

Children with disabilities in Uganda: The hidden reality



The African Child
Policy Forum

Children with disabilities in Uganda: The hidden reality

The African Child Policy Forum (ACPF)

ACPF is an independent, pan-African institution of policy research and dialogue on the African child.

ACPF was established with the conviction that putting children first on the public agenda is fundamental for the realisation of their rights and wellbeing and for bringing about lasting social and economic progress in Africa.

ACPF's work is rights based, inspired by universal values and informed by global experiences and knowledge. Its work is guided by the UN Convention on the Rights of the Child, the African Charter on the Rights and Welfare of the Child, and other relevant regional and international human rights instruments. ACPF aims to specifically contribute to improved knowledge on children in Africa; monitor and report progress; identify policy options; provide a platform for dialogue; collaborate with governments, inter-governmental organisations and civil society in the development and implementation of effective pro-child policies and programmes and also promote a common voice for children in and out of Africa.



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List of Acronyms

ACFODE	Action for Development
ACPF	The African Child Policy Forum
ADD	Action on Disability and Development, UK
AMFIU	Association of Microfinance Institutions in Uganda
AVSI	Associazione Volontari per il Servizio Internazionale
BTVET	Business Technical Vocational Education and Training
CBM	Cristoffel Blinden Mission/Christian Blind Mission
CBR	Community-Based Rehabilitation
COMBRA	Community Based Rehabilitation Alliance
CSO	Civil Society Organisation
DHF	Danish Handicap Forbund (Danish Association for the Disabled)
DPO	Disabled Peoples' Organisation
DRT	Development Research and Training
DWNRO	Disabled Women's Network and Resource Organisation
ESAU	Epilepsy Support Association of Uganda
FHRI	Foundation for Human Rights Initiative
FOWODE	Forum for Women and Democracy
GDP	Gross Domestic Product
GNI	Gross National Income
HIV	Human Immune-Deficiency Virus
HURINET	Human Rights Network
ILO	International Labour Organization
KDMA	KIN Development Management Associates Ltd
MADE	Mobility Appliances by Disabled Women Entrepreneurs
MHU	Mental Health Uganda
MP	Member of Parliament
NAD	Norwegian Association of the Disabled
NCC	National Council for Children
NCD	National Council for Disability
NGO	Non-Governmental Organisation
NUDIPU	National Union of Disabled Persons of Uganda
NUWODU	National Union of Women with Disabilities of Uganda
PMA	Plan for Modernisation of Agriculture
UBIP	Uganda Brain Injury Project

UBOS	Uganda Bureau of Statistics
UDWA	Uganda Disabled Women's Association
UHRC	Uganda Human Rights Commission
UN	United Nations
UNAB	Uganda National Association of the Blind
UNAD	Uganda National Association of the Deaf
UNAPD	Uganda National Action on Physical Disability
UNCRC	United Nations Convention on the Rights of Children
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNDP	United Nation Development Programme
UNESCO	United Nations Education Scientific and Culture Organisation
UNICEF	United Nations International Children's Emergency Fund
UNISE	Uganda National Institute of Special Education
UPE	Universal Primary Education
USDC	Uganda Society for Disabled Children

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PREFACE

Children with disabilities in Africa are among the most neglected groups in the policy domain as well as in the private sphere. The majority of these children face enormous economic, political, and social barriers that have an adverse impact on their physical, social and intellectual development and wellbeing. Many of them do not have access to the most basic needs such as health services and education, experience multiple deprivations even within their family and are invisible in national policy agenda.

The African Child Policy Forum (ACPF) believes that revealing the realities and drawing attention to the life situation of children with disabilities is the first step to lay the foundation for the establishment of sound policies, strategic plans and effective services and support to children with disabilities in Africa. It is within this context that the ACPF took the initiative to document the reality of children with disabilities and their families in Africa through in-depth studies aimed at generating evidence about their situation and by so doing it hopes to encourage greater national commitment to children with disabilities.

The multiple-country study is an effort to make the situation of children with disabilities more visible, so that parents, community leaders, policy makers, as well as child rights activists and their organisations, commit themselves to better protecting and promoting the rights of children with disabilities. The study seeks to analyse how cultural, social, physical and other societal barriers prevent children with disabilities from enjoying their constitutional rights to equality, freedom and human dignity. It also seeks to establish opportunities and practices that could be used to address these barriers to enhance disabled children's participation in society.

Children with disabilities in Uganda: The hidden reality; is therefore part of a multiple-country study conducted by ACPF. We hope that this report serves its purpose and contributes towards guaranteeing children with disabilities to equal opportunities, treatment and full participation in Uganda. It is our greatest hope that this research supports the formulation and implementation of national policies, programmes and legislations that promote the full participation, equality and empowerment of children with disabilities in Uganda.

David Mugawe
Executive Director

EXECUTIVE SUMMARY

Children with disabilities in Uganda: The hidden reality is a result of a joint effort between The African Child Policy Forum (ACPF) and KIN Development Management Associates (KDMA). The study, which took place between February and May 2010, covered 15 districts across all Uganda's regions:

- Central region: Kampala, Nakaseke, Rakai;
- Western region: Bushenyi, Hoima, Kyenjonjo;
- Northern region: Arua, Gulu, Lira;
- North Eastern region: Soroti, Nakapriprit, Kapchorwa;
- Eastern region: Pallisa, Busia and Jinja.

The purpose of the study was to document the realities faced by disabled children in the different aspects of their lives at all levels: household, community, school and workplace. The study also aimed to find out how accessible key services – such as education, health and social – were to disabled children and their families, and how much emotional and financial support they received.

The results of the study are intended to be used to engage policy makers and inform policy reform, legislation and programming for children with disabilities in key sectors, mainly: education and training, social protection and healthcare. It also aims to promoting the full participation, equality and empowerment of disabled children in all aspects of their lives.

The study revealed that there is little statistical information on disability in Uganda for three reasons:

- low investment in information gathering systems;
- the stigma surrounding disability means that surveys are likely to leave out significant numbers of disabled children;
- the definition of *disability* is still contested, even within the disability fraternity.

According to our findings of this study, disease is the number one cause of disability, followed by congenital causes, a number of which could be associated with infection of the unborn child.

Uganda has many enabling policies and laws aimed at protecting the interests of children and creating equal opportunities for disabled people. Unfortunately, policy implementation is weak, and insufficient resources are made available to translate policies into services for disabled persons. Nevertheless, the government remains the main service provider for 47% of Uganda's disabled children, with non-governmental organisations (NGOs) providing services for only 14%.

Poverty still abounds in Uganda and affects the way and standard of life of many Ugandans. The government also blames the nation's poverty for not allocating the resources necessary to implement disability programmes. At household level, the study revealed that caring for a disabled child costs more, and carers are often unable to

provide for their disabled children.

Households, and particularly mothers, remain the primary carers of disabled children, with the majority of children living with their families.

About 62% of the disabled children (aged 9-17 years) in the study were in school. This is an indicator of a significant increase in the enrolment of disabled children in educational establishments at all levels, including university and other tertiary institutions, and is a positive result of affirmative action. However, access to other services – such as healthcare, assistive devices, employment, emotional and financial support – is still encumbered by many barriers, both physical and social. The majority of child respondents had access to regular health services (85.7%) for their regular healthcare needs; and religious faith healers (69.3%) and traditional healers (53.3%) for their spiritual and emotional needs. Only 35% had access to a community-based rehabilitation (CBR) worker and 18.5% to specialised rehabilitation services in their community. Although most respondents were aware of their existence, 62% said they do not use these services because they are expensive.

In spite of increasing awareness about the rights of disabled children among family and community members and the children themselves, negative and non-supportive attitudes remain a challenge – both for social integration and participation. The study revealed that disabled children encounter physical and emotional abuse inside

and outside home, in the community and at workplace.

We conclude with a number of recommendations, including:

- There is need for stakeholders to improve on the available data to aid programming. The upcoming housing and population census (2012) provides an opportunity to collect significant and reliable data on disabled persons and hence sufficient preparations need to be made.
- Several actors, especially within the disability fraternity, need to step up their advocacy and lobbying for the implementation of the many policies and laws pertaining to persons/children with disabilities that have been shelved for some time now. But more so, it is the responsibility of the government of Uganda, as a duty bearer, to ensure that these policies and laws are implemented to benefit persons with disabilities and the country at large.
- While there are many disability-focused NGOs and disabled persons' organisations (DPOs), their activities do not seem to be translating into benefits for disabled children and their families. Further research needs to take place to assess the impact of disability-focused NGOs and DPOs on the planning and delivery of disability services in Uganda, and how they can improve.
- The ministry of gender, labour and social development and the National Council for Disability should develop 'quality standards for effective

disability programming' to guide both state and non-state actors on the effective planning and delivery of interventions.

- Although the government has pronounced that inclusion is the main policy drive for meeting the needs of disabled persons, the allocation of resources within each sector has been incredibly low and unsatisfactory; in some cases non-existent. Disability programming performance indicators should therefore be included in the periodic local government performance assessments.
- State and non-state actors alike should take a more holistic approach to addressing disability. We therefore recommend that the government use the CBR approach to planning and delivering their interventions.
- The government should establish a disability trust fund to support disabled persons – especially children – to access expensive services.

1 INTRODUCTION AND STUDY BACKGROUND

1.1 BACKGROUND

Disability among children is a prevalent problem in Africa, but it is seldom recognised and often deliberately hidden. Children with disabilities face social, political and economic barriers that have an adverse effect on their physical and mental development. The vast majority of these children receive no education; they are absent from school data sets and invisible on the national policy agenda.

Often considered a curse on their families, they are discriminated against and stigmatised at home, in schools, in institutions and in the community. Disabled children are probably the most neglected group in both the policy domain and the private sphere. They are absent, or referred to only marginally, in public policy documents, sectoral (health, education, social) development plans and poverty reduction programmes. National plans of action for children in African countries sometimes make reference to disabled children, but suggest little action to meet their needs.

Actual figures on the prevalence of disability are difficult to find for most developing countries. Uganda's 2002 census, which provides perhaps the most detailed and reliable information for planning purposes, defines disability as "*a condition which denies a person a normal economic and social life, which has lasted or is expected to last 6 months or more*" (UBOS 2003).

According to this definition, 4% of the population (about 1.2 million) had disabilities, compared to 3.3% using the WHO definition. The prevalence rate had increased from 1.1% in the 1991 census, possibly due in part to improvements in data collection methods. The prevalence of disability is not even throughout the country. The 2002 census statistics show that the Northern region has the highest incidence of disability (4.4%) while the Western region has the lowest (2.9%). Eastern and Central regions have rates of 3.6% and 3.1% respectively.

However, these figures have been contested by the disability movement who believe that the national prevalence rate should be higher. As a result of intensive lobbying by the disability movement, the rate was subsequently adjusted in 2006 to 7.2% following the Uganda Demographic Household Survey (UDHS) 2005/06. These changing figures illustrate the difficulties facing planners and policy makers.

The kind of data available in any country is critically important if change is to be brought about in national commitments to disabled children. Data is perhaps the best basis on which to establish sound policies, strategic plans and effective services and support. Therefore, documenting the reality in terms of the nature, extent and magnitude of the problem

is an essential and integral aspect of any effort aimed at ensuring social inclusion, equal opportunities and equal treatment for disabled children.

1.2 PURPOSE/OBJECTIVES OF THE STUDY

The disability movement in Uganda is reputedly one of the most vibrant in Africa, and has played a key role in promoting disability rights throughout the continent. The government has signed and ratified a number of key international and regional conventions such as the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the UN Convention on the Rights of the Child (CRC), and domesticated these into national law through the Persons with Disabilities Act (2006) and the Children's Act (1996).

In spite of these positive developments, the situation for disabled children in Uganda does not seem to have improved proportionately. This study therefore set out to document the reality faced by disabled children in different aspects of their lives at all levels: household, community, school and workplace. The study also aimed to find out how accessible key services – education, health and social – were to the children and their families, as well as levels of emotional and financial support.

This is probably the first in-depth study to document the realities of disabled children in Uganda in terms of both geographical coverage and scope of content. It explores the lives of disabled children in the context of family, neighbourhood and accessibility to the basic services that should be enjoyed as a right by any child anywhere in the world.

The study highlights the fact that, although laws and policies are in place, they do not deliver much to disabled children in terms of enabling them lead fulfilling lives. The study unravels a big gap in terms of what is available and what should be available at different levels.

The study results will be used to engage policy makers to improve legislation and programming in key sectors – education and training, social protection and healthcare – in order to promote the full participation, equality and empowerment of disabled children.

"I am the first beneficiary of this study: it has opened my eyes. There are far more disabled children than we knew about. They are basically living terrible lives. No one cares. I now have evidence to use when asking my council for more money to fund interventions for children with disabilities".
(District probation and welfare officer, Bushenyi – research assistant)

2 STUDY CONTEXT

2.1 THE COUNTRY AND HOW IT FUNCTIONS

Uganda is a landlocked country in east Africa. It lies across the equator and covers a total land area of 241,038 square kilometres. Uganda has a population of about 31 million (UBOS 2009 mid-year population projections), and a high population growth rate of 3.3%. It is expected to hit the 50 million mark by 2023.

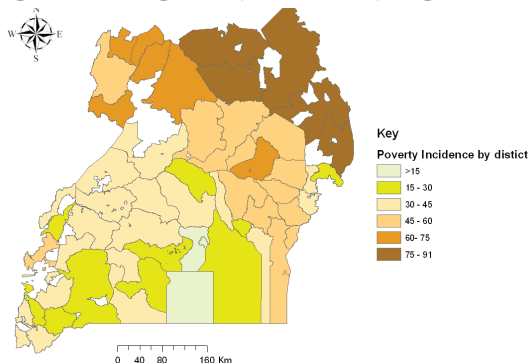
Uganda is endowed with significant natural resources, including ample fertile land, regular rainfall and mineral deposits. The economy has great potential, and it appeared poised for rapid economic growth and development especially with the discovery of commercially viable oil reserves. However, chronic political instability and erratic economic management produced a record of persistent economic decline that has left Uganda among the world's poorest and least-developed countries, with

a human development index ranking of 143rd out of 169 (UNDP, 2010). Nonetheless, Uganda has posted considerably high economic growth averaging over 7% per annum for almost a decade (MFPED, 2007/08: 6) thus reducing poverty levels from over 60% to 31.1% (MFPED, 2010:13)

2.1.1 The population

Uganda's biggest ethnic group is the Baganda, which constitutes 17.3% of the population, followed by the Banyankole (9.8%), the Basoga (8.6%) and the Bakiga (7%). The smallest ethnic group is the Vonoma, with only 119 128 people at the time of the 2002 census. Other groups with fewer than 1,000 people include: Napore (330), Nyangia (332), and Mvuba (863). The eight biggest ethnic groups make up 70% of the population; more than 40 tribes constitute the remaining 30%, (UBOS, 2006).

Map 1: Map of Uganda Showing Poverty Incidence by Region



Source: UBOS and ILRI, 2007

Catholics constitute the biggest religious group (41.9%), followed by the Church of Uganda (Anglican) (35.9%), Islam (12.1%) and Pentecostals (4.6%). Others – including traditionalists and atheists – constitute 5.5%.

2.1.2 Socio-economic context

In recent years Uganda's human development index ranking has risen because of the government's initiative to provide free primary and secondary education. However, 37.7% of the population lives below the national poverty line¹. Uganda has one of the highest fertility rates in the world, with seven children per woman; infant mortality stands at 65 children per 1,000 live births, and maternal mortality at 506 per 100,000 mothers. Life expectancy averages 51.9 years; HIV prevalence is 5.4%. The national income per capita stands at US \$330 (UBOS 2009).

2.1.3 Government and public administration

Uganda gained its independence from the British in 1962. The country's post-independence political history is characterised by instability, changing from a reasonably organised democracy in the early 1960s to military and quasi-military regimes between 1971 and 1996, through to a democratic multiparty dispensation.

The president is the executive head of state. He is assisted by a cabinet of 69 ministers, one of whom is in charge of disability and elderly affairs.

The roles of the central ministries are: policy formulation and planning, quality assurance and technical guidance to local authorities. The 1995 constitution and the 1997 Local Government Act embrace a decentralised governance system. This means that, while the role of service delivery is devolved to local authorities, it is largely the responsibility of civil servants who represent the technical arm of government.

The political structures – from parliament down to local councils – are aimed at mobilising the population for collective and democratic decision making. The constitution and Local Government Act also provide for affirmative action in political representation for disabled people, increasing the visibility of disability as a development issue at the political level.

Parliament comprises more than 305 MPs as well as ex-officio MPs (including ministers that have been appointed outside parliament) and special interest groups representing: women; the Uganda Peoples Defence Forces (UPDF); workers; people (and women) with disabilities; and youth. An electoral college, comprised of the district structures of the National Union of Disabled Persons of Uganda (NUDIPU), elects a total of five MPs to represent disabled people: 4 from the four regions (Central, East, West, North), and 1 woman to represent women with disabilities.

1 World Bank (1993) estimated two relative poverty lines for Uganda, US \$110 and US \$55. The US \$110 represents the minimum per capita income at which the poor can meet basic food needs and other non-food expenditures and the US \$55 represents the minimum per capita income at which only basic food needs can be met.

Local councils provide a forum for citizen participation in governance and decision making. Council members are also elected through universal adult suffrage and electoral colleges for special interest groups including women, disabled people and youth. Local council 1(the sub county) is the lowest local government level while Local Council 4 (otherwise known as the Municipality) and Local Council 5 (district) are higher local governments. It is here that resources are planned for and expended to deliver services to the people.

Today there more than 114 districts and over 56,000 elected councillors who represent disabled people at various local council levels in the country (The New Vision, 7 December 2004).

