Objective 1:** PWDs empowered to advocate and demand for equal opportunities and equitable access to quality disability friendly HIV/AIDS services by 2013

**Strategic Objective 2:** Government, policy makers, service providers and civil society organizations lobbied to develop and implement disability and HIV/AIDS friendly policies, budget and guidelines by 2013

**Programme area 4: NETWORKING AND COORDINATION**

**Strategic Objective 1:** NUDIPIU providing national and regional leadership of the disability fraternity by 2013

**Strategic Objective 2:** NUDIPIU's capacity to provide leadership and be the key network organization at national and regional level strengthened by 2013

**Institutional Capacity Strengthening**

**Strategic Objective 1:** The institutional capacity of the NUDIPIU secretariat and governance to fulfil its mandate of uniting members of all PWDs categories strengthened by 2013

**Strategic Objective 2:** The institutional capacity of NDPOs and DUs to provide holistic services to PWDs strengthened by 2013

Uganda National Association of the Deaf (UNAD) and Uganda National Association of the Blind (UNAB) have been of great significance in the Disability movement in Uganda. For instance, sign-language development and promotion in Uganda is attributed to UNAD efforts. UNAD with financial support from USAID has designed a strategy to mainstream Deaf people in society through sign-language training and advocacy. Sign-language is a pre-linguistic right of Deaf people – without a language, mainstreaming is difficult (UNAD newsletter, 2007). On the other hand, UNAB has ensured that the needs of people with

visual impairments are addressed especially by access to information. As a result of a shift from a "Charity" to Right-based approach, there has been formation of new and promising DPOs. A good example of this is Legal Action for PWDs (LAPD) which focuses on enforcement of implementation of existing laws through helping PWDs to access justice.

### **3.6 Situational Analysis of the Social and Economic Status of People with Disabilities in Uganda**

This section provides an analysis of the current social and economic status of people with disabilities in Uganda. It draws heavily upon the information gathered during the two focus group discussions with disabled people's organisations held in Kampala and Gulu District, as well as drawing upon the invaluable information gathered during the many key informant interviews that were conducted during the 10 days of fieldwork for this report. In addition, reference will be made to the substantial existing research on disability issues that has already been undertaken in Uganda. In the light of the fact that there is such a plethora of research that already exists within this field, space precludes an in-depth analysis of all studies that have been undertaken to date. Rather, within this section, reference will be made to the secondary literature where it embellishes the rich data that was gathered during the fieldwork. A comprehensive bibliography is provided the end of this report for those wishing to delve more deeply.

#### **3.6.1 Disability and poverty**

It is often claimed by those working in the international disability sector that people with disability constitute one of the most marginalised, socially excluded, discriminated and impoverished groups within any society. In general, the evidence in support of this claim is largely anecdotal in nature. However, in the case of Uganda, there has been to extent some rigorous analysis that examines the nexus between disability and poverty. For example, Johannes Hoogeveen from the World Bank Ugandan Office provides a very interesting analysis of the recent situation (Hoogeveen, 2005). The fact that disability and poverty are both a cause and consequence of each other is well recognised, as has been described above. However, what is not well understood is the dynamics that drive this relationship. Furthermore, it is important to highlight that "poverty" should not be perceived solely in terms of economic deprivation. Rather, poverty with respect to disability should be perceived as a multidimensional phenomenon, which encompasses the lack of access to housing, depletion of relational bonds and social capital, the lack of access to clean water, and the like of access and denial to primary education.

A qualitative analysis of the poverty experienced by people with disabilities was conducted under the auspices of the Uganda's Participatory Poverty Assessment, which collected data from 60 sites in 12 Districts (Government of Uganda, 2002). This provided strong anecdotal evidence that people with disabilities do indeed constitute one of the poorest and most marginalised groups in Uganda society. Qualitative analysis of the social and economic status of people with disabilities was also undertaken in the 1991 Ugandan Census. This has been supplemented National Household Surveys undertaken in 1999/2000 and 2002/2003.

In 2008, MoFPED published a report on “Disability and Poverty in Uganda” which analysed the progress and challenges in PEAP implementation from 1997-2007.

Hoogeneveen had attempted to provide a synthesis of the 1991 Census data and the two National Household Surveys and provides very interesting data. He estimates approximately 5% of all households in Uganda are headed by a disabled family member. On average, disabled heads of households are statistically likely to be older than their non-disabled counterparts (38 versus 35 years); have received less education (6.2 versus 7.6 years); are more likely to be illiterate (29% versus 21%); and are more statistically likely to have never married (10% versus 6%). Hoogeneveen, by analysing a whole range of indices that assess the social and economic status of people with disabilities concludes that:

*“The circumstances are worse in households headed by a disabled person is illustrated by housing conditions, but also by the education deficit, which reflects the difference between the number of years a child should have been educated (according to its age) and the actual years of education received. To the extent that education drives the ability to earn an income in the future, it confirms qualitatively and quantitatively that [people with disabilities] are more likely to pass their poverty on to their children. Considering the main source of income, disabled people participate less in the labour market and are more likely to be self-employed. Whereas employee income is the most frequently mentioned income source (45%) amongst non-disabled households, the most frequently mentioned sources of income for disabled households are subsistence farming (27%) and petty trade (25%). Amongst people with disabilities, employee income is only the third most important (21%) source of income” (Hoogeneveen, 2005: 609-610).*

Hoogeneveen proceeds to undertake some secondary analysis of the 1991 census data to derive estimates that compare the percentages of disabled and non-disabled living in poverty, disaggregated by gender and administrative region, which are presented in Table 3.9 below. These statistics only apply to urban areas but nevertheless indicate that people with disabilities in all regions have a greater statistical probability of being poor than their non-disabled counterparts.

Region	Non-Disabled		Disabled	
	Male (%)	Female (%)	Male (%)	Female (%)
Central	17.9	22.6	25.9	30.9
East	36.7	39.2	47.6	49.5
North	52.1	48.9	48.9	56.8
West	32.4	37.7	43.5	51.9

Richard Ssewakiryanga, Executive Director of the Ugandan NGO Forum, (formerly employed by the Ministry of Finance, Planning and Economic Development), in his 2008 seminal work on disability and poverty, provides an insightful analysis of the manner in which poverty affects different impairment groups. His analysis is re-presented and adapted in Table 3.10 above. From this analysis it can be seen that those with visual impairments are among the

poorest, while those with intellectual difficulties are invariably hidden away and excluded for participating in contemporary Ugandan society. This scenario is commonly found in many developing countries, with those with intellectual impairments invariably being the worst off.

<b>Table 3.10 How Poverty affects Different Groups</b>	
<b>Source: Ministry of Finance, Planning and Economic Development, 2008: 21</b>	
<b>Category of Impairment</b>	<b>Poverty Conditions</b>
Visual	<ul style="list-style-type: none"> <li>• Among the poorest;</li> <li>• Will need to be aided in order to perform productive work;</li> <li>• Most are denied education on the pretext that they cannot see and no special teachers;</li> </ul>
Hearing	<ul style="list-style-type: none"> <li>• Can dig and do what others do;</li> <li>• Almost as competitive as non-disabled people</li> <li>• They are exploited because they may not be able to negotiate working conditions.</li> </ul>
Physical	<ul style="list-style-type: none"> <li>• Often not physically strong enough to undertake employment;</li> <li>• The majority are unemployed;</li> <li>• Productivity could be very low because of severity of impairment;</li> <li>• Most rely on light manual work such as painting, knitting, weaving and brewing.</li> </ul>
Intellectual	<ul style="list-style-type: none"> <li>• Are neglected and often hidden in homes;</li> <li>• Are considered "stupid" and "senseless";</li> <li>• Are excluded from society and sometime have been known to scavenge for food.</li> </ul>

Commenting on the relationship between disability and poverty, NUDIPU's strategic plan states:

*Poverty and disability in Uganda are impossible to disentangle. Despite impressive economic gains made by the country in the last 15-20 years, the latest Poverty status Report (2002, UBOS), estimates overall poverty level at 35% (approx. 8.6<sup>1</sup> million people) of the total population. The same report further estimates that approximately 80% of persons with disability live in conditions of long-term poverty. This estimation therefore shows that among the poor, 24% (2.1 of 8.6 million people) are people with disability implying that for every four poor person in Uganda, one of them is person with disability. According to the Northern Uganda Survey 2004, 72% of PWDs are poor with men more likely to live in poor households compared to women. The causes of extreme poverty among the disabled are multiple including; lack of access to education for most of the PWDs and for those who access education most of them do not complete their education especially girls and women. Due to lack of access to education most PWDs do not have skills and competencies required to get employment or get involved in any activities that can give them a livelihood hence most of them are left out in most of the government programs intended to reduce poverty levels among rural communities such as NAADS, PMA etc. In addition, the physically demanding nature of unskilled labour (a brand of most African economies) also makes it difficult for disabled people to be involved in labour intensive activities which would otherwise not require high level skills or competencies. Disability and poverty can also be traced*

<sup>1</sup> UBOS 2002 Population Census report which estimated Uganda's population at 24.7 million people.

*from the deeply rooted negative cultures, where a disabled child is looked at as a curse and more so if the child is a girl then they are denied food, education and health care among others. Hence lack of skills which is a requirement to accessing employment or any form of work that can give them income. This situation of outright social exclusion of PWDs has constrained them from participation in the job market and other IGAs (NUDIPU, 2008: 9-10).*

The evidence presented above strongly concurs with the evidence gathered during the fieldwork undertaken for this study. From both focus group discussions held in Kampala and Gulu District, it was abundantly clear that the large majority of people with disabilities in Uganda are living in poverty. This is because many have encountered so many obstacles in completing even their basic primary education, which is further compounded by the lack of ability in securing long-term and sustainable employment. Many of the focus group discussion participants noted that employers were on the whole unwilling to employ people with disabilities, in the belief that they were incapable of holding down a job. The likelihood of people with disabilities living in poverty is further compounded by the fact that there is no social protection programmes for those with disabilities in Uganda. This is in common with the vast majority of developing countries. Consequently, it is therefore important for DFID Uganda to give serious consideration to how their cash transfer programme can be devised so that it is easily accessible to disabled people.

### **3.6.2 Negative Social Attitudes**

Focus group participants also pointed out they encountered serious challenges in the following areas. People with disability encounter negative social attitudes, particularly in the fields of education, health and justice. Furthermore, there is evidence to suggest that different impairment groups discriminate against each other, and there is discrimination as well within families when there is a disabled family member. Lack of understanding and knowledge about disability, poverty and social exclusion makes some parents with disabled children neglectful of their disabled child's needs. Broader lack of a basic understanding of child health and development coupled with poverty, makes some parents unwilling or unable to access those child health services that do exist, which itself is a continuing cause of preventable disablement. Richard Ssewakiryanga states that "*Parental negligence and failing to address health problems during pregnancy and for children in early years was also blamed for severe and chronic illness in children and contribute to disability in later life. ... However, some of the disabilities among children were a catch to parents' failure to seek antenatal care and immunisation*" (Ministry of Finance, Planning and Economic Development, 2008: 14).

### **3.6.3 The Situation of People with Disabilities Living in Northern Uganda**

There are particular challenges faced by people with disabilities living in the Northern Region of Uganda. In addition to the general challenges outlined above, people with disabilities living in Northern Uganda face the following specific problems due to prolonged war and civil strife:-

- Their needs are not incorporated in “Return and Resettlement” programme for both government and NGOs and yet they are chronically poor;
- High disability prevalence rates;
- Increased poverty level because of isolation... As a direct result of the conflict, many people with disabilities have had their land that they previously owned stolen from them, as well as essential assets such as livestock. Furthermore, many children with disabilities have become orphans, which has resulted in the depletion of their social capital and relational support networks. Therefore, they constitute one of the most vulnerable populations within Northern Uganda;
- Increase in the syndrome of dependence; increase in the school dropouts; loss of properties and assets including “grabbing away” their lands; broken social networks because of massive displacement of people with disabilities. This situation is worse for people with disabilities than for other marginalised groups as many with physical impairments are unable to travel distances to school, to maintain social networks or to reclaim their land or property. In addition, for many people with disabilities, social capital and relational bonds are of vital importance, as family members provide essential practical support and when these are ruptured, there is very little to replace them.
- High levels of HIV/AIDS is also of concern because of anecdotal evidence suggests a high risk of rape of persons with disabilities in the IDP camps;
- People with disabilities are among the last to leave the camps as a result of decline in cultural practices of caring for the elderly and the disabled; and a competition over scarce resources among the ‘vulnerable’ groups – it is also difficult to determine which groups are more vulnerable than others – people with disabilities are merely mentioned as vulnerable group in various concept papers but no concrete strategies exist to ensure that people with disabilities’ issues are addressed. One focus group discussion participant in Gulu very poignantly noted that there is *“No segregation when it comes to bullets”*

Moreover, people with disabilities are generally not included in the “Peace and Recovery” programme which has resulted in additional lack of opportunities. For example, under the Government’s Resettlement Plan, there is a stipulation that for the Government to provide iron sheets for roofing, one has to set up walls of newly built homes first. Will people with disabilities, especially those with physical disabilities and those who are blind be able to meet this condition? It was also found that some representatives or leaders of people with disabilities lack capacity to effectively articulate the needs of people with disabilities. Notwithstanding the fact that many would maintain that the PRDP is not being implemented, given the inherent problems of the public administration infrastructure described above, in concert with the strong negative social attitudes towards disability, it is extremely unlikely that people with disabilities will be included, even if the programme become effectively implemented.

However, evidence gathered during the course of this research also showed that there has been support from some agencies such as USAID/OMEGA, WFP, NUDIPU/APT, which has managed to build capacity of DPOs in Northern Uganda especially in Gulu and Lira Districts, in addition to providing rehabilitation services like mobility appliances. The World Food Programme has helped in distributing food to people with disabilities and their families. The

Association for the Prevention of Torture in collaboration with NUDIPU, has provided some training in basic skills in business development.

The Office of Prime Minister (OPM) in collaboration with the Ministry of Gender, Labour and Social Development in partnership with the Association of Volunteers in International Service, the Norwegian Association of the Disabled, and World Vision is supporting landmines survivors as well as demining unexploded landmines. According to AVSI study in 2005, Gulu District has 2,000 landmines survivors. The OPM with support from UNDP is planning to provide rehabilitation services training in income generating activities, and provide artificial limbs as well as psychological social support. The survey team was also told that all people with disabilities are helped whether landmine survivors or not, but clearly the project under OPM is called "Landmines Survivors Assistance"

### **3.7 Provision of Disability Services**

#### **3.7.1 Community-Based Rehabilitation**

The Ministry of Gender, Labour and Social Development initiated its community-based rehabilitation (CBR) programme in 1992, with a view of enhancing the participation of people with disabilities in their own local communities, particularly in rural areas. Currently the programme operates in 10 Districts (Kabale, Bushenyi, Mbarara, Mukono, Kamuli, Ntungamo, Rukungiri, Tororo, Iganga and Mbale). At the national level, the Norwegian Association of the Disabled is assisting the Ministry in developing this programme. A multi-sectoral, cross-cutting approach to CBR is being adopted. The Ministry has also established a Steering Committee at the national level to oversee the strategic development of the programme. The specific objectives of this CBR programme are as follows:-

- To raise awareness among civic and political leaders, and communities about disability issues;
- To advocate for and promote effective service delivery to people with disabilities across all sectors;
- To promote collaboration between Government and NGOs in delivery of services to people with disabilities;
- To build the capacity of people with disabilities, their families and communities for prevention and management of disability;
- To equip people with disabilities with skills so that they can participate in development activities; and
- To advocate for the equalisation of opportunities for people with disabilities.

