

RESEARCH STUDY ON CHILDREN WITH DISABILITIES LIVING IN UGANDA



SITUATIONAL ANALYSIS ON THE RIGHTS OF CHILDREN WITH DISABILITIES IN UGANDA



THE REPUBLIC OF UGANDA



Nadège Riche, LEAD RESEARCHER
Email: richenadege@gmail.com; Telephone: +256 (0) 790 452 133

James Anyimuzala, RESEARCHER
Email: Jamesani09@gmail.com; Telephone: +256 (0) 793 632 288

Designed by: Mark Turgesen
Email: markturgesen@gmail.com

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Abbreviations and Acronyms

ABEK	Alternative Basic Education for Karamoja	KTU	Ka Tutandike Uganda
ACPF	African Child Policy Forum	LEV	National Association for People with Learning Disabilities in Denmark
AJWS	American Jewish Worldwide Services	MHU	Mental Health Uganda
ANPPCAN	African Network for the Prevention and Protection Against Child Abuse and Neglect	MIS	Management Information System
ALC	Advocacy Learning Centre	MoGLSD	Ministry of Gender, Labour and Social Development
AVSI	Association of Volunteers in International Service	MoES	Ministry of Education and Sports
CBR	Community-Based Rehabilitation	MoFPED	Ministry of Finance, Planning and Economic Development
CIDA	Canadian International Development Agency	MoH	Ministry of Health
CP	Cerebral Palsy	MP	Member of Parliament
CoRSU	Childrens Surgical Rehabilitation Hospital (Formerly called Comprehensive Rehabilitation Services in Uganda)	NAD	National Association of the Deaf
CRC	Convention on the Rights of the Child	NCC	National Council for Children
CRPD	Convention on the Rights of Persons with Disabilities	NCD	National Council for Disability
CSO	Civil Society Organisation	NDP	National Development Plan
CCT	Coordinating Centre Tutor	NHP II	Second National Health Policy
CwDs	Children with disabilities	NGO	Non-Governmental Organisation
DANIDA	Danish International Development Agency	NORAD	Norwegian Agency for Development Cooperation
DES	Directorate of Education Standard	NSDS	Report of the National Service Delivery Survey
DFID	Department for International Development of the United-Kingdom	NUDIPU	National Union of Disabled Persons of Uganda
Disability SitAn	Situational Analysis on the Rights of Children with Disabilities in Uganda	NUWODU	National Union of Women with Disabilities of Uganda
DPO	Civil Society Organisation of Persons with Disabilities	OVC	Orphans and Vulnerable Children
DPOD	Disabled People Organisation Denmark (Formerly called the Danish Umbrella Organisations of Disabled People (DSI) and within Denmark, DPOD is known as DH that stands for Danske Handicaporganisationer)	PSG	Parent Support Group
DSOD	Disabled Sport Organisations of Denmark	PwDs	Persons with Disabilities
EARS	Education Assessment and Resource Services	SL	Sign Language
ECD	Early Childhood Development	SNE	Special Needs Education
ECDC	Early Childhood Development Centres	SN&IE	Special Needs and Inclusive Education
EFA	Education For All Movement	UBOS	Uganda Bureau of Statistics
EOC	Equal Opportunities Commission	UCSD	University of California San Diego
ESC	Education Service Commission	UDHS	Uganda Demographic and Health Surveys
FDDB	Association of Danish Deaf-Blind People	UHRC	Ugandan Human Rights Commission
FENU	Federation of Education Non-Governmental Organisations in Uganda	UJCC	Uganda Joint Christian Council
GDPU	Gulu Disabled People Union	UN	United Nations
GPcwd	Global Partnership on children with disabilities	UNATTU	Uganda National Teachers Trade Union
GUWODU	Gulu Women with Disabilities Union	UNESCO	United Nations Educational, Scientific and Cultural Organisation
ICF	International Classification of Functioning, Disability and Health	UNFPA	United Nations Population Fund
IDAY	International Day of African Childhood and its Youth	UNHS	Ugandan National Household Surveys
IDIWA	Integrated Disabled Women Activities	UNICEF	United Nations Children's Fund
IE	Inclusive Education	UNISE	Uganda National Institute of Special Education
IEC	Information, Education and Communication	UNMHCP	Uganda National Minimum Health Care Package
IF	International Federation for Spina Bifida and Hydrocephalus	UPACLED	Uganda Parents of Children with Learning Disabilities (now called the Uganda Parents of Persons with Intellectual Disabilities (UPPID))
IGA	Income Generating Activity	UPFC	Uganda Parliamentary Forum for Children
iNGO	International Non-Governmental Organisation	UPPID	Uganda Parents of Persons with Intellectual Disabilities (formerly called Uganda Parents of Children with Learning Disabilities (UPACLED))
IT	Information Technology	USAID	United States Agency for International Development
JOAC	Jersey Overseas Aid Commission	USDC	Uganda Society for Disabled Children
KII	Key Informant Interviews	UWOPA	Uganda Women's Parliamentary Association
LC	Local Councillor	WFP	World Food Programme
KCH	Katalemwa Leonard Cheshire Home for Rehabilitation Services	WHO	World Health Organisation
		W3c	World Wide Web Consortium

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On behalf of the Government of Uganda, I wish to express my most sincere gratitude to UNICEF Uganda for the financial and technical support that was rendered during this process.

Similarly, I wish to thank each and every local and international organization that participated in this research by supporting data collection, actively participating in our validation meetings, and ultimately for continuing to prioritize the rights of children in Uganda.

Finally, a special thank you goes to the Department of Disability and Elderly in the Ministry of Gender, Labour and Social Development, Nadege Riche and James Aniyamuzaala Rwampigi for the effective leadership displayed during this study.



Pius Bigirimana

PERMANENT SECRETARY


Foreword

Children with disabilities are first and foremost children, with hopes and dreams just as any other children. The reality, however, is that many children with disabilities remain marginalized and excluded in our society. As a direct result, their basic needs and rights as children are not always fulfilled.

By removing the barriers that children with disabilities face on a daily basis, we can enable them to realize their full potential. When given the opportunity to learn and grow, children with disabilities can become vital and valuable members of their community where their talents and abilities are appreciated.

The Research Study on Children with Disabilities Living in Uganda has led to a deeper understanding of the situation of children with disabilities in Uganda and the bottlenecks that are preventing the realization of their rights. The report highlights how local and national Government institutions and other key stakeholders must collaborate and coordinate extensively in order to holistically address the needs of children with disabilities.

I commend Government and our trusted development partners for the extraordinary efforts to ensure that children with disabilities become more visible in our society, gain universal access to basic services, and ultimately that their rights are realized. Let us join hands in eradicating the various forms of stigma and discrimination towards children with disabilities. By ensuring an enabling environment and removing social and cultural barriers, children with disabilities will continue being valuable members of our society.



Mary Karoro Okurut

MINISTER FOR GENDER, LABOUR AND SOCIAL DEVELOPMENT

Foreword

Children with Disabilities remain subject to various forms of discrimination and marginalization due to negative attitudes, superstition, neglect, social norms and practices, and lack of awareness of their own rights. When children with disabilities are denied their basic rights, such as access to health, education, support and rehabilitation, their ability to develop to their full potential is severely compromised. Removing these barriers to participation is necessary in order to empower children with disabilities.

In the fulfillment of child rights as enshrined in the Convention on the Rights of the Child ratified by Uganda in 1990, the Ministry of Gender, Labour and Social Development and UNICEF Uganda are committed to ensuring protection for the most vulnerable children including children with disabilities. In this respect, this Situation Analysis aims to provide an exhaustive account of the situation of children with disabilities in Uganda. Through this rigorous national assessment of the status and trends of the situation of children with disabilities, this analysis is expected to go a long way in the effective promotion of inclusive planning and the design of programmes appropriate for children with disabilities in order to promote their rights and improve their lives.

I therefore call upon all stakeholders to review and internalize the analysis presented in this report with a view to utilize these research findings to articulate policy and programmatic interventions to address existing shortfalls and disparities to accelerate progress towards national development goals and the fulfilment of the convention on the rights of the child.



Sulaiman Kyebakoze Madada (MP)

MINISTER OF STATE FOR ELDERLY AND DISABILITY AFFAIRS

Executive Summary

1. PURPOSE OF THE STUDY

The Government of Uganda is committed to ensuring special protection for the most disadvantaged children, including children with disabilities (CwDs), upholding their human rights in line with the UN Convention on the Rights of the Child (CRC) and Convention on the Rights of Persons with Disabilities (CRPD) and ensuring their unconditional access to all services. In this context, in the partnership with UNICEF Uganda, the Government has identified the need to increase the general knowledge and awareness about the state of CwDs' human rights in Uganda. This study aims to analyse and consolidate available information rather than to create new knowledge. This will ultimately feed into UNICEF's and Government of Uganda's programmatic response to the issues faced by CwDs from 2015 onwards.

2. METHODOLOGY

For the purpose of this study, the target group is composed of persons below 18 living in Uganda who have physical, sensory, intellectual or psychosocial disabilities resulting from interactions with environmental and attitudinal barriers. A mix of quantitative and qualitative research methods were used to analyse the situation. The desk research, consisting of the gathering of statistics, analysis of the role of Government Institutions, laws and policies as well as the mapping of programmes, provided a theoretical understanding of the situation. Key informant interviews and on-site visits facilitated the collection of factual information.

3. FINDINGS

CwDs are one of the most marginalised and disadvantaged groups in society. Understanding their current situation by assessing the extent to which their rights are realised in Uganda, reviewing available statistical information, analysing the regulatory and institutional frameworks and mapping programmes was of paramount importance. It revealed a gap in addressing or meeting the needs of CwDs by duty-bearers and key stakeholders.

TABLE 1: MEASURING DISABILITY PREVALENCE**Measuring Disability Prevalence**

Measuring disability prevalence is problematic for a number of reasons: i) there are various definitions of disability, with an ongoing shift from a medical to a social and rights-based model of disability, ii) differing individual and cultural perceptions of what impairments and disabilities imply, and iii) design of inadequate data collection tools (wording and number of questions relating to disability varies in different survey and questionnaires).

3.1. Statistics Relating to Children with Disabilities Living in Uganda

Data relating to CwDs is scarce and to some extent unreliable. Significant gaps in information are the lack of disaggregation of statistics by gender and types of disabilities and the inexistence of national and accurate data in other areas than education. Based on estimations, the child disability prevalence is about 13%,¹ i.e. approximately 2.5 million children live with some form of disability in Uganda. The disability prevalence varies across the country: the Northern region appears to have the highest rate while the Eastern and Central regions have the lowest rates.

The statistical information available in Uganda indicates extremely low enrolment and completion of primary and secondary schools by CwDs. In fact, only about 9% of CwDs at school going age attend primary school, compared with a National average of 92%,² and only 6% of them continue studying in secondary schools (National average: 25%).

TABLE 2: SPOTLIGHT - GULU PRIMARY SCHOOL**Spotlight: Gulu Primary School**

Gulu Primary School is a mainstream school with a unit for blind and visually impaired children. Pupils with disabilities and children without disabilities attend the class together. The CwDs are active participants in all courses and non-disabled children are encouraged to assist their disabled peers when necessary. Pupils with disabilities also have specific courses tailored for them, for example how to read and take notes in Braille (a tactile writing system used for the blind and visually impaired).

3.2. Laws and Policies Relating to Children with Disabilities Living in Uganda

The analysis of the regulatory framework shows that Uganda has broadly domesticated the rights of CwDs enshrined in both the CRC and CRPD. Some provisions have been included in the 1995 Constitution and in most of the laws and policies established to promote and protect the rights of persons with disabilities (PwDs) or of children. However, the laws and policies are not fully implemented because of limited budget resource allocation and there is limited attention paid to the specific needs and rights of children with disabilities. Additionally,

1. Uganda Bureau of Statistics (UBOS), Ugandan Population and Housing Census, Fountain Publishers, Uganda, 2005.

2. Source: MoES: Uganda Education Statistical Abstract 2009, 2010 and a.

A 13 year old visually impaired boy attending Gulu Primary School: He started school in 2007 when he was six and he likes it because he can now take care of himself. He finds it easy to get along with his classmates and his best friend is a sighted pupil. His favourite subject is mathematics because it is easy to learn. He wants to become a teacher or a lawyer.

when CwDs' rights are acknowledged, some of the provisions to realise them are not aligned to the CRC and CRPD requirements. For example, recent or about to be adopted Ugandan laws and policies identify inclusive education as a possible way forward (CRPD Article 24), but government policies continue to actively promote special needs education and the establishment of special schools. To conclude, the rights of CwDs are recognised by the Ugandan regulatory framework, but the measures to realise them are partly contradictory with international conventions, if specified at all.

3.3. Programmes and Active Stakeholders Working in the Disability Field in Uganda

Various stakeholders are active in the disability field in Uganda. Several UN agencies, such as the Office of the High Commissioner for Human Rights, the United Nations Population Fund, and the World Health Organisation, have developed programmes targeting persons and children with disabilities. Approximately 10 donor organisations, such as national development agencies and foundations, fund disability programmes. International and Ugandan NGOs also run several programmes targeting CwDs living in Uganda. There is a strong

Disability Movement in Uganda and the national DPOs, such as the National Union of Disabled Persons of Uganda (NUDIPU) and the National Union of Women with Disabilities of Uganda (NUWODU), are relatively well structured and representative of all categories of PwDs. They have also had significant advocacy successes over the years, such as the allocation of five seats in the Parliament of Uganda to represent PwDs from the five regions of the country. However, there is only one Ugandan organisation for CwDs, the Uganda Society for Disabled Children (USDC).

A seven year old blind girl attending Gulu Primary School: She started school in 2011 when she was five and a half years old. She likes it because she has new teachers and got a certificate. She gets along well with her classmates. Her favourite subject is science. Her biggest dream is to have a big home.

TABLE 3: KEY FINDINGS

Key Findings

Statistics, Laws and Policies Relating to CwDs Living in Uganda:

- The child disability prevalence is approximately 13%, or about 2.5 million children live with some form of disability in Uganda.
- About 9% of boys and girls of school going age with disabilities attend primary school and only 6% of them continue studying in secondary school.
- Uganda ratified the Convention on the Rights of the Child (CRC) in 1990.
- Uganda ratified the Convention on the Rights of persons with Disabilities (CRPD) in 2008.

Challenges to the Implementation of the Rights of CwDs;

- Discriminatory attitudes and behaviours towards CwDs.
- A serious gap in implementation of the Ugandan regulatory framework.
- An institutional framework weakened by lack of coordination between Government Institutions, Non-Governmental Organisations and Civil Society Organisations of Persons with Disabilities (DPOs).
- A fragmented programmatic approach resulting in gaps in the responses provided by the duty-bearers.

4. CHALLENGES TO THE IMPLEMENTATION OF THE RIGHTS OF CHILDREN WITH DISABILITIES

A number of barriers to the realisation of the CwDs' rights were identified in the course of the study. Although the Ugandan regulatory framework mostly domesticates the CRPD and CRC, there is a need to clarify the measures to be taken and the responsibility of the Government Institutions to realise the rights of CwDs. The protection mechanism for CwDs is also weak and existing laws and policies are not enforced to their full potential. Finally, lack of coordination between national and local Government Institutions and gaps in knowledge, understanding and capacities of the organisations of the Disability and Child Movement have partly lead to a fragmentation of the programmatic approach answering the needs of CwDs.

The current programmatic responses established by the Government Institutions and key organisations of the Disability and Child Movement are limited in scale and scope. They only address the immediate and obvious needs of CwDs, with only the easy-to-reach children benefitting from these projects. The structural barriers are therefore not addressed, although this is the only way forward to make a profound and sustainable change over time in the life of CwDs. The full realisation of the rights of CwDs will not be realised, unless collective and individual efforts are driven forward by all stakeholders with a leading organisation committed to this goal.

Furthermore, throughout the course of the research study, one of the clearest findings was the ongoing presence of stigmatising attitudes which lead to rejection, neglect, denial of access to basic services, abuse and marginalisation of persons and children with disabilities. This pattern of behaviours based on misconceptions and stigmatisation is associated with disability and dependent on what communities traditionally think of persons and children with disabilities. In conclusion, it can be reasonably extrapolated that negative social norms relating to disability are widely spread in the Ugandan society which leads to their discrimination. Changing these perceptions requires the collective and individual efforts of all stakeholders to promote and protect the rights of CwDs.

TABLE 4: CONVENTION ON THE RIGHTS OF THE CHILD AND CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Convention on the Rights of the Child and Convention on the Rights of Persons with Disabilities

The CRC and the CRPD challenge charitable approaches that regard CwDs as passive recipients of care and protection. Instead, the Conventions demand recognition of each child as a full member of her or his family, community and society. This entails a focus not on traditional notions of 'rescuing' the child, but on investment in removing the physical, cultural, economic, communication, mobility and attitudinal barriers that impede the realisation of the child's rights – including the right to active involvement in the making of decisions that affect children's daily lives.

UNICEF: State of the World's Children 2013 – Children with Disabilities

5. KEY RECOMMENDATIONS

The review of statistical information, the analysis of the institutional and regulatory frameworks and the mapping of programmes have led to a stronger understanding of the situation of CwDs living in Uganda and to the identification of gaps in information and unfulfilled needs of CwDs. Based on the findings of this research study, several recommendations have been produced with the aim to provide UNICEF Uganda and Partners with potential initiatives that can be conducted in the framework of their strategic programming from 2015 onwards.

The situation of CwDs is evolving over time. Assessing their needs and the realisation of their rights should be an on-going process rather than a one off exercise. This requires the consultation of CwDs and conducting of survey and assessment exercises. Both would allow UNICEF Uganda and its partner organisations to design evidence-based initiatives.

The full realisation of the human rights of CwDs enshrined in the CRC and CRPD cannot be achieved without the establishment of strong and sustainable regulatory and institutional frameworks. Laws and policies must domesticate the provisions laid down in both Conventions to guide their realisation in practice. The local and national Government institutions must be granted with powers and capacities to fulfil their role in leading the implementation of the rights of CwDs, while key NGOs and DPOs of the Child and Disability movement should be empowered to continue advocating for them.

Finally, in the course of the study, it has been evidenced that the current programmatic approach is fragmented and lacks sustainability over time. To remedy this situation, UNICEF Uganda and Partners should mainstream the perspective of CwDs in all its programmes, support the government to holistically address needs of CwDs and build the capacity of the organisations working with CwDs. Focus areas of future programmes should address the living conditions and welfare of CwDs by ensuring full access to services, including health services, (re)habilitation and education, changing social norms and raising awareness of the communities to no longer accept and condone stigmatisation and discrimination on the ground of disability. A focus should be placed on designing and running disability preventive interventions, targeting children living in Uganda. Empowering CwDs should be at the core of the design and implementation of all programmes and the role of parents, as primary caretaker of a CwD, should be duly acknowledged. All programmes should be designed, implemented and monitored in close collaboration with all stakeholders working with CwDs. A stronger programmatic approach is needed to tackle the barriers to the realisation of the human rights of CwDs in Uganda and to ensure that CwDs no longer remain invisible.

To conclude, despite all that has been stated in the report and the briefing, CwDs are first and foremost children. They have the same needs as all children and while they in theory have the same rights as others, CwDs living in Uganda are still waiting for the realisation of their basic rights.

TABLE 5: TEN KEY RECOMMENDATIONS**Ten Key Recommendations**

- ▶ Actively consult and listen to CwDs on issues concerning them on an ongoing basis
- ▶ Improve statistical information related to CwDs with the Uganda Bureau of Statistics
- ▶ Review and enforce the Ugandan legal and policy framework
- ▶ Advocate for increased budget allocations to responsible Government Institutions, earmarked for CwDs in related programmes
- ▶ Coordinate efforts among local and national Government Institutions
- ▶ Create a national partnership on CwDs led the Ministry of Gender, Labour and Social Development (MoGLSD)
- ▶ Build the knowledge on the needs and rights of CwDs and strengthen the capacities of key stakeholders and duty-bearers
- ▶ Mainstream the perspective of CwDs in programmes and surveys
- ▶ Design and implement programmes relating to disability prevention, health and (re)habilitation, education, social norms change and awareness-raising to ensure that CwDs are visible and have full access to services
- ▶ Partner with organisations of the Child and Disability Movement

Part 1: Introduction

1. CONTEXT

UNICEF is the United Nations (UN) agency responsible for addressing the long-term needs of children and upholding their human rights in line with the UN Convention on the Rights of the Child (CRC). Its mandate covers all children worldwide with a focus on marginalised groups and this includes fighting against discrimination on the basis of disability (CRC Article 2). Integrating the perspective of CwDs is part of UNICEF's core work and this has gained increasing momentum over the past couple of years, in an international context that has become more aware of and supportive of disability rights.

In addition to the human rights based approach to children contained in the CRC, a relatively new international legal framework, the UN Convention on the Rights of Persons with Disabilities (CRPD), was adopted in 2006. The CRPD provides the universal standard for the human rights of all persons with disabilities (PwDs) worldwide. The CRPD also includes specific obligations to ensure that the rights of CwDs (Article 7) are protected and reaffirms the full enjoyment of their human rights and fundamental freedoms on an equal basis with other children. In response to the CRPD, UNICEF has engaged in various activities and is coordinating the activities of the Global Partnership on Children with Disabilities (GPc wd), a global network promoting the human rights of disabled children. In 2013 UNICEF devoted its annual State of the World's Children flagship report to disability and this exercise to gather information about and analyse the situation of CwDs highlighted the lack of accurate data about these "invisible children".

The policy context in Uganda is forward looking and rights based. In addition to signing and ratifying both UN Conventions (the CRC has been part of the Ugandan legislative and policy framework since 1990 and Uganda ratified the CRPD and its Optional Protocol without any reservation in 2008), the human rights of PwDs are recognised in the Constitution of Uganda, 1995, and the government has enacted progressive disability legislation (for example, the PwDs Act 2006). Another development has been the election of a Ugandan representative to the CRPD Committee, which in itself represents a positive commitment to address the situation of PwDs in the country. In its working relationship with national institutions and partners, UNICEF Uganda has also received very positive feedback from decision-makers and duty bearers - Members of the Parliament of Uganda and the Ministry of Gender, Labour and Social Development (MoGLSD), as lead Ministry, have demonstrated a deep interest in the topic.

2. OBJECTIVE

In this favourable international and national context, UNICEF Uganda has identified a lack of knowledge and awareness about the status of CwDs' human rights in Uganda as the first and immediate challenge and has therefore decided to carry out a research study to explore the situation of CwDs living in Uganda.

The purpose of this research is to gather all existing information about CwDs living in Uganda. The study aim is not to create new knowledge but rather to analyse and make sense of the fragmented information already available. This research coincides with UNICEF Uganda's strategy evaluation and the findings will be used by the UNICEF office to start planning a programmatic response to the issues faced by CwDs from 2015 onwards.