2.2 PREVALENCE OF DISABILITY IN UGANDA

Uganda's first attempts to start

disaggregating disability data were made in the 1991 census. However, the classifications used then and in the subsequent 2002 census did not match those used by the World Health Organisation. Nevertheless, the 2002 census, and the 2005/06 National Demographic Household Survey are currently the most credible sources of information on the prevalence of disability in the country. The 2002 census put disability prevalence at about 4%, but this was adjusted upwards by the 2005/06 national household survey to 7.2% (ILO 2009). Although some in the disability movement have voiced their dissatisfaction with these figures, believing that they are still an understatement, variation in numbers is common in many countries and illustrates how the definition of disability and data collection methods can affect survey results. Nevertheless, these surveys provide some indication on numbers, which is crucial for planners and policy makers.

Table 1: Population of disabled people, by type (2002)

Disability type	Age			Total	%
	0-17	18-30	31+		
Physical	79,884	66,862	207,584	354,330	41.9
Hearing	62,958	16,539	48,196	127,693	15.1
Visual	36,554	22,484	129,712	188,750	22.3
Speech	18,682	6,736	7,205	32,623	3.9
Intellectual	12,862	7,971	9,205	30,038	3.6
Mental illness	10,421	8,142	12,073	30,636	3.6
Epileptic	11,762	4,891	4,671	21,324	2.5
Rheumatism	3,966	2,709	12,254	18,929	2.2
Other	13,715	7,999	18,804	40,518	4.8
Total	250,804	144,333	449,704	844,841	100.0
%	29.7	17.1	53.2	100.0	

Source: UBOS (2005). National population and housing census.

Based on the figures in Table 1, we can conclude that close to 30% of all disabled people in Uganda are children (under 18), and that 42% have physical disabilities.

The social and economic status of disabled people in Uganda is particularly precarious; there is a high correlation between the incidence of poverty and disability. The Northern Uganda survey of 2004 conducted by NUDIPIU estimated that 72% of disabled people in the Northern region were living in a state of chronic poverty, with men far more likely to be poor than women (NUDIPIU, 2008). Other studies have estimated that 80% of disabled people are living in conditions of long-term poverty with limited access to education, health facilities, sustainable housing and employment (Lwanga Ntale, 2003:1).

2.3 GENERAL MANDATES OF GOVERNMENT DEPARTMENTS

2.3.1 Central government ministries

Ministry of gender, labour and social development: Responsible for disability issues, the ministry's primary function is to provide social rehabilitation. This involves creating awareness among the public about disability, ensuring that disabled people are integrated and included in society and all aspects of living. The ultimate goal of social rehabilitation is integration in the workplace and in society as whole, allowing disabled people to lead as normal a life as

possible. In Uganda, this should include vocational and rehabilitation training to ensure that they gain useful skills for independent living.

Unfortunately, these programmes have stagnated due to a lack of funding. Instead, the ministry is promoting and supporting community-based rehabilitation (CBR) programmes as a means to ensure equal opportunities for disabled people. The ministry is implementing these CBR programmes in partnership with local governments and disability-focused organisations².

The Ministry of Gender, Labour and Social Development is also responsible for ensuring that the national policy on disability (NPD) is implemented. This policy, along with the 2006 Persons with Disabilities Act, enjoin the ministry of gender, labour and social development to coordinate disability and elderly issues in the country. The ministry is therefore required to develop and disseminate guidelines for making this policy operational (NPD 2009).

There is a department of Disability and the Elderly which is headed by a Minister of State who is responsible for disability affairs within the ministry.

Ministry of education and sports: The mandate of the ministry is to "plan, formulate, analyse, monitor, evaluate and review policies; provide technical support and guidance; and set national standards for the education sector". The ministry has put in place a department for special needs and career guidance and counselling which

2 These include Norwegian Association of the Disabled (NAD), Uganda Society for Disabled Children (USDC), Community-Based Rehabilitation Alliance (COMBRA), Sight Savers International and other DPOs. Unfortunately, data on the number of people benefiting from these programmes is not currently available.

is responsible for taking the lead in education planning for special needs groups – mainly disabled children.

General primary school enrolment has more than tripled since the government introduced universal primary education in 1997, from 2.63 million children to over 7.6 million reported in 2010. According to World Bank report, since the introduction of Universal Secondary Education in 2007, the enrolment has increased from just over 160,000 to more than 452,000 in 2009³.

Ministry of health: This ministry includes a disability and rehabilitation section and a mental health section, both of which are situated within the department of integrated clinical services. They are responsible for ensuring that appropriate standards and guidelines are developed and enforced. The health delivery system is made up of a number of levels, from health centre 1 (a village-level aid post) to health centre 7 (national referral hospital level). Health centre 4 (county level) includes a resident medical officer and has facilities that can handle minor surgery. There should also be specialist clinical staff such as psychiatric nurses at this level.

In addition there are regional referral hospitals (level 6) staffed by specialists including psychiatrists, general and orthopaedic surgeons, occupational therapists and others to ensure that people can access specialised services at regional rather than national level. However, a number of limitations – such as low funding;

an unwillingness to be posted and work outside Kampala; and a shortage of some specialists such as speech therapists and neurosurgeons – make these regional referral hospitals inadequate for serving disabled people.

The ministry of health, with assistance from NGOs such as Associazione Volontari per il Servizio Internazionale (AVSI) and Uganda Society for Disabled Children (USDC), has established orthopaedic workshops for the manufacture and maintenance of assistive devices in most of the regional referral hospitals, including Arua, Mbarara, Hoima, Mbale, Lira and Gulu. However, although these workshops are staffed, they often run at low capacity due to a lack of raw materials and vital parts. Furthermore, most of the assistive devices they make are for people with mobility problems, not for hearing, visual or other impairments.

2.3.2 Local government

Local governments derive their mandate from the Local Government Act, and are responsible for planning and delivering rehabilitation services. At district level, the department of community services is responsible for social rehabilitation, with a dedicated community development officer. As part of the national strategy for planning and delivering rehabilitation services to disabled people and their families, local governments are supposed to ensure that CBR is implemented in each district.

3 www.worldbank.org

2.3.3 Government agencies

National Council for Children (NCC):

Established by an Act of Parliament in 1996, the NCC's main role is to advise and promote policy and programmes regarding the survival, development and protection of children in Uganda; and to ensure proper planning and coordination of all child-based programmes in the country. Although the NCC Act does not specifically mention disabled children, one of its main objectives is to act as a vehicle to communicate the needs and problems of children to the government and other decision-making institutions and agencies. It also coordinates and provides direction to all persons involved in child-based activities to minimise duplication of effort and wastage of resources. This involves maximising multi-sectoral and integrated approaches to meet the needs of children and solve their problems.

National Council for Disability (NCD):

Established by an Act of Parliament in 2003, one of the NCD's key functions is to act as a national body through which the needs, problems, concerns, potentials and abilities of disabled people can be communicated to government and its implementing bodies. It is also responsible for monitoring and evaluating the extent to which government, NGOs and the private sector include and meet the needs of disabled people. The council also acts as a coordinating body between government departments, service providers and disabled people, and identifies and gives guidelines to organisations working with disabled people. The council is mandated to research and investigate matters or incidents relating to the violation of disabled people's rights and non-compliance with programmes, policies or laws relating to disabilities, and to take appropriate action as necessary. The act also provides for the establishment of district, municipal and sub-county councils all over the country.

2.4 LEGISLATION AND POLICY FRAMEWORK

Table 2: Summary of legislation and policies that shape the provision of services for disabled children

Legislation and policies that underlie the provision of disability services	
<ul style="list-style-type: none"> • The Constitution of Republic of Uganda 1995 • National development plan 2010-2015 • National disability policy, 2006 • Persons with Disabilities Act 2006 • National Council for Disability Act 2003 	
International conventions and protocols that place an obligation on the government to protect the rights of children with disabilities	
<ul style="list-style-type: none"> • Alma Ata Declaration 1978 • International Labour Organisation (ILO) Convention No 159 1983 • ILO Recommendation 168 on vocational rehabilitation and employment of persons with disabilities, October 1991 • World Programme of Action 1983 • World Declaration on Education for All 1990 • Vienna World Conference on Human Rights 1993 • UN Standard Rules for Equalisation of Opportunities 1993 • UNESCO Salamanca Framework of Action on Special Needs Education 1994 • African Decade of Persons with Disabilities 1999-2009 • UN Convention on the Rights of Persons with Disabilities (UNCRPD) 2006 • UN Convention of the Rights of Children (UNCRC) 1989 • African Charter on the Rights and Welfare of the Child, November 29, 1999 	
Legislation and policies of key government departments	
Health	National health policy II National minimum healthcare package District rehabilitation package Guidelines for provision of assistive devices Uganda clinical guidelines
Social Development	Uganda Foundation for the Blind Ordinance 1954 (Laws of Uganda Chapter 58) Children's Act 1996 Equal Opportunities Act 2006 National Council for Disability Act 2003 Persons with Disabilities Act 2006 Social development strategic investment plan National orphans and other vulnerable children policy National child labour policy

Education	Education Act, 2008 Uganda Institute of Special Education (UNISE) Act 1998 Universities and Tertiary Institutions Act 2001 White paper on education 1992 Business, Technical, Vocational Education and Training Act 2008 The education sector strategy plan 2004/5-2014/5 National strategy for girls' education Universal Primary Education Act 1997
Others	Parliamentary Elections Statute 1996 Local Governments Act 1997 Uganda Communications Act 1997 Uganda Traffic and Road Safety Act 1998 Land Act 1998

2.4.1 International legal framework

As shown in Table 2, Uganda is signatory to a number of international conventions which, after ratification, have demanded domestication into national laws. Some of the most important and relevant conventions include:

- *Alma Ata Declaration 1978*: emphasises the rehabilitation approach to primary healthcare.
- *ILO Convention 159 1983 and Recommendation 168* on vocational rehabilitation and employment of persons with disabilities.
- *World Programme of Action 1983*: advocates for full participation of disabled people in the development process.
- *World Declaration on Education for All 1990*: asserts the obligation of government to include all – especially marginalised groups such as disabled people – in the education system.
- *Resolutions from the Vienna World Conference on Human Rights 1993*: stipulate the promotion of disabled people's rights.
- *UN Standard Rules for Equalisation of Opportunities 1993*: guidelines for policy making.
- *UNESCO Salamanca Framework of Action on Special Needs Education 1994*: emphasises that inclusive education is the best way of combating discrimination and improving the education system on the whole.
- *African Decade of Persons with Disabilities 1999-2009*: aims to ignite the commitment of African leaders to promote the rights of disabled people on the African continent by: increasing awareness and reflection on the causes of exclusion and marginalisation of disabled people; and promoting the mainstreaming of disability issues and the participation of disabled people in social and economic development programmes, including national poverty reduction strategies.
- *The UN Convention on the Rights of Persons with Disabilities 2006*: aims to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all disabled people.

- *UN Convention of the Rights of Children (UNCRC) and the African Charter on the Rights and Welfare of the Child*: both ensure that children's rights and welfare are protected.

2.4.2 National legal framework

Table 2 shows that key government departments have passed a number of policies and legislation to provide for the rights of disabled people and children. These include:

- *Uganda Foundation for the Blind Ordinance 1954 (Cap 58)*: provides for the establishment of a trust to promote the welfare, education, training and employment of the blind.
- *Parliamentary Elections Statute 1996*: provides for five representatives of disabled people in parliament, at least one of whom should be a woman, and the use of sign language in parliament where applicable.
- *The Children's Act 1996*: stipulates early assessment of disabilities among children for appropriate treatment, rehabilitation and education.
- *Local Governments Act 1997*: provides for representation of disabled men, women and children at all local government levels.
- *Uganda Communications Act 1997*: provides for the development of techniques and technologies that facilitate accessibility to communications services for disabled people.
- *Uganda Traffic and Road Safety Act 1998*: stipulates that disabled people shall not be denied driving permits on the basis of their disability.
- *UNISE Act 1995*: provides for the establishment of the Uganda National Institute of Special Education, to train teachers and other personnel working in the field of special needs education and rehabilitation to cater for all kinds of persons with disabilities and learning needs.
- *Land Act 1998*: stipulates that any transaction on customary owned land that discriminates against disabled people shall be null and void.
- *Universities and Tertiary Institutions Act 2001*: provides for affirmative action for disabled people in admissions to universities and tertiary institutions.
- *Equal Opportunity Act 2006 and Employment Act (no 6) 2006*: both prohibit discrimination against persons in employment based on their disability.
- *Business, Technical, Vocational Education and Training (BTJET) Act no 12 2008*: promotes equitable access to education and training for all disadvantaged groups, including disabled people.
- *Universal Primary Education Act 1997*: makes it financially possible for families to send their disabled children to school by providing free primary education (initially) to four children in every family, but to implementation challenges, now targets all children of primary school going age.

- *Persons with Disabilities Act 2006*: makes provisions for equal opportunities and the elimination of all forms of discrimination against people with disabilities; also provides for a 15% tax reduction to private employers who employ 10 or more disabled people as employees, apprentices or learners on a full time basis.
- *National Council for Disability Act 2003*: mandates the council to bring any issues concerning disabled people to the attention of the government, NGOs, private sector and individuals, to improve the lives of disabled people.

Although it does not focus on specific interventions for disabled people, it does promote their inclusion, participation and access to basic services as a vulnerable group. It also aims to protect all vulnerable groups from the risks and repercussions of livelihood shocks by overcoming the constraints that impede the development of their productive capacities.

National policy on disability 2006: provides a subtle CBR framework for delivering services to disabled people and empowering them in the development process. Its objectives are to:

2.4.3 National policy framework

This section discusses some of the policies that aim to improve the lives of disabled people in Uganda. However, it should be noted that other policies still need to be properly implemented, including those on: accessibility of public buildings; housing; employment and affirmative action to increase access to tertiary education for disabled people.

The social development strategic investment plan: aims to protect poor and vulnerable groups, working towards the over-arching goals set out in the national planning development plan – formerly the poverty eradication action programme. It aims to improve livelihoods and ensure the full realisation of economic, social, cultural and civic rights, through sustainable and gender-responsive development.

- create a conducive environment for the participation of disabled people
- promote effective friendly service delivery to disabled people and their carers;
- ensure that resources for initiatives targeting disabled people and their carers are mobilised and efficiently utilised;
- ensure that disabled people and their carers can access essential services;
- build the capacity of service providers, disabled people and carers for the effective prevention and management of disabilities.

Education policy⁴: stipulates that all children with special learning needs – including those with disabilities – should access learning in an inclusive environment (*basic education policy and costed framework for educationally*

⁴ Since the early 1960s the Ugandan education system of education has been: seven years of primary education; six years of secondary education (four of lower and 2 of upper secondary); and 3-to-5 years of higher education.

disadvantaged children 2002). However, the policy also states that learners with severe disabilities – including those who are profoundly deaf – are better assisted in special classes or schools (Ministry of education and sports 2005).

Although tremendous achievements have been made in primary school enrolment, there are still many barriers to inclusive education, including a lack of appropriate teaching materials, such as Braille materials and books and audio equipment, and an inadequate number of ordinary classroom and special needs teachers. As a result pupil performance is declining across board. A further problem is that universal primary education has created a higher demand for secondary education.⁵ The government has yet to address this issue with regards to the special needs of disabled children.

Affirmative action to help disabled people access education at all levels has had some impact – for example, public universities now admit disabled students on the basis of affirmative action – but more needs to be done to ensure wider implementation.

Vocational training: The government established 10 vocational rehabilitation centres and sheltered workshops in the late 1960s and early 1970s to provide rehabilitation and resettlement services, but most of these have ceased to provide meaningful services or operate at very low capacity. Currently, only five of these vocational

rehabilitation training centres are open and operating at slightly above 50% capacity. They provide skills training, which include carpentry and joinery, leather craft, tailoring, and handicraft. The ministry of gender, labour and social development works with employment services to provide guidance on employment opportunities for disabled people who have received training at the centres.

While the government's BTVET policy has no clear strategies for vocational training for disabled people, the current vocational rehabilitation training schemes are generally more accessible to persons with physical, hearing and visual disabilities. Children with intellectual disabilities do not seem to be well catered for within this framework, and there are no government-funded independent living schemes for people with intellectual disabilities (offering sheltered workshops, vocational rehabilitation centres, etc).

Health policy: The ministry of health has included disability management as an essential part of the national minimum healthcare package, which has a range of priority services selected on the basis of:

- cost-effectiveness;
- targeting diseases with high burden;
- targeting the poor and disadvantaged, including women, children and disabled people.

The disability management policies

⁵ Starting February 2007 the government introduced universal post-primary education, and the first batch of beneficiaries sat for their O'level exams at the end of 2010.

(the district rehabilitation package) set out minimum levels for staffing, equipment, supplies, management and support to enable districts to develop their own strategic plans. The policies are intended to streamline, strengthen and extend medical rehabilitation services to all districts in line with decentralisation policy. The nine areas of disability included by the package are: hearing impairment; visual impairment; epilepsy; adult mental health; child mental health; orthopaedic appliances and aids; polio and mobility impairment; cerebral palsy; and non-communicable diseases.

To implement this policy, the ministry of health established the disability section and the mental health unit within the department of integrated clinical services.

The government has also reorganised the essential drugs procurement system to facilitate access for health centres and hospitals to drugs through primary healthcare and credit line facilities⁶.

Agriculture policy: The livelihood of Ugandans is largely dependent on agriculture. Disabled people should therefore be empowered to participate in agriculture to enhance their food security, increase their incomes and help them be part of the mainstream economy. The government's plan for modernisation of agriculture (PMA)

provides a strategic and operational framework for environmentally sustainable rural development and for transforming the sector from one based on subsistence to one of commercial agriculture.

The PMA's key actions that target disabled persons are establishing groups of disabled farmers and ensuring disabled people have access to agriculture credit services and household support services.