In each District where the CBR programme has been operationalised, local communities have received public awareness training with respect to disability issues. In addition, basic physiotherapy has been provided within individual homes, as well as providing assistive devices where necessary. Psychosocial support services have been provided where appropriate, particularly in the Northern Region of Uganda, which has been affected by war and civil strife. However, given the challenges in the development of accountable and effective implementation modalities, combine with the lack of robust monitoring and

evaluation systems, it is difficult to foresee how this programme will be able to scale up so that it covers all of Uganda's administrative districts.

If a robust and effective monitoring and evaluation framework were developed, this would provide policy-makers and development practitioners with a more in-depth and nuanced understanding of the needs of different impairment groups. Also, it would enable the Districts to scale up their services, (both in terms of geographical coverage and the portfolio of services provided), because of the more in-depth knowledge that such monitoring and evaluation systems will provide.

### **3.7.2 Education**

Reference has already been made to the hiatus within the development of education policy with respect to children with disabilities in Uganda. Again, in the absence of substantial public sector reform, where the operational modalities of service delivery are significantly overhauled, it is difficult to see how the goal of achieving universal primary education, which is underpinned by the principles of inclusive education will be achieved throughout Uganda in the short to medium term.

The Compulsory Education Act 2008 makes basic schooling compulsory for all children. This can be effectively tied into Universal Primary Education (widely implemented across Uganda); the National Disability Act 2006, which specifically states education is a right for all disabled children, as well as other national poverty alleviation strategies. Implementing an inclusive education project in conjunction with the Ministry of Education and Sports is therefore timely, but requires extra effort to ensure government buy-in.

Other non-governmental organisations are beginning to work within this sector. For example, Leonard Cheshire Disability is beginning to pilot an inclusive education programme in two Districts - Budaka and Mukono, as a model programme, which has the potential to be scaled up and replicated in other districts. The Project partners include the Ministry of Education and Sports – Uganda, Kyambogo University, the National Council of Cheshire Services of Uganda, District Education offices in the above two districts, the respective schools and communities. The main aim of this particular project is to facilitate full participation of children with disabilities in education by attending local mainstream schools. It is anticipated that 1,000 children with disabilities will benefit from this project by enrolling in the 20 schools in the two districts (500 children per district). This will contribute to the Government of Uganda's policy of Universal Primary Education.

It should be noted that whereas the government of Uganda has embraced Universal Primary Education since 1996, the majority of children with disabilities do not benefit from this policy. There are a number of barriers limiting their full participation. The project is addressing some of these barriers.

To date, 90 teachers from Mukono and Budaka districts have been trained in special and inclusive education. The purpose was to introduce teachers to disability and development issues, the theoretical aspects of inclusive education and development, global conventions and declarations on special and inclusive education, the government of Uganda's policies on

disability, special and inclusive education methods, the various disabilities they may encounter while teaching, and methodology of teaching children with special needs.

### **3.7.3 Social Assistance**

It should be noted that the Government of Uganda has yet to develop any form of social assistance for people with disabilities. Although this situation is indeed the case in the vast majority of developing countries, it further exacerbates the already precarious situation whereby the vast majority of people with disabilities in Uganda are living in a state of abject and chronic poverty.

## **3.8 Other Significant Observations from the Fieldwork**

There are some miscellaneous yet important observations that should be recorded from the field work undertaken in this study that do not easily fit within other sections of this report that also require noting.

During 2008, World Vision in collaboration with NUDIPU developed a manual for mainstreaming disability issues within core development programmes. This initiative was funded by USAID. If DFID Uganda wishes to take forward the recommendations that are made within this report, the World Vision manual will be an invaluable resource. It has been written in a manner such that it can be used at the field level, and used by people who do not have high literacy levels. Copies of this can be obtained from the World Vision Uganda Country Office.

It is also important to make some observations regarding what other bilateral and multilateral donor agencies are doing within the field of disability in Uganda. Over the last four years, USAID provided funding to build the organisation capacity of disabled people's organisations in Northern Uganda. The Agency provided funding for an organisational development specialist to work with DPOs full-time over a three-year period. This initiative ended approximately one year ago. However, USAID was of the opinion that despite intensive work with designated funding, one year after this project has ended there is no evidence to suggest that this initiative has had any sustainable long-term impact. This is indicative of the complexities and difficulties in building the long-term organisational capacity of disabled people's organisations. Again, it should be noted that this is not a unique situation that only applies in Uganda, but commonplace throughout African countries.

## **3.9 Stepping Stool to Inclusion**

Table 3.8 below summarises the principal barriers that exist that militate against the effective social inclusion of people with disability in Uganda. This stepping stool to inclusion was originally developed by Philippa Thomas, Social Development Adviser DFID Zimbabwe. In essence, this table summarises the foregoing analysis that has been presented with in this section.

Finally, it is important that we here again highlight some salient key findings. Firstly, Uganda has developed progressive, human rights-based disability policies, evidenced by the Persons with Disabilities Act 2006 and ratification of the UN Convention on the Rights of Persons with Disabilities in September, 2008. Notwithstanding these progressive rights-based policies, the main impediment to the effective implementation of a human rights-based approach to disability issues is an inherent "implementation gap". This is manifested by a lack of coordination between the line Ministries on cross-cutting issues such as disability, combine with a highly decentralised governmental structure, and that the total lack of robust statistical data with respect to disability. Given this dysfunctional policy environment, where there is little appreciation of good and accountable governance structures and processes, it is difficult to foresee how this situation will improve in the short to medium-term. It is also important to highlight that the disability movement is considered to be one of the strongest throughout Africa, and has indeed achieved a great deal over the 20 years. However, it also has to be recognised that the disability movement is currently under-capacitated in terms of its own organisational capacity to lobby Government to implement effective and sustainable disability policy and practice.

<b>Table 3.8: DISABILITY SCOPING STUDY FOR DFID UGANDA</b>		
<b>Stepping Stool to Inclusion</b>		
	<b>Key roles and functions</b>	<b>Sample indicative assessment questions</b>
<b>STATE</b>	<ul style="list-style-type: none"> <li>• The Ugandan Constitution explicitly recognises the rights of persons with disabilities               <ul style="list-style-type: none"> <li>- Article 16 explicitly endorses the of persons with disabilities and their right to human dignity;</li> <li>- Article 21 guarantees equality and freedom from discrimination for all minority groups;</li> <li>- Article 35 addresses the political rights of persons with disabilities;</li> </ul> </li> <li>• The Ugandan Government signed the UN Convention on the Rights of Persons with Disabilities on the 25<sup>th</sup> September, 2008;</li> <li>• The Ugandan Government have passed the following legislation that specifically addresses disability issues:               <ul style="list-style-type: none"> <li>- Universal Primary Education Policy, 1997;</li> <li>- Affirmative Action for Access to Higher Education, 2002</li> <li>- National Council for Disability Act, 2003;</li> <li>- The Persons Disabilities Act, 2006;</li> <li>- Equal Opportunities Act, 2006;</li> <li>- Education (Pre-Primary, Primary and Post-Primary), 2008.</li> </ul> </li> <li>• The Ministry of Gender, Labour and Social Development published its National Policy on Disability in February, 2006.</li> </ul>	<ul style="list-style-type: none"> <li>• At the National level, the Ministry of Gender, Labour and Social Development is the lead Government Department with regard to disability issues;</li> <li>• There are five MPs with disabilities within the Ugandan Parliament, each representing several Districts</li> <li>• There are over 50,000 councillors with disabilities at all levels at local and District level</li> <li>• Disability policy making is disjointed and fragmented, this being indicative of poor governance structures and processes:-               <ul style="list-style-type: none"> <li>- Policy formulation and the development of adequate implementation modalities are totally divorced</li> <li>- Lack of sufficiently robust monitoring and evaluation frameworks vis-à-vis disability policy implementation</li> <li>- Lack of robust statistical data with regard to the political, social and economic status and livelihoods of people with disabilities, particularly at District and local Government levels</li> <li>- Lack of inter-ministerial dialogue and collaboration on cross-cutting issues, especially disability</li> <li>- Hence, the largest and most entrenched barrier to effective policy making in the Ugandan disability sector is an <u>"implementation gap"</u></li> </ul> </li> <li>• There are no social assistance programmes for disabled people in Uganda</li> </ul>