As an initial outcome, a review of the statistical information and data relating to CwDs has provided firstly an estimation of the disability and child disability prevalence in Uganda, which is then compared with international rates, and secondly of access to education – the enrolment of CwDs in pre-primary, primary and secondary schools. With the exception of these two major areas of statistical information, there is very little other data available. So there is a significant gap in data and research relating to the everyday life of CwDs. This concerns, among others, the causes of disability, the birth registration status of CwDs, the enjoyment of their human rights, the links between disability and poverty, the effects of humanitarian crisis on CwDs and their access to health and (re)habilitation services.

The second outcome of this research study consists of an analysis of the Ugandan institutional and regulatory frameworks as well as a mapping of programmes. CRPD Article 4 (1) requires State Parties to take into consideration and implement the rights of PwDs, enshrined in this Convention, by all means at their disposal. This includes the adoption, amendment and review of legislation (Article 4 (1) (a) and (1) (b)) as well as “the protection and promotion of the human rights of PwDs in all policies and programmes” (Article 4 (1) (c)). An analysis of the institutional and regulatory frameworks is therefore an essential aspect of this research. In this way it is possible to identify and assess how the laws and policies support and protect the human rights of CwDs living in Uganda and the types of initiative that the national and local Government Institutions have taken to address their rights and needs. In addition, a review of various programmes, interventions and projects implemented by various key stakeholders operating in this field has been undertaken. These stakeholders include donors, International Non-Governmental Organisations (INGOs), Ugandan NGOs, Ugandan and foreign Civil Society Organisations of Persons with Disabilities (DPOs). This mapping exercise provides an overview of what has been done in the past, what is currently ongoing, what has been achieved and what has been less successful.

The literature review and analysis reveal the gaps in knowledge and institutional responses targeting CwDs. This is reflected in this Disability SitAn that analyses the extent to which the human rights of CwDs are being met and explains the barriers and bottlenecks that are preventing their full realisation in Uganda. Finally a number of areas are identified where there is the potential for future intervention and a set of recommendations for future implementation by UNICEF Uganda and Partners.

Part 2: Methodology

This research study on CwDs living in Uganda commissioned by UNICEF Uganda was conducted between November 2013 and April 2014. The scope of the research covers all CwDs aged zero to 18 living in Uganda.

1. SCOPE OF THE RESEARCH STUDY: TARGET GROUP AND GEOGRAPHICAL COVERAGE

CRC Article 1 defines as a child “any human being below the age of 18years”, which is also the age of majority in Uganda. In the CRPD Preamble, disability is considered as an “evolving concept [...] that results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (CRPD (e)). For the purpose of this research, the target group will therefore be composed of persons below 18 who have physical, sensory, intellectual or psychosocial disabilities.

The research study covers the territory of the Republic of Uganda and as stated above, any child with a disability living in Uganda will be covered by this study. Most of the key informant interviews took place in Kampala where the majority of stakeholders are based. A field visit to Gulu was also organised.

2. RESEARCH METHODS

The CRPD and CRC, which define the human rights that any child living with a disability is entitled to enjoy and exercise worldwide, are the foundations of this research study and Disability SitAn. Both documents constitute the theoretical framework against which the situation of CwDs living in Uganda is assessed.

A mix of quantitative and qualitative research methods were used for the empirical analysis of the situation. Quantitative research allowed the gathering of statistical knowledge and an initial evaluation of the phenomenon, while qualitative research provided an in-depth assessment of the situation and how stakeholders perceive it.

Desk research and field interviews were used with the aim to triangulate the data. The desk research, consisting of the gathering of statistics, analysis of the role of Government Institutions, laws and policies as well as the mapping of programmes, provided a theoretical understanding of the situation. Later key informant interviews facilitated the collection of factual information from the field. This two-pronged approach provided a comprehensive picture of the situation of CwDs living in Uganda. The analysis revealed gaps in both the information available and in the institutional responses structured to target them.

2.1. Data Collection on Children with Disabilities Living in Uganda

During the first stage of the study, statistics existing at both global and national level were collected. The majority of international disability statistics are produced by the UN agencies and consists of the following: the World Health Organisation (WHO)/World Bank World Report on Disability 2011, the WHO World Health Survey of 2002-04, the WHO Global Burden of Disease Report 2004, the UNICEF State of the World's Children 2013 – CwDs and the Education For All (EFA) Global Monitoring Report 2010 - Reaching the Marginalised. Nationally, sources of statistical information are mainly provided by the Uganda Bureau of Statistics (UBOS) and contained in the Uganda Population and Housing Census/Analytical Report on Gender and Special Interest Groups 2002, the Uganda Demographic and Health Surveys (UDHS) 2006 and 2011 as well as the Ugandan National Household Surveys (UNHS) 2005/06 and 2009/10. The Ministry of Education and Sports (MoES) also releases a Uganda Education Statistical Abstract every year. The African Child Policy Forum (ACPF) has produced a unique set of data relating to CwDs with its Report Children with Disabilities in Uganda: The Hidden Reality.

2.2. Analysis of the Ugandan Institutional and Regulatory Frameworks

Legislative and policy documents were analysed as a way to identify how they protect the human rights of CwDs and how they define the responsibility of the local and national Government Institutions in relation to CwDs. Although the influence of international law was taken into consideration, the main focus was on Ugandan legislation and policies since they have a direct effect on the situation of CwDs living in Uganda. The Constitution of the Republic of Uganda, 1995,³ was carefully reviewed because it sets out the fundamental rights and precedents according to which the State of Uganda is organised. The National Development Plan (NDP) 2005/06 – 2009/10, 2010,⁴ sets the overall policy framework for Uganda. The Local Government Act, 1997,⁵ the National Council for Disability (NCD) Act, 2003,⁶ the National Council for Children (NCC) Act, 1996,⁷ the Equal Opportunities Commission (EOC) Act, 2007,⁸ and the Uganda National Institute of Special Education (UNISE) Act, 1995,⁹ amended by the University and Other Tertiary Institutions Act, 2001,¹⁰ were examined to assess the role, powers and structure of local Government Institutions and of each Government Ministry and Agency. Those pieces of legislation whose scope cover disability matters (i.e. the PwDs Act¹¹ and National Policy on Disability in Uganda from 2006)¹² and child issues (i.e the Children Act, 1996,¹³ the Child Labour Policy, 2006,¹⁴ and the National Orphans and Other Vulnerable Children Policy, 2004¹⁵) were then considered. Finally the laws and policies relating to

3. Government of Uganda, Constitution of the Republic of Uganda, 1995.

4. Government of Uganda, National Development Plan 2005/06 – 2009/10, 2010.

5. Government of Uganda, Local Government Act, 1997.

6. Government of Uganda, National Council for Disability Act, 2003.

7. Government of Uganda, National Council for Children Act, 1996.

8. Government of Uganda, Equal Opportunities Commission Act, 2007.

9. Government of Uganda, Uganda National Institute of Special Education Act, 1995.

10. Government of Uganda, University and Other Tertiary Institutions Act, 2001.

11. Government of Uganda, Persons with Disabilities Act, 2006.

12. Government of Uganda, National Policy on Disability in Uganda, 2006.

13. Government of Uganda, Children Act, 1996.

14. Government of Uganda, Child Labour Policy, 2006.

15. Government of Uganda, National Orphans and Other Vulnerable Children Policy, 2004.

education, such as the Education Act, 2008,¹⁶ the Draft Non Formal Education Policy for Educationally Disadvantaged Children, 2012,¹⁷ and the Draft Policy on Special Needs and Inclusive Education (SN&IE), 2011,¹⁸ and to health - the Second National Health Policy (NHP II), 2010¹⁹ - were analysed.

2.3. Mapping of Programmatic Initiatives

A mapping of programmes, interventions and projects implemented by various key stakeholders operating in the disability and child field in Uganda was undertaken. They are organisations such as international agencies, foreign development agencies, foundations, INGOs, Ugandan NGOs, Ugandan and foreign DPOs.

A literature review provided the primary source of information and the Key Information Interviews (KII) were an opportunity to gather additional information about the impact of on-going programmes. Due to the fragmentation of information and lack of specific and relevant documentation relating to these interventions targeting CwDs, an online survey was set up and opened for contributions from mid-December 2013 to the end of January 2014. This was sent to approximately 100 organisations and about 30 responses were collected.

2.4. Key Informant Interviews

Field interviews were conducted to compare how the theoretical situation corresponds to the reality encountered by CwDs living in Uganda. This was also an opportunity to gather additional information about the implementation of laws and policies, and the impact of on-going programmes run by INGOs and similar organisations. Semi-structured interviews were held, as the purpose is to collect a consistent set of complementary information and personal experience on data and statistics, law and policies as well as programmes and actions from a variety of stakeholders. They took the form of one-to-one interviews.

15 interviews were conducted with various key stakeholders:

- Ugandan Government Institutions and Agencies: the MoGLSD/ Directorate of Social Protection/Department of Elderly and Disability;²⁰ the MoES/SN&IE Department;²¹ the Ministry of Health (MoH)/Disability Rehabilitation and Prevention Department;²² UBOS;²³ NCD;²⁴ and a member of the Parliament of Uganda.²⁵
- Foreign Development Aid Agencies: the Norwegian Agency for Development Cooperation (NORAD);²⁶ and the United-States Agency for International Development (USAID).²⁷

16. Ministry of Education and Sports (MoES), Education (Pre-Primary, Primary and Post-Primary) Act, 2008.

17. Ministry of Education and Sports (MoES), Draft Non Formal Education Policy for Educationally Disadvantaged Children, 2012.

18. Ministry of Education and Sports (MoES), Draft Policy on Special Needs and IE, 2011.

19. Ministry of Health (MoH), Second National Health Policy, 2010.

20. Kaggya Nabulime, Beatrice, Ministry of Gender, Labour and Social Development (MoGLSD), Interviewed by Nadège Riche, 2013.

21. Okecho, Christopher Wimon, Ministry of Education and Sports (MoES), Interviewed by Nadège Riche, 2013.

22. Bongole, Rose, Ministry of Health (MoH), Interviewed by Nadège Riche, 2014.

23. Helen Nviiri, Pamela Kakande, Uganda Bureau of Statistics (UBOS), interviewed by Nadège Riche, 2013.

24. Adong, Caroline, National Council for Disability (NCD), Interviewed by Nadège Riche, 2013.

25. Baba Diri (Hon.), Margaret, Women Member of Parliament (MP) for Koboko District, Interviewed by Nadège Riche, 2014.

26. Engh, Ida-Eline, Agencies: the Norwegian Agency for Development Cooperation (NORAD), Interviewed by Nadège Riche, 2014.

27. Muwanga, Catherine, United-States Agency for International Development (USAID), Interviewed by Nadège Riche, 2014.

- INGOs: Plan²⁸ and Save the Children.²⁹
- Ugandan NGOs for CwDs: the Uganda Society for Disabled Children (USDC).³⁰
- Ugandan DPOs: the National Union of Disabled Persons of Uganda (NUDIPU),³¹ the National Union of Women with Disabilities of Uganda (NUWODU)³² and the Uganda Parents of Persons with Intellectual Disabilities (UPPID).³³
- A not-for-profit hospital and (re)habilitation centre: the Children's Surgical Rehabilitation Hospital (CoRSU).³⁴

2.5. Field Research

Gulu was identified as the most interesting and appropriate District for this study for several reasons. There is evidence that a higher proportion of people and children with disabilities live in the Northern part of the country, as a consequence of 20 years of civil war. Additionally it also corresponds to UNICEF Uganda's geographical area of intervention and the majority of donors target the North of Uganda.

Four representatives from local Government Institutions (Gulu District/ Department of Community Development³⁵ and Gulu District Council for Disability³⁶) and from DPOs (Gulu Disabled Persons Union (GDPU)³⁷ and Gulu Women with Disabilities Union (GUWODU)³⁸ were interviewed.

Gulu Primary School which is a mainstream school with a unit for blind and visually impaired children was also visited. Pupils with disabilities and children without disabilities attend classes together where they study all courses such as English or History and non-disabled children are encouraged to assist their disabled peers as and when necessary. Pupils with disabilities also take specific courses to learn how to read and take notes in Braille. The visit to the School began with two consecutive discussions with the Head Teacher and the Head of the Unit for Blind Children about the successes of having blind and partially sighted children completing primary school and the challenges faced by the school to keep these children in school and learning. Four pupils with visual disabilities were interviewed to hear the testimonies of CwDs themselves, talking about their life. For this purpose, a specific CwDs-friendly interview process was designed: an ice breaker was introduced to mix and mingle before the individual interviews with the four pupils actually took place.

28. Senyonjo, Jessica, Adupa, Patrick, PLAN, Interviewed by Nadège Riche, 2013.

29. Bakundana, Flavia, Heijnen-Maathuis, Els, Save the Children, Interviewed by Nadège Riche, 2013.

30. Naswa Were, Dolorence, Uganda Society for Disabled Children (USDC), Interviewed by Nadège Riche, 2013.

31. Luyima, Ronald, National Union of Disabled Persons in Uganda (NUDIPU), Interviewed by Nadège Riche, 2013.

32. Asamo, Helen Grace, National Union of Women with Disability in Uganda (NUWODU), Interviewed by Nadège Riche, 2014.

33. Byamugisha, Isidor, Uganda Parents of Persons with Intellectual Disabilities (UPPID), Interviewed by Nadège Riche, 2013.

34. Simpson, Malcolm, Children's Surgical Rehabilitation Hospital (CoRSU), Interviewed by Nadège Riche, 2013.

35. Jawoko, Perry, Gulu District, Interviewed by Nadège Riche, 2013.

36. Okwera, Albert, Gulu District Council for Disability, Interviewed by Nadège Riche, 2013.

37. Ojok, Simon, Gulu Disabled People Union (GDPU), Interviewed by Nadège Riche, 2013.

38. Luwar, Teddy, Gulu Women with Disabilities Union (GUWODU), Interviewed by Nadège Riche, 2013.

3. STUDY LIMITATIONS

Although at the design stage of this study, the expectation had been to review a certain number of laws and policies, no copies of the Draft Mental Health Policy or Guidelines for Provision of Assistive Devices could be found. The main challenge in conducting the institutional and regulatory analysis was the unavailability of legal documents. It was therefore assumed that, if none of the key stakeholders has a copy of these, then they are not referred to for implementation. This might explain to a limited extent the serious gap in implementation that has been identified.

The fragmentation of information and the lack of relevant documentation made it problematic to collect accurate data about ongoing or successful programmes. For that reason, several complementary methods, desk research and KII, were initially planned but further into the research cycle it became necessary to set-up an online survey to provide additional information. This was successful as none of the programmes presented by the people responding were identified during the literature review phase.

The major limitation of this study however lies in the lack of any large-scale and representative consultation of CwDs living in Uganda. Only four pupils with disabilities were interviewed, all living in the same region and having the same disability. The younger CwDs did not speak much English, resulting in their teacher, who was present during all the interviews, acting as a translator when needed. The interviewer at times wondered if she answered on behalf of the children or if she was only translating. To conclude, this study did not explore and identify what CwDs themselves see as the most pressing needs and issues in their lives.

Part 3: Summary and Analysis of Statistics Relating to Children with Disabilities in Uganda

CRPD Article 31 requires State Parties to “collect appropriate information, including statistical and research data” relating to PwDs. The collection and dissemination of disaggregated information and data relating to PwDs are clearly important. It enables an assessment of the overall situation - i.e the needs of the population of PwDs, the barriers they face in accessing their rights and the demand for services and their provision by the public administration and the private sector. This information also provides the basis for policy formulation, implementation and evaluation. For this reason the first step of this research study has been to carefully review and analyse the available statistical information and data.

This report does not aim to create new data sets, but rather to present the statistical information available at both the worldwide and Ugandan levels. Relevant sources of information used include studies and reports issued by the UN and international bodies such as UNICEF, the UN Educational, Scientific and Cultural Organisation (UNESCO), the WHO and the World Bank. National sources of information were also reviewed, and in particular the statistics produced by UBOS and the results of the surveys conducted by the Uganda MoGLSD and MoES. The main issues associated with the collection of disability statistics are considered. The presentation of the relevant statistics begins with an analysis of the disability and child disability prevalence in Uganda, which are compared with international rates. This is followed by a focus on access to education - enrolment in pre-primary, primary and secondary schools of CwDs. With the exception of these two major areas of statistical information, there is very little other data available. Finally, other significant figures relating to the everyday life of CwDs (i.e. the causes of disability, the birth registration status of CwDs living in Uganda, the enjoyment of human rights, the links between disability and poverty, the effects of humanitarian crisis on CwDs and the access

to health and (re)habilitation services) are presented.

Based on the statistical information relating to the situation of CwDs living in Uganda reviewed in this Report, an analysis of the shortcomings and gaps in information and the need for additional data is presented.

1. MAIN SOURCES OF INFORMATION

The statistical information relating to persons and children with disabilities presented and analysed in this Report come from international and national sources.

1.1. International Sources of Information

The majority of international disability statistics are produced by the UN agencies such as UNESCO, UNICEF and WHO and by the World Bank.

The UN Disability Statistics Database (DISTAT) refers to available national statistics but is not up-to-date. For example, it refers to the 1991 Uganda Population and Housing Census, although a census was conducted in 2002 and national surveys carried out in 2006, 2010 and 2011. Consequently statistics from DISTAT were disregarded for this Report.

The WHO/World Bank World Report on Disability 2011 is the most important international reference source for disability issues: “it assembles the best available scientific information on disability to improve the lives of people with disabilities and facilitate the implementation of the CRPD.”³⁹ Statistics presented in this WHO/World Bank Report are based on multiple sources - country report estimations of the disability prevalence in their population, the WHO World Health Survey of 2002-04 and the WHO Global Burden of Disease Report 2004. Of all these sources, only the WHO Global Burden of Disease Report 2004 aggregates statistics relating to CwDs of zero to 14 years of age. Data presented in the WHO/World Bank World Report on Disability 2011 covers the disability prevalence worldwide and a wide range of topics (e.g. education). Reliance on this statistical source is unavoidable as there have been no other global aggregation of surveys since the publication of this Report and it therefore provides the main basis for this review and analysis of statistics. It is, however, important to consider the limitations of this work. The figures date back to 2004 and the situation has changed and evolved during the last decade. Children aged 15 years and above fall in the category of adults (aged between 15 and 59 years). Therefore the data relating to CwDs presented in the WHO Global Burden of Disease Report 2004 does not include all CwDs. The WHO and the World Bank also recognise the limitations of this Report and “the prevalence estimates [...] should be taken not as definitive but as reflecting current knowledge and available data.”⁴⁰

39. World Health Organisation (WHO), World Bank, Summary World Report on Disability, Geneva: WHO/World Bank, 2011, p. 7.

40. World Health Organisation (WHO), World Bank, World Report on Disability 2011, Geneva: WHO/World Bank, 2011, p. 28.

The UNICEF State of the World's Children 2013 – CwDs also contains statistics relating to the child disability prevalence worldwide. In this study UNICEF has not conducted any new surveys to collect data relating to CwDs but has used existing figures. These sources for the State of the World Children 2013 - CwDs are similar to those used in the WHO/World Bank World Report on Disability 2011, and therefore have similar limitations as presented above.

UNESCO leads the EFA Movement which is a global commitment to provide quality basic education for all children, youth and adults. At the World Education Forum in 2000 in Dakar, 164 governments identified six main goals to be achieved by 2015 and various stakeholders (development agencies, Non-Governmental Organisations (NGOs), Civil Society Organisations (CSOs) and private organisations) have joined the collective commitment enshrined in the Dakar Framework for Action since then. In order to accelerate education for all in Africa, the EFA Movement launched the “Big Push”, an initiative aiming to support selected and advanced African countries to reach these six goals by 2015. A first round comprising eight countries started in March 2013 and then a second round of 11 countries, including Uganda, was initiated in October 2013. Uganda has therefore committed itself to accelerate its efforts towards education for all, including CwDs, in the coming years.

The EFA Movement also produces an annual publication presenting the results in relation to a specific issue. The EFA Global Monitoring Report 2010 - Reaching the Marginalised is considered to be the most recognised international source of information in terms of access to education for CwDs. Data presented in this EFA Report is both reliable and comparable because most of the statistics were collected using the UNESCO Institute for Statistics (UIS) standard questionnaires. Data was collected for the school year ending in 2008 and processed for presentation in May 2010 by the UNESCO UIS.⁴¹

1.2. National Sources of Information

The censuses and surveys used to collect national statistics of persons and children with disabilities living in Uganda are carried out by national public institutions.

UBOS, the public body in charge of statistics in Uganda, has conducted one census and several surveys capturing the disability prevalence among the Ugandan population.

The latest such national census was conducted by UBOS in 2002. Another census was initially planned for the financial year 2011/12 but has now been rescheduled for 2013/14 due to a lack of funding. The Uganda Population and Housing Census/Analytical Report on Gender and Special Interest Groups 2002 presents data relating to women, young people, older people, children and PwDs. Information about CwDs is based on children aged between five and 17

41. United Nations Educational, Scientific and Cultural Organisation (UNESCO), Education for All (EFA) Global Monitoring 2010 - Report Reaching the Marginalised, 2010, p. 296.

years as UBOS considers that it is difficult to assess the disability of a child below the age of five. This information from the Census of 2002 is now therefore 12 years old and not representative of the whole population of CwDs. However, the information collected is the only source to date for which the same definitions of disability and survey questions have been applied nationwide. It is for this reason that this data has been used in the Intermediary Report – Summary and Analysis of Statistics.

The UDHS 2006 and 2011 are part of a global framework, the Demographic and Health Survey Project. Both surveys follow those conducted in 1988/89, 1995 and 2000/01. Only the UDHS 2006 and 2011 have a nationwide scope and have therefore been used in the framework of the Intermediary Report – Summary and Analysis of Statistics. Both surveys aim to collect data on demography and health and one of the specific objectives is to gather information relating to disability. The surveys have been conducted on a representative sample of about 10,000 households living in Uganda. The set of six questions relating to disability was designed using the guidelines of the UN Washington Group on Disability Statistics (Refer to Section C). The questions reflect a partial shift away from an “impairment” to a “limitation in functioning” approach. As with the national census of 2002, CwDs are counted from five years upwards and consequently both surveys again underestimate the number of CwDs living in Uganda.

The UNHS 2005/06 and 2009/10 intend to “collect high quality and timely data on demographic, social and economic characteristics”⁴². Both surveys are composed of six modules: the Socio-Economic Module looks at household characteristics and individual characteristics of household members, including disability. The survey questionnaires of the UNHS 2005/06 and UNHS 2009/10 include a section on “disability and malaria” to assess the difficulties faced by people in performing certain types of daily life tasks (e.g. seeing). Although the questions relating to disability are based on functional difficulties, the title of the module, which links disability with the malaria disease, reflects a medical approach to disability. Despite this shortcoming, the statistical data relating to CwDs collected in the UNHS 2005/06 and 2011 are presented in the Intermediary Report – Summary and Analysis of Statistics. Another UNHS is planned for the financial year 2012/13 but no questions relating to disability are to be included in this survey.⁴³

The census and these surveys are the best national sources of information available to estimate the -child- disability prevalence among the Ugandan population. However, the methodologies used differ across these studies. UBOS has moved from an “impairment” to a “difficulties in functioning” approach to disability. So in the Census 2002, disability is considered as “a condition which denies a person a normal economic and social life, which has lasted or is expected to last six months or more”, while, in the UNHS 2009/10, “disability is defined as permanent and substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environmental barriers

42. Uganda Bureau of Statistics (UBOS), Ugandan National Household Surveys (UNHS) 2009/10, Socio-Economic Module, Abridged Report, November 2010, p. 1.