Decentralisation policy: The government has created an enabling environment for disabled people to organise, mobilise and participate in the decision-making process. *The Local Government Act 1997* exceptionally empowers disabled people and provides them with an opportunity for representation at every level of political governance. Accordingly, there are over 56,000 elected leaders (persons with disabilities) who represent the interests of the disability fraternity in the country.

National orphans and other vulnerable children policy: Together with the national strategic programme plan of interventions for orphans and other vulnerable children, this policy acknowledges disabled children as one of the categories of vulnerable children. As a result, both national and local government responses have included supporting civil society organisations

6 The Government health facilities receive supplies under two programmes: Primary Healthcare (PHC) and Credit Line. Under PHC, the Ministry of Health advises the Ministry of Finance to send money directly to districts for procurement of drugs and other medical supplies. Procurements under PHC comprise about 70% of all drugs supposed to go to each district. The remaining 30% falls under the Credit Line programme, through which NMS supplies. Under Credit Line, NMS supplies on credit according to orders from the district as well as the budget allocation for that district, which is determined by the Ministry. After delivering the drugs to the district, NMS sends invoices to the Ministry asking to be paid for the drugs supplied.

(CSOs) that target children with disabilities such as Uganda Society for Disabled Children, Katalamwa Cheshire Home and NUDIPU through the Civil Society Fund.

Sports policy: The physical education and sports department mentions the development of sports programmes for special groups including disabled people, elderly people and women. However, apart from sports and recreational services organised by CSOs (especially DPOs) – such as Uganda National Association of the Deaf, Special Olympics Uganda and Right to Play – the ministry of education and sports has not done much to translate its policy intentions into action.

2.5 STAKEHOLDERS IN DISABILITY WORK IN UGANDA

There are many stakeholders involved in disability work in Uganda. These include government ministries, departments and institutions; non-governmental organisations of and for disabled persons; and some foreign missions (embassies). Majority of the stakeholders are involved in supporting health related activities mainly involved with medical rehabilitation needs. Some fewer stakeholders focus on production and supply of assistive devices, education, vocational, entrepreneurial and employment; human rights advocacy; capacity building for DPOs; peace and conflict management; and poverty eradication. A full list of stakeholders and what they do can be found in table 19 in appendix 1.

3 RESEARCH METHOD

3.1 POPULATION

This study involved 540 children aged 9-17 with a physical, visual, hearing, intellectual or developmental impairment, or a combination of these selected randomly from different districts of Uganda. It included children with attention disorders, learning difficulties, speech impairment and autism.

To ensure national representation, disabled children living both in conventional settings (with their family) and in unconventional settings (on the streets, in boarding schools or in rehabilitation centres/institutions) were included, to capture their life experiences and benefit from their views and perceptions.

3.2 METHODOLOGY

3.2.1 Process

To meet the objectives of the study, both quantitative and qualitative data collection approaches were applied. The combination of these approaches was aimed at allowing the research teams to gather complementary information on disabled children, their family and primary carers, and their communities. This helped to give a better understanding of the social, economic and emotional situation of disabled children.

3.2.2 Sampling frame and unit of investigation

The specific unit of investigation was originally planned to be a parish, given the number of disabled children that needed to take part in the survey. The sampling frame comprised a list of panel counties, sub-counties and parishes and the team aimed to select two parishes from each of the two sampled sub-counties from each district. However, researchers, data collectors and key stakeholders felt that it would be difficult to find the required number of respondents aged 9-17 from the four major categories of disability in such a limited area. It was therefore agreed that the unit of investigation be upgraded to sub-county level.

Table 3: Selected survey districts by region

Region	Sub-regions	Districts
Central	Acholi Lango West Nile	Arua Gulu Lira
North Eastern	Karamoja Teso	Soroti Nakapripit Kapchorwa
Eastern	Elgon Busoga	Jinja Busia Pallisa
Central	Buganda Kampala Metropolitan	Kampala Nakaseke Rakai
Western	Mid-West + South West	Hoima Kyenjonjo Bushenyi

3.2.3 Data collection tools

Both qualitative and quantitative methods were used. The quantitative method used two sets of structured questionnaires: child questionnaire and a carer questionnaire. The qualitative methods included: key informant interviews, focus group discussions and a *Day in the life* exercise. These provided the opportunity to gather rich information on the views and perceptions of children, carers and important duty bearers including: teachers, health service providers, community leaders and local government representatives.

a) Quantitative data collection

The team gathered quantifiable data on the characteristics of the target population and the environment in which they live. The questionnaires – one for disabled children aged 9-17 and one for their primary carers – were administered to 540 child respondents and an equal number of caregiver respondents across the 15 districts targeted by the study. It probed on the situation of disabled children – from their and their carers' perspectives – in terms of access to education, healthcare, employment, finance and social inclusion. The results from this exercise provided measurable estimates on the nature, extent and depth of problems that disabled children and their families face.

b. Qualitative techniques

Various techniques and formats of qualitative data collection were employed in this study, including:

- *Six focus group discussions*: four with children and two with carers, in Bushenyi, Kyenjonjo, Jinja, Busia, Arua and Lira; these all followed a uniform guide.
- *In-depth interviews with key informants*: including teachers, health workers, local administrators and community leaders, who were selected to represent their regions, roles and functions as duty bearers in the day-to-day lives of disabled children; two sets of interview guides were used: one for teachers and healthcare providers and the other for local administrators and community leaders.
- *A day in the life*: closely following and observing a routine day of six children (three disabled and three non-disabled), to identify the experiences and most common challenges that disabled children face in their daily lives. This method was expected to give insights on how to improve service delivery and care for disabled children. To a limited extent, the inclusion of non-disabled children allowed researchers to compare the situations of both.
- *Literature review*: of data and information from a number of official documents relating to disability in general and disabled children in particular to provide the national context and a picture of the environment in which disabled children are living in Uganda. Most of these documents were obtained from official sources already in the KDMA resource room and data bank.

3.3 STUDY LIMITATIONS

Although, at the design stage of this study, it was expected to use district-level sampling frames, this information was not available. In some cases lists were held by disability organisations and DPOs, but these were not exhaustive and often lacked some of the elements that would have aided selection, such as location, age or nature of disability. The research team therefore had to devise an alternative option that would generate a sample frame for the specific target sub-counties

Efforts to use 2002 census sample frames were deemed unhelpful as they would not provide the specific cohorts that this study was targeting. Furthermore, a number of districts and sub-counties had been created since the census took place.

As a result, the researchers had to rely on various sources, including local councillors representing disabled people, disability organisations and schools, to compile lists for the study. This delayed the process of identifying the respondents.

Finding participants of the different disability types within the age range was quite a challenge, and researchers struggled to find children with some disabilities, such as visual impairments, which were not common in some areas.

Getting respondents in urban areas – like Kampala City, Lira, Arua and Gulu – was not easy, as the majority of the city dwellers are very busy people. As will be discussed later, the study findings also revealed that many city people live in a state of denial, and do not want to admit that their children are disabled.

In some areas, such as Nakapripit district, which is occupied by pastoralists with a good representation of warriors, the exercise was occasionally hampered by insecurity. A few respondents turned hostile on the data collectors, with some demanding payment in exchange for data. The main reason was fatigue: many had been asked similar questions over and over again, but had never seen any gains out of it. The feeling is that researchers gain out of their children's disabilities without giving anything back.

4 RESULTS, ANALYSIS AND DISCUSSION

4.1 PROFILE OF RESPONDENTS

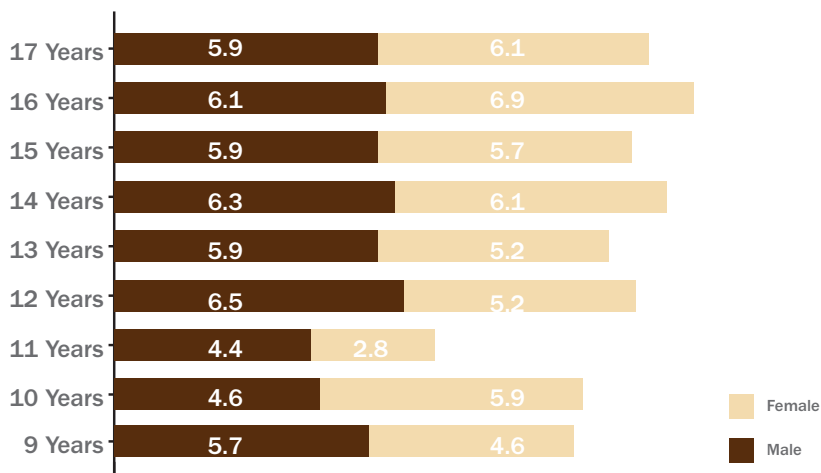
4.1.1 Distribution

a) Age and gender

The study findings indicate that the majority of those interviewed were over 12 years old, with the highest proportion in the 16-year-old bracket (13%). Although the ideal situation would have been a gender balance, it was a challenge to find children in unconventional settings to join the

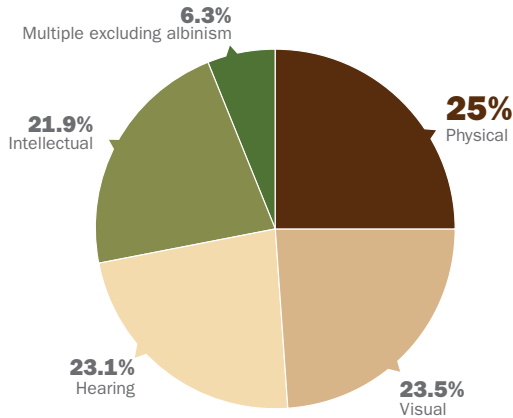
study. As a result, if the team identified a disabled child of the appropriate age who was living on the street or in an institution, they were included regardless of gender. As a result, more boys were mapped than girls: out of the 60 children from non-conventional settings, 63% were boys.

Figure 1: Distribution of Child Respondents by Age and sex



b) Type of disability

Figure 2: Distribution of child respondents by disability



Although the sampling methodology was clear in terms of the major disability representation, namely; physical, hearing, visual and intellectual, 6% of the children interviewed had multiple disabilities, which explains the imbalance among the major disabilities. Figure 2 shows that overall there was a fair distribution of respondents across all the four major disabilities.

A number of multiple disabilities were children affected by cerebral palsy with a number of them having a combination of mobility and intellectual challenges.

c) Religion

Out of the 540 child respondents, 44% were Catholics, 37% Protestants, 8% Muslims and 10% Pentecostals. Compared with national statistics⁷ on religion representation, the only noticeable deviation is with Pentecostals. There are two possible explanations: either there has been an upsurge in the growth of Pentecostal practitioners because their worship style is more appealing especially to young people⁸; or the Pentecostals' belief in and practice of miracle healing attracts more disabled people, who believe their faith may 'cure' their disability.

⁷ According to the 2002 Population and Housing Census, Catholics constitute 41.6%, followed by Anglicans/Protestants at 36.6, Muslims at 12.3% and Pentecostals at 5%.

⁸ An opinion based on observation and interaction of the researcher and young people who attend Pentecostal churches and charismatic worship masses of the Catholic church, whose liturgy is similar to that of Pentecostals.

Table 4: Religious profile of child respondents

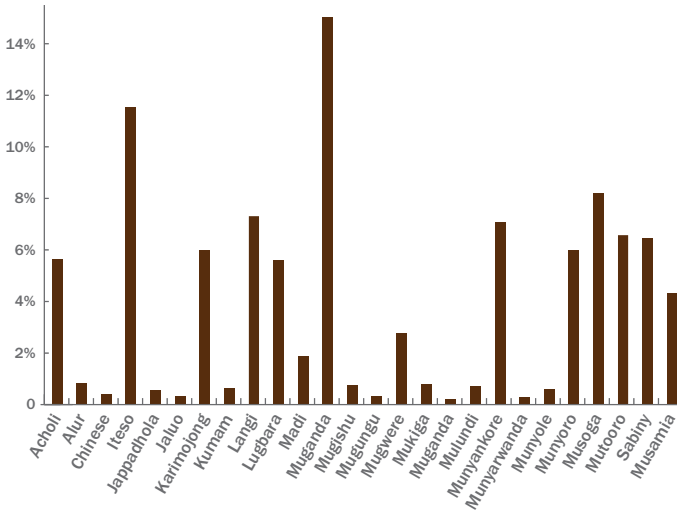
	Gender of child respondent					
	male	%	female	%	total	%
Rural						
Anglican	68	12.6	74	13.7	142	26.3
Catholic	96	17.8	88	16.3	184	34.1
Muslim	10	1.9	6	1.1	16	3.0
Seventh-day Adventist	1	0.2	1	0.2	2	0.4
Pentecostal	9	1.7	18	3.3	27	5.0
Traditionalist	1	0.2	0	0.0	1	0.2
None	2	0.4	0	0.0	2	0.4
Total	187	34.6	187	34.6	374	69.3
Urban						
Anglican	30	5.6	26	4.8	56	10.4
Catholic	29	5.4	25	4.6	54	10.0
Muslim	16	3.0	12	2.2	28	5.2
Seventh-day Adventist	0	0.0	0	0.0	0	0.0
Pentecostal	16	3.0	12	2.2	28	5.2
Traditionalist	0	0.0	0	0.0	0	0.0
None	0	0.0	0	0.0	0	0.0
Total	91	16.9	75	13.9	166	30.7

d) Ethnicity

Uganda has over 50 ethnic groupings, some with very small populations. The major ones include Baganda, Banyankole, Basoga, Iteso, Langi, Acholi, Bagisu, Lugbara, Banyoro. Although ethnicity was not much considered during the sample selection, the findings are comparable with national statistics, with some minor variations. For example, the Bakiga are underrepresented because

none of the districts which are predominantly inhabited by Bakiga were selected. Likewise, the seemingly over-representation of ethnic groups such as Batooro, Banyoro, Karamojong, Basimia and Bagwere were also down to the choice of districts in which the survey was conducted. Outside of the more cosmopolitan urban areas, Ugandan ethnic groups tend to live in very confined geographical locations (districts or even parts of districts).

Figure 3: Ethnicity of child respondents

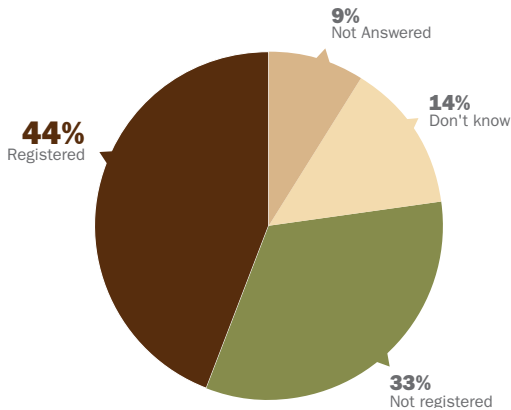


e) Registration of citizenship

Registering a child’s birth establishes their identity and is generally a prerequisite for the issuing of a birth certificate. They help a child secure the right to his or her origins and a nationality, and to safeguard other

rights – to an education, healthcare, etc. Although birth registration was neglected for a long time, it has gained prominence since the late 1990s. Article 18 of Uganda’s constitution obliges the state to register every birth and death occurring in the country;

Figure 4: Registration status of child respondents



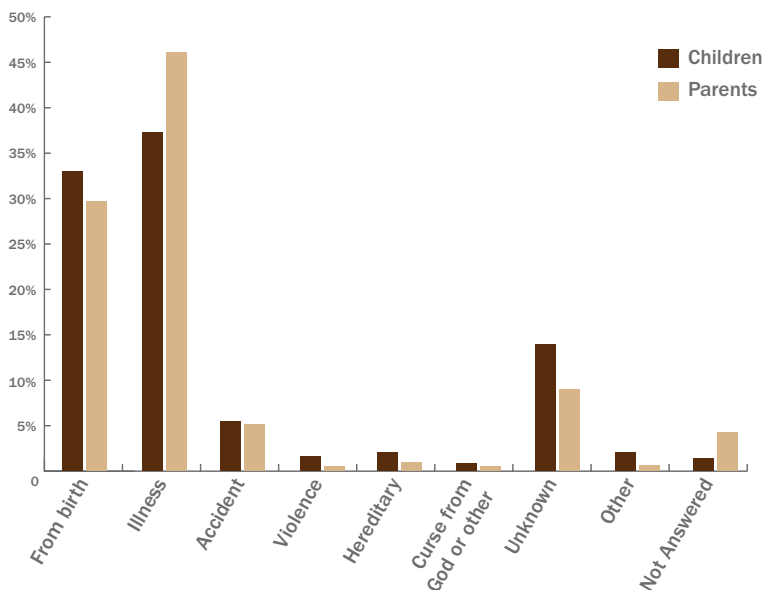
while the Children's Act, the Local Governments Act, the Uganda Bureau of Statistics Act and the Birth and Death Registration Act all provide for the registration of births. Support from UNICEF and other international NGOs such as Plan International has also helped give birth registration a high priority.

Our study found that 44% of child respondents' births had been registered with a government authority; 33% were not registered; 13.7% did not know, while 9% declined to answer. This is far below the national average of 62%⁹.

4.1.2 Cause and onset of disability

The cause of disability as perceived by the children and their carers was fairly consistent, with only slight variations. Illness is the leading cause of disability in Uganda, with 39% of children and 50% of carers reporting it to be the cause of their disability. The carers' response compares well with the 2002 census, which puts it at 50.9%. However, 34% of children and 32% carers reported that disability occurred before or at birth (congenital or around birth), much higher than the census findings of 13%. Children and carers were consistent in attributing disability to accidents (6%) and a curse from God (1%).

Figure 5: Causes and onset of disability (child and carer questionnaires)



⁹ A survey completed in 2000 indicated that only 4% of births in Uganda were registered. By 2005, this had improved to 62%, but only 26% with birth certificates.

The study revealed that there is significant awareness on the causes of disability among the community and that superstitious beliefs are very low (only 1% attributed the cause of disability to a curse). For instance one caregiver in a focus group discussion in Nakapripit, Karamoja region observed:

“Some children become disabled due to the negligence of parents. For instance some parents don’t take their children for immunisation against the known tropical diseases, hence disability”.