**Table 3.8: DISABILITY SCOPING STUDY FOR DFID UGANDA**

**Stepping Stool to Inclusion**

	<b>Key roles and functions</b>	<b>Sample indicative assessment questions</b>
<p><b>DISABILITY SERVICES</b> (E.g. rehabilitation, assistive devices, support services for disabled children, specialist vocational training, etc.)</p>	<ul style="list-style-type: none"> <li>• The Ministry of Gender, Labour and Social Development is running Community-Based Rehabilitation programmes in six Districts</li> <li>• Leonard Cheshire Disability is implementing inclusive education programmes in two Districts;</li> <li>• The Ministry of Education has made a commitment to implementing inclusive education in all Districts, and is also providing and building special schools</li> <li>• The Ministry of Gender, Labour and Social Development and the Ministry of Finance, Planning and Economic Development are in principle agreed that cash transfers for the chronically poor, particularly for people with a disability, as proposed by DFID Uganda is beneficial               <ul style="list-style-type: none"> <li>- However, the Ministry of Finance, Planning and Economic Development has concerns that the design of the programme is problematical, as there may very well be “leakages”;</li> </ul> </li> </ul>	<p><b>Education</b></p> <ul style="list-style-type: none"> <li>• The Government of Uganda as ratified the UN Convention on the Rights of Persons with Disabilities. Article 24 – Education, explicitly states that “States Parties shall ensure an inclusive education system all levels and lifelong learning”.</li> <li>• The Ministry of Education in principle supports an inclusive education approach</li> <li>• However, many disabled people’s organisations have lobbied for more special schools, in the belief that by so doing, children with disabilities will receive a higher standard of education.</li> <li>• Furthermore, following a rally on international disability day (3rd December, 2008), the President issued a decree for more special schools to be built.</li> <li>• In rural areas of Uganda, particularly within the Northern Region, the physical infrastructure and the design of school buildings preclude the effective social inclusion of children with disability from accessing mainstream schools;</li> <li>• Therefore, education policy with respect to disability is currently an ambiguous “stalemate” position.</li> <li>• NGOs and DPOs working within the disability sector have found engaging and lobbying the Government to raise the political profile of disability issues to be extremely problematic. Once again, this can be attributed to the fact that disability is seen in terms of charity - not human rights.</li> </ul>

<p><b>DISABLED PEOPLE'S ORGANISATIONS</b></p>	<ul style="list-style-type: none"> <li>• The National Union of Disabled Persons in Uganda (NUDIPU) is the national umbrella disabled person's organisation in the country             <ul style="list-style-type: none"> <li>- Established in 1987, its mandate is to campaign for the promotion and enforcement of disability rights for all impairment groups;</li> <li>- NUDIPU runs programmes on economic empowerment, HIV/AIDs and human rights</li> <li>- NUDIPU's membership is comprised of District Unions of people with disabilities in 56 Districts;</li> </ul> </li> <li>• Uganda also has a number of national single impairment groups, which include:-             <ul style="list-style-type: none"> <li>- The Uganda National Association of the Deaf</li> <li>- The Uganda National Association of the Blind</li> <li>- Uganda National Action on Physical Disabilities</li> <li>- The National Union of Women with Disabilities in Uganda</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• NUDIPU has a very strong international reputation, and is perceived as one of the leading disabled people's organisations in the African continent;</li> <li>• it has had some degree of success in lobbying the Ugandan Government in enacting progressive human rights-based disability legislation;</li> <li>• However, from a organisational capacity assessment published in December, 2008 it is clear NUDIPU lacks robust managerial capacity, including a deficiency of transparent and accountable governance systems and procedures;</li> <li>• It is also apparent that there is a lack of communication between NUDPU and the disability caucus of MPs in the Ugandan Parliament.</li> </ul>
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## Section Four

# Recommendations

### 4.1 Introduction

The rationale behind the recommendations made within this report is to enable DFID Uganda to undertake strategic, well-focused interventions that will facilitate the promotion of the human rights and the social inclusion of people with disabilities in the country. A concerted effort has been made to ensure that the recommendations are in alignment with the overall strategic direction of DFID Uganda, as described in the concept notes of DFID Uganda's proposed future programmes that were made available to the consultants (DFID 2009a, 2009b, 2009c and 2009d). Furthermore, for each of the recommendations are aware delineated below, an attempt has been made to provide the rationale and reasoning why they had been made. These recommendations have been made within the context of the constraints and development challenges that categorise contemporary Ugandan society, particularly the challenges presented by weak governance structures and processes combined with the paucity of robust statistical data, especially within the disability sector

### 4.2 List of Recommendations

#### Accountability/Direct Budget Support

- 1. That DFID Uganda undertakes a baseline survey to determine the prevalence rates of children with disabilities in 2 Districts**

Given that there is such a paucity of robust statistical data regarding disability in Uganda, it is recommended that DFID Uganda funds a baseline survey of the number of children with disabilities in two Districts, one in a rural area and one in an urban environment. Such an enterprise will provide the basis for the initial effective planning and implementation of inclusive education policy, which the Government of Uganda is morally and legally obliged to implement, as they have ratified The UN Convention. It will also provide some in-depth analysis of the systemic factors that militate against the effective social inclusion of children with disabilities in mainstream schools, and will therefore the potential to influence key decisions within the Ministry of Education and Sports. It is recommended that DFID Uganda works closely with the Ministry of Education and works in conjunction with the Kyambogo University in Kampala which has a specialist academic department on Special Education. In terms of accessing international best practice in this area it is recommended that DFID Uganda works with EEnet, based at the University of Manchester. <<http://www.eenet.org.uk/>>.

- 2. That DFID Uganda funds inclusive education programmes in 2 Districts**

Access to universal primary education is a foundational catalyst to the inclusion of children with disabilities, because such an education plays a major role in securing sustainable long-

term employment and significantly enhanced levels of well-being. In the absence of receiving any education, (which is the most common experience of children with disabilities in developing countries), it is extremely likely people with disabilities will continue to live in a state of chronic poverty. It is therefore recommended DFID Uganda funds the development and implementation of the inclusion education programmes in two Districts, again one rural and one urban, as a pilot project. This will determine what would be the best, appropriate model of inclusive education to be adopted and replicated throughout Uganda. These could possibly be in the same Districts where the baseline surveys have been undertaken. Furthermore, by spearheading these "demonstration projects", it will be possible to investigate what are the most appropriate models of inclusive education can be developed within contemporary Ugandan society.

Once again, this recommendation has direct relevance to DFID Uganda's strengthening accountability programme, in its endeavour to provide high quality services are both effective and value for money. It also will make a significant contribution to achieving the Millennium Development Goal of achieving universal primary education by 2015, to which the UK Government is committed.

**3. That DFID Uganda, through its direct budget support, encourages the Government of Uganda to develop a national inclusive education policy, in alignment with the UN Convention**

It was also considered appropriate, that DFID Uganda in collaboration with other bilateral and multilateral agencies encourage and assist the Government of Uganda to implement a national inclusive education policy. It is duly acknowledged that, given the significant challenges that exist in the provision of public services that are already being described, that the development of a viable national inclusive education policy will need several years to become fully operational. However, as the Government of Uganda has ratified the UN Convention, there is at least a moral, as well as a legal obligation for the government to implement such policies. Leverage provided by DFID Uganda and other donor agencies may provide the necessary catalyst for such a progression to take place.