43. Helen Nviiri, Pamela Kakande, Uganda Bureau of Statistics (UBOS), interviewed by Nadège Riche, 2013.

resulting in limited participations.” The set of about six questions used in the UNHS and UDHS focuses on the person’s difficulties in performing certain tasks, rather than their impairment(s) or condition(s). For example questions ask: “Do you have difficulties in seeing/hearing/walking or climbing stairs/remembering or concentrating/self-care/communicating?” Compared to the UNHS 2009/10 and UDHS 20006 and 2001, the UNHS 2005/06 has a larger set of questions: the person is asked if they have mobility problems, psychosocial or emotional difficulties or difficulties in taking part in social activities or learning.⁴⁴ The use of various methodologies and definitions across these studies suggests that the variation in the -child- disability prevalence rate between the census and these different surveys is most probably due to an improvement in data collection, rather than a steep increase in the number of persons and children with disabilities living in Uganda.⁴⁵

In addition to the UBOS census and surveys, the MoES publishes the Uganda Education Statistical Abstract every year. This publication presents the number of children, pupils and students enrolled in pre-primary, primary, secondary, post-primary, non-formal and tertiary institutions in Uganda. Since 2007, a set of questions target four categories of CwDs: physical, visual, hearing and intellectual impairments as well as people with multiple “handicaps”.⁴⁶ Only the Uganda Education Statistical Abstract 2009, 2010 and 2011 will be considered for this Study, as no copies of the 2007 and 2008 Abstracts could be found. Data is based on voluntary responses to the Annual School Census form from both public and private schools in Uganda. The response rate, including pre-primary, primary, secondary and post-secondary schools, was 71.4% in 2009 but is not available for 2010 and 2011. The MoES, however, points out that there are strong limitations regarding the response rates from schools, and in particular for privately-operated institutions. Statistical information about attendance and completion of primary and secondary school by children and CwDs will be presented since they are the only available figures for Uganda. However, it must be emphasised that the figures are only a partial reflection of the actual situation.

In 2012, the MoGLSD carried out a mapping exercise of the OVC,⁴⁷ as part of the Sunrise-OVC project of USAID/Uganda, which includes CwDs, living in the 32 “new” districts⁴⁸ which have now been created. Various problems affected the data collection - certain areas were too remote to be reached, there was a lack of computers and technical facilities to enter the data and there were an insufficient number of collectors to interview people. The MoGLSD Consolidated Report on the OVC Mapping Exercise 2012, however, gives an indication of the number of CwDs living in these districts and it is therefore presented in this Intermediary Report – Summary and Analysis of Statistics.

44. Uganda Bureau of Statistics (UBOS), Ugandan National Household Surveys 2005/06 - Report on the Socio-Economic Module, 2006, p. 174.

45. Northern Uganda experienced war for 20 years. The Western and Northern regions have seen an increase in the number of refugees due to conflicts in the neighbouring countries. This suggests that the number of persons and children with disabilities living in Uganda should have indeed increased in the past decade. However, no evidence could be found in the course of this Study to confirm or invalidate this statement.

46. Christopher Wimon Okecho, Ministry of Education and Sports (MoES), interviewed by Nadège Riche, 2013.

47. Ministry of Gender, Labour and Social Development (MoGLSD), Consolidated Report on Orphans and Vulnerable Children Mapping Exercise 2012, 2012.

48. These 32 “new” districts are: Agago, Alebtong, Amudat, Buikwe, Bukomansimbi, Buhweju, Bulambuli, Butambala, Buvuma, Buyende, Gomba, Kalungu, Kibuuku, Kiryandongo, Kole, Kween, Kyankwanzi, Kyegegwa, Lamwo, Luuka, Lwengo, Mitooma, Namayingo, Napak, Ngora, Ntoroko, Nwoya, Otuke, Rubirizi, Serere, Sheema and Zombo.

Finally, in 2011, ACPF conducted a study about the situation of CwDs living in Uganda. The outcomes are presented in the Report called *Children with Disabilities in Uganda: The Hidden Reality*. This ACPF Study engaged with 540 CwDs and aims to be a representative study of CwDs living in Uganda. Children had various impairments covering the disability spectrum and were aged from nine to 17 years. They live either with their family or in “unconventional settings (on the streets, in boarding schools or in (re)habilitation centres/institutions)”⁴⁹ and came from all of the five regions of Uganda. Data collection tools included six focus group discussions, in-depth interviews with key-informants, a day in the life of six CwDs and a literature review. The Study has generated unique quantitative information and is therefore fully considered in this Intermediary Report – Summary and Analysis of Statistics.

1.3. The Issue of Measuring –Child- Disability Prevalence⁵⁰

Measuring the disability prevalence world- or country-wide is problematic for a number of reasons. So, for example, there are the various definitions of disability with an ongoing shift from a medical to a social and rights-based model of disability. Differing individual and cultural perceptions of what functional limitations and disabilities imply lead to over- or under-estimation of -child- disability prevalence. The design of data collection tools, the wording and number of questions relating to disability included in the different survey questionnaires also affect the quantity and quality of the collected information. The stigma relating to disability also negatively affects the value and resources that are allocated to disability statistics.

“Measuring child disability presents a unique set of challenges. Because children develop and learn to perform basic tasks at different speeds, it can be difficult to assess function and distinguish significant limitations from variations in normal development. The varying nature and severity of disabilities, together with the need to apply age-specific definitions and measures, further complicate data collection efforts. In addition, the poor quality of data on child disability stems, in some cases, from a limited understanding of what disability is in children and, in other cases, from stigma or insufficient investment in improving measurement.”⁵¹

To respond to these many challenges, The UN has set up the Washington Group on Disability and Statistics. The Group does not actually produce any data on the disability prevalence in the global population but has as its main objective “the promotion and coordination of international cooperation in the area of health statistics by focusing on disability measures suitable for censuses and national surveys. The aim is to provide basic necessary information on disability which is comparable throughout the world.” The Washington Group on Disability and Statistics uses the WHO International Classification of Functioning, Disability and Health (ICF) to develop its question sets. In 2008, the Group decided to

49. African Child Policy Forum (ACPF), *Children with Disabilities in Uganda: The Hidden Reality*, Addis Ababa: The African Child Policy Forum, 2011, p. 17.

50. Further information relating to the problems around disability statistics is available in the Chapter 6 Measuring Child Disability of the United Nations Children's Fund (UNICEF), *The State of the World's Children 2013 - Children with Disabilities*, 2013, pp. 63-71.

51. United Nations Children's Fund (UNICEF), *The State of the World's Children 2013 - Children with Disabilities*, 2013, p. 65.

develop “an extended set of questions on environmental factors as they relate to the measurement of [child and youth] disability”⁵² and established a specific Sub-Working Group for that purpose. In 2011, UNICEF formally joined the Sub-Working Group. It seems that the final question set relating to CwDs was approved in October 2013, although at the time of writing this report no public information had been made available.

In addition there are a number of issues that are specific to the collection of statistics relating to -child- disability prevalence in Uganda. Some data sources have been quoted in various reports and studies but no original copies can be located. Inadequate financial and human resources restrict the capacities of public institutions to appropriately conduct surveys. CwDs living in Uganda are in many cases “invisible” hidden by their families or communities and therefore excluded from censuses and surveys.

2. CHILD DISABILITY PREVALENCE IN UGANDA

2.1. Disability Prevalence Worldwide

The WHO/World Bank World Report on Disability 2011 is the most reliable source of information relating to disability prevalence. It estimates that 15% of the population or over one billion people live with some form of disability worldwide.⁵³ Among them, between 110 and 190 million “have very significant difficulties in functioning - the equivalent of disability inferred for conditions such as quadriplegia, severe depression, or blindness.”⁵⁴ Women are more likely to acquire disability in their life course than men for reasons such as “poorer working conditions, poorer access to quality health care, gender-based violence and birth child”⁵⁵.

In the State of the World 2013 – CwDs, UNICEF concludes that “the estimated number of CwDs between zero and 18 years ranges from 93 to 150 million depending on the source.”⁵⁶ The WHO Global Burden of Disease Report 2004 estimates that about 5% of the children aged zero to 14, or 95 million children, have a moderate or severe disability.⁵⁷ “‘severe’ disability is the equivalent of having blindness, Down syndrome, quadriplegia, severe depression, or active psychosis [while] moderate and severe [is] the equivalent of having angina, arthritis, low vision or alcohol dependence. Additionally, the WHO/World Bank World Report on Disability 2011 reports that, in low- and middle-income countries, the child disability prevalence varies from 0.4 to 12.7% depending on the study and assessment tool.”⁵⁸ The UN Population Information Network

52. United Nations Disability Statistics Database (DISTAT), Washington Group, <http://unstats.un.org/unsd/methods/citygroup/washington.htm>, 2013, (accessed on 26 November 2013).

53. World Health Organisation (WHO), World Bank, World Report on Disability 2011, Geneva: WHO/World Bank, 2011, p. 28.

54. World Health Organisation (WHO), World Bank, World Report on Disability 2011, Geneva: WHO/World Bank, 2011, p. 44.

55. World Health Organisation (WHO), World Bank, World Report on Disability 2011, Geneva: WHO/World Bank, 2011, p. 28.

56. United Nations Children's Fund (UNICEF), Children and Young People with Disabilities Fact Sheet, May 2013, p. 10.

57. World Health Organisation (WHO), Global Burden of Disease Report, 2004, p. 34.

58. World Health Organisation (WHO), World Bank, World Report on Disability 2011, Geneva: WHO/World Bank, 2011, p. 10

estimates that 90% of children with mental disabilities die before the age of five.

In addition, it is generally considered that disability is more common in low- and middle-income countries and in Africa than in other countries.⁵⁹ “Out of the 100 million CwDs under five years of age worldwide, 80% live in developing countries”⁶⁰ and most of them are in Sub-Saharan Africa.⁶¹ This also suggests that, due to the young populations in developing countries, disability prevalence will increase in the coming years.

2.2. Disability Prevalence in Uganda

The disability prevalence among the Ugandan population varies across sources and time.

In 2002, the disability rate was estimated at 3.5%. The Census 2002 counted 343,700 women with disabilities or, in other words, 44.1% of the total population of PwDs are women. The Northern Region had the highest disability prevalence (4.8%) while the Western region had the lowest disability rate (2.9%). Eastern and Central regions had respectively rates of 3.6% and 3.1%.⁶² Prevalence increased with age and 13% of PwDs has multiple disabilities.⁶³

TABLE 6: POPULATION OF PWDS PER AGE AND IMPAIRMENTS, IN NUMBER (UGANDA, 2002)

Disability Type	Age 0-17	Age 18-30	Age 31+	Total	Percentage (%)
Physical	79,884	66,862	207,584	354,330	41.9
Deaf dumb [Hearing]	62,958	16,539	48,196	127,693	15.1
Vision [Visual]	36,554	22,484	129,712	188,750	22.3
Speech	18,682	6,736	7,205	32,623	3.9
Mental Retardation [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
Non stated [Others]	13,715	7,999	18,804	40,518	4.8
Total	250,804	144,333	449,704	844,841	100.0
Percentage (%)	29.7	17.1	53.2	100.0	-

Source: Ugandan Bureau of Statistics (UBOS), Ugandan Population and Housing Census, Fountain Publishers, Uganda, 2005.

59. World Health Organisation (WHO), Global Burden of Disease Report, 2004, p. 34.

60. United Nations Children's Fund (UNICEF), Children and Young People with Disabilities Fact Sheet, May 2013, p. 17.

61. United Nations Educational, Scientific and Cultural Organisation (UNESCO), Education for All (EFA) Global Monitoring 2010 - Report Reaching the Marginalised, 2010, p. 181-182. 62. Uganda Bureau of Statistics (UBOS), Uganda Population and Housing Census - Analytical Report Gender and Special Interest Groups 2002, 2003, p.96, 97.

63. Uganda Bureau of Statistics (UBOS), Uganda Population and Housing Census - Analytical Report Gender and Special Interest Groups 2002, 2003, p.56.

In 2006, the disability prevalence varies from 7% of the population or 3.2 million PwDs living in Uganda according to the UNHS 2005/06 to “20% for persons age five years and above” quoting the UDHS 2006. This variance in the disability rate is largely due to differences in the methodologies used and wording of the survey questions.

The UNHS 2005/06 presents a breakdown of PwDs per type of impairments: Physically-impaired people account for the highest proportion of impairment in Uganda (34%). They are followed by visually-impaired (22%) and hearing-impaired people (15%). Other types of impairments considered are people with mental health conditions, persons who are speech-impaired and people who have learning difficulties. The place of residence (urban versus rural) also varies between persons with and without disabilities: 12% of PwDs live in cities whereas this increases to 16% for persons without disabilities.⁶⁴

With the UNHS 2009/10 and UDHS 2011, the disability rate similarly varies between 16% and 19% respectively of the population aged above five years. The UNHS 2010/11 also acknowledges that the disability prevalence increases with age.

The variations in disability prevalence across the different studies demonstrate the lack of reliability of statistics in Uganda - so for example the percentage of PwDs has risen by more than 10 points over 10 years. This is most probably attributable to the shift from an “impairment” approach to a “limitations in functioning” approach and to the improvements in data collection, rather than any actual increase in the number of PwDs living in Uganda. This trend is also visible internationally reflecting the same issues in collecting accurate data relating to disability.

Comparing the various disability rates of the UBOS census and studies with the international statistics of the WHO and the World Bank, it can be estimated that about 15% of the Ugandan population are PwDs. About five million people live with some form of disabilities in Uganda. This comprises all types of impairments. The disability prevalence varies across the country: the Northern region has the highest rate while the Eastern and Central regions have the lowest rates.⁶⁵ There are also larger numbers of people with physical and sensory impairments (about 70% of the population of PwDs according to UNHS 2005/06). The main gap relating to the disability prevalence information in Uganda is a breakdown by gender - there is a lack of recent data on the number of women with disabilities across the country.

2.3. Child Disability Prevalence in Uganda

Similarly, the disability prevalence among the child population varies across different sources and time.

64. Uganda Bureau of Statistics (UBOS), Ugandan National Household Surveys 2005/06 - Report on the Socio-Economic Module, 2006, p. 130-135.

65. These variations between Northern Uganda and the rest of the country might be explained by the war, which took place in Northern Uganda, and many people acquired disabilities. However, no evidence has been found to confirm or invalidate this statement.

The Census 2002 reported that 205,272 children or 2% of the children aged five-17 years lived with disabilities - of these, 115,000 are boys (66% of CwDs) and 95,000 are girls (44% of CwDs).⁶⁶ All together 250,804 CwDs aged between zero to 17 were counted representing 29.7% of the overall population of children. The number of CwDs disaggregated by the different classifications of impairment has also been extracted by UBOS. They counted 79,884 children with physical disabilities, 62,958 with hearing disabilities, 36,554 with visual disabilities, 18,682 with speech disabilities, 12,862 with intellectual disabilities, 10,421 with mental health conditions, 11,762 as being epileptic and 3,966 as having rheumatism. A further 13,715 have another form of disability (Table 1).⁶⁷

The UNHS 2006 indicates that the child disability prevalence had increased. Again this is mostly due to improvements in data collection. The overall child disability rate aged five to nineteen years is slightly below 10% or 594,703 CwDs, while it falls to less than 5% for children aged five to nine years. Slightly more boys than girls have a disability.⁶⁸ The disability prevalence again varies across the regions: the highest rate can be found in the Northern region, followed by the Eastern and Western regions. The Central region and Kampala have the lowest child disability prevalence.⁶⁹ Finally, the UNHS 2006 reveals that the age structure differs between the population with and without disabilities: "among all PwDs, children constitute 31%, while for persons without disabilities, children constituted 60% of the population."⁷⁰

The UNHS 2009/10 finds that around 10% of the children aged between five and 19 live with some form of disability.⁷¹ Child disability prevalence slightly increases with the findings of the UDHS 2011: 12% of children between age five to nine are CwDs while the disability rate for people aged between five and 29 is of 13%. 53% of the population of PwDs is aged between six and 19 years of age.⁷²

In addition there are various estimations of the numbers of CwDs living in Uganda.⁷³ UBOS considers that there are 1.7 million CwDs living in Uganda, while the NUDIPU estimates that they are between 3 and 3.8 million.⁷⁴ USDC estimates the number of CwDs living in Uganda to be 1.22 million.⁷⁵

Additionally the Consolidated Report on the OVC Mapping Exercise 2012, conducted by the MoGLSD and supported by UNICEF Uganda, gives an up-to-date picture of the number of CwDs in the 32 "new" districts covered by the Study. These figures are not so helpful in isolation. They are, however, considered in this Intermediary Report - Summary and Analysis of Statistics for

66. Uganda Bureau of Statistics (UBOS), Uganda Population and Housing Census - Analytical Report Gender and Special Interest Groups 2002, 2003, p. 20-22.

67. Ugandan Bureau of Statistics (UBOS), Ugandan Population and Housing Census, Fountain Publishers, Uganda, 2005.

68. Uganda Bureau of Statistics (UBOS), Ugandan National Household Surveys (UNHS) 2005/06 - Report on the Socio-Economic Module, 2006, p. 130-131.

69. Uganda Bureau of Statistics (UBOS), Ugandan National Household Surveys (UNHS) 2005/06 - Report on the Socio-Economic Module, 2006, p. 155.

70. Uganda Bureau of Statistics (UBOS), Ugandan National Household Surveys (UNHS) 2005/06 - Report on the Socio-Economic Module, 2006, p. 132.

71. Uganda Bureau of Statistics (UBOS), Ugandan National Household Survey (UNHS) 2009/10, 2011, p. 136.

72. Uganda Bureau of Statistics (UBOS), Uganda Demographic and Health Surveys (UDHS) 2011 Full Report, 2012, p27.

73. Helen Nviiri, Pamela Kakande, Uganda Bureau of Statistics (UBOS), interviewed by Nadège Riche, 2013.

74. Ronald Luyima, National Union of Disabled Persons in Uganda (NUDIPU), interviewed by Nadège Riche, 2013.

75. Ugandan Society for Disabled Children (USDC), Annual Review April 2011 – March 2012, 2012.

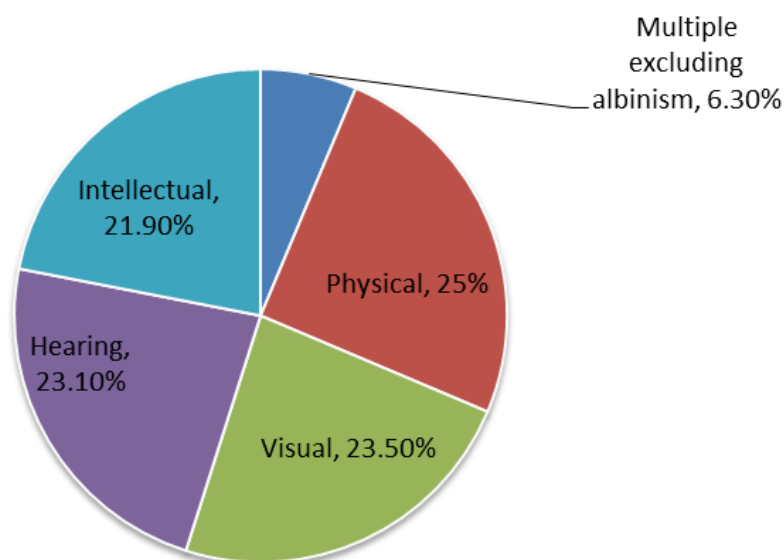
a reason: further information about CwDs is available but not fully exploited. Analysing the primary data collected in the framework of this OVC Mapping Exercise 2012 may provide with a better understanding of the situation of CwDs living in these 32 “new” Districts. It would for example be useful to have the percentage of CwDs in the district child population rather than numbers.

TABLE 7: CWDS PER GENDER AND PER THE 32 “NEW” DISTRICTS, IN NUMBER (UGANDA, 2012)

District	Female	Male	Total
Agago	833	1,115	1,948
Alebtong	1,389	1,823	3,212
Amudat	288	371	659
Buikwe	665	887	1,552
Bukomansimbi	410	434	844
Buhweju	374	563	937
Bulambuli	660	880	1,540
Butamabala	353	459	812
Buvuma	207	264	471
Buyende	1,028	1,456	2,484
Gomba	282	349	631
Kalungu	564	458	1,022
Kibuuku	1,417	1,904	3,321
Kiryandongo	537	889	1,426
Kole	437	571	1,008
Kween	282	404	686
Kyankwanzi	168	231	399
Kyegegwa	439	620	1,059
Lamwo	611	799	1,410
Luuka	686	873	1,559
Lwengo	1,080	1,399	2,479
Mitooma	609	911	1,520
Namayingo	240	361	601
Napak	758	872	1,630
Ngora	218	290	508
Ntoroko	263	338	601
Nwoya	655	760	1,415
Otuke	199	292	491
Rubirizi	410	556	966
Serere	847	1,326	2,173
Sheema	285	425	710
Zombo	851	1 186	2 037
Total	18 045	24 066	42 111

Source: MoGLSD, Consolidated Report on the OVC Mapping Exercise 2012, 2012

FIGURE 1: CWDS IN UGANDA PER TYPES OF IMPAIRMENTS, IN PERCENTAGE (%)
(UGANDA, 2011)



Source: African Child Policy Forum (ACPF), Children with Disabilities in Uganda: The Hidden Reality, Addis Ababa: The African Child Policy Forum, 2011, p.22.

As with the disability prevalence among the Ugandan population, the child disability rate varies over time and is dependent on different sources. This is again largely due to the use of different methodologies and improvements in data collection.

Comparing the various disability rates of the UBOS census and studies and the estimations of other stakeholders, the number of CwDs living in Ugandan is estimated between 1.22 to 3.8 million, with between 7 to 13% of children having a disability. Balancing the available data and taking into account what is known in the international context, it can be estimated that the disability prevalence among CwDs is about 12%, i.e. about 2.5 million children live with some form of disability in Uganda. The child disability prevalence varies across the country: the Northern region has the highest rate while the Eastern and Central regions have the lowest rates.

3. DISABILITY AND EDUCATION

The statistical information available worldwide and in Uganda indicates an extremely low enrolment and completion of primary and secondary schools by CwDs. As with the data relating to child disability prevalence, the figures and estimations vary according to the different sources of information, definition of disability used and the assessment tools used.