(Carer focus group discussion, Katana, Lomu parish)

This observation is particularly true in a region like Karamoja, where immunisation coverage rates are very low. Keith McKenzie, head of the UNICEF in Uganda, recently described Karamoja as “the worst place to be in for a child in Uganda”: it has the worst health indicators, high levels of early childhood mortality and morbidity

and extremely low access to and utilisation of basic health services (24% compared with 72% nationally)¹⁰.

4.1.3 Limitations on functioning

Since a good number of the respondents had not been to school, many did not answer this question, particularly the parts that related to literacy and numeracy skills. However, from those who responded to questions related to functional limitations, about 20% indicated that they generally do not need any assistance, while a combined 26% needed either help from another person; device and or both to be able to function in a number of areas.

About one-third of the children need support to learn, write or count either from a person, a device or both while about two-third of them do not any need to stand for a long time; eat or drink.

Table 5: Functional limitations (child questionnaires)

Child's functional limitations	Needs help from:			Does not need any help
	a person	a device	a person and a device	
Looking and seeing	10.9	29.1	3.9	56.1
Hearing and listening	40.6	12.6	5.9	41.0
Sitting for a long time	12.8	15.3	4.1	67.9
Standing for a long time	15.2	24.4	7.8	52.5
Moving body around	21.4	12.1	9.8	56.7
Getting into a vehicle	52.0	7.3	9.3	31.5
Learning and writing	57.7	6.6	12.3	23.4
Learning to count and do mathematics	58.7	6.1	11.2	24.0

¹⁰ <http://www.unhcr.org/refworld/docid/48e5c9881e.html>

Child's functional limitations	Needs help from:			Does not need any help
	a person	a device	a person and a device	
Thinking/concentrating	48.8	2.9	3.7	44.6
Understanding others when they speak, write or use sign language	59.1	5.3	4.9	30.7
Speaking or signing very well so that people can understand	52.2	1.7	6.1	40.0
Writing and being understood by others	56.2	4.6	10.3	28.8
Washing yourself	43.0	3.0	3.8	50.2
Taking care of your body	47.9	3.0	3.4	45.7
Going to the toilet	32.1	11.7	5.4	50.8
Dressing	35.8	3.0	1.5	59.7
Eating and drinking	22.6	5.5	3.5	68.3
Moving around your area	20.7	25.4	10.5	43.4
Going to your friends' houses	21.5	26.6	9.4	42.6
Going to shops in your neighbourhood	27.7	22.5	12.5	37.3
Going to religious venues – eg mosque, church	26.4	21.6	13.9	38.1

Despite these figures, no more than 5% had access to assistive devices and about 50% of these said that using the device improved their functioning. Of those who had access to an assistive device, 5.4% had a white cane; 4.1% a wheelchair; 2.4% eye glasses; 1.9% a walking stick; and 1.1% braille materials. Thirteen per cent of those with mobility problems found that their device solved or at least improved their problem, while 15.3% of those with access to braille materials noted an improvement.

Overall, the analysis revealed that those with mobility problems – arising from physical or visual impairments – have more access to assistive devices than those with other functional

problems such as hearing, learning, counting, or needing assistance with self-care issues including toileting, washing, bathing or dressing.

4.2 HOUSEHOLD AND FAMILY DYNAMICS

4.2.1 Family dynamics

a) Household composition

Of the 480 households surveyed, 58% of household members were children (sons and daughters of the household head); 15% were household heads; 12% spouses and 7.4% grandchildren.

The gender divide was generally well balanced: 49.4% of household members were male and 50.6%

female. The majority (66.8%) of household members had primary education, 16.5% had attained at least secondary education (O'level) or equivalent; while 10% had a university education.

Table 6: Household composition (carer questionnaire)

Category	%
Children (sons and daughters)	58.0
Head of household	15.0
Husband/wife	12.2
Grandchild of head of household	7.4
Other relative	3.6
Son/daughter-in-law	0.9
Parent of head/spouse	0.3
Brother/sister of head/spouse	2.3
Non-relative	0.2
Not answered	0.3
	100.0

b) Primary carer – child relationships

Overall, 62% of carer respondents were female: 41.3% of the children were cared for primarily by their biological mothers; 27.2% by their biological fathers; 5.5% by their grandmothers; 7.5% by extended family members. The majority of those who were cared for by non-relatives lived in institutions.

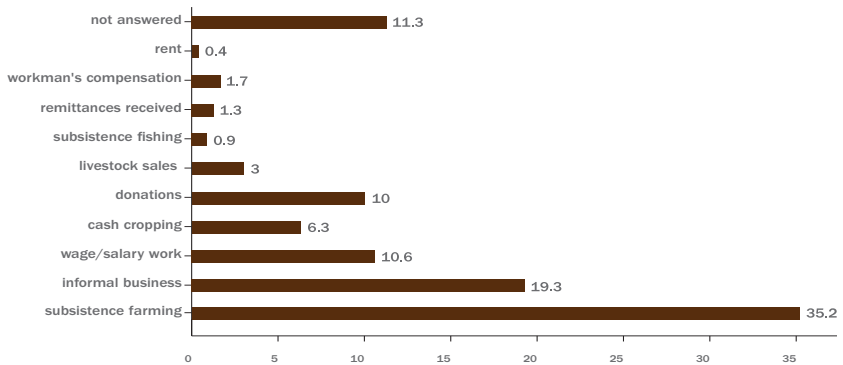
c) Household income

Although more than 80% of Ugandans depend on agriculture for their livelihoods, only about 45.1% of the households covered by this study indicated that they did so. This may be a reflection of a general shift towards a market economy as more Ugandans

move into informal trade in urban centres and abroad. The few who reported to be working in urban areas said they sent remittances back to their rural homes to support their families and relatives. Raising a disabled child places an extra financial burden on the family, who has to look for that cash through work, trade or donations.

The majority of institutions caring for disabled children which took part in the study depended on donations. A good percentage (11.3%) of respondents could not disclose their income source. There could be several reasons for this including having no income and being embarrassed to admit it or fear of taxation.

Figure 6: Sources of household income



d) Participation in family activities

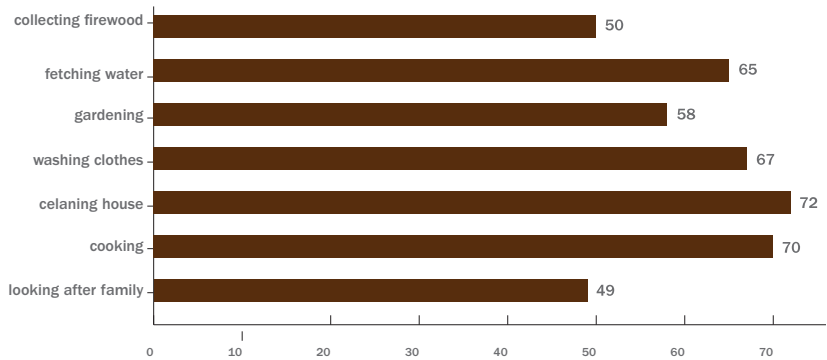
The survey revealed that about 83% of child respondents participated in household chores, while 17% did not. Chores included washing clothes, fetching water, gardening and collecting firewood, all of which are traditionally the expected roles of children aged 9-17.

Figure 7 gives a comparative analysis of participation in household chores by gender, and reveals that, although both boys and girls participated in household chores, the jobs they did were skewed towards traditional gender roles. For example, the girls

were more involved in looking after the family, cooking, cleaning house and collecting firewood while the boys were more likely to do the gardening.

The study revealed that disabled children participate in family work irrespective of their disability. For example, Rukia Ondoru is an active participant in the household chores despite being blind: *“On a typical day I wake up and join in the household chores like any other member of the family. I help out with almost every activity in the home – cooking, fetching water, cleaning household utensils and even a bit of playing with my siblings”*. (See Rukia’s story on p. 27)

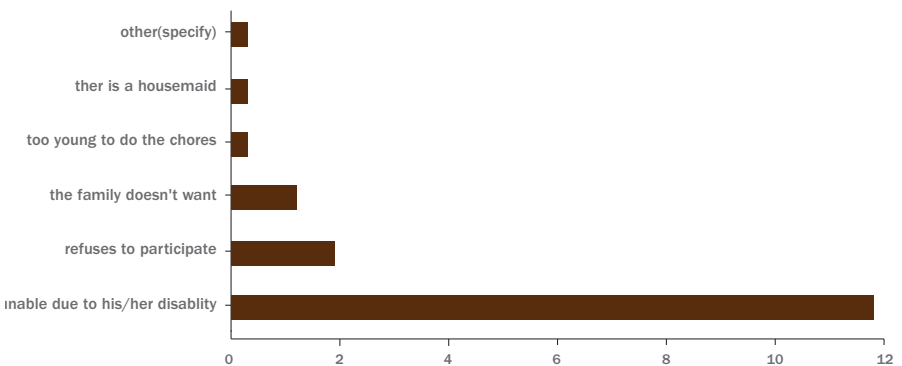
Figure 7: Participation in household chores by gender (child questionnaire)



For the children not participating in household chores, there were varied reasons. They included: disability (12%), refusal of the child (2%) and refusal by the family (1.1%). The latter could be attributed to either negative attitude or protection.

This is confirmed by findings in another study by Lwanga-Ntale in various districts of Uganda on chronic poverty and disability which revealed that community members complained why disabled children were being involved in agriculture “which were considered as hard tasks”, as part of their routine schedules (Lwanga-Ntale, 2003).

Figure 8: Reasons for non-participation in household chores (child questionnaire)



(visually disabled)

Photo 1: Rukia (in the green dress) helps out with household chores



My name is Rukia Ondoru and I am 17 years old. I live with my parents in Arua Hill, near Arua municipality. Ours is generally a typical rural life. I have three brothers and three sisters. One of my younger brothers is also blind. I am fond of my younger brother who doubles as my guide when I need help, particularly when I have to go a long distance – such as to the well to fetch water. I do not go to school. I stay at home like any other child who doesn't go to school. On a typical day I wake up and join in the household chores like any other member of the family.

I help out with almost every activity in the home – cooking, fetching water, cleaning household utensils and even a bit of playing with my siblings. Fetching water is not easy as there

are always long lines with many other children fetching water at the same time. Without the help of my brother, it is difficult for me.

My morning starts with helping my mother to prepare breakfast for the family. I then help wash the utensils, and cleaning the compound and the house. If there is washing to do, I also help wash the family's clothes. Around mid-day I help my mother prepare lunch. After lunch, I help clean the plates once again. Then I go to help my grandmother who lives in the same homestead. I also get to have a chat, rest or get friends to attend to my hair.

In the late afternoon, with my brother's help, I go to fetch water and help prepare supper – by pounding cassava or grinding millet or simsim. After dinner, I love listening to folklore stories and chatting with my siblings. We take supper at about 8.00 pm, after which I take bath and go to bed at 10.00 pm.

I am happy that I am allowed to participate in all this work. I feel I do not miss anything apart from sight. I am happy when my family members recognise my contribution, which they often do. On Fridays I go for prayers like any other devout Muslim.

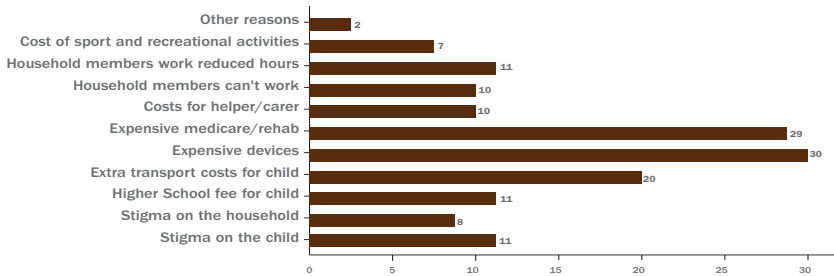
(Rukia's additional photographs are in Appendix 3.)

e) Family income and the financial impact of caring for a disabled child

Caring for a disabled child inevitably affects a family’s income and finances: 13.7% of respondent households reported that the additional expenditure incurred by their child’s disability affected the family’s functioning and financial wellbeing. Additional expenses were related to: purchasing an assistive device (29.8%), paying for medical care or rehabilitation (29.1%), and accessible transport (20.4%).

The survey also revealed that stigma prevented 11% of disabled children who wanted to work to lighten the financial burden on their carers or families from doing so. A small but nonetheless worrying number of carers reported that having a disabled child impeded their ability to earn an income: 8% said that the stigma associated with the household prevented them from getting a job, while 11% had to work reduced hours to care for their child. At the same time, 11% had to pay more towards school fees because of their child’s disability.

Figure 9: Impact of child’s disability on family finances



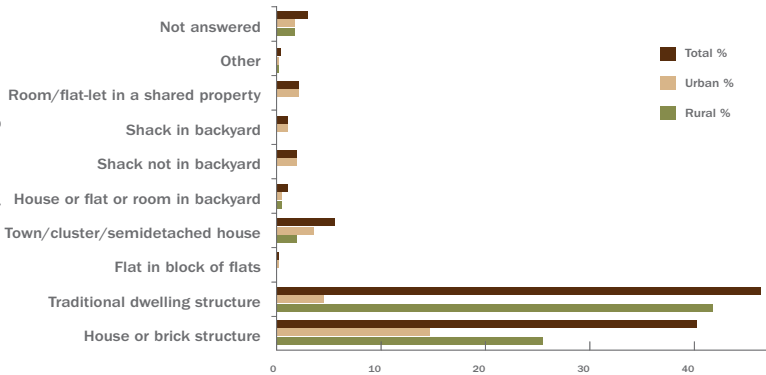
4.2.2 Dwelling

a) Nature of family dwelling

More than half of child respondents lived in traditional dwellings, typical of rural Uganda. In the Northern, Eastern and West Nile regions these are constructed out of mud and wattle, with

grass thatched roofs. In the Central and Western regions, they tend to have tin-roofs and mud and wattle walls. Quite often these are two-bed roomed houses, with children sleeping in one room and the parents in the other.

Figure 10: Housing type



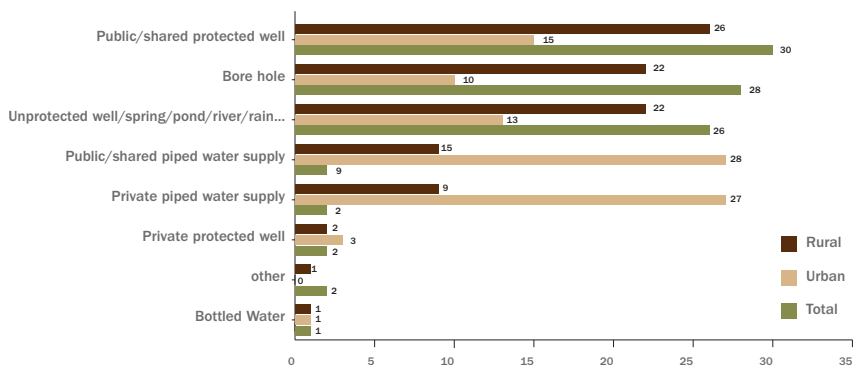
Almost half of the urban respondents (22.4%) or an unprotected source lived in a brick house, most likely (22.2%). Another 28% of households, mainly urban dwellers, reported to have access to a public or shared piped supply. In aggregate terms, the majority of disabled children who participated in the survey (about 48%) were living in reasonable accommodation, while only 3% lived in squalid conditions (a shack).

b) Access to water

The study revealed that the main sources of water for respondent households were: a public or shared protected well (25.7%); a borehole (25.7%); a borehole

About three-fourth of disabled children and their households had access to 'safe water' while a quarter of them depended on unprotected sources. This compares very well with national figures for improved water access, which puts the figure at about 64% (rural) and 87% (urban) (UDHS 2005/06).

Figure 11: Source of water for the household



c) Access to sanitation

Sanitation is a very important component of our lives and is particularly pertinent for disabled children, both at home or school. About 80% of the households covered by the

survey had access to safe sanitation in terms of having a flush toilet or private pit latrine; 9% used communal pit latrines, which in most cases were dirty; 8% had no access to a toilet or used bushes.

Table 7: Sanitation or toilet access for respondent households

Toilet facility for the household	Rural %	Urban %	Total %
flush toilet	0.6	0.4	4.6
pit latrine (private)	55.6	2.1	76.5
pit latrine (communal)	5.6	0.4	9.1
none	7.5	0.1	8.4
not answered	0.7	0.1	1.5
Total	69.8	3	100

d) Physical accessibility

Only 6.3% of respondents said they had adapted their dwelling or accommodation to improve access for the disabled child; 83.1% had done nothing to adapt their dwellings, while 6.9% were not aware of adaptation as an issue.

The majority of the 6.3% who had adapted their dwellings were institutions which are specialised in caring for disabled children. Adaptations included: ramps (29%); handrails (34%); disabled toilet facilities (18%); adjusting furniture (20%); widening doors (20%); and adjusting light switches (37%).

Table 8: Adaptations to dwellings

Adaptations to house	Rural %		Urban %		Total %
	male	female	male	female	
Adapted	0.9	0.9	1.5	3	6.3
Not adapted	21.9	39.6	8.7	13	83.2
Don't know	2.2	2	0.9	1.7	6.8
Not answered	0.9	1.3	0.9	0.6	3.7
Total	25.9	43.8	12	18.3	100

Our research showed that adapting living environments for disabled children was a challenge not only at home but also in schools and other public places, as revealed in this interview with a community leader in Jinja:

“The services are not user-friendly, especially for physically disabled children using wheel chairs. For example, [communal?] latrines are not accessible by wheelchair, so the children have to crawl on their hands on the dirty floor”.