**4. That DFID Uganda support the Uganda Bureau of Statistics and the National Council for Disability to develop input, output and outcome indicators that effectively monitor the extent to which disability has been mainstreamed and included in public services**

Evidence gathered during the fieldwork for this study has categorically demonstrated that there is a paucity of robust statistical data with regard to disability issue within Uganda, with contrasting prevalence rates being quoted. The Uganda Bureau of Statistics has begun to do some preliminary work on the collation of more robust data, but this needs further elaboration and development. Moreover, at District and local government level, there is virtually no statistical data with regard to disability issues. The absence of such data results in the creation of a significant "democratic deficit", in as much as it is impossible for people with disabilities and their representative organisations to hold their governments to account for the implementation of the principles and tenets of the UN Convention on the Rights of

Persons with Disabilities. In addition, without robust data was the regard to disability issues, it is virtually impossible for government agencies to effectively monitor how efficient and effective their programmes and services are in addressing the explicit needs of people with disabilities.

It is therefore recommended that DFID Uganda continue to work with the Uganda Bureau of Statistics in developing more robust statistical data. The National Council for Disability as an arm of government responsible for monitoring and evaluating government and non-government programmes in mainstreaming disability issues should be supported to effectively undertake this useful task. By so doing, DFID Uganda will be strengthening civil society institutions, particularly disabled people's organisations, to hold their government to account for implementing the UN Convention, in addition to the provision of publicly-funded services within the disability sector.

**5. DFID Uganda funds disability awareness training to senior civil servants in all line Ministries and District authorities in the next 5 years**

It was very clear from the key informant interviews undertaken for this study, that the vast majority of senior civil servants working within line Ministries have little appreciation and understanding of human rights-based approach to disability issues. With the exception of the Ministry for Gender, Labour and Social Development, virtually no civil servants who have direct responsibility for implementing policy, demonstrated such an understanding. Given that the Government of Uganda has ratified the UN Convention on the Rights of Persons with Disabilities, it is imperative that this apparent deficiency is addressed. Furthermore, at District and local government levels, it is also apparent that elected councillors and officials working within the public sector also had a lack of disability awareness. It is therefore recommended that, over the next five years, disability awareness training be provided to all Government Ministries. For example, it was very clear that officials working in the Ministry of Transport and Works had no understanding of disability issues nor implications of including people with disability within their activities. Such training should be facilitated by people with disabilities, who have a nuanced understanding of the principles of the social model of disability. In the first instance, priority should be given to training those civil servants who have direct responsibility for implementing disability policy and practice.

By undertaking such an initiative, this will enable DFID Uganda to achieve its strategic objective of strengthening the accountability of the Ugandan public sector, by assisting the Government to address crosscutting issues such as disability. Furthermore, it will strengthen the Government over Uganda's commitment to implementing sector wide approaches in its programming.

**Northern Uganda**

**6. That DFID Uganda considers providing assistance to people with disabilities to return to their homelands**

It was abundantly obvious from the two-day reconnaissance visit and the focus group discussion held in Gulu District, that people with disabilities living in the Northern Region of Uganda encounter and live with acute levels of social exclusion and discrimination that are of a far more protracted nature than those experienced by people with disabilities living in other regions. This is primarily because of the war that engulfed the Northern Region for the past 20 years. It was abundantly clear that people with disabilities were the last to leave the IDP camps. For many people with disabilities, the whole of their lives have been spent in such environments. Moreover, in the aftermath of the war, their lands have been grabbed by others. There is also strong evidence to suggest that it has been extremely hard for people with disabilities to access mainstream humanitarian aid, for example that provided by the World Food Programme. The Government of Uganda has attempted to provide assistance to enable those living in IDP camps to return to their homes, but the criteria for accessing such aid is discriminatory. For example, in order to receive iron sheets for building a new home in their former homelands, beneficiaries must first demonstrate that they have built the walls of their new home. For the vast majority of people with disabilities, this is impractical, due to the nature of their impairments. This precarious situation is further compounded by the inevitable mobility difficulties that people with disabilities encounter when attempting to move from the IDP camps. Consequently, it is not beyond the bounds of possibility to envisage a situation whereby, in the future IDP camps are essentially "disability ghettos"

Given the deeply entrenched, systemic social inclusion encountered by people with disabilities living in the Northern Region, it is recommended that DFID Uganda provides significant financial resources to assist people with disabilities to leave the IDP camps in order to rebuild their lives in their former homelands. This assistance ideally should be of an extremely practical nature. For example, DFID Uganda could provide financial support to employ builders to build their homes. Furthermore, consideration should be given to providing financial assistance to people with disability to travel back to their former homelands as well as assisting them to start income generating activities.

Adopting such an approach will assist DFID Uganda in achieving its strategic objective of enabling people in Northern Uganda to "benefit from peace through improved livelihoods opportunities, better services and increased state capacity", ( DFID 2008b: 1). It also has the potential to make a significant contribution to the number of people that are living in chronic poverty, thereby increasing the opportunity of people with disabilities accessing better quality and education health services within this region.

**7. That DFID Uganda undertakes a comprehensive needs assessment of the assistance needed by people with disabilities in the North.**

The issues that are faced by people with disabilities in Northern Uganda are complex and interrelated, and it was therefore impossible for the consultants to comprehensively assess the needs and aspirations during a two-day reconnaissance visit. In addition to that, the independent evaluation of the PEAP commissioned by the Government of Uganda states that "Poverty head count declined from 46% to 31% over the PEAP period 1997-2007 although income inequality persists especially in the North and Eastern Region". It is therefore recommended that DFID Uganda undertakes an in-depth, comprehensive needs

analysis of people with disabilities living in the Northern Region of the country. Such an analysis should investigate the needs and aspirations of different impairment groups, as well as being sensitive to any gender disparities that may exist. Moreover, this analysis will provide DFID Uganda to make strategic and well targeted interventions, thereby making a significant contribution to the resettlement and effective social inclusion of people with disabilities.

**8. That DFID Uganda actively consult and engage with DPOs and other people with disabilities during this needs assessment**

When undertaking such a needs assessment, it is imperative that DFID Uganda consults and engages with disabled people's organisations that are based in the Northern Region. This is based upon the assumption that participatory approaches to project design, implementation and evaluation result in long-term significant sustainable change. Furthermore, as has been argued about, the experiences of disabled people's organisations based in the Northern Region are likely to be very different from their counterparts who are based in Kampala.

**Social Assistance**

**9. That DFID Uganda implements its cash transfer programme in all six Districts**

It is recommended that DFID Uganda proceeds with its intention of assisting the Government of Uganda to implement a social protection programme, as delineated in the project concept note that was made available to the consultants, and that cash transfer initiatives for persons with disabilities are piloted in six Districts. Where possible, particular attention should be given to how people with disabilities can effectively access such programmes. Notwithstanding the fact that the vast majority of developing countries do not make any provision for the social protection of people with disabilities whatsoever, (with notable exceptions in South Africa and Costa Rica), there is strong evidence to suggest that such programmes have the potential to make a significant impact on reducing the proportion of those persons with disabilities living in a state of chronic poverty. Moreover, drawing upon international comparative analysis, Sophie Mitra convincingly argues that social safety nets that are specifically targeted at people with disabilities will have a three-fold positive impact. First, they will make significant progress in reducing chronic poverty. Secondly, such provision has the potential to play a long-term development role, by reducing income inequalities and reducing the likelihood of long-term asset depletion. Finally, they can also play a significant role in the prevention of long-term disabilities (Mitra, S. 2005).