3.1. Worldwide Statistics

UNESCO states that 98% of CwDs in low- and middle-income countries are not enrolled in school⁷⁶ and that 99% of girls with disabilities are illiterate.⁷⁷ On the contrary, the WHO and World Bank estimate that the primary school completion for PwDs in low income countries is 45.6% for boys and 32.9% for girls, compared to 55.6% and 42% respectively for male and female without disabilities. Similarly, the mean years of education are of 5.63 years for boys with disabilities and 4.17 for girls with disabilities, compared to 6.43 and 5⁷⁸ respectively for male and female.

The WHO and World Bank also report that the school enrolment rates vary across the impairment spectrum: “children with physical impairments generally fare better than those with intellectual and sensory impairments.”⁷⁹ These large variations cannot be explained in the framework of this Intermediary Report – Summary and Analysis of Statistics. It can however be concluded that CwDs are significantly less likely to attend and complete primary (and secondary) school compared to their peers without disabilities.

3.2. Ugandan Statistics

Similar estimations and conclusion apply to Uganda.

3.2.1. Enrolment Rates of Children with Disabilities in Pre-Primary, Primary and Secondary School

Statistical information relating to the enrolment in pre-primary, primary and secondary schools is available for pupils and students with disabilities.

The Census 2002 counted that 19% of CwDs aged seven to 16 have never been to school (compared to 10% of children without disabilities on average) and 39% of those aged 17 to 22 had completed fewer than four years of education (compared to 26% of those without disabilities on average).⁸⁰

UBOS included questions relating to school enrolment and completion by PwDs in the UNHS 2005/06. It reports that 80% of PwDs attended primary school (81% of people without disabilities). 65% of the PwDs aged 13 years and above and out of school had not completed primary level (compared to 53% of the people without disabilities). 13% of PwDs explained that they had no problem to attend school. However, 41% said they were limited all the time and in particular this is true for 60% of the visually-impaired people. Persons who have difficulties in self-care were less likely to attend school. 66.6% of persons with mental health conditions aged from six to 24 had their school attendance either fully or partially affected by their disability.⁸¹ Similar rates have been found as part of the UNHS 2009/10.

76. United Nations Educational, Scientific and Cultural Organisation (UNESCO), Policy Brief on Early Childhood, Inclusion of Children with Disabilities: The Early Childhood Imperative, N° 46, April-June 2009.

77. United Nations Educational, Scientific and Cultural Organisation (UNESCO), From Exclusion to Equality: Realising the rights of persons with disabilities – Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol, United Nations, Geneva, 2007.

78. World Health Organisation (WHO), World Bank, World Report on Disability, Geneva: WHO/World Bank, 2011, p. 207.

79. World Health Organisation (WHO), World Bank, Summary World Report on Disability, Geneva: WHO/World Bank, 2011, p. 8.

80. United Nations Educational, Scientific and Cultural Organisation (UNESCO), Education For All Global Monitoring 2010 Report Reaching the marginalised, 2010, p.184.

81. Uganda Bureau of Statistics (UBOS), Ugandan National Household Surveys 2005/06 - Report on the Socio-Economic Module, 2006, p. 130-35.

In addition to the UBOS census and surveys, the MoES included questions relating to disability in its annual survey counting the number of pupils and students enrolled in pre-primary, primary and secondary schools since 2007. Despite the strong limitations of these Annual Surveys, this is the best source of available data relating to school enrolment of CwDs living in Uganda and it is therefore presented here.

In 2008, the registered number of CwDs in primary and secondary school was of respectively 183,537 and 11,415 CwDs.⁸²

According to the surveys conducted by the MoES, the number of CwDs in pre-primary, primary and secondary school is low:

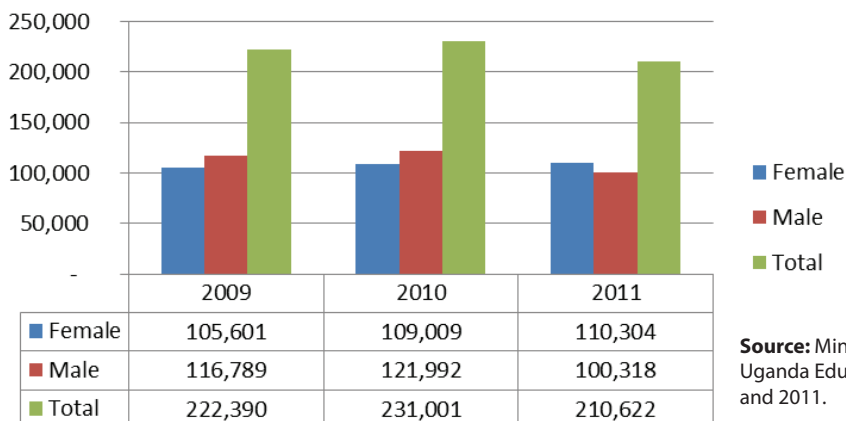
- In 2009, 4,620, 204,352 and 13,418 CwDs were enrolled respectively in pre-primary, primary and secondary school (Figure 2 and Table 3).
- In 2010, 12,465, 205,018 and 12,993 CwDs were enrolled respectively in pre-primary, primary and secondary school (Figure 2 and Table 3).
- In 2011, 4,347, 197,200 and 3,075 CwDs were enrolled respectively in pre-primary, primary and secondary school (Figure 2 and Table 3).

This statistical information suggests that about 9% of the 2.5 million CwDs living in Uganda were enrolled in either pre-primary, primary or secondary schools over the 2009-11 period. This is a strikingly different from the figures produced by the UNHS 2005/06 and must be due to the use of different methodologies.

The 2010 enrolment rate in pre-primary school is presented in the Figure 2 and Table 3. However these figures cannot be compared to those of 2009 and 2011 as, in 2010, in addition to the CwDs in nursery, community and home based centres, enrolment in day care centres was also considered, which was not been the case in 2009 and 2011. This explains the higher enrolment rate in pre-primary schools in 2010.

FIGURE 2: CWDS IN PRE-PRIMARY, PRIMARY AND SECONDARY SCHOOL PER YEAR, IN

CwDs in pre-primary, primary and secondary school per year, in number



Source: Ministry of Education and Sports (MoES), Uganda Education Statistical Abstract 2009, 2010 and 2011.

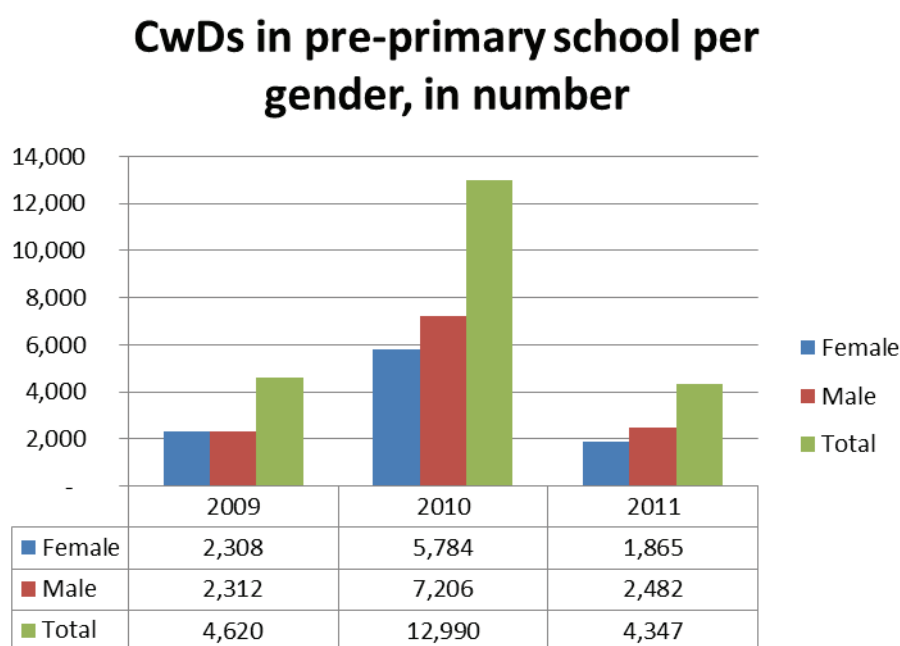
82. Government of Uganda, United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), Uganda's Initial Status Report 2010, 2011, p. 35.

TABLE 8: OVERALL SCHOOL ENROLMENT OF CWDS PER SCHOOL LEVEL AND PER YEAR, IN NUMBER (UGANDA, 2009, 2010 AND 2011)

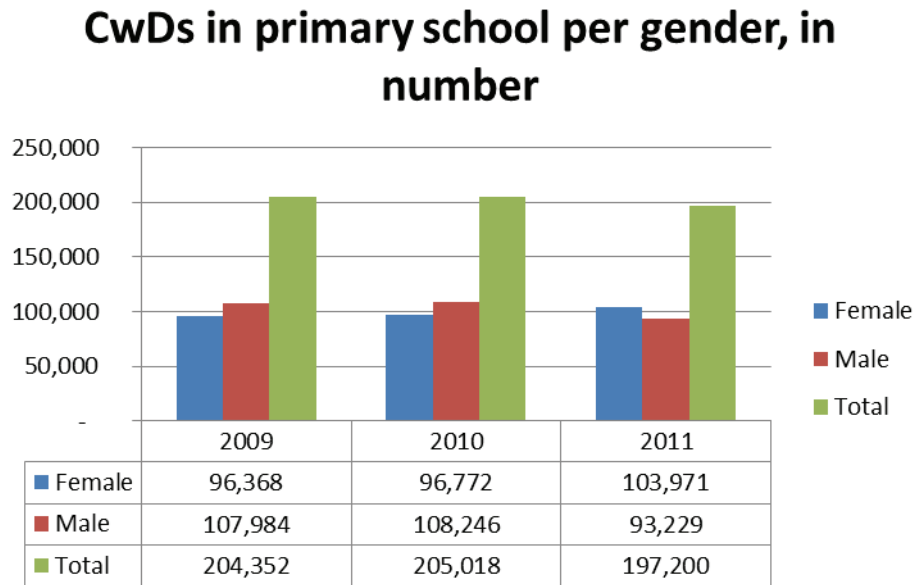
	Pre-Primary	Primary	Secondary	Total	Total of children enrolled in pre-primary, primary and secondary	Percentage (%)
2009	4,620	204,352	13,418	222,390	9,649,236	2.3
2010	12,465	205,018	12,993	230,476	10,006,324	2.3
2011	4,347	197,200	9,075	210,622	3,387,003	2.2

Source: Ministry of Education and Sports (MoES), Uganda Education Statistical Abstract 2009, 2010 and 2011.

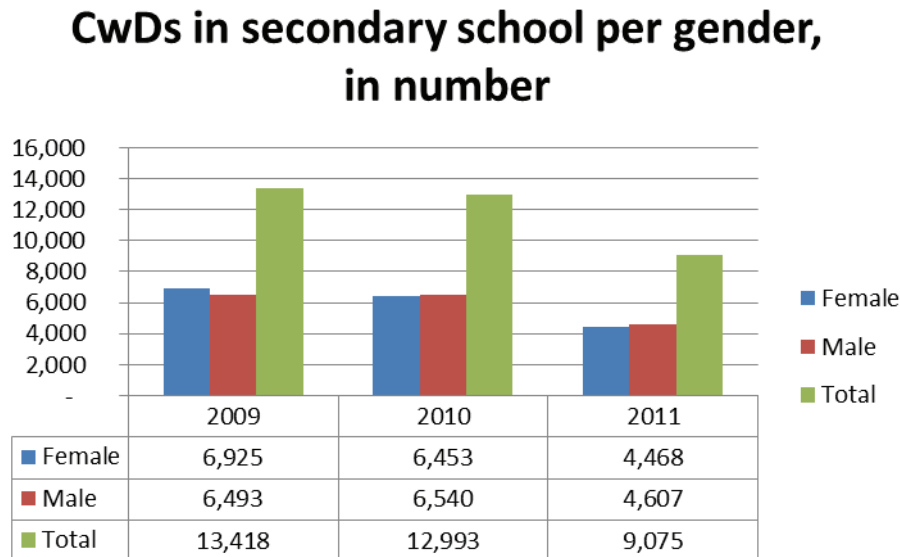
It is also significant to note that overall, the gender parity gap was closed at 50% for both boys and girls with disabilities. The enrolment rate for male and female CwDs is similar over time (2009, 2010 and 2011) and over education levels (pre-primary, primary or secondary schools). This means that there is an equivalent number of boys and girls with disabilities attending school.

FIGURE 3: CWDS IN PRE-PRIMARY SCHOOL PER GENDER, IN NUMBER (UGANDA, 2009, 2010 AND 2011)

Source: Ministry of Education and Sports (MoES), Uganda Education Statistical Abstract 2009, 2010 and 2011.

FIGURE 4: CWDS IN PRIMARY SCHOOL PER GENDER, IN NUMBER (UGANDA, 2009, 2010 AND 2011)

Source: Ministry of Education and Sports (MoES), Uganda Education Statistical Abstract 2009, 2010 and 2011.

FIGURE 5: CWDS IN SECONDARY SCHOOL PER GENDER, IN NUMBER (UGANDA, 2009, 2010 AND 2011)

Source: Ministry of Education and Sports (MoES), Uganda Education Statistical Abstract 2009, 2010 and 2011.

3.2.2. Drop-Out Estimations

During the period 2009-2011, about 201,190 pupils with disabilities were in primary school and about 11,829 went on to secondary school on average. This suggests that about 94% of CwDs drop out of school between the primary and secondary levels. Approximately 6% complete primary school and continue studying in secondary school. This dropout rate of CwDs is much higher than the 25 to 50% average. In other words, only 6% of CwDs complete primary school, whereas 50 to 75% of children without disabilities pass the primary school level.

This partly corroborates USDC estimations. USDC reports that between 5 to 10% of CwDs complete primary school level. Out of the 5 to 10% of CwDs completing primary school, only 25% access secondary school. This is due to, among other reasons, poor teaching or the inaccessibility of buildings and toilets⁸³.

USDC estimates that one third of all children out of school in Uganda are CwDs. They constitute the largest minority group dropping out and not completing primary school, although it is estimated that 60% of all CwDs could attend school with no special adaptations and 85% could benefit from education with minor adaptations⁸⁴.

The MoES has no data on the drop-out rate or on the numbers of CwDs out of school⁸⁵.

3.2.3. Disaggregation by Impairments

Between 2009-2011, the largest percentage of CwDs in pre-primary school had hearing disabilities followed by children with mental health conditions, children with visual disabilities, children with physical disabilities and then children with autism. The lowest percentage was children with multiple disabilities (Figures 6).

In 2009 and 2010, the highest percentage of the pupils with disabilities in primary school had hearing disabilities. Other CwDs include pupils with visual disabilities, pupils with mental health conditions, pupils with physical disabilities, pupils with autism and then pupils with multiple disabilities (Figure 7).

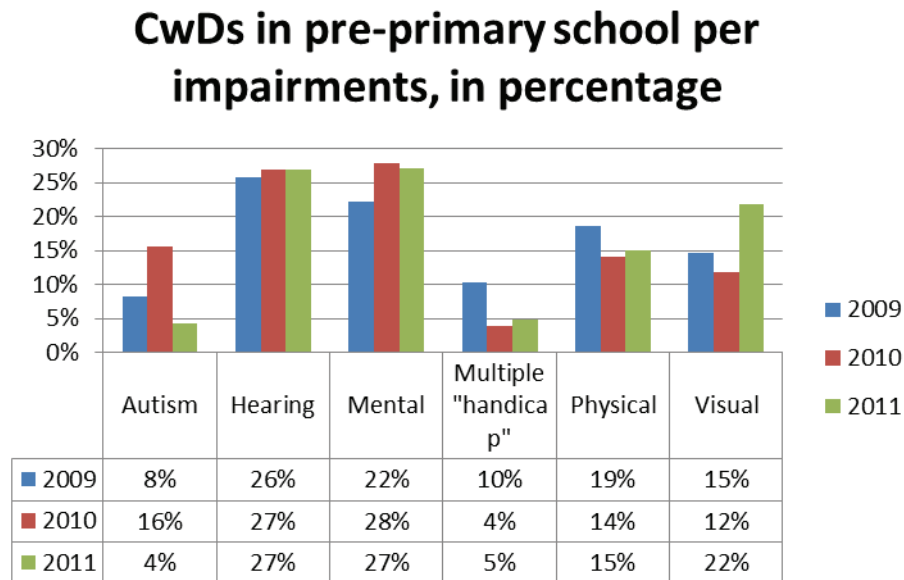
In 2010, the highest percentage of students with disabilities in secondary school had visual disabilities, followed by students with physical disabilities, students with hearing disabilities, students with mental health conditions, students who have multiple disabilities and then students who have autism (Figure 8).

Overall, children with sensory disabilities (e.g. visually- and hearing-impaired children) have the highest chance to access schools and complete primary level, whereas children with mental and cognitive disabilities (e.g. autism) and children with multiple disabilities are less likely to attend school.

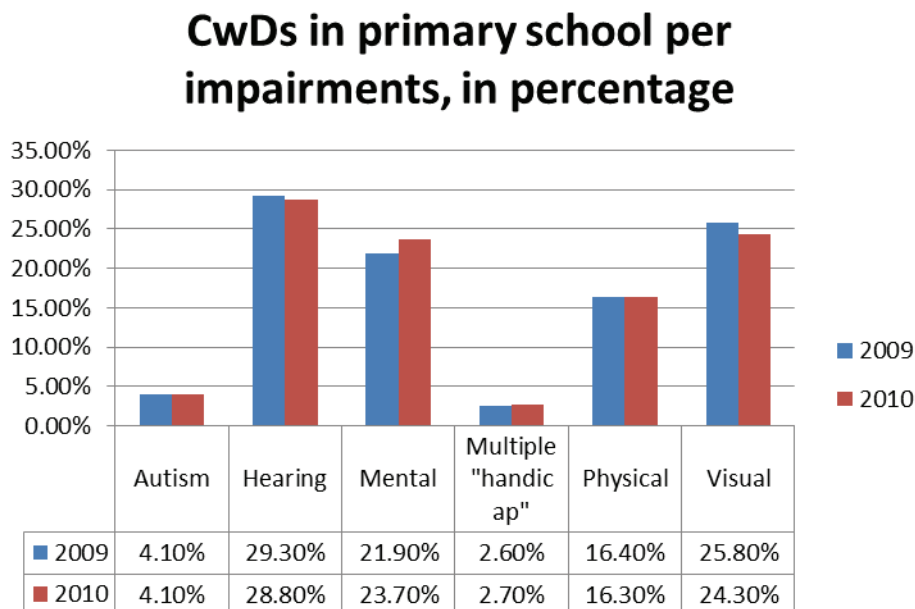
83. Dolorence Naswa Were, Uganda Society for Disabled Children (USDC), interviewed by Nadège Riche, 2013.

84. Uganda Society for Disabled Children (USDC), USDC Advocacy Strategy 2013-16, 2012, p.2.

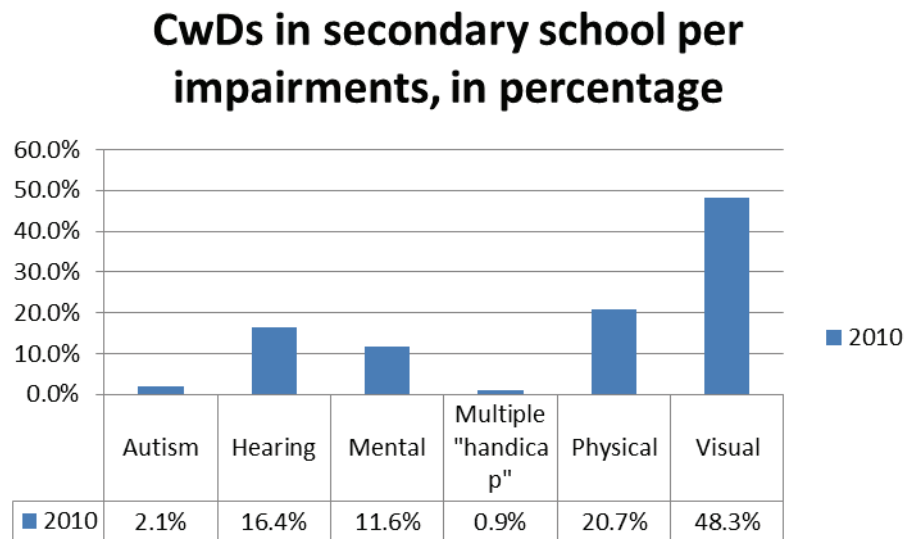
85. Christopher Wimon Okecho, Ministry of Education and Health (MoES), interviewed by Nadège Riche, 2013.

FIGURE 6: CWDS IN PRE-PRIMARY SCHOOL PER IMPAIRMENTS, IN PERCENTAGE (UGANDA, 2009, 2010 AND 2011)

Source: Ministry of Education and Sports (MoES), Uganda Education Statistical Abstract 2009, 2010 and 2011.

FIGURE 7: CWDS IN PRIMARY SCHOOL PER IMPAIRMENTS, IN PERCENTAGE (UGANDA, 2009 AND 2010)

Source: Ministry of Education and Sports (MoES), Uganda Education Statistical Abstract 2009 and 2010.

FIGURE 8: CWDS IN SECONDARY SCHOOL PER IMPAIRMENTS, IN PERCENTAGE (UGANDA, 2010)

Source: Ministry of Education and Sports (MoES), Uganda Education Statistical Abstract 2010.

3.2.4. Geographical Coverage

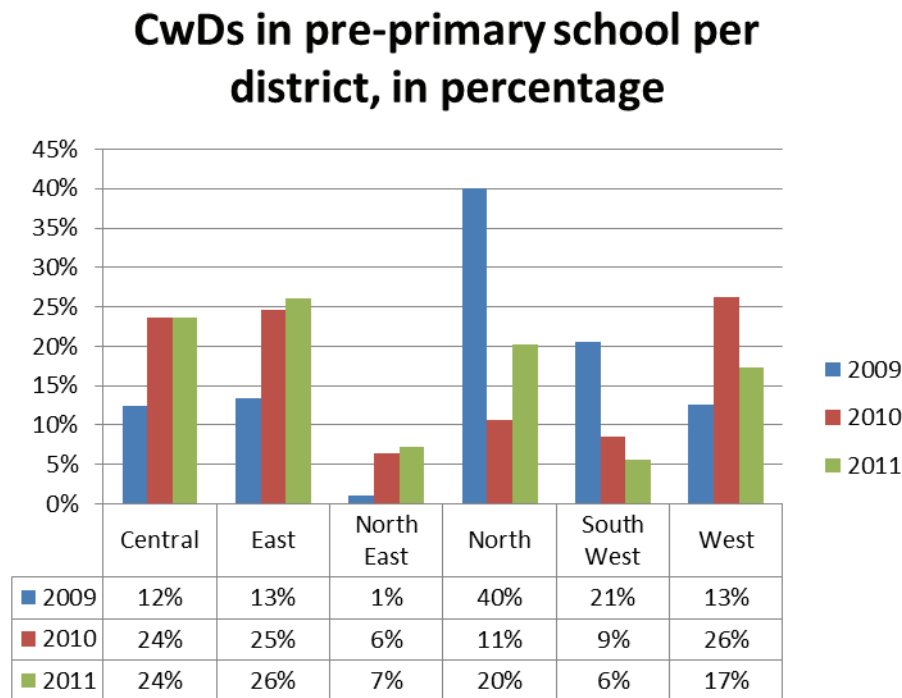
A regional analysis indicates that the highest proportion of CwDs in pre-primary school over the period 2009-11 are from the Northern region (24%), followed by the East (21%), Central (20%), West (19%), South-West (12%) and North-East (5%) regions (Figure 10).