(Community leader, key informant, Jinja district)

Table 9: Sources of support for adaptations

Sponsor of Adaptations	Rural	Urban	Total
household members/institution	1.5	2.4	3.9
members of the community	0.4	0.4	0.8
community or NGO	0.4	1.5	1.9
organisation	0	0.6	0.6
government	0	0.9	0.9
other	0	3.7	3.7
not answered	65.2	23	88.2
Total	67.5	32.5	100

Out of the 64 households or institutions (6.3%) that made adaptations to increase accessibility for the disabled child(ren) who lived there, 21 had met the cost of adaptation themselves and 13 received funding from an NGO. The government had sponsored at least five households to adapt their dwellings, while members of the community had supported four.

Overall, the issue of physical accessibility in Uganda is pretty dismal: although laws have been enacted to provide for accessibility, little effort has been made to enforce them. The government and corporate sector (mainly large multinationals and

international companies) are making some efforts to ensure that any new public buildings are fully accessible. However, in private buildings – shopping arcades, offices, and accommodation – the issue of accessibility remains largely unaddressed.

Uganda National Action on Physical Disability (UNAPD), with support from a Danish DPO, has developed a set of accessibility standards as a case of good practice (see Box 2) and in fulfilment of its mission. UNAPD is currently working with pilot districts to sensitise the public about issues of accessibility standards.

Box 2: Good practice in promoting accessibility standards

A report of an inspection on buildings and construction for Kampala, Mpigi and Wakiso districts in August 2007 revealed that 95% of the buildings in use, both old and new, were not accessible to disabled people. However, no action was taken against the builders for this non-compliance in spite of some existing accessibility guidelines in place.

These were some of the challenges that UNAPD sought to address in a project on accessibility. In a meeting with the officials of the Ministry of Works and Transport, earlier in 2007, UNAPD learnt that a Buildings Bill had been drafted but not yet presented to cabinet for approval, while some accessibility guidelines were already in place but were not being enforced. The disability fraternity under the auspices of NUDIPU led by UNAPD took this opportunity to participate on the revision of the bill to ensure it catered for the accessibility needs for disabled people in this era of technology where building designs are becoming more sophisticated, and the world more dependent on automated technology.

With support from an engineer from its Danish sister organisation, Danish Handicap Forbund (DHF), UNAPD developed accessibility standards and lobbied the government to adopt them. UNAPD is currently piloting the standards with five sub-counties in eight districts of Kampala, Wakiso,

Kapchorwa, Soroti, Masindi, Hoima, Nebbi and Yumbe.

The project aimed to develop UNAPD's expertise in the area of accessibility, enabling them to provide concrete advice to stakeholders on, for example, building standards to ensure accessibility. UNAPD lobbied the ministry of gender and social development to ensure they would input into the development of new building standards. The resulting 'Accessibility standards manual' is co-owned by UNAPD and the ministry: by putting its name to the manual, the government has agreed to adopt the UNAPD's accessibility standards as an official standard. However, the Ministry of Gender, Labour and Social Development has not yet put in place mechanisms for the enforcement of these standards.

To UNAPD, developing the accessibility standards is one of its most important achievements. The standards offer guidelines to constructors and developers for building and installing ramps, accessible toilets, lifts, roads, and many others.

This case illustrates the importance of having evidence first, as this makes it easier to lobby and enhances the success rate of advocacy efforts.

A copy of the manual can be downloaded from: <http://unapd.org/introduction.pdf>

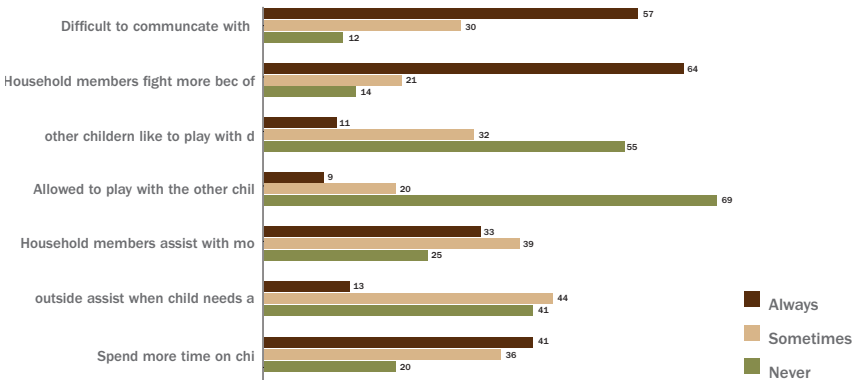
4.3 ACCESS TO SOCIAL SERVICES AND SUPPORT

4.3.1 Attitudes towards disabled children

The survey revealed that societal attitudes towards disabled children are gradually improving and becoming more supportive. For instance, the majority of households did not exclude their disabled children from family (66.7%) or religious events (79.3%). Within the family, 62.4% treated the

children with respect and did not hurt or abuse them because of their disability, but 38% of children were hurt or abused by members of their community. A majority (68.7%) of carers allowed their disabled children to play with other children in the community, while 54.8% reported that other children in the community liked to play with their children. Further, 40.7% of child respondents said they always got emotional support from family members when they felt sad, troubled or upset.

Figure 12: Attitudes and practices that promote or limit disabled children's social integration (carers questionnaire)



Child respondents said that household members had positive attitudes and were generally supportive of them. Based on those who reported 'always and sometimes', results were mostly positive – for example:

- 84% said they could go to people they live with for emotional support when they felt sad, troubled, upset or needed advice
- 67.4% reported that family or household members helped them

with things and activities that were difficult for them because of their disabilities

- 61% reported that the people they lived with let them make decisions about their lives.

However, when children in a focus group discussion in Jinja were asked to express their feeling through art on how they were treated in the community, the drawings carried mixed

messages: some expressed that their families treated them well while others expressed suffering harsh treatment at the hands of their guardians or parents.

“Children with disabilities suffer more ridicule and other forms of harsh treatment as compared to their counterparts with no disabilities at all... Such forms of mistreatment include being denied their rights to education, health services, food and shelter”.

(Child participant, Jinja focus group)

The survey also revealed that a number of children encountered non-supportive attitudes both in their household and the wider community – for example, 26% reported that they were sometimes excluded from family events, while 6% said they were always excluded; 13% said they were sometimes excluded from religious events because of their disability, while 5.4% were always excluded. Furthermore, 38.3% reported that people outside their household sometimes said hurtful things or hit them because of their disability, while 16.3% said that they were always hurt or hit by outsiders; 34% reported that people within the family or household hurt or hit them. This is consistent with views from a focus group discussion in Lira:

“Family members at times neglect children with disabilities to the extent of not providing necessities like clothes [or] bedding... Sometimes our own brothers, sisters and peers in the community call us abusive names, leading to stigmatisation”.

(Child participant, Ngeta Girls’ Primary School focus group)

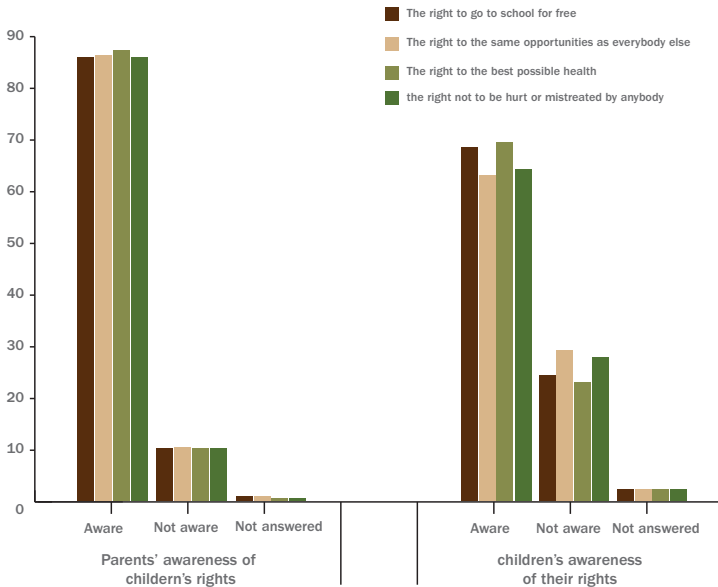
4.3.2 Awareness of the right to access services and support

The study revealed different levels of awareness about children’s rights among carers and children – for example:

- 86% of carers and 69% of children were aware of a disabled child’s right to education;
- 86% of carers and 64% of children knew that disabled children have the right to the same opportunities and treatment as others;
- 87% of carers and 70% of child respondents were aware of a disabled child’s right to healthcare;
- 86% of carers and 64% of children were aware of the child’s right not to be hurt or mistreated.

These figures show that there is a real need for duty bearers and other stakeholders to reach disabled children and make them more aware of their rights.

Figure 13: Awareness of children's rights (carer and child questionnaire)



4.3.3 Access to education and learning support

a) Access to education

Of the 540 child respondents, 62% were in school while 38.3% said they were not. Although this is a marked improvement, in terms of school enrolment for children with disabilities, it still lags behind the net enrolment rate (for all Ugandan children) of 94.6% (UNDP Human Development Indicators, <http://hdr.undp.org>)¹¹. Nevertheless, these figures show that a significant number of disabled children are

in school. Of the 37.4% not in school, 18% had dropped out and 19% had never been to school.

Of those who had never been to school, the majority (22.9%) said their carer did not allow them to go; 12.8% said they were not interested; and 7.3% thought they did not have the ability to learn. Other reasons included: the school refusing to enrol them (10.1%); illness (10.1%); the family being unable to afford the school fees (7.3%), while 6.4% reported that teachers felt that they were unable to teach them.

11 It is difficult to make enrolment comparisons between disabled children and their non-disabled counterparts, because a number of disabled children start school late or lag behind due to the learning challenges they encounter. It is normal to find 15-year-olds still at primary level when the majority of their non-disabled peers would be in secondary school.

Figure 14: Proportion of children respondents who are in and out of school

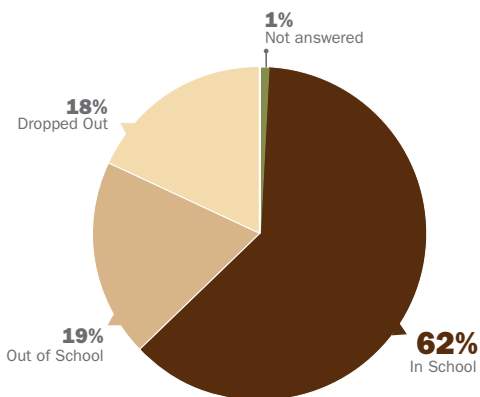


Table 10: Reasons for not attending school (child questionnaire)

Reasons for not attending school	Frequency	%
The people with whom the child lives do not want the child to attend school	25	22.9
The child is not interested in school	14	12.8
The school will not let the child go because of her/his disability	11	10.1
The child is ill/sick	11	10.1
The household cannot afford the fees to send the child to school	8	7.3
The child thinks they cannot learn	8	7.3
The teachers feel they are unable to teach the child	7	6.4
There is no school nearby	6	5.5
The nearby school is not accessible	6	5.5
Other reasons	5	4.6
Not answered	5	4.6
No transport available	3	2.8
Total	109	100.0

The children who had dropped out of school also had varied reasons. The majority (18.4%) dropped out because they could not afford the school fees, while 16.3% of children were not interested in school.

Other major reasons included: the child being ill (10.2%); the teacher feeling unable to teach the child (10.2%); and the school not allowing the child to continue because of his/her disability (9.2%) – this may also be related to the previous point.

Table 11: Reasons for dropping out of school

Reasons for dropping out of school	Frequency	%
Could not afford the school fees	18	18.4
Child was not interested in school	16	16.3
Carer did not want the child to continue going to school	10	10.2
Teachers felt that they were unable to teach the child	10	10.2
Child was ill/sick	10	10.2
School would not let the child continue due to disability	9	9.2
No school nearby	6	6.1
No transport available	4	4.1
Child failed and quit	4	4.1
Child got discouraged by the attitudes of others	3	3.1
Other reasons	3	3.1
Nearby school was not accessible	2	2.0
Child has to work to support themselves/the family	1	1.0
Child thinks they could not learn	1	1.0
Child does not think being in school will help in the future	1	1.0
Total	98	100.0

Seventy-one per cent of child respondents indicated that they had missed school for two or more consecutive weeks. The main reasons were medical (38.6% due to an operation and 21.2% due to illness) followed by a lack of money to pay school fees (6.1%).

Table 12: Reasons for missing school for two or more weeks

Reasons for missing school for 2 or more weeks	Rural		Urban		Total %
	Male %	Female %	Male %	Female %	
Operation	13.10	14.6	5.7	5.2	38.6
Illness	6.70	6.7	3.5	4.3	21.2
Suspension	0.20	0	0	0	0.2
No money to go	1.50	1.7	2	0.9	6.1
No one to take the child to school	0.90	0.7	0.4	0	2
Agricultural activities	0.00	0.2	0.4	0	0.6
Household work	0.40	0.4	0.2	0	1
Paid activities	0.50	0.2	0	0.5	1.2
Not answered	11.30	10.2	4.6	3	29.1
Total	34.60	34.7	16.8	13.9	100

Nearly half of those in school (46.8%) walked there, like many other children in rural Uganda. A few used private transport (2.3%) or public transport (2.2%); while 2% used the school bus. These were mainly children in

urban centres. Four per cent used wheelchairs, but unfortunately, the study could not establish how many children in school need a wheelchair but do not have one.

Table 13: Transport to and from school

Type of Transportation	Rural		Urban		Total %
	Male %	Female %	Male %	Female %	
Walk	17.6	16.3	7	5.9	46.8
Private transport	0.4	0.9	0.6	0.4	2.3
Public transport	0.2	0.6	0.7	0.7	2.2
School Bus	0.4	0.4	0.6	0.6	2
Cart/mule/horse	0.6	0.7	0.2	0	1.5
Wheelchair	1.3	1.7	0.4	0.7	4.1
Not in school	11.5	11.7	4.3	4.8	31.7
Not answered	2.8	3	3.1	0.7	9.4
Total	34.8	34.7	16.9	13.8	100

For a disabled child, attending school comes with an extra cost, and if the family cannot afford it, there is a very high likelihood that the child will drop

out. The extra costs are illustrated in Joseline Mbabazi's story (Box 3): she has to take a *boda boda* (motor cycle taxi)¹² to get her to school and back.

¹² The minimum fare for a boda boda (motor cycle taxi) is Ushs1,000 [about US \$50 cents] for a single journey. This means that her family spends about US \$1 every school day or approximately US \$75 per term. For a poor household this means that the disabled child's going to school could be an equivalent of a member of the family sacrificing 3 meals a day for the duration of the school term.

Box 3: A day in the life of Joseline Mbabazi, 13 (physically disabled)

I am 13 years old. I live near Hoima town with my parents and my sisters. Our house is roofed with 'mabaati' (iron roof).

Photo 2: Joseline enjoys a meal in the living room at home



I usually wake up very early, around 6 am, to give me time to get ready since my disability makes me slow. After waking up I kneel to pray, and then I read my Bible. I took a picture of the Bible, which I read every day. I also pray to God to enable me to succeed in life. Then I wash my face and get dressed for school.

To get to school, I am helped by a boda boda cyclist who is paid by my father. Going by boda boda makes it very easy for me to go to school since it is very difficult for me to walk. The help I get from my younger sisters also makes my life easier.

My physical disability makes it very difficult for me to walk to school. Generally I feel very happy, especially about going to school since this will make me an important and

independent person in the future. I love my sister who helps me a lot in a number of things I do.

I was at school one Monday when I collapsed. Many children feared for my life, but my teachers helped me and got in touch with my father who came and took me home. I was completely weak and could not do anything. It was a very difficult moment in my life as I could have died, had it not been for the support of my teachers and my father. My fellow pupils and teachers kept giving me simple first aid. I felt that they loved me. The day was very different from most, because I could have died that day.

I normally go to bed at around 9.30pm. My younger sister Gloria normally helps me. Before I go to sleep I listen to the radio. The last thing I do is read my Bible and pray because I know that my life for all this time has depended on God's love. I sleep in the same house with my parents and sisters.

When I am at school, many people appreciate my efforts and compare me with other non-disabled children. I find difficulties in situations where I also need to move very fast like other people. My legs are so weak that walking from the room where I sleep to the latrine takes me a long time. I feel bad about that.

(Joseline's additional photographs are in Appendix 3.)

b) Access to learning support

Almost 16% of child respondents who were in school did not need extra support to do their school work. However, 9% felt they needed support but did not get any. Of those who

did, it was mostly from their mothers (31%), siblings (10.3%) and fathers (6%); 0.6% said they got support from a friend or classmate. These figures stress the need to enhance the capacity of parents, carers and siblings to offer such support.

Figure 15: Source of support with school work (child questionnaire)

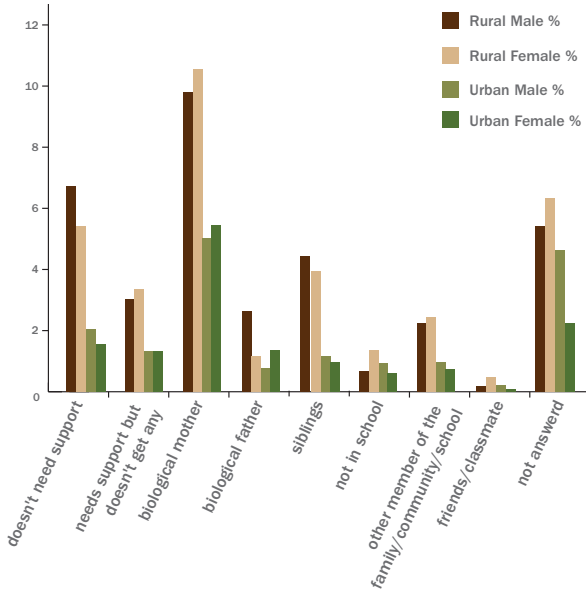


Photo 3: Bonny Kulaba participating in class work in Walukuba Primary School. An example of a well lit classroom



The child questionnaires revealed that 53% of respondents got extra time to finish tasks at school. However, no further questions were asked in relation to this, so we were unable to determine whether extra time was ever denied or how often it was required.