**10. That monitoring and evaluation frameworks developed for this programme explicitly assess the extent to which people with disabilities have been included, and the impact on the lives of PWDs.**

From the key informant interviews undertaken during the fieldwork for this study, it was clear that the Ministry of Gender, Labour and Social Development and the Ministry of Finance, Planning and Economic Development are in broad agreement in principle, that the

development of effective social protection programmes and cash transfers will have a significant positive impact on reducing levels of chronic poverty within Uganda. However, the Ministry of Finance, Planning and Economic Development raised concerns that such cash transfers may not actually reach people with disabilities, because of potential linkages within any programme that is devised. It is therefore recommended that DFID Uganda undertakes an evaluation of its cash transfer programme at the end of the second year to ensure that people with disabilities are being equitably served. By so doing, DFID Uganda will be in a position to accurately assess to what extent people with disabilities have access such programmes, and make any necessary changes in order to increase uptake in subsequent years.

**11. That DFID Uganda continue to encourage the Government of Uganda to include a cash transfer scheme under gender and social protection thematic area within the National Development Plan (NDP).**

The Uganda Government is currently developing a 5 year National Development Plan (2009/10 – 2014/15) to become a successor plan to the Poverty Eradication Action Plan (PEAP). PEAP is the overall planning framework for guiding public action on development/poverty reduction in Uganda. Since 1997, PEAP has been revised every 3 years so as to incorporate emerging lessons and issues. The latest version of the PEAP was formulated in 2004 and thus expired in June 2008.

It is recommended that DIFD should continue to encourage the Ugandan Government to develop a cash transfer scheme that will be included in the NDP within thematic area number 2 which is “Gender and Social Protection” (NPA, October 2008). This is also in alignment with PEAP Independent Evaluation recommendation iv which states “The NDP process should adopt a new policy mix with reoriented strategy for economic transformation and sustainable poverty eradication”

**12. That DFID Uganda encourages the Government of Uganda to investigate developing other forms of social protection for people with disabilities as part of a national social protection policy framework and action plan**

Finally, it is recommended that DFID Uganda, in collaboration with other bilateral and multilateral donor agencies, encourages the Government of Uganda to develop a more comprehensive social protection programme for people with disabilities. Such an endeavour will make a significant contribution in achieving the Millennium Development Goal of reducing poverty by half by 2015. It will also have the potential to significantly reduce the number of people with disabilities living in chronic poverty, thereby facilitating their sustained social inclusion within contemporary Ugandan society. DFID Uganda could draw on international experience of implementing social protection programmes specifically for people with disabilities in other countries.

**General Recommendations**

**13. That DFID Uganda hosts a seminar for other bilateral and multilateral donor agencies to disseminate the findings and recommendations of this Disability Scoping Study**

In order to ensure that the findings, inferences and policy recommendations generated from this Disability Scoping Study result in sustained positive improvements on the lives and livelihoods of people with disabilities in Uganda, it is recommended that DFID Uganda hosts a policy seminar for other bilateral and multilateral donor agencies. By so doing, existing and potential synergies for donor collaboration can be explored, thereby increasing the impact of this study. Exploring potential collaboration in providing assistance to people with disabilities living in the Northern Region of Uganda is a particular priority, where the level of social exclusion and marginalisation is most ingrained and deeply entrenched. It is also recommended that Mr Ambrose Murangira, (Chairman, Uganda National Association of the Deaf), presents at this seminar, given that he was national research consultant recruited for this study.

**14. That if DFID Uganda is serious in mainstreaming disability throughout its core programmes, then consideration be given to a specific allocation of financial resources for disability in each of its core programmes**

The effective mainstreaming of disability issues within mainstream international development is a complex issue, and one where there is no universally agreed strategy of best practice. International experience would suggest that bilateral and multilateral donor agencies are currently grappling with how this can be achieved in the most sustainable and effective manner. Furthermore, globally mainstreaming disability issues are rising up the political agenda of donor, given the successful negotiation and enforcement of the UN Convention on the Rights of Persons with Disabilities. Notwithstanding the complexity of this issue, it is recommended that DFID Uganda includes a specific budget line within each of its core programmes that in their totality will constitute DFID Uganda's next five-year strategy. While due recognition and acknowledgement by the consultants is given to the fact that DFID Uganda is not going to establish a new specific disability programme, it is nevertheless obvious that if a budget line on disability is included in each of the main core programmes, it will ensure that at some level, disability issues are addressed. Unless some specifically designated funding is set aside to include disability issues within DFID's core programmes in the next five years, it is extremely likely, that by default, people with disabilities will not benefit from such activities. The consultants do not deem it appropriate to recommend what level of funding is allocated for this budget line, but will encourage the senior management of DFID Uganda to give this recommendation serious consideration.

**15. That DFID Uganda gives consideration to how to include people with disabilities in their road construction programme**

It was very clear to the consultants that the public transport infrastructure was totally inaccessible to people with disabilities. Also, due to bad lighting, roads are potentially hazardous for those with visual impairments and those with difficulty with mobility. Within Kampala and other major cities in Uganda, some consideration may be given to making

some buses accessible and ensuring that bus stops are adapted so that they can be disability friendly.

## Appendix I

# Terms of Reference for the Study

### 1. Objective

To conduct a scoping study to identify strategies and concrete actions to enable DFID Uganda's new programme to be more inclusive of disabled people

### 2. The Recipients

The recipient of the services that are subject to this contract is DFID Uganda.

### 3. Scope

This study will:

- Provide an overview and assessment of the current situation of disabled people in Uganda
  - indicate the scale and prevalence of disability using existing data sources (census, UDHS) and through discussions with Uganda Bureau of Statistics
  - indicate poverty levels, causes and consequences of poverty among disabled people, using existing data
  - assess perceptions and attitudes towards disability
  - provide an overview of the role of the state, disability services and disabled people's organizations in Uganda using as a tool of analysis the "Stepping Stool to Inclusion" (see Annex)
  - consider the specific needs of different groups within the disability community (e.g.: disabled women and girls, people with learning impairments, deaf or blind people) and responses to these needs
- Map disability issues and channels of support for disabled people in the following key areas relevant to DFID's new programme:
  - education sector / budget support
  - transport / roads sector
  - Northern Uganda / post-conflict recovery
  - social protection
  - map government services for disabled people in the above areas
  - map organizations for and of disabled people providing support and services to disabled people, and the types of support being provided
  - map current sources of donor funds for disability in Uganda
- Identify specific strategies to make DFID Uganda's new programme more inclusive of disability issues and disabled people

## 4. Methodology

The study will provide an overview and rapid assessment of disability issues in Uganda. Research techniques will include the following:

- Desk review of literature
  - disability specific research (e.g.: Disability and Poverty Study; Uganda Demographic and Health Survey; DRT disability research; World Vision Including Disability in Development)
  - DFID publications on disability and related topics (e.g.: Disability, Poverty and Development; Realising Human Rights for Poor People; Social Exclusion Policy, selected outputs from the Disability KAR programme)
  - sector specific documentation in Uganda (e.g.: Education sector documentation; PRDP for Northern Uganda; roads sector documentation); social protection documentation
- Key informant interviews
  - staff of relevant government ministries (MGLSD, MoWT, OPM, MoES)
  - organizations for and of disabled people (including NUDIPU, UNAD, UNAB, ADD, UNAPD, USDC)
  - key development partners (Irish Aid, RNE and UNICEF for education; World Bank and EC for roads; UNICEF and World Bank for North)
  - DFID staff
  - a cross-section of disabled people (men/women; rural/urban dwellers, people with different impairments) and their carers
- Focus group discussions with disabled people and DFID staff
- Stakeholder workshop

## 5. Reporting

The consultant will report to the Social Development Adviser. The following outputs will be expected from the consultant.