Pupils in primary school from 2009 to 2011 primarily come from the East region (27%), followed by the North (27%), Central (18%), West (13%), South-West (9%) and North-East (1%) (Figure 11).

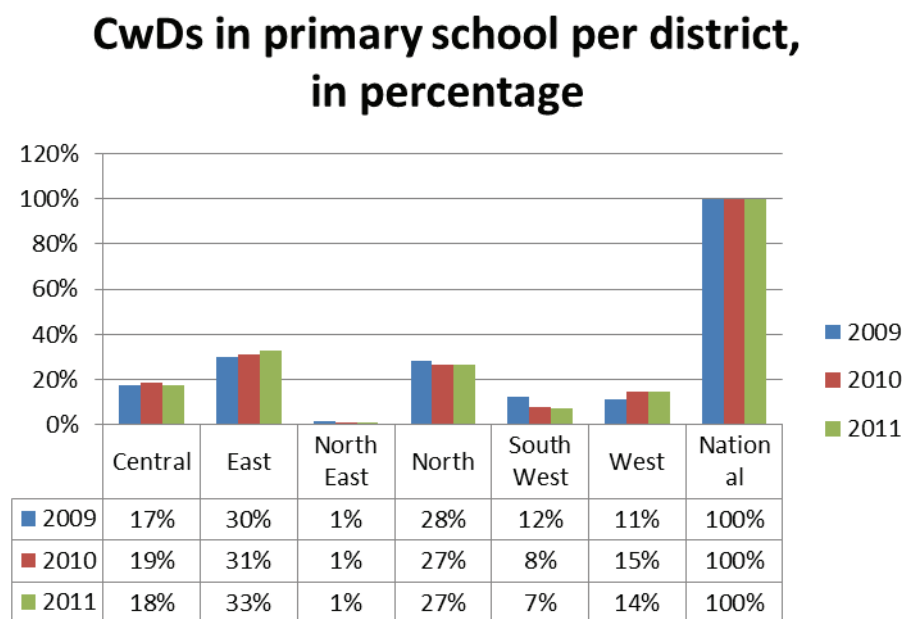
Over the same period, the highest proportion of students with disabilities in secondary schools is from the Central region (37%) while the lowest proportion is from the North-East (1%). In-between, it decreasingly ranges from 27% in the East, 16% in the North, 10% in the South-West and 5% in the West regions (Figure 12).

These figures do not take into account or assess the widespread evidence that there are more CwDs in the Northern regions of Uganda. Whereas higher rates are seen in the Northern region, the lowest rate is in the North-East region that has also been affected by the war. It can also be argued that the variations in percentages of CwDs attending schools across the regions are due to the irregular geographic coverage of special schools or schools with an annex for CwDs. CwDs in schools often come from other distant Districts.⁸⁶

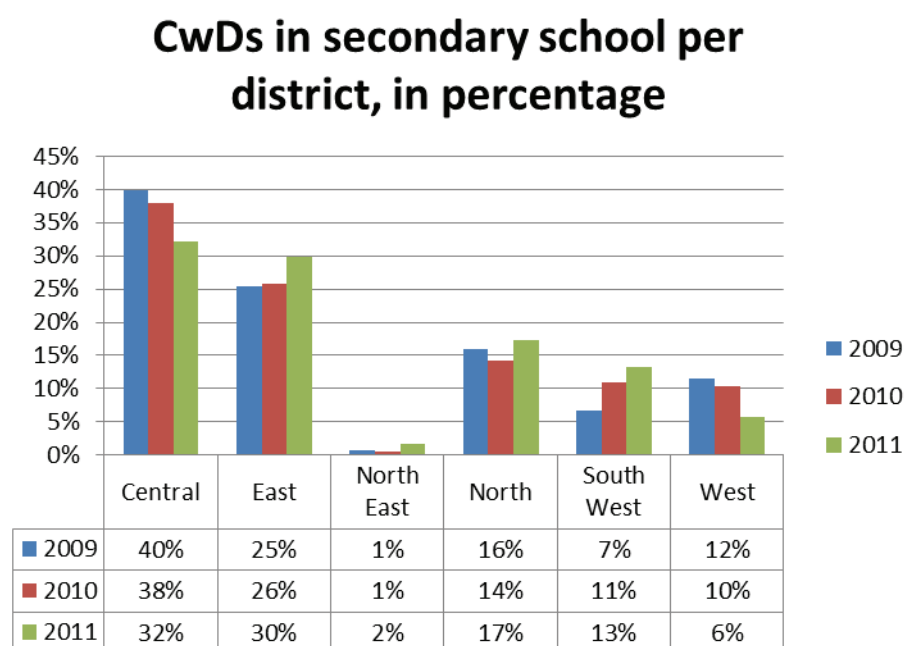
86. Welsey Apio, Alfred Ojok, Jimmy Opiyo and Salomon Opiyo, four CwDs attending Gulu Primary School, interviewed by Nadège Riche, 2013.

FIGURE 9: CWDS IN PRE-PRIMARY SCHOOL PER DISTRICT, IN PERCENTAGE (UGANDA, 2009, 2010 AND 2011)

Source: Ministry of Education and Sports (MoES), Uganda Education Statistical Abstract 2009, 2010 and 2011.

FIGURE 10: CWDS IN PRIMARY SCHOOL PER DISTRICT, IN PERCENTAGE (UGANDA, 2009, 2010 AND 2011)

Source: Ministry of Education and Sports (MoES), Uganda Education Statistical Abstract 2009, 2010 and 2011.

FIGURE 11: CWDS IN SECONDARY SCHOOL PER DISTRICT, IN PERCENTAGE (UGANDA, 2009, 2010 AND 2011)

Source: Ministry of Education and Sports (MoES), Uganda Education Statistical Abstract 2009, 2010 and 2011.

3.2.5. School Attendance and Household Wealth Status

UNESCO has researched the impact that levels of wealth or household poverty have on school attendance of CwDs. From the figures presented in Table 4 below, it is clear that CwDs living in Uganda have a lower enrolment rate compared to the average of children: 19% of CwDs aged seven to 16 years have never been to school, compared to 10% of children on average. The rate even increases to 28% of CwDs who have never been to school and who live in the 20% poorest households. Unsurprisingly, the poorer a household is, the less chance there is of CwDs to attend school.

TABLE 9: EDUCATION INDICATORS PER DISABILITY STATUS OF HEAD OF HOUSEHOLD AND WEALTH, IN PERCENTAGE (%) (UGANDA, 2002)

7- to 16-year-olds who have never been to school	7- to 16-year-olds who have never been to school	7- to 16-year-olds who have never been to school	17- to 22-year-olds with fewer than 4 years of education	17- to 22-year-olds with fewer than 4 years of education	17- to 22-year-olds with fewer than 4 years of education
Average	Disabled	Disabled* from poorest 20%	Average	Disabled	Disabled* from poorest 20%
3	21	28	6	30	44

* 'Disabled' refers to self-reported disability status of the household head.

Source: United-Nations Educational, Scientific and Cultural Organisation (UNESCO), Education for All (EFA) Global Monitoring 2010 - Report Reaching the Marginalised, 2010, p. 184.

3.2.6. *Conclusions on Education and Disability*

To conclude, there are problems with the reliability of the statistical information about CwDs in pre-primary, primary and secondary schools and therefore it is only possible to partly assess the situation of CwDs in education. Very few CwDs complete a primary level of education and even fewer attend and complete secondary school. Boys and girls with disabilities have similar enrolment rates across all educational level. With regards to CwDs, Uganda is therefore far from attaining Millennium Development Goal number two which aims to achieve primary education for all.

In addition the data mostly refers to children with visual or hearing impairments.⁸⁷ Children with intellectual disabilities, multiple disabilities or psychosocial disabilities are less likely to attend school.

UNICEF identified that, in Africa, only 5% of CwDs attend Inclusive Education (IE) schools and 10% go to Special Needs Education (SNE) Schools (i.e. special schools or a school with an annex for CwDs).⁸⁸ In Uganda, no data has been made available to show whether the identified children are being educated in special schools, annexes and units or within mainstream schools. However, clearly the percentage of CwDs enrolled in school remains low compared to the estimated numbers of PwDs in the population as a whole.

3.2.7. *School Environment*

The inaccessible school environment (i.e. access to classrooms and latrines) plays a significant role in the drop-out of CwDs.⁸⁹ UNESCO reports that 50% of the schools “in developing countries do not provide healthy learning environments with water and sanitation facilities that are accessible for CwDs.”⁹⁰

4. DISABILITY AND VARIOUS FIELDS RELATING TO THE EVERYDAY LIFE OF CHILDREN WITH DISABILITIES

Aside from the child disability prevalence and access to primary and secondary education, sources of statistical information relating to CwDs worldwide and in Uganda are scarce. This section presents an overview of the situation in other fields relating to the everyday life of CwDs by presenting the available data.

4.1. **Causes of Disability**

The ACPF is the only organisation that has studied the causes and onsets of disability in Africa and Uganda. “The major causes of disability in Africa are communicable diseases, war, accidents, and inadequate prenatal and neonatal health care services”. Among children in Africa, the leading cause of disability is illness acquired before the age of five years, accounting for one third to half of the cases. The majority of these disabilities are preventable.”⁹¹

87. Ronald Luyima, National Union of Disabled Persons in Uganda (NUDIPIU), interviewed by Nadège Riche, 2013.

88. United Nations Children's Fund (UNICEF), Fast Facts - Day of the African Child: Uganda, 2012, p. 1.

89. Dolorence Naswa Were, Uganda Society for Disabled Children (USDC), interviewed by Nadège Riche, 2013.

90. United Nations Educational, Scientific and Cultural Organisation (UNESCO), Education for All (EFA) Global Monitoring 2010 - Report Reaching the Marginalised, 2010.

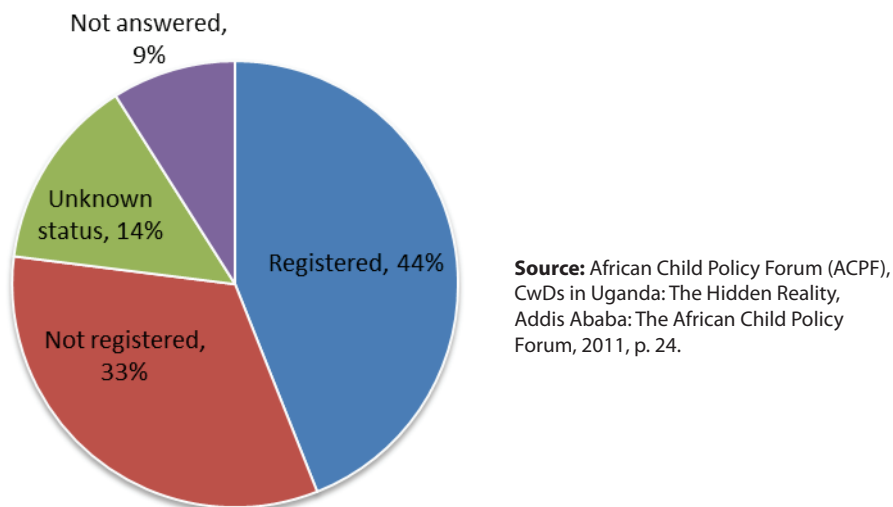
91. African Child Policy Forum (ACPF), Children with Disabilities in Africa: Challenges and Opportunities, Addis Ababa: The African Child Policy forum, 2011, p. XXXV.

In Uganda, the major onset of disability among children is illness as evidenced in the UBOS Census 2002 and ACPF Report 2011. The second cause of disability is congenital or acquired around birth. The remaining reasons which are given are accidents and curse from God (or similar). This suggests that people have acquired a better awareness of disability and its causes and that only a minority of people today attribute disability to a curse or a malediction. Although this is true that few Ugandan people still believe that a curse or God is the cause of disability, this is not considered as the main reason of disability any more.

4.2. Disability and Birth Registration

Although the understanding of the causes of disability has improved, CwDs are still referred to as “invisible” children. They are often kept at home, hidden from society by their families and most of them are not registered at birth or death. The ACPF Study Children with Disabilities in Uganda – the Hidden Reality 2011, however, estimates that the situation appears to be improving. Almost half of the 540 CwDs (44%), who were involved in the Study, are registered. Another 33% are not registered while 14% have an unknown status and 9% did not answer the question (Figure 13).

FIGURE 12: BIRTH REGISTRATION OF CWDS, IN PERCENTAGE (%) (UGANDA, 2011)



4.3. Enjoyment of Human Rights

Globally, the CRC Committee estimated in 2007 that CwDs are “five times more likely to be victims of abuse”. This includes mental and physical violence and sexual abuse.⁹²

In Uganda, USDC and the NCC issued a report assessing the abuse, protection and promotion of rights of CwDs in Uganda in 2011 corroborating the CRC Committee estimations. The Study is based on fact findings in the four districts of Iganga, Jinja, Kampala and Masaka. USDC considers that 90% of CwDs do not access or enjoy their rights to survival, development, protection and

92. Convention on the Rights of Child (CRC) Committee, General Comments No. 9 - The Rights of Children with Disabilities (CRC/C/GC/9), 27 February 2007, p. 12-13.

participation. Although most parents and local decision-makers are aware of the needs and challenges faced by CwDs, socio-cultural beliefs and attitudes prevent the realisation of the human rights of CwDs. It means that “many communities perceive impairment or disability as something beyond their comprehension. Unless disability is as a result of accident, knowledge seems to be overshadowed by mystery once sickness reaches the level of impairment and is considered as bad omen and curse.”⁹³ Disability remains difficult to be understood and accepted by the families and communities and this is the primary reason why CwDs cannot access care, protection, health or education.⁹⁴

4.4. Disability and Poverty

People living in low- and middle-income countries are significantly more likely to have or incur a disability within their lifetime. This is relatively well evidenced in Uganda, although the available data is 10 years old. In 2003, a Study reported that about 80% of PwDs live in conditions of long-term poverty. “If this figure is taken as an indicator of poverty level among PwDs then, according to the current population estimate, there are about one million poor PwDs. In other words, out of every 10 Ugandans living in abject poverty one is a person [with disabilities].”⁹⁵ In 2004, NUDIPU conducted a Survey on the situation of PwDs in Northern Uganda⁹⁶ and established a high correlation between poverty and disability - 72% of PwDs live in a chronic state of poverty in the Northern region of Uganda. However, this survey took a qualitative approach and did not produce any reliable quantitative data and focused on the Northern Region only.⁹⁷

4.5. Disability and Humanitarian Crisis

Statistical information relating to CwDs facing humanitarian emergencies and crisis are extremely rare. No data is available for Uganda. The Atlas Alliance and CBM consider that, “for every child killed in conflict, three are injured and permanently [have acquired disabilities]”⁹⁸.

4.6. Disability and (re)habilitation

Access to health and (re)habilitation is the first practical step to enable CwDs to move around, go to school and participate in social life.⁹⁹ USDC considers that only 10% of CwDs living in Uganda actually benefit from (re)habilitation services.¹⁰⁰ Based on their representative sample, ACPF presents a slightly better picture of the situation. Most carers of CwDs reported that they have access to health care services and around 20% of CwDs have access to (re)habilitation services. The vast majority of these services are provided by the Government

93. Network on Disabled Children, Uganda Society for Disabled Children (USDC), National Council for Children, The State of Abuse, Protection and Promotion of the Rights of Children with Disabilities in Uganda, 2011, p. 14.

94. Network on Disabled Children, Uganda Society for Disabled Children (USDC), National Council for Children, The State of Abuse, Protection and Promotion of the Rights of Children with Disabilities in Uganda, 2011.

95. Development Research and Training (DRT), Study on Chronic Poverty, 2003.

96. National Union of Disabled Persons of Uganda (NUDIPU), Northern Uganda Survey 2004, 2004.

97. Norwegian Agency for Development Cooperation (NORAD), Mainstreaming disability in the new development paradigm - Evaluation of Norwegian support to promote the rights of persons with disabilities - Uganda country report, February 2012, p. 9.

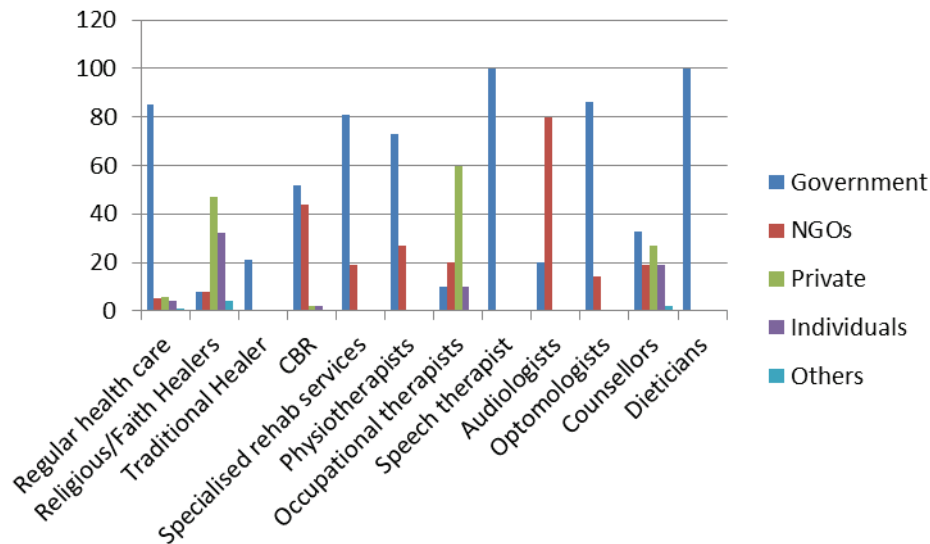
98. Atlas Alliance, CBM, Factsheet: Disability in Conflicts and Emergencies, 2011.

99. Caroline Adong, National Council for Disability, interviewed by Nadège Riche, 2013.

100. Network on Disabled Children, Uganda Society for Disabled Children (USDC), The State of Abuse, Protection and Promotion of the Rights of Children with Disabilities in Uganda, 2011.

followed by NGOs. One third of CwDs report that they would like to use health services but cannot for various reasons: the services are too expensive or too far from home or parents, families or carers do not see the value of bringing the CwDs to a health care or (re)habilitation centre.

FIGURE 13: HEALTH CARE SERVICE PROVIDERS USED BY CWDs, IN NUMBER (UGANDA, 2011)



Source: African Child Policy Forum (ACPF), CwDs in Uganda: The Hidden Reality, Addis Ababa: The African Child Policy Forum, 2011, p. 49.

Part 4: Presentation and Analysis of the Institutional and Regulatory Frameworks

CRPD Article 4 (1) requires State Parties to take into consideration and implement the rights of PwDs, enshrined in this Convention, by all means at their disposal. This includes the adoption, amendment and review of legislation (Article 4 (1) (a) and (1) (b)) as well as “the protection and promotion of the human rights of PwDs in all policies and programmes” (Article 4 (1) (c)).

is therefore an essential exercise. In this way, it is possible to identify and assess how the laws and policies support and protect the human rights of CwDs living in Uganda and the types of initiative that the national and local Government Institutions have taken to address their rights and needs. The role, powers and structure of the Ugandan Government Ministries and Bodies, whose initiatives directly impact on the realisation of the rights of CwDs, are discussed. The decentralisation of government in Uganda through the role of Districts and its impact in relation to CwDs is also considered and the example of the Gulu District is provided. While the influence of international laws is explained, the main focus is on Ugandan legislation and policies as they have a direct effect on the living situation of CwDs in Uganda. Each piece of legislation and the policies relating to disability, children, education and health and directly targeting CwDs are presented and analysed in depth (Annexe 2).

1. THE INSTITUTIONAL FRAMEWORK: THE ROLE OF NATIONAL AND LOCAL GOVERNMENT INSTITUTIONS

This section outlines the role, powers and mandate of various government ministries, national councils and commissions as well as local government institutions in promoting and protecting the rights of CwDs living in Uganda.

The ministries, councils and commissions include the MoGLSD, MoES, MoH, the Ministry of Finance, Planning and Economic Development (MoFPED), the NCD, the National Council for Children (NCC), the Uganda Human Rights Commission (UHRC), the EOC and the Local Government Institutions at district, sub-county, parish and village level.

1.1. National Government Institutions

1.1.1. The Ministry of Gender, Labour and Social Development

The MoGLSD aims to provide better standard of living, equity and social cohesion and specifically targets the most disadvantaged parts of the Ugandan population. It is the lead Ministry for disability issues. The Ministry is responsible for the protection and promotion of the human rights and for improving the welfare of “vulnerable” populations through the initiation and implementation of legislation, policies and programmes relating to their empowerment and their social, economic and cultural development. The Ministry also supervises the work of all stakeholders working in the social development and human rights sector. The Ministry has a Department of Children and Youth Affairs which is responsible for children and youth empowerment programmes as well as a Department of Elderly and Disability Affairs responsible for older people and PwDs development programmes.

The Disability and Elderly Department of the MoGLSD runs several programmes which indirectly cover and impact on CwDs.

1.1.1.1. The Community-Based Rehabilitation Programme ¹⁰¹

WHO defines Community-Based Rehabilitation (CBR) as follows: “CBR focuses on enhancing the quality of life for PwDs and their families, meeting basic needs and ensuring inclusion and participation. CBR was initiated in the mid-1980s but has evolved to become a multi-sectoral strategy that empowers PwDs to access and benefit from education, employment, health and social services. CBR is implemented through the combined efforts of PwDs [themselves], their families, organisations and communities, relevant government and non-government health, education, vocational, social and other services.”¹⁰²

CBR is the main programme targeting PwDs in Uganda and was introduced in 1992 with the support of the Norwegian Association of Disabled (NAD). The first phase of the implementation of the CBR programme in Uganda consisted of a successful pilot project in the three Districts of Iganga, Mukono and Tororo. This was rapidly expanded to the seven other Districts of Busenyi, Kabale, Kamuli, Mbale, Mbarara, Mtungama and Mutero. The programme had a comprehensive approach and the activities covered the various areas of the everyday life of PwDs. This consisted of awareness raising events to challenge the negative attitudes of the communities towards PwDs, nutrition and health assessment, provision of counselling services and of assistive devices, design of projects to

101. Katende Phoebe, Chapter 12: The Process of Community-Based Rehabilitation and its Unfolding Evolution in Uganda, In Katende Phoebe, Hon. Ndezi Alex, Batesaki Barbara, Mwesigye James, Dr. Nganwa Alice, A Handbook on Disability experiences and approaches in Uganda, 2010. This article presents a detailed history of the CBR programmes implemented in Uganda.