About two-thirds of respondents (71%) were satisfied with the way their teacher was teaching them and said the teacher made it easy for

them to understand; 31% said they got extra lessons from their teachers; 52% that teaching aids were adapted to enable them learn better; and 62.7% that they received help from another person in the classroom. Furthermore, 55% reported that their class environment had been adapted for them – for example, they had been given additional space, could sit at the front of the class, or there had been changes to the lighting.

Photo 4: Classroom block at Walukuba Primary School, with an accessible ramp for pupils with mobility difficulties such as Kulaba



Only 12% of child respondents said they had access to communication aids – communication boards, software, voice output devices – to help them in their learning process. This is comparatively low given the number of visually impaired respondents. The reason is that many teachers in inclusive classrooms do not know Braille, and Braille material (particularly Braille paper) is not readily available. Of those who had access to communication devices, only 10.7% reported that text was put in Braille or large font or audio taped to aid their

learning, although 19% used hearing or visual aids; 31.6% had someone using sign language with them.

Playing and games are an important part of learning. It is therefore important that all children can access play and recreation facilities at school. While 75.2% child respondents said school playgrounds were accessible, 25%, a high proportion of whom were visually impaired, said they were not.

Although the government's education policy stresses inclusive education, in some unique situations these goals are

hampered by a combination of factors. For example, basic service delivery in Karamoja is always challenging, as the population is seasonally on the move, and there are a multitude of social problems. Even when the government installs facilities, professionals do not want to work there.

The government should build us a boarding school for all vulnerable

children, since no other alternative seems to be working favourably for us”.

(Disabled children’s focus group discussion, Nakapripit, Karamoja)

In Karamoja the elders have historically resisted formal education, regarding it as an agent of colonialism¹³. It is therefore essential that the elders are involved in any formal education initiative.

Box 4: Key landmarks in inclusive education provision in Uganda

Since the introduction of universal primary education (UPE) in 1997, there has been a sharp increase in school enrolment among disabled children. At the same time, the government’s approach to education shifted from the previous narrow definition of special education, with clearly identified and categorised disabilities, to an inclusive approach that targets a much broader and larger group of learners who need special educational input in the mainstream system.

The 1992 white paper on education clearly spells out the government’s commitment to provide UPE to all learners, irrespective of ethnic origin, social group, religious affiliation, gender and disadvantaged groups. These included disabled learners and others who encounter barriers to learning and development. As

a result, the conceptualisation of UPE was meant to address the issue of inclusiveness by offering education to such disadvantaged groups, including: street children; children with health problems; girls; traumatised children; gifted and talented children; parenting children; working children; children from pastoral/rural communities; children from very poor families; and children with disabilities and special learning needs.

Even before the start of implementing UPE, the government used the following strategies to extend education to disabled children: training teachers through initial and in-service programmes; running workshops and seminars; disseminating information through the mass media; in-house training of all those working in special needs;

¹³ The Karamajong is a pastoralist tribe in Uganda’s North Eastern region which numbers about 1 million inhabitants. They ceremoniously buried a pen in the 1930s as a sign of resisting formal education. It wasn’t until 2001 that the Karamojong elders were persuaded to accept an adapted education system, and they performed another ceremony to unearth the pen.

collaboration between NGOs and line ministries; raising public awareness through local council meetings.

Every disability-focused organisation and DPO was interested in supporting the issue of education for disabled children. Mass campaigns followed and parents were convinced to take their children to existing schools. As a result there was an increase from 26,429 in 1997 to 218,286 in 2004 (Ministry of Education and Sports, 2005) although this has dropped to 204,352 in 2009 (UBOS, 2010) due to reasons such as lack of appropriate special instructional materials and assistive devices, physical barriers, lack of

teachers and many other reasons (Uganda Human Rights Commission, 2009). Nevertheless, there are more disabled children sitting for Primary Leaving Examinations (PLE) in secondary schools and joining tertiary institutions than ever before in the history of Uganda. For instance, there were 9,088 students with disabilities enrolled in secondary schools in 2008.

At the tertiary level, one of the notable successes for the disability movement is that all disabled learners who qualify for university are given a place at a government university on government sponsorship.

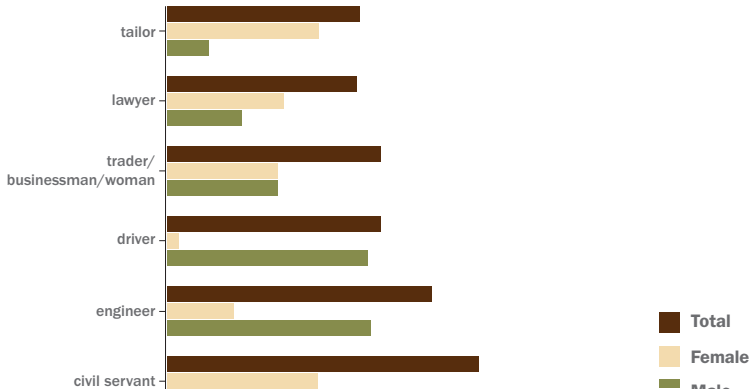
The children's focus groups from Ngeta Girls' Primary School put together a comprehensive list of recommendations that could improve the situation of disabled children's access to education and learning support. These are listed in Box 7, Section 5.2.

c) Dreams for the future

A clear majority of child respondents had dreams and ambitions. While 12% did not think they would ever have a job, a similar number wanted to become a teacher or a nurse; 9% a doctor; 5.4% a civil servant and 4.6% an engineer.

Other possible future careers ranged from domestic worker to president of Uganda (see Table 24 in Appendix 1 for the full list). It was interesting that the majority of respondents associated themselves with the caring professions, as illustrated by this comment from disabled children during focus group discussion in Nakapripit district, one of the remotest and most vulnerable parts of Uganda: *"If we are given an opportunity to go to school, we can become doctors, nurses or even ministers. But we need books, pens and food to be able to go to school"*.

Figure 16: Dream careers for child respondents



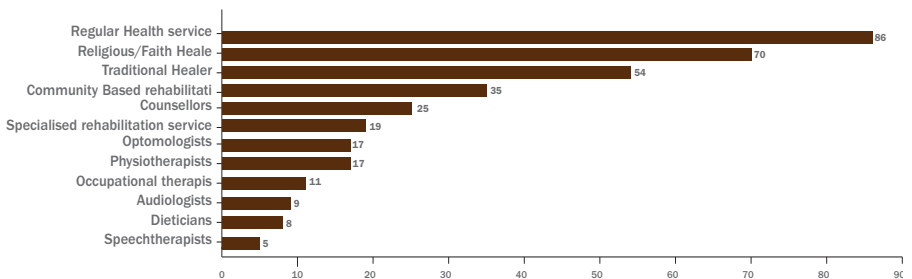
4.3.4 Access to healthcare and wellbeing

The vast majority (86%) of carers said they had access to regular health services; 70% to a religious faith healer; 54% to a traditional healer; and 35% to a community-based rehabilitation worker. Furthermore, 18.5% reported that they had access to specialised rehabilitation services

in their community. The least available specialists were: speech therapists, audiologists, dieticians, occupational therapists, physiotherapists, ophthalmologists and counsellors.

The study also revealed a big gap in the levels of awareness of most of these specialised services: 23% did not know what these services were, or whether they existed in their community.

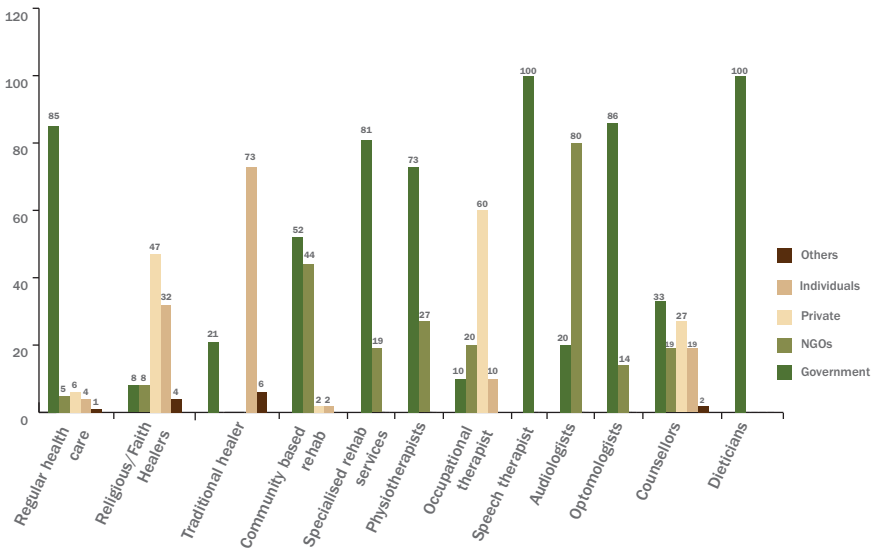
Figure 17: Knowledge of carers on availability of healthcare services



The regular health services available to and used by the majority of child respondents were offered by the government (85%). Individuals provide traditional healing for the majority

(75%) of the children who used such services. The bulk of the services of audiologist and occupational therapists are made available by NGOs and the private sector respectively.

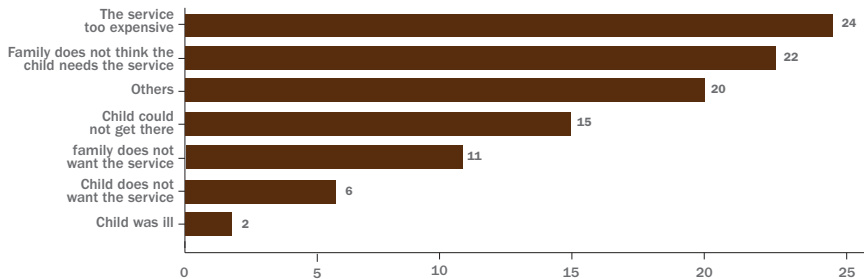
Figure 18: Health care service providers used by child respondents



However, 15% of the children said they never used regular health services; 31% did not use them although they would like to, while 6% indicated that they did not want the services that were

on offer. More reasons given for this low take-up included: too expensive (24%); did not need them (22%); too far away (15%); or the carer did not want the child to use the service (11%).

Figure 19: Reasons for non-utilisation of available health services (carer questionnaire)



A community leader in Jinja agreed that the services were beyond the financial reach of most disabled children: "There are services which can

benefit children with disabilities such as psychosocial support, education, nutritional services, surgery and many others. However, some of these services

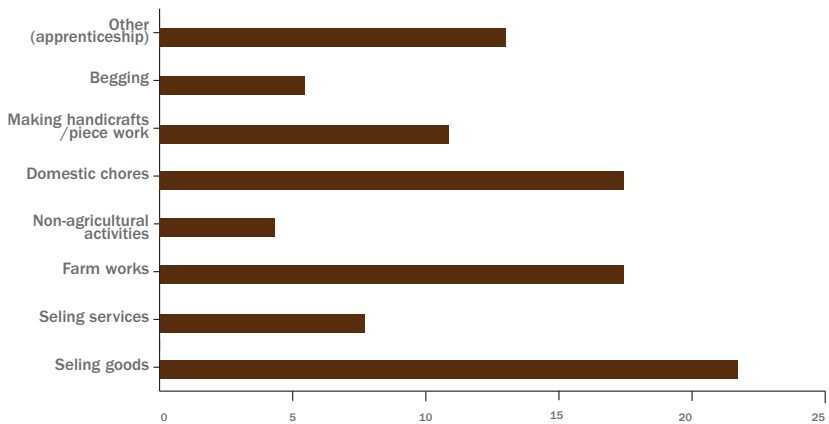
such as surgery are not accessible and all are too expensive and not affordable by parents of children with disabilities". (Key informant interview)

4.3.5 Access to work

Out of the 540 children surveyed, only 12.4% were doing paid work outside their homes. Most (22%) were engaged in selling goods; 18% were doing farm work, 18% domestic work; 11% making handicrafts; and 5.5% were begging for a living. In Uganda the minimum legal working age is 14 years, on the condition that the work is not hazardous to mental or physical

health, and does not prevent the child from attending school. None of the children engaged in formal or informal employment were under 14. Because many children with disabilities between the age of 14 and 18 years become disillusioned about the future prospects with their education, the study revealed that their parents seek alternatives in skills training. A good number of the respondent children were learning skills through informal apprenticeship placement with local artisans, where occasionally they were paid (though irregularly) for their work.

Figure 20: Nature of paid work outside the home



The majority of those children who worked for a living said they enjoyed their work, and that contributing to the family's wellbeing helped them feel a sense of responsibility and worth. Ten per cent said they were forced to work by other people, while 23% indicated they have to work to survive.

Of concern was that approximately half of the children who worked (50.6%) felt that it took them away from their school work; 52% felt their salary or wages were low and a similar number said neither their jobs nor their income were stable. The children's perception of their work is illustrated in Table 14.

Table 14: How working children feel about their work (child questionnaire)

	%	
	Yes	No
It helps me feel independent	70.5	29.5
It helps me to feel accepted	73.6	26.4
It helps me to learn skills I need for the future	72.4	27.6
It helps me to support others in my household	63.6	36.4
I am forced to work by other people	10.2	89.8
I am forced to work to survive	23.0	77.0
My working conditions are dangerous	29.5	70.5
I can spend the money I earn however I want	56.8	43.2
I would rather have more time for school than to earn money in this way	50.6	49.4
I would rather have more time with family and friends than to earn money in this way	28.2	71.8
The money I make is low	51.8	48.2
The money I make comes now and then	51.2	48.8

The majority (75.3%) of the children who worked said they walked there, although 18% reported that it was difficult to reach their workplace. Only 4% used private transport while 2.7% children used wheelchairs to get to work. Twelve per cent said that transport services were not disability friendly, and 18% feared getting attacked on their way to work, both of which could explain why a small number use public transport.

Most were happy in the workplace: 62.7% said they had friends at work; 47% felt their workplace had the right conditions to enable them do their work; and 26% were comfortable with the working conditions. Only 23% said there were other disabled people in the workplace. At least 64% of children reported that they always or sometimes had someone to help them at the workplace if they had a problem. At the same time, about 47% said that their

fellow workers always or sometimes came to them for help when they had a problem, which is a sign of mutual respect.

In spite of this generally supportive work environment, about 38% of respondents reported that other people at work sometimes hit, hurt or say nasty things to them. Employers clearly need to put in place policy measures for protecting disabled workers in the workplace and to foster a climate where diversity is appreciated. Only 41% had accessible toilets at work – another issue for employers to follow up.

Sixty-four per cent felt they had no opportunities for advancement and promotion, while 22% reported that they sometimes have. Since any form of discrimination in the workplace is against the law, measures need to be taken to mitigate this.

4.3.6 Access to financial and emotional support

When you average out all the sources of support shown in Table 15, 61.7% of child respondents felt they received no support at all, while 11.7% received emotional support, and a paltry 2.5% received financial support. The main source of emotional support was from religious organisations, followed by family, neighbours and then friends. Overall, the family was the biggest combined source of emotional, financial and any other

support for child respondents. Given the needs of disabled children, the government is expected to be doing much more especially in terms of established structures particularly, rehabilitation offices in the districts than what it is currently doing. Likewise, although NGOs and DPOs are mobilising disabled people in the country, they did not feature much among organisations offering emotional support, which many carers and children with disabilities expected from them.

Table 15: Sources of emotional and financial support

Source of support	Emotional	Financial	Other support	No support	Not answered
Family	18.5	10.7	9.8	47.4	13.5
Neighbours	18.3	0.7	8.5	59.3	13.1
Friends	15.9	1.5	14.8	55.0	12.8
Religious organisation or people	19.3	0.7	7.8	59.3	13.0
Community leaders	10.6	0.7	5.9	70.0	12.8
Politicians	8.0	0.4	5.2	73.7	12.8
Government officials or civil servants	8.0	1.9	6.5	70.0	13.7
NGOs	5.4	5.4	7.2	67.8	14.3
Other source	1.1	0.9	1.5	53.1	43.3
All support (from all sources)	11.7	2.5	7.5	61.7	16.6

The focus group discussion with parents from Nakapripit district, Karamoja, wondered why NGOs had neglected them, while their area is probably the most vulnerable in Uganda: *“Karamoja is characterised by poverty, violence, cattle rustling, a lack of health services, education services and chronic food shortage, which leaves the children of Karamoja more*

prone to disabilities. But there are no NGOs in our area to help us and our disabled children”.

Disabled children are fairly knowledgeable about where to go for help when faced with difficulty: participants in a focus group discussion in Jinja identified the police post and the local council authorities.

They preferred approaching the church rather than the community elders for counselling. To them, the community elders disregarded their issues as trivial and saw them as timewasters because of their disability: “some elders shout at us when we approach them for help...” (14-year-old pupil, focus group participant, Jinja).

It is important to note that in Uganda it is not customary to expect financial support from anyone who is not a family member. For this reason it is more sustainable to strengthen the capacity of disabled people and their families to be more innovative and join

wealth creation schemes¹⁴.

4.4 SOCIAL INTEGRATION

4.4.1 Participation in the family

Negative attitudes are the biggest barrier to social integration. The study revealed that disabled children still face non-supportive attitudes and practices at both family and wider community levels. Within the family, 32% of child respondents were excluded from gatherings and social events; 35% were verbally or physically abused; and about 21% were excluded from family time because of their disabilities.