- Inception report outlining how the consultants will undertake the mission
- Stakeholder workshop
- 3 reports:
  - Summary report (maximum 15 pages) outlining key findings and recommendations;
  - Situation analysis of disability in Uganda
  - Mapping of support for disability in Uganda and in key sectors

## 6. Time frame

The consultancy should take 30 person days, split between a lead researcher and a local researcher. Work is expected to commence around 19 January. All outputs are to be completed by end February 2009.

<b>Activity</b>	
Field work in Uganda	January 2009
Final report	end February 2009

## **7. DFID Coordination**

For technical direction the consultant will liaise with the Social Development Adviser and the Head of Programmes.

## **8. Background:**

Recent estimates on the extent of disability in Uganda range from 3.5% (Census) to 20% (UDHS) of the population. Poverty is both a cause and consequence of disability, with up to 80% of disabled people experiencing long term poverty. Poverty also affects the families of disabled people disproportionately. The majority of adults and children with disabilities find their chances of going to school, working for a living, enjoying family life and participating as equals in social life are severely restricted, not only because of their impairments but also due to attitudes, discrimination and exclusion. Disabled women in Uganda face "double discrimination", and are more likely to be poor or destitute, and have less chance of founding a family and benefiting from family relationships, than do men with disabilities. Disabled people are also more likely to be victims of sexual abuse and violence, and disabled women in particular are more at risk of contracting HIV and AIDS.

DFID Uganda is developing a new 5 year country programme which will aim to enhance the rate of progress on off-track MDGs, support Uganda to sustain high growth, and continue to support improvements in governance. At least 50% of the programme will be provided through general budget support, with the objective of improving effectiveness in key sectors including health, education, water, roads and agriculture. Additional programmes will support recovery in Northern Uganda, infrastructure, social protection, and accountability.

Government of Uganda has a National Disability Policy, with progressive disability legislation in place and an Equal Opportunities Commission about to commence operations. Programmes are being implemented in both the education and the social development sectors, targeting assisting children with disabilities to access schooling and integrating disabled people into community life through community based rehabilitation. However, these programmes are limited in reach. Similarly, efforts at mainstreaming disability are patchy. DFID Uganda has supported advocacy and awareness raising activities such as through the National Union of Disabled Persons of Uganda (NUDIPU), and Action on Disability and Development (ADD). We have also supported research on disability and poverty through the Ministry of Finance. DFID Uganda is keen to find workable and effective strategies for greater engagement on disability through our new programme.

## 9. Key reference documents

Uganda Disability Policy (GoU)  
Peace, Recovery and Development Plan (PRDP, OPM)  
Disability and Poverty Study (MoFPED)  
Chronic Poverty and Disability (DRT)  
Including Disability in Development (World Vision)  
Strategic Plans for Education, Roads, and Social Development

## 10. Skills & Experience Required

The study should be carried out by a team of two researchers, to be contracted jointly:

### *Lead Researcher*

- international / regional disability expert
- extensive experience in conducting disability research using the social model
- experience of working on working with disability approaches in a budget support / multi – donor environment
- organizational development and capacity building
- knowledge of Uganda an advantage
- knowledge of DFID policies and procedures

### *Local Researcher*

- disability activist and researcher
- experience of working in a budget support / multi-donor environment

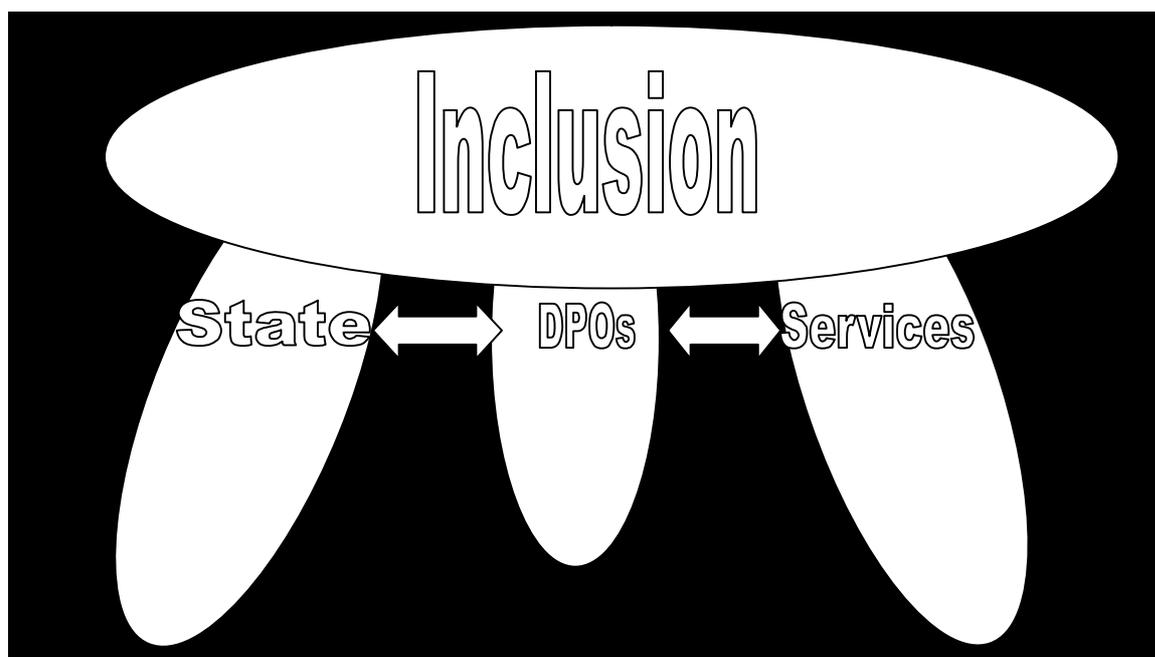
## ANNEX 1

### EQUALITY OF RIGHTS AND OPPORTUNITIES FOR DISABLED PEOPLE: THE STEPPING STOOL TO INCLUSION

Disability is increasingly being acknowledged as a human rights issue. Indeed, members of the disability movement see disability rights as the last liberation struggle. The new UN Convention on the rights of persons with disabilities was adopted in January 2007, and many countries have passed their own domestic disability rights laws. Some of the most comprehensive disability legislation exists in developing countries, such as South Africa.

However, translating rights on paper into real improvements for the lives of disabled citizens is much harder. If organisations, such as DFID are to effectively enable such a transformation, it is necessary to have a basic understanding of the foundations of inclusion to achieve equality of rights and opportunities for disabled people in a society. Presented below is a simple tool to assist this.

#### THE STEPPING STOOL TO INCLUSION TOOL



#### Aim:

The tool aims to capture and present in a simple visual format the basic components and their inter-relationships needed to support the inclusion of disabled people to realise their equality of rights and opportunities.

#### Use

The tool can be *used* to:

- Provide a basic assessment of the status of disability issues within a country
- Identify the areas where interventions are likely to be the most enabling and thus effective

**Explanation**

There are *three essential components* necessary to support the process of inclusion. They are:

- The state
- Disability services
- Disabled people’s organisations (DPOs)

*Each component has distinct roles and functions* (outlined in the table below).

These components can be visualised as the three supporting legs of the Stepping Stool to Inclusion.

*The components must be in equilibrium and interact with each other in mutually supportive and reinforcing ways*, otherwise the Stepping Stool to Inclusion will be unbalanced or the legs may splay outwards causing the stool to collapse.

The strength of each component or ‘leg’ in a country can be assessed by finding the answers to few simple questions (see table below). Then the Stepping Stool to Inclusion can be drawn to visually represent the basic status of disability issues within a country.

The role of a donor like DFID is to design and implement interventions that will:

- strengthen weaker components
- facilitate the key components (state, disability services and DPOs) to interact with each other in mutually supportive ways
- ensure balance and equilibrium between the key components

As a minimum, the donor actions should avoid anything that further unbalances the Stepping Stool to Inclusion.