102. World Health Organisation (WHO), Community-Based Rehabilitation (CBR), <http://www.who.int/disabilities/cbr/en/>, (Accessed on 3 February 2014).

access education and vocational trainings as well as livelihood activities.

In 2000, the MoGLSD established the national CBR Steering Committee to monitor and evaluate the implementation of the CBR programme countrywide. Two major concerns were identified. Despite the running of the programme over eight years, a lack of participation of PwDs was identified in all Districts and the Tororo District concentrated all types of problems encountered in the running of the CBR programme in Uganda.

In 2008/09, NAD withdrew and the CBR programme is now funded by the MoFPED and run by the MoGLSD in the 24 Districts of Arua, Budaka, Buhweju, Buikwe, Butaleja, Busia, Hoima, Kaliro, Kanungu, Kasese, Kayunga, Kyegegwa, Masaka, Mitooma, Nakasongola, Paliisa, Rubiziri, Sheema, Tororo and Wakiso. However, the MoGLSD lacks technical and financial support to expand the CBR programme outside of the 24 Districts where it is currently operational.

A core element of the CBR programme is to address the needs and rights of CwDs. The specific activities targeting CwDs consist of identifying CwDs and assessing their needs with appropriate referral to health services, including nutrition and counselling, and (re)habilitation, education and vocational training and raising awareness of parents, guardians and caretakers to challenge their misconceptions about disability.¹⁰³

In this respect, the MoGLSD and USDC work in partnership and run several activities together. These are implemented in eight Districts: Adjumani, Apac, Arua, Hoima, Lira, Luwero, Masaka and Masindi. In Apac, Luwero and Masindi, parents of CwDs have formed groups registered under the MoGLSD and run the centres. These Parent Support Groups (PSGs) support the set-up of (re)habilitation centres for CwDs in the Referral Hospitals in these eight Districts with support of the Ministry. These centres consist of a physiotherapy unit, an orthopaedic workshop and a hostel to stay before/after the surgery.

In parallel, USDC has an office in the Districts of Adjumani, Arua, Hoima, Lira and Masaka. They supervise and lobby the District and/or MoGLSD to establish partnerships whereby the government gives a plot for free while USDC builds a (re)habilitation centre, with donors' support, which then belongs to the government. Both government and USDC pay staff. The centres also serve as workshops to build assistive technologies, for which the government has provided material (e.g. metal, leather) for free. USDC also organises many outreach clinics and the sensitisation of parents and children can be better achieved when it is delivered closer to where families live.

1.1.1.2. The Mine Victim Assistance Programme¹⁰⁴

In place since 2009/10, this programme targets landmine survivors, many of whom are children who have acquired a disability. The MoGLSD and MoH

103. Kaggya Nabulime, Beatrice, Ministry of Gender, Labour and Social Development (MoGLSD), Interviewed by Nadège Riche, 2013.

104. Kaggya Nabulime, Beatrice, Ministry of Gender, Labour and Social Development (MoGLSD), Interviewed by Nadège Riche, 2013.

assess their situation and support both medical and psychosocial treatment and (re)habilitation as well as livelihoods. Both Ministries also partner with other organisations: UNDP has provided assistive technologies and mobility devices in several districts, and Plan supports Tororo local government in the care of CwDs under this Programme. Additionally, because Gulu Referral Hospital is unable to take care of the numerous people needing medical treatment, people are also sent to the orthopaedic workshops in Bulouba and Kumi Hospitals.

1.1.1.3. The Special Grants for PwDs¹⁰⁵

This countrywide and decentralised programme aims to support Income Generating Activities for PwDs. At present, non-disabled parents of CwDs cannot benefit from it but the MoGLSD has put a proposal forward to address this with the support of the District Local Governments (which allocate the Grants).

1.1.1.4. The Social Protection Programme¹⁰⁶

This has two components. Senior Citizens Grants is a pilot project in 14 Districts and benefits Ugandans who are 60 years and over. Because many CwDs stay with their grandparents, they indirectly benefit from this Grant. The Vulnerable Family Grants target those with low labour capacity and a high dependency on others because they cannot work. Again some of these families include CwDs.

1.1.1.5. Other programmes¹⁰⁷

The MoGLSD working through its Social Development Strategic Planning group promotes the adoption of a Social Protection Framework covering vulnerable populations which will impact on CwDs living in Uganda.

1.1.2. The Ministry of Health

The MoH is in charge of policy formulation and implementation in the health sector and the coordination of the provision of health services in Uganda. The MoH has three Departments that are able to conduct activities targeting CwDs:

- The Disability and Rehabilitation Department: This consists of a Head of Unit, three Senior Officers, some “volunteers” and support staff such as a secretary.
- The Mental Health Department.
- The Child Health Department.

The Disability and Rehabilitation Unit has six programmes which target PwDs of all ages:

- The Assistive Devices Programme: the MoH provides PwDs and CwDs with wheelchairs, the most expensive assistive device. A hundred are given out each year by the Leonard Cheshire Centres. The MoH also gives adapted wheelchairs to Cerebral Palsy (CP) children.
- The Visually-Impaired and Blindness Programme

105. Kaggya Nabulime, Beatrice, Ministry of Gender, Labour and Social Development (MoGLSD), Interviewed by Nadège Riche, 2013.

106. Kaggya Nabulime, Beatrice, Ministry of Gender, Labour and Social Development (MoGLSD), Interviewed by Nadège Riche, 2013.

107. Kaggya Nabulime, Beatrice, Ministry of Gender, Labour and Social Development (MoGLSD), Interviewed by Nadège Riche, 2013.

- The Hearing and Deafness Programme
- The Physically-Impaired Programme
- The Injury Prevention and Control Programme
- The Older People Programme

The MoH works through the Hospitals. By law, each Regional Hospital should have a physiotherapy department with three physiotherapists and an occupational therapy department with one occupational therapist. Each District Hospital should have one practicing physiotherapist. Six orthopaedic workshops are based in the regional centres of Arua, Gulu, Fort Portal, Mbale, Mbarara and Mulago. Mulago is considered to be the national centre and people are referred there from all over Uganda. These workshops built assistive devices locally and distribute them to PwDs and CwDs.¹⁰⁸

1.1.3. The Ministry of Education and Sports

The MoES is responsible for education and sports policy formulation and implementation. The Ministry also coordinates and supervises the provision of education and sports services at all levels. The SN&IE Department is in charge of promoting education for CwDs.

The MoES has no specific and ongoing projects targeting CwDs, although the Universal Primary and Secondary Education Programmes benefit CwDs.

Similarly, the School Facilities Grant (FSG), which is offered by the Uganda National Education Support Centre through its Poverty Action Fund Programme, aim to improve primary school infrastructural facilities. Individual schools may apply for funding and the Grant must be used for constructing classrooms, latrines or teacher housing and for purchasing desks and is distributed through the local government. Under the NDP 2010/10 - 2014/15, it is specified that the FSG should be used to “expand and improve classrooms, teachers’ houses, pit latrines and other related facilities in order to improve hygiene, safety and security of children at school.”¹⁰⁹ The FSG has therefore been used to provide accessibility of educational buildings and latrines to CwDs. It has, however, been discovered that in some schools, teachers lock the accessible latrines and keep them for their own use because they are nicely designed.¹¹⁰

1.1.4. The Ministry of Finance, Planning and Economic Development

The MoFPED is responsible for releasing and budgeting finances to support the implementation of policies and programmes aimed at promoting equal opportunities for vulnerable populations including CwDs. The Ministry works in close collaboration with the line Ministries, national councils and commissions. The Ministry does not have a specific department relating to PwDs or CwDs.

1.1.5. The Uganda Human Rights Commission

The UHRC is one of the constitutional bodies established to promote and protect

108. Bongole, Rose, Ministry of Health (MoH), Interviewed by Nadège Riche, 2014.

109. Government of Uganda, National Development Plan 2010/11 – 2014/15, 2010, p. 20.

110. Asamo, Helen Grace, National Union of Women with Disability in Uganda (NUWODU), Interviewed by Nadège Riche, 2014.

human rights, including the rights of persons and children with disabilities. The UHCR monitors the implementation of Chapter Four of the Constitution of Uganda (Bill of Rights) and reports on the state of human rights to the Government and Parliament of Uganda. The UHRC also educates the public about their human rights. The UHCR has a Department for vulnerable populations that processes all issues related to human rights violations of vulnerable populations including persons and children with disabilities.

1.1.6. The Equal Opportunities Commission

The EOC is the constitutional body established by the EOC Act, 2007, to strengthen opportunities for all, including CwDs. The Commission ensures that there is equal access to opportunities for all through investigation, documentation, legal action and reporting to the Parliament of Uganda. There is a representative for PwDs who is also assumed to be the voice of CwDs. While the EOC focuses on the promotion of equal opportunities for all, the UHRC promotes and protects the human rights of all persons. Both Commissions have powers equivalent to powers of a Court in so far as this enables the Commissions to investigate or inquire into, on their own initiative or on a complaint, any grounds which seems to amount to or constitute discrimination, marginalisation or to otherwise undermine equal opportunities and human rights. However, the judgements of both Commissions do not have legal force as the judgment of a Court would have.

1.1.7. The National Council for Disability

The NCD is a semi-autonomous government body established by the NCD Act, 2003, to monitor and audit all government and non-government legislation, policies and programmes at all levels. The Council aims to ensure that they include the perspective of PwDs and comply with the CRPD and 1995 Constitution of Uganda in relation to the protection and promotion of the rights of PwDs. The NCD is decentralised with District and Sub-county Councils for Disability which monitor programmes at their respective levels. The NCD also promotes the inclusion of PwDs and reports to the Parliament of Uganda on the situation of PwDs including CwDs annually. Finally, the NCD carries out research and documentation on issues relating to all categories of PwDs.

1.1.8. The National Council for Children

The NCC is a semi-autonomous government body established by the NCC Act, 1996, to communicate the needs and challenges affecting children in Uganda to Government. "Its mandate is to provide a structure and mechanism which will ensure proper coordination, monitoring and evaluation of all policies and programmes relating to the Survival, Development, Protection and Participation of the Child and for other connected matters."¹¹¹

Since 2012, the NCC has initiated work with CwDs and their representative organisations:

111. National Council for Children (NCC), A brief about National Council for Children Advocacy Role, 2014, p. 1.

- In 2011, the NCC and USDC have issued a report assessing the abuse, protection and promotion of rights of CwDs in Uganda.¹¹²
- On the occasion of the International Day of the African Child 2012 dedicated to CwDs, the NCC gathered approximately 100 CwDs in a national conference that ultimately produced the CwDs Petition on the Accessibility to Rights that was presented to the Parliament of Uganda.
- The NCC chairs a National Disability Forum that meets four times a year. The Forum gathers all government and non-government stakeholders working with CwDs living in Uganda and aims to define strategic planning and coordination of activities in view of protecting CwDs.
- The NCC organises regular radio and TV talk show with the purpose of raising awareness about children issues. Several of these talk shows focused on the rights of CwDs.
- The NCC mainstreams the perspective of CwDs in several types of its activities: the specific rights of CwDs have been discussed during the Partners' Fora that are organised on a regular basis (i.e. the Stop Child Labour National Partners Forum, the Children and HIV/AIDS National Forum, the Early Childhood National Forum) and CwDs have been visited during field trips assessing the situation of children in Uganda.¹¹³

1.2. The Parliament of Uganda

"The Parliament of Uganda derives its mandate and functions from the 1995 Constitution, the laws of Uganda and its own Rules of Procedure. The Constitution contains articles which provide for the establishment, composition and functions of the Parliament of Uganda and empowers Parliament "to make laws on any matter for the peace, order, development and good governance of Uganda", and "to protect the Constitution and promote democratic governance in Uganda".¹¹⁴ Uganda has been the first country in the world to have reserved seats for elected disability representatives to the Parliament¹¹⁵ and now has five Members of Parliament (MPs) representative of PwDs.

In relation to children, the Parliament of Uganda has set up the Uganda Parliamentary Forum for Children (UPFC). This Forum advocates for child rights by including a children's perspective in legislation and by budgeting for children. It monitors the implementation of government programmes. The perspective of CwDs is also mainstreamed in all activities of the Forum and one MP, Honorary Baba Diri, acts as the Champion or the watchdog advocating for the rights of CwDs'.¹¹⁶

1.3. The Local Government Institutions

The role and powers of local government institutions in relation to their responsibilities for CwDs are mainly defined by the Local Government Act, 1997, the Children Act, 1996, and the Education Act, 2008.

112. Network on Disabled Children, Uganda Society for Disabled Children (USDC), National Council for Children, The State of Abuse, Protection and Promotion of the Rights of Children with Disabilities in Uganda, 2011.

113. National Council for Children (NCC), A brief about National Council for Children Advocacy Role, 2014.

114. Parliament of Uganda, <http://www.parliament.go.ug/new/index.php/about-parliament>, 2014, (Accessed on 20 April 2014).

115. Jacobsen, Charlotte B., Giving all Children a Chance - A study of personhood, childhood and educational integration for children with mental disability in Uganda, 2010.

116. Baba Diri (Hon.), Margaret, Women Member of Parliament (MP) for Koboko District, Interviewed by Nadège Riche, 2014.

The Districts play a very important role in ensuring that all children, including CwDs, access the appropriate education, health and other services that they are entitled to receive. The District Local Government headed by the Local Councillor (LC) 5 allocates resources and appoints the Secretary for Children Affairs to support the realisation of the rights of all children. The Community Development Officers implement all government programmes targeting children and other vulnerable populations. The Secretaries for Health and Education ensure that child related issues are integrated in education and health district programmes. The District Disability Councils monitor and audit District development programmes to ensure that they include persons and children with disabilities.

The LC 1 and LC 2 ensure that the community development programmes in their areas target all children including CwDs. The Secretary for Children Affairs and Secretary for Disability Affairs at village and parish level ensure that the issues of these vulnerable populations are addressed and integrated in community development programmes.

The Gulu District has been analysed to provide a detailed example of how the issues relating to CwDs are handled at local level. Unlike other Ugandan districts that only have a CDO, Gulu District has two positions: a CDO and a DRO. There is no specific position for CwDs.¹¹⁷

The role of Gulu District Council for Disability is to advocate for PwDs' rights and to monitor their implementation in the District. The Council is composed of nine people: three of them are disabled, while the remainder are civil servants. The District Rehabilitation Officer (DRO) acts as Secretary for the Council. The Chairperson of the Council is nominated by GDPU and validated by Gulu District. The Council has very restricted means: no office, no facilitation and no budget to support it. The Council meets three times a year.¹¹⁸

Since 2009/10, Gulu District has a special grant for PwDs of 26 million Uganda Shillings per financial year. A maximum of two million Uganda Shillings is given to groups or organisations of at least 10 PwDs to start up income generation activities (e.g. pig and goat rearing, farming activities and revolving loans schemes). At present, any group of PwDs can benefit from it. Gulu District does not consider either the leadership or the entrepreneurial skills within the group as a criterion for the allocation of these grants. There is an overwhelming demand.¹¹⁹

Overall, Gulu District has several activities targeting CwDs:

- Gulu District is in charge of education and there are several schools with units supporting CwDs: the Laroo School for the Deaf, the Gulu Prison School for children with mental disabilities (called this because the prison is nearby) and the Gulu Primary School for blind and visually impaired children.

117. Jawoko, Perry, Gulu District, Interviewed by Nadège Riche, 2013.

118. Okwera, Albert, District Disability Council of Gulu, Interviewed by Nadège Riche, 2013.

119. Jawoko, Perry, Gulu District, Interviewed by Nadège Riche, 2013.

- Gulu District provides some CwDs with wheelchairs thanks to the support of the Association of Volunteers in International Service (AVSI). According to the law, Districts are responsible for providing assistive technologies and mobility devices (e.g. white canes, hearing devices) but are not delivering these to PwDs, probably due to lack of funding. In the area of health, Gulu District only identifies CwDs who need (re) habilitation and refers them to Gulu Referral Hospital. This public hospital has an orthopaedic workshop.
- Gulu District allocates the PwDs Grants through the office of the Chief Administrative Officer (CAO).

Immediately after the war, the Campaign to end Paediatric HIV / AIDs (CEPA) and several churches have been active in Gulu District donating wheelchairs, but they have phased out or stopped their activities targeting persons and children with disabilities.¹²⁰

2. THE REGULATORY FRAMEWORK RELATING TO CHILDREN WITH DISABILITIES LIVING IN UGANDA

The legal and policy provisions targeting CwDs living in Uganda comprise the international Conventions ratified by Uganda, i.e. the CRPD and the CRC, and the national legislation and policies.

2.1. International Conventions and Instruments

2.1.1. *The United-Nations Convention on the Rights of the Child*

Uganda signed and ratified the CRC in 1990.

“The CRC acknowledges the rights of [children, including] CwDs and the primary role of parents and the family in the care and protection of children, as well as the obligation of the State to help them carry out these duties. The CRC consists of forty-one articles which promote and protect the rights of CwDs.

These rights are grouped together under the following themes:

- Survival rights (Articles 23, 24, 25 and 39) include the CwDs’ right to life and the needs that are most basic to existence, such as treatment, nutrition, shelter, an adequate living standard and access to medical services.
- Development rights (Articles 28 and 29) include the right to education, health, play, leisure, cultural activities, access to information, and freedom of thought, conscience and religion.
- Protection rights (Articles 2, 19, 22, 32 and 34) ensure that children are safeguarded against all forms of abuse, neglect and exploitation, including special care for refugee children; safeguards for children in the criminal justice system; protection for children in employment; protection and (re)habilitation for children who have suffered exploitation or abuse of any kind.

120. Okwera, Albert, District Disability Council of Gulu, Interviewed by Nadège Riche, 2013.

- Participation rights encompass CwDs' freedom to express opinions, to have a say in matters affecting their own lives, to join associations and to assemble peacefully. As their capacities develop, children should have increasing opportunity to participate in the activities of society, in preparation for adulthood.

The CRC includes four articles that are given special emphasis. These are also known as "general principles". [These principles are the foundation upon which the Convention is based and consist of the following]:

- All the rights guaranteed by the CRC must be available to all children without discrimination based on any grounds (Article 2).
- The best interests of the child must be a primary consideration in all actions concerning children (Article 3).
- Every child has the right to life, survival and development (Article 6).
- The child's view must be considered and taken into account in all matters affecting him or her (Article 12)."¹²¹

2.1.2. *The United-Nations Convention on the Rights of Persons with Disabilities*

In 2008, Uganda signed and ratified the CRPD and its Optional Protocol without any reservation.

"The CRPD addresses the specific measures needed to protect the rights of PwDs including CwDs. It does this in three ways:

- In some instances, for example the best interests of the child, the CRPD simply re-affirms an existing right and emphasises that it must be respected for CwDs on an equal basis with all other children.
- With regard to some rights, such as protection from violence, access to education, access to justice, access to health, and collection of data and statistics, it outlines in more detail than the CRC what needs to be done by governments.
- Finally, there are some additional provisions covered by the CRPD, for example, respect for integrity, living independently, sport, personal mobility, and habilitation and (re)habilitation. These provisions do not constitute new human rights. Rather they introduce specific obligations on Governments to remove the barriers that currently impede the realisation of the rights of CwDs.

The implementation of the CRPD is a co-operative process for the States of the world. Article 32 of the CRPD emphasises that international co-operation is vital if the provisions of the Convention are to be realised for all PwDs. When States ratify the Convention, they are not only committing to implementation in their own country, but also, where appropriate, to provision of support and cooperation with other States. In particular, it proposes that governments introduce measures which include international co-operation, including international development programmes, which are inclusive of and accessible to PwDs. It is important that CwDs are also explicitly acknowledged in these programmes.

121. Children Rights Alliance Ireland, www.childrensrightrights.ie, (Accessed on 14 February 2014).

[This includes]:

- Facilitating and supporting capacity building through the exchange and sharing of information, experiences, training programmes and best practices is encouraged,
- Facilitating co-operation in research and access to scientific and technical knowledge and
- Providing technical and economic assistance, including by facilitating access to and sharing of accessible assistive technologies and through the transfer of technologies.

However, the commitment to international co-operation does not undermine the responsibility of individual States to fulfil their obligations within their own country.”

2.1.3. Other International Instruments

In addition to the ratification of the CRPD and CRC, Uganda is a signatory to various international instruments that aim to promote education for all, with emphasis on learners with special needs. These include among others the Jomtien Agreement of 1990 according to which world leaders pledged to provide all children with an appropriate education regardless of their individual differences. The 1994 Salamanca Agreement was further impetus to the provision of special needs education. In 2000, the Millennium Development Goals and the World Education Forum in Dakar, Senegal, set the goal of achieving universal primary completion and Education for All by 2015 by including within the educational mainstream all traditionally excluded and marginalised groups.¹²²

2.2. The Ugandan Regulatory Framework Relating to Children with Disabilities

The Ugandan legal and policy framework defines a child with a disability as a person below 18 years “with a substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environment barriers resulting in limited participation” (PwDs Act/Part 1, Section 1). In the educational context, learners with disabilities are persons with: “i) Intellectual Impairments, ii) Specific Learning Difficulties, iii) Hearing Impairment, iv) Visual Impairment, v) Physical Impairments, vi) Health Impairments, vii) Speech and Language Disorders, viii) Social, Emotional and Behavioural Difficulties/ Disorders, and those who are; Gifted and Talented, ix) Left handedness and x) Multiple disability (a combination of two or more impairments)” (Draft Policy in SN&IE/Section 3 (4)).

Non-discrimination on the ground of disability is emphasised in Article 21 of the Constitution of Uganda, while the fight against stigmatisation and the discrimination of persons and children with disabilities is reiterated in the National OVC Policy (Section 4(3)). Furthermore, the Ugandan framework promotes affirmative action and equal opportunities for PwDs, which includes CwDs, to address the imbalances and inequalities they face in life (Constitution/Article 32).

122. Save the Children, Promoting the Rights of Children with Disabilities, 2008.

2.2.1. The Regulatory Framework Relating to Health

This section analyses how the existing Ugandan laws and policies promote and protect the right to life, access to health services and the (re)habilitation of CwDs. In the health and (re)habilitation fields, they consist of the Constitution of Uganda of 1995, the NDP of 2010, the PwDs Act of 2006, the National Policy on Disability of 2006, the Children Act of 1996, the National OVC Policy of 2004 and the NHP II of 2010.

These laws and policies promote and protect the rights of CwDs as follows:

Article 22 (2) of the Constitution of Uganda recognises the right to life to any person and this provision also applies to unborn CwDs.