Table 16: Perceptions of children on attitudes of their carers & others towards them

Perceptions	Always	Sometimes	Never
Child excluded from family gatherings and social events	6.1	25.7	65.7
Child excluded from religious events	5.4	13.0	79.3
Child excluded from family time because of disability	2.4	18.1	77.2
Household members say nasty or hurtful things or hit the child	1.5	33.9	62.4
Other people say nasty or hurtful things or hit the child	16.3	38.3	43.1
Carer spends more money on the child than on other children	17.0	41.3	39.3
Carer spends more time with the child than with other children	19.8	36.3	41.7
Other household members give emotional support to child	40.7	44.1	12.8
Other household members give financial support to care for the child	25.0	39.1	33.0

14 AMFIU and NUDIPU have initiated a joint project to increase the uptake of disabled people who access the services of microfinance institutions. It includes training on successful projects, saving, bookkeeping and many others. However, the best recommended model should be to encourage disabled people to join mainstream Village Savings and Loans Associations (VSLA) to learn the culture of saving and how to invest. This would also promote inclusive development.

Perceptions	Always	Sometimes	Never
Child allowed by carer to play with the other children in the community	68.7	19.6	8.9
Other children in the community like to play with the child	54.8	31.7	11.1
People in the household fight more because of the child	13.5	20.9	64.1
Household members find it difficult to communicate with child	11.9	29.8	56.7

While it was encouraging that the majority of carers disagreed with most of the negative statements about disabled children – for example, some 27% of the carers believed that disabled children cannot lead independent lives while 23% believed that children with a learning disability are not as smart as their non-disabled peers.

Table 17: Beliefs and attitudes of carers towards disabled children

Statements	Agree	Neutral	Disagree
Disability is a curse, either on the disabled child or on their parents	13.5	13.1	72.6
People can 'catch' disability from disabled children	5.9	10.4	82.8
Children with a learning disability are not as smart as other children	23.1	19.8	55.7
Children with disabilities cannot look after themselves and need to be cared for forever	26.7	26.3	45.9
Children with disabilities should not be allowed in mainstream education	20.2	12.8	65.4
Children with disabilities should not have access to any education	3.3	5.7	90.0
Having a child with a disability strains your relationships with other adults in the household	20.4	28.0	50.9
Having a child with a disability strains your relationships with other [children?] in the household	24.6	25.2	49.3
In the future, the child will be financially independent	46.9	34.8	17.2
In the future, the child will support you financially	43.5	37.0	18.5
In the future, the child will have a family of his/her own	57.4	30.4	11.3
In the future, the child will live a full life just like any non-disabled person	50.9	31.3	17.0

One key informant at a focus group discussion with community leaders in Jinja district graphically summed up the many challenges and barriers that disabled children have to contend with:

“The situation for disabled children is poor because they are helpless and their carers are not committed to their situation. They are neglected in the community because community members have negative attitudes towards them... [They] are stigmatised and their families are too... Some carers lack resources and cannot provide for the basic necessities for their children... some lack knowledge about where to get the services from... A common practice also is that carers do not participate in

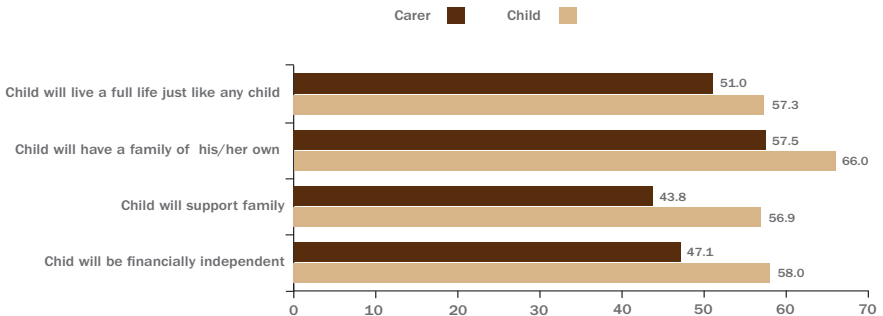
the planning meetings to tell us about their needs so that we can include them in our community and government plans”.

(Community leader from Jinja District)

In the focus group of disabled children from Ngeta Girls’ Primary School participants explained how the negative attitudes and practices of others affect them:

“We feel unhappy when we are discriminated against, both in our families and in the community. The worst is when we are called abusive names – such as ‘atwang’ (derogatory term for a blind person), ‘angwalo odole’ (lame), ‘apoa’ (mad), – which are very common in our community”.

Figure 21: Vision of the future of the Child (carers and child questionnaires)



It was also encouraging to find that a good number of carers were positive about the future. Of the disabled children in their care as exhibited in Figure 21 above, nearly half of the carers believed that in future their child would be financially independent, while 44% believed that their child would support them financially. About 6 out of 10 believed that their child would have a family of their own and 51% believed their child would live a full life like any

non-disabled person.

On the other hand, 58 percent of the child respondent believed that in future they would be financially independent; two-third of the children believed that in the future, they would have a family of their own; while more than half believed that in the future, they would support their family financially, and 58% believe that in the future, they would live a full life like any non-disabled person.

The majority of child respondents were quite positive about their future, like Joseline Mbabazi: *“Generally I feel very happy, especially about going to school since this will make me an important and independent person in the future”*.

A number of child respondents were well integrated in their families, schools and communities, as Bonny Kulaba’s story gives testimony (see Box 5). Bonny, 14, is physically disabled and leads the typical life of any child in the family and the neighbourhood.

Box 5: A day in the life of Bonny Kulaba, 14 (physically disabled)

Photo 5: Bonny Kulaba in his school uniform



My name is Bonny Kulaba. I am 14 years old. I live in Walukuba, Jinja district and I go to Walukuba Primary School. I am in grade 5. I usually wake up at 6am except on Saturdays and Sundays.

When I wake up I help sweep the compound, then I bathe, take tea, put on my shoes and uniform and go to school. At school, it is the usual routine: attending classes, taking a break at 11am, lunch at 1pm. When I get back from school at 5.30pm, I help my mother and brothers in household chores, like fetching water and cleaning utensils. I also play a bit with my brothers. I like watching TV,

especially football.

Photo 6: Bonny in class



We take supper at 7.30 or 8pm and I go to bed at 9pm and sometimes 10pm. I don’t need help while going to bed. I like eating; when I don’t, I feel very hungry in the morning. I and my three brothers share a bedroom which we have nicknamed “The Big Brother House”.

I like my brothers although we fight sometimes. But that is normal and we remain friends. I also like my uncle’s children. They are my friends. I enjoy celebrating big days like Easter and Christmas. The only situation that makes me feel bad is when I don’t have anyone to play with.

(Bonny’s additional photographs are in Appendix 3.)

4.4.2 Participation in community life

Acceptance by and respect from other community members are prerequisites for full participation in community life. Children with disabilities face double discrimination: first as children and secondly as disabled people.

Children in most Ugandan communities are not given space to participate in decision making; they are only asked to participate when their labour is required. Their chances of participation are even further diminished when they are disabled.

About 55% of child respondents were verbally or physically abused by people outside the household. Such negative attitudes remain a barrier to their full integration into their communities. A community leader in Jinja said: “*The*

community sees disabled children as cursed, non-performers in decision making, dependants and a burden to the community. They (children with disabilities) don't have any specific role to play in the community”.

Playing and having fun is one way of promoting social inclusion or integration, and 78% of child respondents revealed that they liked inviting children to play and a similar number said they go out to play with other children.

The study revealed that disabled children and their carers had a positive outlook for the future, foreseeing a future where disabled people are socially integrated and participate meaningfully in their families and communities.

5 CONCLUSIONS AND RECOMMENDATIONS

5.1 CONCLUSIONS

Disability policy development and implementation

In recent years, as a result of intensive lobbying, UBOS – the official source of data on population issues – has picked interest in disability issues, which has led to some improvement in the availability of data on disability. However, inadequate methodologies sometimes cast doubt on the integrity of the data and give cause to contest it. Yet without credible data planning and policy making is very difficult. This is an area the disability movement and relevant government departments need to pay close attention to, particularly as the country draws closer to the 2012 housing and population census.

Uganda already has very good disability policies and laws aimed at protecting the rights and interests of disabled children in particular and disabled people in general. However, they are rarely implemented due to the lack of resources available to invest in disability, rehabilitation and other pro-disability interventions. Although Uganda's main policy thrust is inclusion, most ministries – apart from social development, education and health – do not have guidelines on how to mainstream policy within their own sectoral policy frameworks. Besides, resource constraints can be huge obstacles in the implementation of policies.

Services for disabled people

Like the majority of Uganda's population, most disabled children and their families live in rural areas. Although most of these families are poor, they remain the main source of financial and emotional support for their disabled children. External interventions – mainly from the private sector, government and NGOs – tend to target very specific needs, such as corrective surgery, provision of assistive devices or sponsoring education.

Most service providers do not target families in a holistic manner, yet disability affects the entire family as much as it affects the individual. This research revealed that the government and NGOs are very detached from disabled children and do not provide the support that is expected of them. Although disability-focused organisations and DPOs are many in number, they are not making a huge impact on the lives of disabled children; their presence is barely felt by the children or their families, particularly in terms of emotional support. The same is true for the government, despite it having the structures in place to penetrate deeper into the communities. Both need to do more in this respect.

Knowledge, attitudes and practices

The study revealed that public awareness about disability issues has since the mid-1990s increased, and there is evidence of improvements in attitudes and practices among family members and communities. The majority of respondents – both carers and children – were aware of the rights of disabled children. In addition, and partly as a result of this increased awareness, attitudes and practices towards disability at family level are generally supportive, and members of the household are aware of the rights of disabled children as evidenced in high level of participation among disabled children in household work and family events. However, the study also revealed that the wider community continues to exhibit some negative attitudes and practice which work against social integration. And, a substantial number of children reported harassment, abuse and discrimination in the community and workplace – both issues that need to be addressed.

Accessibility

The majority of Ugandans are not aware of adaptation issues to make homes accessible for disabled people. Although there are a number of laws and policies that provide for accessibility, it is an area that still requires a lot of advocacy.

Education

Uganda's policy thrust on education for disabled children is for inclusive education. This has undoubtedly increased the number of disabled learners enrolled in institutions at all levels. However, disabled learners

are expected to attend mainstream classes that are often taught by teachers who know little about the condition of disabled children. There were also notable physical obstacles and barriers in the school environment, and a number of children indicated that their learning environment has not been adapted to meet their needs.

Health

While many people are aware of, and would like to use, medical rehabilitation specialists and other specialised rehabilitation experts, these are often out of reach for disabled children. Services are either too expensive or too far away, while those closer by might not be relevant to the children in the locality.

Employment

Although many of the disabled children who worked outside the home said they had friends at their workplace and enjoyed their work, there were still episodes of physical or verbal abuse from fellow workers. The study also revealed that many disabled workers are not given equal treatment or opportunities for advancement. This points either to a lack of workplace and human resource policies for protecting workers from bullying or, if such policies are in place, to their ineffectiveness.

5.2 RECOMMENDATIONS

Policy development, planning and implementation

- a) Uganda will soon be preparing for another housing and population census in 2012. This is a unique

opportunity to get more credible data on disability, and it is vital that the disability movement and the relevant government departments and agencies such as the National Council for Disability become more involved and influence the framing

of census questions. They should also lay strategies for training census enumerators to understand the dynamics of disability and learn how to ask more effective questions on disability.

Box 6: Parents' recommendations on how to improve the situation of disabled children

- *Sensitise parents, communities, policy makers and implementers about the issues of disabled children.*
- *Establish special units within existing mainstream schools where children who need special attention can receive the special classes or help they need.*
- *Train disabled children in life skills.*
- *Provide assistive devices to disabled children.*
- *Recruit and place specialised rehabilitation professions at district level.*
- *Incorporate social economic security interventions or enterprises for households of disabled children.*
- *Invest more in home-based care activities as part of CBR to enable professionals to interact with other household members.*
- *Ensure that schools and other public structures and infrastructures such as hospitals, public offices, toilets and places of worship are accessible and user-friendly.*
- *Provide community sporting and recreational facilities that are accessible and user-friendly to enable disabled children to participate and interact with their non-disabled counterparts.*

Parents' focus group, Bushenyi, Uganda

- b) Uganda has many good disability laws and policies which remain partially implemented. A thorough review must take place to ascertain the status of implementation and the related impact this would have. The review should also give recommendations on sanctions and actions for non-implementation. Any outcomes should inform the advocacy agenda for the disability fraternity. It is high time for them to step up their advocacy and lobbying for the implementation of the many policies and laws that have been
- and remain shelved.
- c) The National Council for Disability, with support from the ministry of gender, labour and social development, should develop disability mainstreaming for all government ministries and agencies as well as non-state actors to ensure that disability is included in all sectoral plans and policies.
- d) The National Council for Disability should undertake a study on the impact of disability-focused NGOs and DPOs to assess their impact on the planning and delivery of

disability services in the country, and recommend improvements.

- e) The National Council for Disability should develop quality standards for effective disability programming, to guide both state and non-state actors on how to plan and deliver effective interventions.

Rehabilitation services

- a) Government delivery of services to disabled people, particularly in the area of social rehabilitation, is still very far from satisfactory, as resource allocation to the sector is incredibly low. We recommend that performance indicators for disability service delivery are included in local government performance assessments. This will urge local governments and central government departments to pay more attention to the issue of disability.
- b) Despite the fact that disability affects entire families, not just the individual, most interventions are focused on helping the disabled child. It is therefore important to encourage actors to take a more holistic approach to addressing disability from a wider angle. We recommend that more actors adopt the CBR strategy as an approach to planning and delivering their interventions.
- c) We recommend that the government establishes a disability trust fund to support disabled people – and children in particular – to access funds for their specialised rehabilitation needs including: purchasing expensive assistive

devices; undergoing complicated rehabilitation procedures such as corrective surgery; and purchasing learning equipment and software. The trust fund should be established with seed money from the government, and donors should be encouraged to support it. But the government can also be lobbied to charge a small tax on all income tax payers that goes directly into the fund.

Accessibility

- a) UNAPD's efforts to develop accessibility standards are commendable, but they now need to be adopted by government and rolled out to all local governments and sectors. Simple messages on how to make adaptations at home need to be developed and disseminated on posters, TV and radio. Accessibility standards should also be strictly adhered to in all public areas in cities and urban centres and in all public buildings including schools, places of worship, recreational facilities, etc.

Rights promotion

- a) Whereas there have been commendable efforts to promote the rights of children in general in Uganda, the rights of disabled children have been obscured within the larger realm of child rights. We recommend that organisations working in this area, such as the Uganda Child Rights NGO Network, take on the agenda of developing campaigns for promoting the rights of children with disabilities.

- b)** We also recommend that the government allocates more resources to the responsible agencies – such as the ministry of gender, labour and social development and the National Council for Disability – to ensure the implementation of national and international laws and policies such as the UNCRPD, the relevant sections of the constitution, the Persons with Disabilities Act 2006, the national disability policy and others. Their implementation would naturally increase awareness among the public and translate into direct benefits in the form of services to disabled people.

- c)** The government should consult and involve DPOs, other disability-focused organisations, and politicians representing disabled people at various levels and technical personnel working the public service and CSOs to ensure impact.

Employment

- a)** Disability organisations led by NUDIPU and NUWODU should develop guidelines for developing a workplace disability policy for all companies, organisations and institutions that employ people.

- b)** The corporate sector has not been sufficiently informed of the tax benefits of employing disabled people as stipulated in the Persons with Disabilities Act, 2006. NUDIPU and the National Council for Disability should mount a campaign to mobilise the corporate sector to employ skilled disabled people.

Education

- a)** The ministry of education and sports needs to undertake a thorough review of inclusive education to identify any gaps and barriers in the system and develop appropriate measures to fill the gaps.
- b)** The government, with support from Save the Children, has been piloting alternative basic education for Karamoja (ABEK), a more flexible form of education that responds to the needs of pastoral communities. We recommend this is rolled out to all areas of Karamoja.
- c)** There must be increased involvement of teachers and parents in the planning of education for disabled children to ensure that children's needs and rights are met. The generalised inclusive policy framework could miss these, so teachers and parents can be an important resource in this regard.

Box 7: Disabled children's recommendations on how to improve education

- *Parents should continue to support the education of disabled children and advocate for their rights.*
- *People in the community should be sensitised to know the rights of disabled children and to put a stop to discrimination and the use of abusive language against them.*
- *Parents should avoid encouraging their disabled children, especially girls, into early marriage as an escape route from continuing to support their education.*
- *The government should provide appropriate instructional materials to schools to facilitate education for disabled children.*
- *More special needs teachers should be trained, posted to schools and motivated to stay and provide dedicated service to their schools.*
- *Community leaders should establish projects to improve the wellbeing of disabled children and their families.*
- *Disabled children whose parents are willing to keep them at school should be encouraged not to drop out.*
- *Secondary schools for disabled children should be established and maintained so that more disabled children are encouraged to proceed to secondary education.*
- *Sanitary facilities, such as adapted toilets and ramps, should be available in all learning institutions.*

Children's focus group, Ngeta Girls Primary School, Lira.

Health

- a) The government should recruit and place more medical rehabilitation specialists at district-level health facilities to enable disabled people to access their services at a lower cost. Physiotherapists, occupational therapists, counsellors, ophthalmologists, speech therapists, psychiatric clinical officers and audiologists should work together as a team and be within easy access to those who need to use their services.

The ACPF hopes that stakeholders, particularly the government of Uganda, would take note of these recommendations and translate them into action to improve the life situation of children with disabilities and ensure their equal participation in development endeavours at all levels and spheres of engagement.