Table: roles and functions of the key components *(cont. next page)*

	<b>Key roles and functions</b>	<b>Sample indicative assessment questions</b>
<b>STATE</b>	<ul style="list-style-type: none"> <li>• Define rights and entitlements through legislative and policy framework</li> <li>• Set standards and monitor implementation</li> <li>• Provide resources as much as the economic development of the country permits</li> <li>• Ensure that mainstream services, particularly health and education, are accessible to disabled people</li> </ul>	<ul style="list-style-type: none"> <li>• Is there any disability rights legislation? Are there any policies addressing disability issues?</li> <li>• Which ministry or ministries take responsibility for disability issues? Is disability recognised as a cross-cutting issue?</li> <li>• Do the ministries of health and education have any policies or plans on disability?</li> <li>• What resources does the state provide to ensure implementation of any disability legislation, policies and plans?</li> <li>• Are there any mechanisms in place to monitor and enforce the rights of disabled people and their entitlements?</li> <li>• Does the state engage with disability service providers and DPOs? If so, in what ways? Does the state take on any responsibility for coordination?</li> </ul>

<p><b>DISABILITY SERVICES</b>  (E.g. rehabilitation, assistive devices, support services for disabled children, specialist vocational training, etc.)</p>	<ul style="list-style-type: none"> <li>• Reduce the impact of impairments</li> <li>• Enable disabled people to access their rights</li> <li>• Services can be provided by the state, international and local NGOs, DPOs</li> </ul>	<ul style="list-style-type: none"> <li>• What services are available? Are there any major services gaps? (e.g.: mental health services, services for the hearing impaired)</li> <li>• Who are the main service providers? The state? Civil society? Combination of the two? Do service providers cooperate with each other?</li> <li>• Broadly what proportion of disabled people has access to the basic services they need? Nearly all? Most? Very few?</li> <li>• How sustainable are the existing services?</li> <li>• What are the main barriers preventing access to services?</li> <li>• What is the quality of existing services? Are there any standards? If so, are they monitored?</li> <li>• Are services well coordinated? Is there a good geographical spread?</li> </ul>
<p><b>DISABLED PEOPLE'S ORGANISATIONS</b></p>	<ul style="list-style-type: none"> <li>• Represent disabled people</li> <li>• Advocate and lobby for disability rights</li> <li>• Ensure that the state and service providers are responsive to the needs and rights of disabled people</li> </ul>	<ul style="list-style-type: none"> <li>• Is there a national, cross-disability, umbrella DPO?</li> <li>• Are there national DPOs representing people with different impairments?</li> <li>• Are there DPOs at provincial, district and local levels?</li> <li>• Do DPOs have a rights-based approach to disability?</li> <li>• How united or divided are DPOs?</li> <li>• In what ways do DPOs engage with the state and service providers?</li> </ul>

## Appendix II

### List of Participants attending Focus Group Discussions

#### Kampala – Tuesday 3<sup>rd</sup> February, 2009

##### Names

Laura Kanushu  
Ronald Luyima

Hellen Asamo

Wahab Turyasima  
Joyce Ndagire  
Higenyi Higgins

W B Lugemoi  
Geoffrey Katende  
Deborah Oyuu

Agnes Aserait

Nicholas Nsubuga

Robert Nkwangu  
Zachary Kaddu

##### Organisations

Legal Action for PWDs (LAPD)  
Uganda National Association of the Blind (UNAB)

National Union of Disabled Persons of Uganda (NUDIPU)

NUDIPU

UNAPD

Uganda National Association of Physically Disabled (UNAPD)

Action on Disability and Development (ADD)  
UNAB

Uganda National Association of the Deaf (UNAD)

National Union of Disabled Persons of Uganda (NUDIPU)

Uganda National Association of the Deaf (UNAD)

NUDIPU

Makerere University Disabled Students Association (MUDISA)

#### Gulu District, Monday 9<sup>th</sup> February

##### Names

Peter Lotada  
Vento Labongo  
Richard G Ochan  
Lucy O Lajara  
P Okello Catheline  
Florence Aciro  
Hellen Aserua  
Calvin Idha  
Lucy Adong  
Ali Odongo  
Albert Okwera  
Santo Okumu  
Simon Okema

##### Organisation/District

Pader District Union of PWDs  
Pader District Union of PWDs  
Kitgum District Union of PWDs  
Kitgum District Union of PWDs  
Gulu District Union of PWDs  
Gulu District of PWDs  
Adjuman District Union of PWDs  
Adjuman District Union of PWDs  
Gulu District Union of PWDs  
Apac District  
Gulu District Union of PWDs  
Gulu District Union of PWDs  
Gulu District

Jessica Ababiko  
Augustine Okello  
Anna Etim  
Sunday Lamunu  
Monica Piloya

Adjuman District  
Lira District Union of PWDs  
Lira District  
Gulu District  
Gulu District

**Appendix III  
Timetable of Fieldwork – 2<sup>nd</sup> – 13<sup>th</sup> February, 2009**

Time	Monday, 2 <sup>nd</sup>	Tuesday, 3 <sup>rd</sup>	Wednesday, 4 <sup>th</sup>	Thursday, 5 <sup>th</sup>	Friday, 6 <sup>th</sup>	Saturday, 7 <sup>th</sup>	Sunday, 8 <sup>th</sup>
8:30am			UNICEF/Wassago				
9:00am	DFID	FGD starts	Mps for PWDs	Ass. Commissioner Building (MoWT)			Travel to Gulu
9:30am	DFID	FGD	Continues	Continues			
10:00am	DFID	FGD	Ends	Ends	Dean SNER, Kyambogo University		
10:30am		FGD			Continues		
11:00am		FGD	IRI Country Representative		End of the interview		
11:30am		FGD	Continues				
12:00noon		FGD	Ends	Hon. Minister for Disability and Elderly			
12:30pm		FGD ends					
01:00pm							
01:30pm							
02:00pm	Commissioner for Disability and Elderly (MGLSD)	Continues		Senior Economist, MoFPED			Arrival in Gulu
02:30pm	Continues	Interview ends		Continues			
03:00pm	Interview ends		WVI/Elizabeth	End of the interview			Visiting DPs Camps for on spot observation
03:30pm			Continues		MOWT		57
04:00pm	DFID/Joan	OPM/Woboya	Ends				
04:30pm		Continues					
05:00pm		Ends					

Week II

<i>Time</i>	<b>Monday, 9<sup>th</sup></b>	<b>Tuesday, 10<sup>th</sup></b>	<b>Wednesday, 11<sup>th</sup></b>	<b>Thursday, 12<sup>th</sup></b>	<b>Friday, 13<sup>th</sup></b>
<b>9:00am</b>	<b>FGD in Gulu</b>	E.D NGO forum	Mp for PWDs (Northern Uganda)	Summary Report writing at Sheraton Hotel	Presentation to the stakeholders' workshop
<b>9:30am</b>	FGD	Continues	Continues		
<b>10:00am</b>	FGD	End of the Interview	End of the interview		
<b>10:30am</b>	FGD	Commissioner SNE/MoES/Omagor			
<b>11:00am</b>	FGD	Continues	USAID/Smith		
<b>11:30am</b>	FGD	End of the Interview	<b>Continues</b>		
<b>12:00noon</b>	FGD	WB's Social Protection Specialist	End of the interview		
<b>12:30pm</b>	FGD ends	<b>Continues</b>			
<b>01:00pm</b>		<b>Ends</b>			
<b>01:30pm</b>					
<b>02:00pm</b>		Kyambogo University/Lecturer/Nuwaga ba			
<b>02:30pm</b>					
<b>03:00pm</b>			NUDIPU/Chairman		
<b>03:30pm</b>			Continues		

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<b>04:00pm</b>			End of the interview		
<b>04:30pm</b>					
<b>05:00pm</b>		KCH/Chairman	DFID/Joan		

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