Some policies assess the current situation and barriers faced by PwDs, including CwDs, in accessing (re)habilitation and health services. The NDP identifies the lack of orthopaedic workshops and of affordable assistive devices as two of the main problems and calls upon Government and stakeholders to address these challenges (Section on the social sector and education subsector). Unfriendly and inaccessible health infrastructures, negative attitudes of hospital and health centre staff towards PwDs and CwDs are also identified as some of the challenges faced by persons and children with disabilities (National Policy on Disability / Section 1 (4) (8) and NHP II / Section 2 (8) (2)).

To address these barriers, the right to equal access to health services by PwDs is reiterated (PwDs Act / Section 7, National OVC Policy / Section 5 and NHP II / Section 6 (1)). The measures, which need to be taken to deliver these services to PwDs, including CwDs, are described in several laws and policies. The Children Act provides for assessment and (re)habilitation of CwDs (Section 9). The PwDs Act identifies several provisions: provision of accessible medical information, integration of sign language (SL) training in the health professional curriculum and specific training in the needs of PwDs, provision of specific sexual and reproductive health services to women and girls with disabilities to keep them alive (Section 7). However, the realisation of these services has so far not been realised due to inadequate resource allocation.

2.2.2. The Regulatory Framework Relating to - Inclusive- Education

This section analyses how the existing Ugandan legal and policy framework promotes and protects the right to education of CwDs. This consist of the Constitution of Uganda of 1995, the NDP of 2010, the Education (Pre-Primary, Primary and Post-Primary) Act of 2008, the UNISE Act of 1995 amended by the University and Other Tertiary Institutions Act of 2001, the draft SN&IE Policy, the draft Non-Formal Educational Policy for Educationally Disadvantaged Children, the PwDs Act of 2006, the National Policy on Disability of 2006, the Children Act of 1996 and the National OVC Policy of 2004.

These laws and policies promote and protect the rights of CwDs as follows.

The 1995 Constitution of Uganda provides for the constitutional right to education for all (Article 30) and the equalisation of opportunities for all disadvantaged groups, including CwDs (Article 32). The PwDs Act, 2006, specifically outlines the legal provision of access to education for persons and children with disabilities (Sections 5 and 6) and calls for not less than 10% of the education budget to be allocated to the education needs of CwDs. This provision is reaffirmed in the draft SN&IE Policy (Section 2 (11)). This right to education is directly or indirectly reiterated in several laws and policies (Education Act/ Schedule 1, part I and II, section 4 (2) and (3); National Policy on Disability/ Section 1 (4) and National OVC Policy/ Section 5)). The provisions for SNE and IE are described in the draft SN&IE Policy and draft Non-Formal Education Policy for Educationally Disadvantaged Children (Section 1 (1), (2) and (3)).

Specific barriers and challenges, which restrict access to education for CwDs, are identified and measures to overcome them outlined. The first barrier to be identified is the inaccessibility of education buildings, including latrines, toilets and classrooms, for CwDs (NDP/Section on the social sector and education subsector; PwDs Act/ Sections 12 and 20; and Draft SN&IE Policy/ Section 2 (4)).

The second challenge consists of the lack of alternative formats of the educational curriculum and of accessible scholastic material (Draft Non-Formal Education Policy for Educationally Disadvantaged Children/ Section 2 (2); NDP / Section on the social sector and education subsector; Draft SN&IE Policy/ Sections 2 (4) and 5 (7)). It is the responsibility of the Faculty of Special Needs and Rehabilitation of Kyambogo University to address these specific needs of pupils and student with disabilities as well as to provide assistive devices and train teachers in SN&IE (UNISE Act/ Section 5 (d)).

The final challenge identified in these laws and policies is the lack of SN&IE trained teachers. It is therefore planned to include a SN&IE training module in the teacher training curriculum and specific SN&IE training for teachers to enable them to teach all children including CwDs in mainstream schools (PwDs Act/ Section 5; draft SN&IE Policy/ Section 2 (3); NDP/ section on social sector and education subsector; and UNISE Act/ Section 4 and 5 (a) and (g)).

2.2.3. The Regulatory Framework Relating to Protection of Children

This section analyses how the Children Act, the National OVC Policy and the Child Labour Policy form the child protection legal framework defining the rights of all children, including CwDs, and protecting them from all violence and abuse.

These laws and policies aim to create an environment where CwDs can live safely and fulfil their maximum potential.

The Children Act is the main legislation that instrumentalises Article 34 of the 1995 Constitution of Uganda which calls for the enactment of legal provisions promoting and protecting the rights of all children. The overall aim of the Children Act is to lay out the measures that must be put in place to ensure the welfare of all children, including CwDs. Both the National OVC Policy and

the Child Labour Policy specifically targets CwDs, among other categories of vulnerable children, to protect them from abuse and violence (Section 5) and to eliminate CwDs' labour in communities (Section 10).

2.3. Overview of National and Local Government Institutions Leading the Implementation and Monitoring of Each Legislation and Policy Targeting Children with Disabilities Living in Uganda

Although all national and/or local Government Institutions are responsible for the application of legislation and policies, some Ministries or District Institutions are leading their implementation and monitoring. Table 1, below, shows this in detail.

TABLE 10: OVERVIEW OF THE NATIONAL AND LOCAL GOVERNMENT INSTITUTIONS LEADING THE IMPLEMENTATION AND MONITORING OF EACH LEGISLATION AND POLICY TARGETING CWDS LIVING IN UGANDA

	MoGLSD	MoES	MoH	MoFPED	EOC	NCD	NCC	Districts	District Council for Disability
Constitution of Uganda	X	X	X	X	X	X	X	X	X
Local Government Act	X					X	X	X	X
NDP				X				X	
PwDs Act	X					X		X	X
National Policy on Disability	X	X	X	X		X	X	X	X
NCD Act	X	X	X	X		X		X	X
EOC Act	X				X				
Children Act	X						X	X	
NCC Act	X						X	X	
Child Labour Policy	X						X	X	
National OVC Policy	X						X	X	
Education Act		X						X	
UNISE ACT		X							
Draft Non-Formal Education Policy	X	X	X	X				X	
Draft SN&IE Policy	X	X	X						
NHP II		X							

Part 5: Mapping of Programmes and Active Stakeholders Working in the Disability Field in Uganda

Various stakeholders are active in the disability field in Uganda. Several UN Agencies have developed programmes targeting persons and children with disabilities. Approximately 10 donor organisations such as national development agencies and foundations fund programmes. The Ugandan Disability Movement is one of the most vibrant in Sub-Saharan Africa and mainly supported by counterpart DPOs from Denmark and Norway. International and Ugandan NGOs also run several programmes targeting CwDs living in Uganda.

In addition to this section, a comprehensive overview of programmes operating in the fields of education, health and (re)habilitation and sport and of projects targeting girls with disabilities, empowering CwDs and promoting their human rights, mainstreaming the perspective of CwDs and building the capacity of Ugandan DPOs are presented in Annex 1. This mapping exercise provides an overview of what has been done in the past, what is currently ongoing, what has been achieved and what has been less successful.

1. UNITED-NATIONS AGENCIES

Identifying activities led by other UN Agencies represents the basis for potential coordination within the UN bodies present in Uganda. This will ultimately benefit CwDs, who are the adults with disabilities of tomorrow. At present, three UN Agencies run programmes targeting persons and children with disabilities in Uganda.

1.1. The Office of the High Commissioner for Human Rights

The OHCHR is the UN Agency responsible for the protection and promotion of all human rights, including disability rights. In Uganda, the OHCHR

focuses on the domestication of the CRPD and supports the reporting process of the Government of Uganda to various UN Committees (e.g. Human Rights Committee or CRPD Committee). In practice, the OHCHR office in Uganda is involved in several activities relating to disability rights.

Initially, the OHCHR organised awareness-raising and advocacy events for the ratification of the CRPD by Uganda what was successfully achieved in September 2008. Since then, the OHCHR has shifted its engagement and trained representatives of Ugandan DPOs and of national authorities mandated with promoting the rights of PwDs. This aimed to ensure that national decision-makers and stakeholders are granted the necessary knowledge and understanding of the disability rights enshrined in the Convention. Similar trainings are planned for 2014/15 at regional level.

The OHCHR has also delivered technical assistance to Uganda to support the state obligations and the domestication of the Convention. In 2009, the Office has screened the Ugandan legal framework relevant to PwDs in comparison to the CRPD obligations.¹²³ Then, the OHCHR has assisted the Government of Uganda in drafting its Initial Report to the CRPD Committee. This has been delivered in December 2012.¹²⁴ In addition, the OHCHR supports the establishment and review of legislation and policies in line with the CRPD provisions. Recently, it has engaged with the MoH and submitted a human rights commentary to the proposed Mental Health Bill. The OHCHR has also closely followed the discussions between Government Ministries on the review of the PwDs Act from 2006 and strongly advocates for an inclusive approach to education (rather than a special needs education one).

Furthermore, the OHCHR has created a framework to monitor Uganda's implementation of the recommendations arising from the international human rights mechanisms (i.e. Treaty body mechanisms and the universal periodic review). Based on a thematic clustering, this tool highlights the recommendations and provides with base-line targets. The OHCHR in Uganda does not aim to cross-cut the mandate of other UN Agencies and considers that UNICEF Uganda should take responsibility of the several recommendations relating to CwDs.

Finally, the OHCHR currently designs a programme on transitional justice and has decided to mainstream the perspective of PwDs. Together with the MoH, the needs of persons with various disabilities have been taken into account. This included the establishment of four surgery centres, the provision of assistance for people with mental and psychosocial disabilities and the need for a better understanding of disability as a consequence of conflicts in the region.

1.2. The United Nations Population Fund

The United Nations Population Fund (UNFPA) mission is "to address population and development issues with an emphasis on sexual and reproductive health and

123. Office of the High Commissioner for Human Rights (OHCHR), Working Paper – A Review of the Ugandan Legal Framework Relevant to Persons with Disabilities - Comparative Analysis to the Convention on the Rights of Persons with Disabilities, August 2008.

124. Government of Uganda, United Nations Convention on the Rights of Persons with Disabilities, Uganda's Initial Status Report 2010, 2010.

gender equality.”¹²⁵ In Uganda, the UNFPA office has mainstreamed disability in their activities and recently produced two studies:

- Conducted in 2012, the first study aims to assess how maternal health services are delivered to women with disabilities across the country.¹²⁶ It specifically addresses services accessibility at sexual and reproductive health and HIV/AIDS services delivery points in the three districts of Moroto, Mubende and Oyam. The study found out that PwDs do not feel discriminated and that the attitudes of staff are seen as positive, except for pregnant woman with disabilities. This is most probably due to the lack of accessibility of health material. The main problems, which were identified, are the remote geographical situation of these service delivery points and the lack of accessibility of the buildings.
- In 2013, UNFPA supported the MoGLSD to conduct a legal audit of the existing policies, laws and programs in regard to sexual and reproductive health of PwDs.¹²⁷ The report highlights that the legislation is broadly in line with the provisions of the CRPD and other UN Treaties, but their implementation remains a challenge. On the basis of these outcomes, it is recommended to adopt a multi-sectoral approach and invest in the implementation of policies.

1.3. The World Health Organisation

The WHO is “the directing and coordinating authority for health within the UN system.”¹²⁸

In Uganda, WHO has no specific programme or project to prevent disability among children. However, WHO supported the adoption of the Decade of Action on Road Safety Action Plan that is built on five pillars, namely: (a) road safety management, (b) safer roads and safer mobility, (c) safer vehicles, (d) safer road users and (e) post-crash response. Road safety cuts across sectors including, among others, education, works, urban planning, health and police. All these sectors were involved in the adoption of this action plan and each one of these contain activities in its jurisdiction to reduce crash related-deaths and acquisition of impairments. This also indirectly benefits children.

2. DONOR ORGANISATIONS

2.1. National Development Agencies

Three national Development Agencies have specific programmes funding initiatives relating to PwDs and CwDs living in Uganda. The three of them have been supporting PwDs for over ten years. Their focus is on capacity building of Uganda DPOs (Danish International Development Agency (DANIDA) and

125. United Nations Population Fund (UNFPA), <http://www.unfpa.org>, 2014, (Accessed on 4 April 2014).

126. United Nations Population Fund (UNFPA), Aids Information Centres Uganda (AIC), National Union of Disabled People in Uganda (NUDIPU), Services accessibility for people with disabilities at sexual and reproductive health and HIV/AIDS services delivery points, Report of a Study in three Districts of Uganda (Mubende, Oyam and Moroto), 2010.

127. United Nations Population Fund (UNFPA), Ministry of Gender, Labour and Social Development (MoGLSD), An Audit Report on the Key Existing Policies, Laws, Plans, Programs and Guidelines on Sexual Reproductive Health, HIV/AIDS and Gender Based Violence, on their compliance to the rights of Persons with Disabilities, 2013.

128. World Health Organisation (WHO), <http://www.who.int/about/en/>, 2014, (Accessed on 4 April 2014).

USAID), education of children and persons with disabilities (DANIDA) and CBR (NORAD).

2.1.1. The Danish International Development Agency

DANIDA addresses the needs and promotes the rights of persons and children with disabilities in Uganda. For example, in 1992, DANIDA funded the creation and running of the Education Assessment and Resource Services (EARS). This led to the establishment of the Special Needs/IE Department within the MoES and of UNISE, now Faculty of Kyambogo University. This DANIDA programme has now phased out.

DANIDA also funds many programmes targeting persons and children with disabilities through the Disabled People Organisation of Denmark (DPOD) and its disability specific member organisations. DPOD, which is the national organisation of PwDs in Denmark, directly funds NUDIPU and NUWODU. LEV, the Danish organisation representing parents of children with intellectual disabilities, supports the activities of UPPID. These DANIDA grants allocated via the Danish DPOs target both the building of organisational and advocacy capacities of Uganda DPOs and specific projects relating to various areas (e.g. education, gender, HIV / AIDs - Refer to Section 7).

2.1.2. The Norwegian Agency for Development Cooperation

In the past decade, NORAD has taken a human rights approach and mainstreamed the perspective of PwDs in all its programmes. Published in 2012, two reports have assessed how the Norwegian aid promoted the disability rights between 2000 and 2010¹²⁹. “Between 2000 and 2010 the total funding targeting PwDs was 240 million US dollars. In addition to the targeted support, the report identifies a few general programs in which disability aspects have been mainstreamed. These projects had a total budget of 1.6 billion Norwegian kroner of which only a small part (less than 1%) went to facilitating the inclusion of PwDs.”¹³⁰ Around 2% of the development and humanitarian aid received by Uganda from Norway directly targets PwDs¹³¹. The majority of this support goes to the funding of CBR activities¹³² and the main effects of the Norwegian aid are therefore visible in the (re)habilitation and health sector¹³³.

NORAD continues its efforts in this direction. It has recently designed a new human rights Policy, which includes disability rights. In 2013, the Norwegian Ministry of Foreign Affairs developed the document “Norway’s international efforts to promote the rights of PwDs”. With this, NORAD aims to strengthen

129. Norwegian Agency for Development Cooperation (NORAD), Mainstreaming disability in the new development paradigm - Evaluation of Norwegian support to promote the rights of persons with disabilities, 2012; and Norwegian Agency for Development Cooperation (NORAD), Mainstreaming disability in the new development paradigm - Evaluation of Norwegian support to promote the rights of persons with disabilities - Uganda country study – Summary, 2012. These are both the same title

130. Norwegian Agency for Development Cooperation (NORAD), Mainstreaming disability in the new development paradigm - Evaluation of Norwegian support to promote the rights of persons with disabilities, 2012, p. iii.

131. Norwegian Agency for Development Cooperation (NORAD), Mainstreaming disability in the new development paradigm; Evaluation of Norwegian support to promote the rights of persons with disabilities; Uganda country study – Summary, February 2012, p. 4.

132. Basil Kandyomunda, Baseline Report of the Research and Documentation Project: Existing Documentation related to CBR Programmes in Uganda.

133. Norwegian Agency for Development Cooperation (NORAD), Mainstreaming disability in the new development paradigm; Evaluation of Norwegian support to promote the rights of persons with disabilities; Uganda country study – Summary, February 2012, p. 4.

its human rights based mainstreaming approach in the allocation of grants. NORAD implementing partner organisations also have the obligations to take the perspective of persons and children with disabilities on board. Practical guidelines for the Norwegian Foreign Service about a human rights-based approach to development, which includes disabled people as one of several vulnerable groups in international development, are in the making but not yet published.

In practice, NORAD has taken a two-fold approach: (a) mainstreaming and inclusion of the perspective of persons and children with disabilities, for example in the education and health sectors, and (b) targeted projects for the specific needs of PwDs and CwDs based on the explicit demand of DPOs, for example CBR activities. Both approaches are important and complement each other.

NORAD has several departments and sections directly involved with disability issues:

- The Section for Rights and Gender Equality of the Department for Economic Development, Gender and Governance is the focal point for disability matters.
- The Section for Education of the Department for Global Health, Education and Research acts as technical advisor to the Norwegian Ministry of Foreign Affairs and Embassies. Bilateral and multilateral funds are channelled through the Norwegian Ministry of Foreign Affairs: for example, the education sector support programme is supposed to mainstream disability and provide for the educational needs of pupils and students with disabilities, alongside the needs of any other children.
- The Section for Development Initiatives of the Civil Society Department channels funds to CSOs, including DPOs.¹³⁴

Currently, NORAD has cooperation or project agreements with several CSOs, DPOs and NGOs implementing programmes targeting CwDs in Uganda. In 2013, the Adina Foundation received approximately 117,000 US dollars (USD) from NORAD, the Atlas Alliance one million USD, Lions Aid Norway 61,000 USD, Plan Norway approximately 1,4 million USD, Right to Play 567,000 USD, Save the Children Norway approximately four million USD and the Strømme Foundation approximately 696,000 USD.

2.1.3. The United-States Agency for International Development

In 1997, USAID adopted a Disability Policy Paper aiming to mainstream the perspective of PwDs in its aid programmes and to support disability specific projects to fight discrimination on the grounds of disability. In 2002, USAID established the Omega initiative which “provides funding and technical support through subgrants for a broad range of advocacy, awareness raising, and (re)habilitation services for civilians with disabilities that resulted from war” in Sub-Saharan Africa. In December 2013, USAID intensified its efforts and

134. Engh, Ida-Eline, Norwegian Agency for Development Cooperation (NORAD), Interviewed by Nadège Riche, 2014.

opened a Disability Grant Programme. Supported by the Centre of Excellence on Democracy, Human Rights and Governance, this programme aims to support the active involvement of PwDs in the USAID aid programmes relating to, among others, education or gender equality. It also provides for the capacity building of DPOs. Finally, USAID is a member of the GPcwd.

In 2005, Uganda was chosen as a focus country to further implement the USAID Disability Policy and specific funding of one million US dollars was made available under the Omega initiative.¹³⁵ In 2008, USAID/Uganda identified disability as a cross-cutting issue but has no specific disability plan.¹³⁶ USAID/Uganda has provided capacity-building support to Uganda DPOs such as NUDIPU and USDC.

Finally, USAID/Uganda currently funds three major programmes relating to OVC and they also include CwDs: the SCORE project, the SUNRISE project and the Inter-Religious Council of Uganda (IRCU) project (Refer to Annex 1 for detailed information). Another relevant project targeting persons and children with disabilities is the CSOs Fund, which USDC benefited from. USAID/Uganda plans to continue implementing programmes targeting OVC: two major programmes are currently being designed. As long as there will be OVC projects, CwDs will be covered.

2.2. Foundations

British, Dutch, Italian, Liechtenstein, Norwegian and US-based foundations support small scale projects mainly run in partnership with Ugandan DPOs. Those initiatives relating to CwDs focus on access to health, (re)habilitation, education and sport.

Motivation UK “is an international development charity supporting people with mobility disabilities. Motivation UK design high-quality and low cost wheelchair for PwDs living in developing countries and run four programmes relating to survival, mobility, empowerment and inclusion.”¹³⁷ In Uganda, Motivation UK has supported many orthopaedic and plastic surgical outreaches.¹³⁸ The organisation currently funds the SIDU project on access to sport by children and young PwDs led by GDPU.

The Jersey Overseas Aid Commission (JOAC) aims to reduce poverty in the poorest countries in Latin America and Africa by making a sustained contribution. The JOAC’s grants fund projects in the area of health and care, WASH, education, humanitarian crisis and food security.¹³⁹ In Uganda, JOAC co-funds the Bringing Health Services Closer to CwDs project led by USDC.

135. United-States Agency for International Development (USAID), Fifth Report on the Implementation of USAID Disability Policy, 2008, p. 18.

136. United-States Agency for International Development (USAID), Fifth Report on the Implementation of USAID Disability Policy, 2008, p. 21.

137. Motivation, <http://www.motivation.org.uk/>, 2013, (Accessed 13 December 2013).

138. Ssebadukka, Fred, Were, Dolorence, Dr. Baingana Nganwa, Alice, Chapter 10: Health care services for People with Disabilities (PWDs) in Uganda, in A Handbook on Disability experiences and approaches in Uganda, 2010.

139. Jersey Overseas Aid Commission (JOAC), <http://www.jerseyoverseasaid.org.je/Home/>, 2013, (Accessed 20 November 2013).

The Liliane Foundation aims to “open the world for CwDs in in developing countries by giving them access to healthcare, education, employment and legal systems.”¹⁴⁰ Based in the Netherlands the Liliane Foundation works through partnership with local organisations and has a coordination team in Uganda. Liliane Foundation funds USDC activities relating to education, health and (re) habilitation.

“The Terre Des Hommes International Federation is a network of 10 national organisations working for the rights of children and to promote equitable development without racial, religious, political, cultural or gender-based discrimination.”¹⁴¹ The Terre des Hommes Netherlands funds programmes in Uganda and it supports several USDC projects: the Health, Education and Training for CwDs and the Protecting and Promoting the Rights of Disabled Children in Uganda Project. It additionally funds an UPPID project to support the enrolment of children with intellectual disabilities in school.

The AVSI Foundation is an international NGO and its mission is “to support human development in developing countries with special attention to education and the promotion of the dignity of every human person, according to Catholic social teaching.”¹⁴² In the past ten years, AVSI has been involved in many programmes aiming to improve the living conditions of persons and children with disabilities. The organisation has supported many orthopaedic and plastic surgical outreaches.¹⁴³ It continues to be involved in CBR activities and runs a project aiming to improve quality of life of CwDs in Uganda in partnership with USDC.

Medicor Foundation funds “projects in the field of education, health and social care in order to improve the wellbeing and empowerment of vulnerable and disadvantaged people in countries in Africa, Latin America, the Caribbean and Eastern Europe.” In Uganda, Medicor Foundation co-funds the Bringing Health Services Closer to CwDs project led by USDC.