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Appendix 1: Tables of key findings

Table 18: Selected development indicators for Uganda

Total population 2010 (UBOS projection)	31.8 million
Under 15 years (%) (2004)	50.4
Urban population (%) (2005)	13
Population growth (2008)	3.3
Infant mortality rate (2009)	65/1,000
Under five mortality (2005)	136/1,000
Life expectancy (2008)	54.1
Population not using an improved water source (%) (2006)	36
Adult HIV prevalence (%) (2007)	5.4
Deaths from malaria (% of all deaths)	28.5
Public expenditure on health (% of total government expenditure)	10
Primary school enrolment (% net)	94.6
Combined gross enrolment ratio in education (%) (2009)	62.3
Education index (2007)	0.698
Adult illiteracy rate (% aged 15+) (1999-2007)	26.4
Female combined gross enrolment ratio (%) (2007)	61.6
Male combined gross enrolment ratio (%) (2007)	62.9
Public current expenditure on primary education (US \$ per pupil)	110
Public expenditure on education (% of total govt expenditure)	18.3
GDP (US \$ billions) (2008)	14.5
Gross national income per capita (Atlas method) (US \$) (2008)	420
External debt stocks (% of GNI) (2007)	14
Human poverty index rank (2007)	91
Population living on less than US \$1.25 a day (%) (2000-2007)	51.5
Population living below the national poverty line (%) (2000-2006)	37.7
Unemployment rate (%) 2005/2006	1.9

Compiled from: UNHS 2005/06, UNDP (International Human Development Indicators) Accessed: 1/13/2011, 4:57 PM from: <http://hdr.undp.org>; MFPED MDG Report, 2010, and CIA World Fact Book (www.theodora.com/.../uganda/uganda_economy.html), UBOS, 2010 Statistical Abstracts

Table 19: Stakeholders involved in disability work in Uganda

Theme	Government ministries, institutions and departments	Non-state actors
Health	<ul style="list-style-type: none"> Ministry of health (disability rehabilitation section and mental health unit). Mulago and Butabika national referral hospitals. Regional referral hospitals. District hospitals and health centres. 	AVSI; USDC; CURE Children's Hospital; Lions Aid Norway; GLRA; Lions Clubs and Rotary Clubs; Basic Needs UK; Leonard Cheshire Homes; Foundation of People with Disabilities; ESAU; MHU; UNAPD (UBIP project).
Assistive devices (rehabilitation)	<ul style="list-style-type: none"> Mulago orthopaedic workshops. Regional hospital workshops in: Arua, Gulu, Hoima, Kabale, Kabarole, Masaka, Mbale and Mbarara. 	AVSI, USDC, Mobility Appliances by Disabled Women Entrepreneurs (MADE).
Education	<ul style="list-style-type: none"> Ministry of education and sport (department of special needs education and career guidance). UNISE at Nsamizi Institute. 92 SNE resource centres at mainstream schools. Ministry of gender, labour and social development (functional adult literacy programme). 	USDC, COMBRA, CBM, UNAD, UNAB and NADBU, Blind But Able Organisation.
Social service	<ul style="list-style-type: none"> Ministry of gender, labour and social development (sponsors the CBR programme). 	USDC, ADD, OURS
Vocational training	<ul style="list-style-type: none"> Ministry of gender, labour and social development (vocational training centres). 	USDC
Entrepreneurial skills training	<ul style="list-style-type: none"> Ministry of gender, labour and social development. 	ADD, USDC, ILO, Irish Embassy, NUDIPI, NUWODU
Capacity building for CBR	<ul style="list-style-type: none"> Nsamizi Institute. Kyambogo University (UNISE). Makerere University. 	COMBRA
Capacity building for DPOs	<ul style="list-style-type: none"> Ministry of gender, labour and social development. 	ADD, NUDIPI

Theme	Government ministries, institutions and departments	Non-state actors
Human rights and gender equality	<ul style="list-style-type: none"> Uganda Human Rights Commission. 	FOWODE, ACFODE, UWONET, FHRI, HURINET, NUWODU, DWNRO.
Post-conflict interventions	<ul style="list-style-type: none"> Office of the Prime Minister, Northern Uganda Social Action Fund. Ministry of health. 	AVSI, World Vision, NUDIPI, DPOD.
Poverty eradication programmes	<ul style="list-style-type: none"> Micro-finance access to rural finance services for the poor (Bonabagagawale programme).. Ministry of agriculture and animal industry (plan for modernisation of agriculture and national agricultural advisory services). 	ILO, ADD, NUDIPI, NAD, Association of Microfinance Institutions in Uganda (AMFIU).

Table 20: Age and gender profile of child respondents

Age	Gender of child respondent				Total	%
	Male	%	Female	%		
9	31	5.7	25	4.6	56	10.4
10	25	4.6	32	5.9	57	10.6
11	24	4.4	15	2.8	39	7.2
12	35	6.5	28	5.2	63	11.7
13	32	5.9	28	5.2	60	11.1
14	34	6.3	33	6.1	67	12.4
15	32	5.9	31	5.7	63	11.7
16	33	6.1	37	6.9	70	13.0
17	32	5.9	33	6.1	65	12.0
	278	51.5	262	48.5	540	100.0

Table 21: Child respondents' relationship with their primary carer – urban and rural settings

Relationship with child		Gender of child respondent		
		Male %	Female %	Total %
Rural	Biological mother	2.0	29.1	31.1
	Biological father	17.6	2.6	20.2
	Brother	0.9	0.9	1.9
	Sister	0.0	0.9	0.9
	Grandmother	0.4	4.3	4.6
	Grandfather	2.2	0.0	2.2
	Aunt	0.2	0.9	1.1
	Uncle	1.1	0.2	1.3
	Other relatives	0.6	2.0	2.6
	Non-relative	0.6	1.9	2.4
	Not answered	0.4	1.1	1.5
	Total	25.9	43.9	69.8
Urban	Biological mother	0.9	9.3	10.2
	Biological father	5.7	1.3	7.0
	Brother	0.2	0.2	0.4
	Sister	0.2	0.2	0.4
	Grandmother	0.0	0.9	0.9
	Grandfather	0.4	0.0	0.4
	Aunt	0.0	0.9	0.9
	Uncle	0.9	0.0	0.9
	Other relatives	0.0	0.7	0.7
	Non-relative	3.0	4.1	7.0
	Not answered	0.7	0.6	1.3
Total	11.9	18.1	30.2	

Table 22: Child's position in the family

	Gender of respondent					
	Male	%	Female	%	Total	%
Rural						
Son/daughter of head/spouse	108	20	182	33.70	290	53.7
Grandchild of head/spouse	19	3.5	21	3.89	40	7.4
Brother/sister of head/spouse	2	0.4	3	0.56	5	0.9

	Gender of respondent				Total	%
	Male	%	Female	%		
Rural						
Other relative	6	1.1	5	0.93	11	2.0
Not related	2	0.4	9	1.67	11	2.0
Not applicable	2	0.4	12	2.22	14	2.6
Not answered	1	0.2	5	0.93	6	1.1
Total	140	25.9	237	43.89	377	69.8
Urban		0.0		0.00		0.0
Son/daughter of head/spouse	37	6.9	57	10.56	94	17.4
Grandchild of head/spouse	2	0.4	8	1.48	10	1.9
Brother/sister of head/spouse	1	0.2	3	0.56	4	0.7
Other relative	2	0.4	3	0.56	5	0.9
Not related	1	0.2	0	0.00	1	0.2
Not applicable	21	3.9	25	4.63	46	8.5
Not answered	1	0.2	2	0.37	3	0.6
Total	65	12.0	98	18.15	163	30.2

Table 23: Attitudes or practices that promote or limit the child's social integration – the full list of responses

	Always	Sometimes	Never	Not answered
Excluded from family events because of disability	6.1	25.7	65.7	2.4
Excluded from religious events because of disability	5.4	13.0	79.3	2.4
[Carer?] misses events because they are caring for the child	4.4	22.0	71.3	2.2
Child excluded from family time because of child's disability	2.4	18.1	77.2	2.2
Household members hurt or hit child	1.5	33.9	62.4	2.2
Outsiders hurt or hit child	16.3	38.3	43.1	2.2
Carer has to spend more money on the child because of their disability	17.0	41.3	39.3	2.4
Carer spends more time with child [than with other children in the household?]	19.8	36.3	41.7	2.2
[Child?] receives emotional support from other household members	40.7	44.1	12.8	2.4

	Always	Sometimes	Never	Not answered
Child receives financial support from household members	25.0	39.1	33.0	3.0
Child is allowed to play with the other children in the community	68.7	19.6	8.9	2.8
Other children in the community like to play with the child	54.8	31.7	11.1	2.4
Household members fight more because of child	13.5	20.9	64.1	1.5
It is difficult to communicate with child	11.9	29.8	56.7	1.7

Table 24: Dream careers for children with disabilities – the full list of responses

	Male %	Female %	Total %
I don't think I will ever have a job	6.5	5.9	12.4
Nurse	1.5	10.6	12.0
Teacher	4.4	7.4	11.9
Doctor	5.9	3.1	9.1
Farmer	3.1	2.2	5.4
Civil servant	2.8	2.6	5.4
Engineer	3.5	1.1	4.6
Driver	3.5	0.2	3.7
Trader/businessman/woman	1.9	1.9	3.7
Lawyer	1.3	2.0	3.3
Tailor	0.7	2.6	3.3
Accountant	1.9	0.6	2.4
Domestic worker	1.1	0.6	1.7
Mechanic	1.3	0.4	1.7
Taxi driver	1.5	0.2	1.7
Artist	0.6	0.9	1.5
Policeman/woman	1.1	0.4	1.5
Politician	1.3	0.2	1.5
Pilot	0.7	0.6	1.3
Painter/decorator	0.2	0.9	1.1
Fulltime parent/housewife	0.2	0.7	0.9
Priest	0.6	0.4	0.9
Computer operator	0.4	0.4	0.7

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	Male %	Female %	Total %
Construction worker	0.6	0.2	0.7
Sportsman/woman	0.6	0.2	0.7
University student	0.6	0.2	0.7
Mason	0.6	0.0	0.6
Actor/actress	0.2	0.4	0.6
Carpenter	0.2	0.2	0.4
Labourer	0.0	0.4	0.4
President/leader of country	0.4	0.0	0.4
Scientist	0.2	0.0	0.2
Housewife	0.2	0.0	0.2
Others	12.6	7.3	19.4
Not answered	2.2	1.3	3.5

Appendix 2: Terminology

Accessibility

A general term used to describe the degree to which a product, device, service or environment that is accessible by as many people as possible. Accessibility is often used to focus on people with disabilities and their right of access to services and facilities. Accessibility is strongly related to universal design when the approach involves 'direct access'. It is about making things accessible to all people (whether they have a disability or not).

Assistive devices

These are tools that are designed, fabricated or adopted to assist a disabled person in performing a particular task – for example, callipers, wheelchair, white cane, hearing aid.

Community-based rehabilitation

This is a holistic approach to rehabilitation within general community development for rehabilitation that includes equalisation of opportunities and social inclusion for all disabled children and adults.

Disability

In accordance with the Persons with Disabilities Act, 2006, 'disability' means a substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environment barriers resulting in limited participation. This is the context and meaning we use in this study.

Disability or rehabilitation specialists

In Uganda this term refers to trained professionals whose specialised knowledge is needed to assess, rehabilitate or provide specialised care for disabled people. They include: speech therapists; audiologists; occupational therapists; physiotherapists; ophthalmologists; psychiatrists; psychiatric clinical officers and nurses; orthopaedic surgeons; orthopaedic officers; technicians and technologists; neurosurgeons; special needs teachers; community-based rehabilitation officers; social workers; counsellors, etc.

Disabled person/person with disabilities:

A person who has a physical, intellectual, sensory or mental impairment which substantially limits one or more of their major life activities.

Discrimination

This is the act of treating people in a different (usually bad) manner on grounds of the group or category to which they belong (eg class, race, disability, gender or other) rather than on their merits as individuals.

Family

In most of Uganda's ethnic groups, the term is used to describe the extended family which includes not only biological or adopted parents, brothers and sisters, but also immediate relatives such as grandparents and any other individuals that depend on the family or household head.

Inclusion

Used in the context of education, this term expresses commitment to educating each child, to the maximum extent appropriate, in the mainstream school and classroom that he or she would normally attend. It involves bringing the support services to the child (rather than moving the child to the services) and requires only that the child will benefit from being in the class (rather than having to keep up with the other students). Proponents of inclusion generally favour newer forms of education service delivery.

Impairment

This refers to any loss or abnormality of psychological, physical, neurological or anatomic function or structure.

Mainstreaming

Mainstreaming a [disability] perspective is the process of assessing the implications for [disabled persons] of any planned action, including legislation, policies and programmes, in all areas and at all levels. It is a strategy for making [disabled persons'] concerns and experiences an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes in all political, economic and societal spheres so that [people with disabilities] benefit equally and inequality is not perpetuated. The ultimate goal is to achieve [disability] equality". *From: UN ECOSOC (1997) quoted in Vera Hendriks, 2009:16*

Participation

This is the process of taking part in different spheres of societal life: political, economic, social, cultural and others.

Social integration

This is a term that is increasingly being dropped from use in preference for mainstreaming and inclusion. Looked at positively, the concept of social integration, has an inclusionary goal, implying equal opportunities and rights for all human beings. Ultimately, becoming more integrated implies improving life chances. However, increasing integration also has negative connotations, conjuring up the image of an unwanted imposition of uniformity and this is why it is no longer in much use.

Appendix 3: 'A day in the life' stories

Story 1: A day in the life of Ayikoru Beatrice, 17 (non-disabled)

My name is Ayikoru Beatrice. I am 17 years old and I go to Niva Primary School near my home in Arua Hill. I am in Primary 7. I am a day pupil so I stay at home with my parents and help with the household chores like any other girl of my age when I am not at school.

My typical day starts at 5.30 am when I wake up and ends at about 11 pm when I go to bed.

When I wake up at 5.30 am I start preparing some breakfast for the family as well as helping my mother get my younger brothers and sisters washed and dressed for school. After they have left for school at about 7am I sweep the compound and clean the house. I take my breakfast at about 7.30 am and then I leave for school. I use a *boda boda* (motorcycle taxi) to go to school. At 8am, classes begin, with break time at 10.30 when I usually chat with my friends or consult on some difficult class work. I like talking to my friends about science subjects which are really very hard for me. I have three friends who I normally hang around with.

At 11am, it's back to class again until 1.30, when it is time for my stream to have lunch. Then it's back to class from 2 to 4.30 when I go back home. I walk home and like it because I chat with my friends on the way.

Once at home at about 5.30 I help with washing the plates, cooking pans and dishes used at lunch time by the family and then go with my younger sisters to fetch water from the nearby borehole. There is normally a long line as many people are fetching water at this time. When it is difficult, we go to the unprotected spring which is very far away.

I help my mother prepare supper at about 6pm until 8pm. Between 8pm and 10.30pm, I do my homework or revise my books. This is sometimes not easy as the other members of the family are talking and chatting and making noise. I sleep with my two younger sisters in the same room. At 10.30 I take a bath and go to bed at about 11.

Photo 7: Ayikoru Beatrice sweeping the compound



Photo 8: Ayikoru washing dishes



Photo 9: Ayikoru Beatrice learning knitting at home



Photo 10: Ayikoru Beatrice with friends and sisters playing after lunch.



Story 2: A day in the life of Rukia Onduru, 17

*(visually impaired)
additional photographs
from Rukia's story in
Box 1*

Photo 11: Rukia with her brother



Photo 12: Rukia and family members in front of their family home



Story 3: A day in the life of Bonny Kulaba, 14

*(physically disabled):
additional photographs
and information from
Bonny's story in Box 5*

Bonny said: I was with my brother while taking the photographs both at home and at school. I enjoyed so much taking the photographs.

Photo 15: Bonny's parents



Photo 16: Bonny (centre) with his friends at school



Story 4: A day in the life of Ibra Nkutu, 11 (non-disabled)

My name is Ibra Nkutu. I live with my parents in Bugembe near Jinja town. I go to Bugembe Primary School. I am 11 years old and in primary 4.

My normal day starts at 7 am, when I wake up and wash myself, take tea, dress and leave for school at 8 am. My mother helps me prepare for school. What makes it easy for me is doing something which I have experience in. On the other hand what makes it difficult is when I do difficult work. I feel good and proud of myself because of the situation I am in.

I took some photos at home, some at school and some at my brother's place. It was hard for me to take photos of enemies. When taking photos I was always with my friend because he loves me so much and I felt good.

I always go to bed at 9 pm and my mother helps me get ready. The last thing I do before going to bed is helping to feed my sisters and brothers and putting them to bed.

Yesterday was different from other days because I never took breakfast.

I feel good when I'm playing football and I feel bad when I'm not allowed to play football. I like playing football with my friends at school.

Photo 13: Ibra with his brother and sister



Photo 14: Two of Ibra's best friends



Story 5: A day in the life of Joseline Mbabazi, 13 (physically disabled): additional photographs from Joseline's story in Box 3

Photo 17: Joseline's Bible

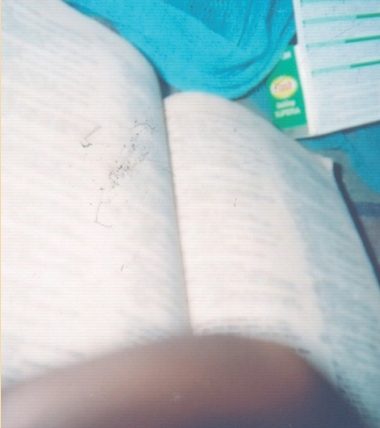


Photo 19: Joseline's sister Catherine



Photo 18: An avocado tree in the yard



Photo 20: Joseline's family home



Story 6: A day in the life of Kiiza Marion (non-disabled) – 12 years

My name is Kiiza Marion I am a Munyoro by tribe. I go to school. I wake up at 5:30am. I first communicate to God through prayers. I feel very nice because of my health.

One day I was on my way to school when a car knocked me down. I cried so much. It was very difficult. I was with my friend because I love her so much. I felt so bad. It was a painful day.

I go to sleep at 10pm. My mother helps me get ready. I wish my parents goodnight because I love them. I sleep on a bed in my father's house.

Photo 22: Family house



Photo 21: Kiiza Marion's sisters



My birthday party makes me feel good. One other thing that makes me sad is when I remember my dead uncle. He loved me so much.



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