Based in Norway, the Strømme Foundation aims for “a world without poverty and runs long-term development work with local partner organisation in the South in the education and micro-finance field.”¹⁴⁴ In 2013, the Strømme Foundation received 4,173,000 Norwegian Kroner (or approximately 696,000 US dollars) from NORAD¹⁴⁵. The Foundation currently runs the Community-Based Education Intervention and Economic Empowerment Programme across the country which aims to strengthening basic, formal and informal education. One of the activities in partnership with UNICEF is to study the causes of school dropout rates of children, including CwDs.

140. Liliane Foundation, <http://www.lilianefonds.org/>, 2013, (Accessed 11 November 2013).

141. Terre des Hommes Netherlands, www.terredeshommesnl.org, 2013, (Accessed 3 December 2013).

142. Association of Volunteers in International Service (AVSI), <http://www.avsi.org/who-we-are/>, 2013, (Accessed 12 December 2013).

143. Ssebadukka, Fred, Were, Dolorence, Dr. Baingana Nganwa, Alice, Chapter 10: Health care services for People with Disabilities (PWDs) in Uganda, in *A Handbook on Disability experiences and approaches in Uganda*, 2010.

144. Strømme Foundation, <http://strommestiftelsen.no/english>, 2013, (Accessed 13 December 2013).

145. Engh, Ida-Eline, Norwegian Agency for Development Cooperation (NORAD), Interviewed by Nadège Riche, 2014.

The American Jewish World Service (AJWS) is a “Jewish human rights and development organisation working to realise human rights and end poverty in the developing world by providing financial support to local grassroots and global human rights organisations [worldwide]”¹⁴⁶. The organisation focuses on three areas of work: (a) Advancing the health and human rights of women, girls and LGBT people, (b) Promoting recovery from conflict and oppression and (c) Defending access to food, land and livelihoods. In Uganda, AJWS run a Northern Uganda CwDs Programme and funds projects run by NUWODU, GUWODU and USDC.

Bread for the World is “a collective Christian voice urging US decision makers to end hunger at home and abroad. By changing policies, programmes and conditions that allow hunger and poverty to persist, [Bread for the World] provides help and opportunity” for all.¹⁴⁷ Bread for the World supports USDC activities in promoting the rights of CwDs and access to health and rehabilitation services in Hoima District.

3. CIVIL SOCIETY ORGANISATIONS OF PERSONS WITH DISABILITIES RUNNING PROGRAMMES TARGETING CHILDREN WITH DISABILITIES LIVING IN UGANDA

Uganda has a strong Disability Movement and the national DPOs such as NUDIPU and NUWODU are relatively well structured and representative of all categories of PwDs. They have also had significant advocacy successes over the years, such as the allocation of five seats in Parliament of Uganda to represent PwDs from the five regions of the country. However, there are very few Ugandan organisations of or for CwDs.

Established in 1985, USDC is the only national and cross-disability organisation voicing the needs and rights of CwDs. The main objectives of the organisation consist of “raising public awareness about disability, empowering parents through PSGs, lobbying for disability inclusive policies, programmes and legislation at local and national government levels, empowering CwDs and sensitising primary students through Child Rights Clubs and facilitating individual CwDs to access services for rehabilitation.”¹⁴⁸ At present, USDC operates in only 14 Districts (Arua, Adjumani, Buliisa, Hoima, Iganga, Jinja, Kampala, Luwero, Masaka, Masindi, Moyo, Nebbi, Soroti and Yumbe) and reaches out to around 7,000 CwDs every year.

Two other small organisations representing and targeting CwDs have also been identified:

- Established in the 2000s, Save the Children with Disabilities is a small Ugandan organisation active in the Western region. They currently run a project in Ntungamo using Ugandan private sources. The organisation

146. American Jewish World Service (AJWS), <http://ajws.org/>, 2013, (Accessed 20 November 2013).

147. Bread for the World, <http://www.bread.org>, 2013, (Accessed 12 December 2013).

148. Uganda Society for Disabled Children (USDC), USDC Strategic Plan 2013-2019, 2012.

aims to identify and assist CwDs in their everyday life, sensitise the families, communities, care givers and decision makers.¹⁴⁹

- “Ka Tutandike Uganda (KTU) is a community-based organisation, founded in 2006, whose mandate is to empower vulnerable communities in Uganda. We are primarily child focused, employing a multi-sectoral approach to unlock the potential that exists within poor communities.” KTU leads the Uganda National Coalition for the Deaf (UNCD): this is a national coalition of NGOs working on deafness which started in August 2011. The UNCD organised a National Symposium on Education of the Deaf Child on 17th August 2011. One of the outcomes consisted of recommendations to the drafting of the SN&IE Policy. In addition, KTU carried out workshops about reproductive health awareness and life skills acquisition for children in three schools for the deaf and trainings in SL for professionals and service providers in Masaka District.¹⁵⁰

Last but not least, the role of parents of a CwD is pivotal because they are the primary persons who will take care of and educate the child. The only organisation involving parents of CwDs is UPPID. Formerly called Uganda Parents of Children with Learning Disabilities (UPACLED), it was founded in 1995 and registered as an NGO in 1998 so that parents could come together to find ways and means to support their CwDs. Since the beginning, UPPID has been supported by LEV. UPPID exists in 39 Districts with a District Executive Committee and countrywide with three regional offices based in Mbale, Fort Portal and Kampala. The headquarters are in Entebbe. UPPID aims to mobilise, sensitise and empower parents of CwDs. UPPID representatives go to Districts to identify and speak with parents of CwDs. Their first objective is to support parents to “accept they have a child like that and help them to bring their child outside for the community to see”. UPPID also organises meetings with knowledgeable people such as physiotherapists and education specialists in order to build the awareness and capacity of parents to take care of their child.¹⁵¹ As part of the LEV funded Jombola project, self-help groups of parents have been formed in the Districts.

Most Ugandan DPOs are financially and technically supported by foreign DPOs. Danish and Norwegian DPOs have been active in Uganda for several decades. In most cases, these foreign DPOs support their Ugandan counterparts. DPOD, the national umbrella organisation of Denmark, has been working in Uganda since the 1980s and it supports the national umbrella organisations of Uganda, NUDIPU and NUWODU. The Danish disability specific organisations support their disability counterparts – so for example LEV supports UPPID, the Danish Mental Health Association (SIND) supports Mental Health Uganda (MHU) and the Association of Danish Deaf-Blind People (FDDB) supports NADBU.

However sometimes DPOs from the same country form an association and specialise in disability and development. So, for example, the Atlas Alliance

149. Save the Children with Disabilities, http://www.ugandangodirectory.org/index.php?option=com_mtree&task=viewlink&link_id=68&Itemid=2, 2013, (Access on 17 November 2013).

150. Ka Tutandike (KTU), www.katutandike.org, 2013, (Accessed 15 November 2013).

151. Byamugisha, Isidor, Uganda Parents of Persons with Intellectual Disabilities (UPPID), Interviewed by Nadège Riche, 2013.

consisting of Norwegian organisations of PwDs, parents and patients is involved in international development work. It receives funding from NORAD to conduct its programmes in Uganda, although its focus is on young PwDs and not on CwDs. The Atlas Alliance received approximately 6 million Norwegian Kroner (approximately 1 million US dollars) in 2013. They work with local partners and have a mix of mainstreaming and disability-specific projects. They have four programmes:

- Grant to the Uganda National Association of the Blind (UNAB) to support its organisational development (518,000 Norwegian Kroner or approximately 86,000 US dollars).
- Grant to finance the regional offices of UNAB (756,000 Norwegian Kroner or approximately 126,000 US dollars)
- Economic empowerment, National Union of the Disabled People of Uganda (NUDIPU): develop a model for saving and credit self-help groups of disabled in order to include PwDs in Microfinance. It is handed in partnership with the government to increase inclusion of farmers with disabilities (3,634,000 Norwegian Kroner or approximately 606,000 US dollars).
- Education in conflict areas, Education for blind and partially sighted children and youth in Northern Uganda (1,120,000 Norwegian Kroner or approximately 187,000 US dollars)¹⁵².

4. NON-GOVERNMENTAL ORGANISATIONS RUNNING PROGRAMMES TARGETING CHILDREN WITH DISABILITIES LIVING IN UGANDA

Many child-specific INGOs are active in Uganda but few of them have specific programmes targeting CwDs. However, with the CRPD adoption and ratification worldwide, these INGOs have started to get involved with this specific target group.

4.1. Able Child Africa

AbleChildAfrica is another INGO running programmes targeting CwDs living in Uganda. AbleChildAfrica was “initially founded in 1984 as USDC to support children injured by the Ugandan Civil War in the 1970s and 1980s. In 2007, USDC in the UK became AbleChildAfrica and began supporting work with CwDs in other countries such as Kenya and Tanzania. AbleChildAfrica works towards a world in which all CwDs are fully included as equal members of society and are able to achieve their full potential.”¹⁵³ AbleChildAfrica continues to support USDC activities.

4.2. The African Child Policy Forum

“ACPF is an independent, not-for-profit, pan-African institution of policy research and dialogue on the African child.”¹⁵⁴ ACPF has assessed the situation

152. Engh, Ida-Eline, Norwegian Agency for Development Cooperation (NORAD), Interviewed by Nadège Riche, 2014.

153. AbleChildAfrica, <http://ablechildafrica.org/>, 2013, (Accessed 11 November 2013).

154. African Child Policy Forum (ACPF), <http://www.africanchildforum.org/site/index.php/who-we-are.html>, (Accessed 12 November 2013).

of CwDs living in Uganda. With the support of Save the Children Sweden, ACPF undertook a multi-country study to evaluate the situation of CwDs in East Africa in 2011. The ACPF Report CwDs in Uganda – A Hidden Reality is one of the most comprehensive studies on the topic.

4.3. Humane Africa

“Humane Africa works with local implementing partners in Southern and Eastern Africa to protect children from harmful practices such as mutilation and the removal of body parts and abuse and discrimination of CwDs. Using a social norms process, communities’ design and implement responses designed to bring the entire community to collectively abandon these harmful practices.”¹⁵⁵ Humane Africa has very recently produced a study briefly assessing the situation of CwDs in Uganda taking a behavioural approach.

4.4. L’Arche

The L’Arche community in Uganda is based in Kampala. It supports 19 persons with learning disabilities and a further 20 PwDs are welcomed in the day provision service. Most of these young children and adults are orphaned or abandoned because of the stigma attached to learning disabilities. The L’Arche programme are dedicated to institutional (re)habilitation for CwDs.¹⁵⁶

4.5. Plan

Plan mainstreams disability in its child protection programmes - one of the components of its ‘Strengthening National Protection System’ programme concerns CwDs. Its purpose is to ensure that laws and policies are put into practice. This programme is running in five Districts (Kamuli, Tororo, Luwero, Lira and Alebtong) from 2011 until 2015. It is funded by NORAD. Plan has a Memorandum of Understanding (MoU) with the MoGLSD for the implementation of the programme. This component has four main principles underlying its activities: delivering (re)habilitation to CwDs, inclusion in access to social services (e.g. education, health and transport), integration in family life and empowerment of children. It is composed of two core activities targeting CwDs:

- The CBR aspect focuses on medical (re)habilitation: Plan refers CwDs to CoRSU and pays for all costs of the surgery. Around 100 children have been operated on so far and the budget is 30 million Uganda Shillings.
- Plan promotes disability as a social issue and targets parents of CwDs via the 100 parents’ support group existing in Uganda. Through awareness raising programmes, parents of CwDs realise that their children are not sick or cursed. They are also trained to make their own AT as this is more affordable.

Additionally, Plan has a MoU with the NCD. However, the NGO considers that the NCD is weak and needs support to develop its strategic planning capacity.¹⁵⁷

155. Humane Africa, <http://www.humaneafrika.org/>, (Accessed 5 February 2014).

156. L’Arche, http://www.ugandangodirectory.org/index.php?option=com_mtree&task=viewlink&link_id=126, (Accessed 13 November 2013).

157. Senyonjo, Jessica, Adupa, Patrick, PLAN, Interviewed by Nadège Riche, 2013.

Finally, through Plan Norway, NORAD funds two projects mainstreaming CwDs in Uganda. In 2013, NORAD allocated 8.7 million Norwegian Kroner (or approximately 1.4 million US dollars) to Plan. These programmes are the following ones:

- Strengthen child protection mechanisms in Uganda: The overall development goal of the programme is to strengthen the national child protection system in Uganda to effectively respond to and prevent violence against children, particularly marginalised children including CwDs and girls (Approximately 5,780,000 Norwegian Kroner or approximately 964,000 US dollars).
- Inclusive participation of children and youth in Lira and Kamuli: The overall development goal of the project is “to create inclusive opportunities for children and youth voices to be heard and influence decision-making and actions in local and national development” (2,920,000 Norwegian Kroner or approximately 487,000 US dollars)¹⁵⁸.

4.6. Save the Children

Save the Children in Uganda has not developed any systematic mainstreaming of the perspective of CwDs or designed projects specifically targeting them. During the design and implementation of education-related projects, issues relating to CwDs have however been raised by some stakeholders and Save the Children then tends to start taking into account their perspective in its activities.

Through Save the Children Norway, NORAD funds five programmes in Uganda for an amount of 24 million Norwegian Kroner (approximately 4 million US dollars) in 2013. All programmes are supposed to mainstream the perspective of CwDs: this implies that the activities are designed for all children but that there are no additional and specific activities targeting CwDs. However, NORAD is unsure as to which degree CwDs are included in all the Save the Children programmes. These programmes are the following ones:

- Education, Uganda District Education Office: Save the Children, in cooperation with partners, aims to improve the quality of education, increase access to schooling for hard to reach out of school children, increase access to quality Early Childhood Development Education programmes, increase access to quality non-formal, post-primary vocational training, as well as increase government financing to the Education Sector (18,401,000 Norwegian Kroner in 2013 or approximately 3 million US dollars).
- HIV/AIDS Uganda, Mitigate the impact of HIV and AIDS on children and their families: it aims to improve access to quality HIV and AIDS prevention, care and treatment services, including mother to child transmission of HIV, for children and their families (542,000 Norwegian Kroner or approximately 90,000 US dollars).
- Child protection: Save the Children in Uganda works with over eighteen partners on a broad range of child protection work. The strategic objectives aim at strengthening community based child protection systems to

158. Engh, Ida-Eline, Norwegian Agency for Development Cooperation (NORAD), Interviewed by Nadège Riche, 2014.

prevent and respond to abuse, exploitation and violence against children and advocacy for increased government capacity to prevent and respond to child protection issues (1,854,000 Norwegian Kroner or approximately 309,000 US dollars).

- Uganda Child Rights NGO Network (UCRNN). The project aims to strengthen systems and mechanisms at national and local levels for monitoring and reporting on the CRC, enhance the capacity of the Government of Uganda towards accountability for the rights of the child and strengthen the knowledge and capacity of children, caregivers, community members, civil society to respect and promote child rights. (2,852,000 Norwegian Kroner or approximately 476,000 US dollars).
- Emergency Preparedness and response: Children have their immediate needs covered, have access to education, and are protected and supported to return to a normalised living environment (457,000 Norwegian Kroner or approximately 76,000 US dollars)¹⁵⁹.

In addition, following the African Day of the Child dedicated to CwDs in 2012, Save the Children in Uganda held an internal and organisational self-assessment in relation to disability. This consisted of a disability related session during a staff meeting. Several men and women with disabilities were invited to discuss with Save the Children staff how the organisation takes into account, or does not, the perspective of CwDs. Topics covered the inaccessibility of the Save the Children offices and the need to consult with CwDs in the strategic planning processes of the organisation. An action plan was developed to change the internal processes of the organisation, although no outcomes are as yet visible.

Save the Children also undertook a rapid mapping exercise in the Karamoja region in 2012 to assess the needs of children and CwDs. This exercise notably demonstrated that CwDs require assistive devices to be able to attend school. For example, in one case study, a CwD studied for three consecutive years at P7 level because he was unable to take the final examination of primary school in Braille. Inspectors were interviewed and they considered that the attitude of teachers and head masters was a decisive factor for CwDs to attend school. Inspectors also reported that they lack training in Special Needs and IE. However, there are strong concerns about the results of this mapping. The mapping primarily considered children and only incidentally CwDs. The methodology was not precisely described and it seems that the approach taken to count CwDs was medically-oriented, focusing on the impairments of children.

Globally, Save the Children has developed a monitoring and evaluation tool that all offices must use to evaluate the quality of the learning environment (QLE) to design and assess the implementation of a project. This tool is based on four guiding principles: (a) a safe and protective environment, (b) an emotionally stable environment, (c) learning based on children needs and (d) partnership between schools and communities. None of these principles take either inclusiveness and/or accessibility into consideration. Despite this limitation, the

159. Engh, Ida-Eline, Norwegian Agency for Development Cooperation (NORAD), Interviewed by Nadège Riche, 2014.

tool was applied in Uganda and has uncovered relevant issues for CwDs. For example, during the design of a project relating to access to literature in Gulu, it has been assessed that there was a need for support material for CwDs.

Finally, Save the Children in Uganda runs projects relating to non-formal education. This is important because many children cannot go to school for a number of reasons. For example, there may be no primary school nearby home or there is a risk of violence on the way to/back from school. Save the Children focuses on the first three levels of education (P1 to P3) and hands over to Government from P4 level onwards. Neither an IE approach has been taken nor has any specific activity targeting CwDs going to school been implemented or included as part of this Save the Children project. However, some feedback has been received during the implementation. Teachers do not feel trained to include and teach CwDs. The attitudes of parents, communities, teachers and head masters play a vital role in including CwDs in school.

On the basis of this incidental feedback, Save the Children has recently started to take into consideration the perspective of CwDs. The organisation partnered with USDC to present the situation of pupils and students with disabilities in one of the weekly poll out sessions about education run by Save the Children. USDC and Save the Children are also discussing the signature of a MoU between both organisations. This strategic partnership would include a review of the Save the Children strategic planning within a disability framework, the organisation of a disability capacity building and awareness raising programme for the staff at national and field offices by USDC and the establishment of a partnership with local communities with whom both Save the Children and USDC work.¹⁶⁰

4.7. War Child

War Child Holland “empowers children and young people in conflict areas by providing psychosocial support, stimulating education and protecting children from violence”¹⁶¹. In Uganda, War Child Holland has run the Sports for Social Inclusion project in 2010 and, recently decided to mainstream the perspective of deaf children into its psychosocial programmes.

4.8. World Vision

World Vision is a “Christian humanitarian organisation dedicated to working with children, families, and their communities worldwide to reach their full potential by tackling the root causes of poverty and injustice.” The organisation is present in 38 Districts and operates 53 Area Development Programmes across Uganda. World Vision mainstreams disability in all its programmes and leads small-scale disability specific projects targeting CwDs - supporting access for CwDs in Gulu to water and sanitation (WASH) and classrooms¹⁶² and distributing wheelchairs to CwDs in Kabale.

160. Bakundana, Flavia, Heijnen-Maathuis, Els, Save the Children, Interviewed by Nadège Riche, 2013.

161. War Child Holland, <http://www.warchildholland.org/>, 2014, (Accessed 5 February 2014).

162. Ojok, Simon, Gulu Disabled People Union (GDPU), Interviewed by Nadège Riche, 2013.

5. CONCLUSIONS ON THE MAPPING OF PROGRAMMES

In the course of this Study, 46 ongoing or completed programmes have been identified. Two-thirds of them address access to education, health and (re) habilitation services for CwDs, while the remaining third focus on areas such as sport, the needs of girls with disabilities or the empowerment and promotion of the rights of CwDs. Very few organisations mainstream the perspective of CwDs in their programmes and even fewer projects address the building of the capacity of Ugandan organisation representing CwDs or parents of CwDs.

Although some of the programmes are run across Uganda, most of them have very limited areas of coverage – for example one or two Districts. Many of them operate in the most deprived areas of Uganda in the Northern and Eastern regions.

The programmes deliver tangible outcomes that impact on the lives of some CwDs living in Uganda. So, for example, some CwDs will benefit from an outreach surgical operation and have improved mobility or an NGO will build accessible classrooms and toilets and improve access to school. These activities can definitely change the life course of a CwD. However, most of these projects are small-scale and lack long term sustainability over time. By their very nature these programmes do not address the need for a structural change that would make a profound impact on the lives of CwDs in Uganda.

These programmes are funded by two types of donor organisations. The Danish, Norwegian and American development agencies have engaged with the disability movement in Uganda for the past 10 to 20 years and about 10 foundations and NGOs based in the UK, the Netherlands, Italy, Liechtenstein, Norway and the US have carried out or are still conducting smaller-scaled activities targeting CwDs living in Uganda.

The Ugandan Disability Movement is vibrant and DPOs are relatively well structured and representative of all categories of PwDs with some visible successes of their advocacy work. For example, NUDIPU successfully advocated for five Members of Parliament who now represent PwDs. However, CwDs living in Uganda are not properly represented: NUDIPU and NUWODU implement projects partly covering their specific needs and rights, but mostly focus on young persons and adults with disabilities. USDC is the only organisation advocating for the needs of CwDs, but is an organisation of adults speaking on the behalf of the CwDs. UPPID supports parents of CwDs but their aim is to mobilise parents of children with intellectual disabilities. There is clearly a gap in the representation of CwDs in the Uganda Disability Movement.

Finally, some INGOs whose focus is on children rights, such as Plan, Save the Children and War Child, have mainstreamed to some extent the needs and rights of CwDs in their own programmes or implemented specific projects relating to CwDs. The impact of the mainstreaming approach is however difficult to assess at this stage and this appears to be a rather recent trend to include the perspective of CwDs.

Part 6: The Disability Situational Analysis

1. THE SITUATION OF THE RIGHTS OF CHILDREN WITH DISABILITIES LIVING IN UGANDA AS REFLECTED BY THE STATISTICS, LAWS AND POLICIES

This section explores the current situation for the realisation of the rights of CwDs in Uganda. The assessment draws upon a review of available statistical information highlighting their inherent limitations. The analysis of the laws and policies reveals the extent to which Uganda has domesticated the CRC and CRPD provisions.

1.1. Available Statistical Information Relating to Children with Disabilities Living in Uganda

Statistical information relating to CwDs living in Uganda is in general unreliable and therefore gives an incomplete picture of the actual reality. Most statistics are unreliable for numerous reasons. So, for example, there are the various definitions of disability used with an ongoing move away from a medical to a social and rights-based model of disability. Differing individual and cultural perceptions of what functional limitations and disabilities imply lead to over or under-estimation of child disability prevalence. The design of data collection tools and the wording and number of questions relating to disability included in the different survey questionnaires also affect the quantity and quality of the collected information. The stigmatisation of disability also negatively affects the value placed upon and resources that are allocated to disability statistics. Because of this, surveys exclude a significant number of persons and children with disabilities. This is, however, a global concern and not only true of Uganda.

Based on the available data, child disability prevalence is about 13% or 2.5 million children living with some form of disability in Uganda. The available data indicates no gender discrepancy: there is an equivalent number of boys and girls with disabilities in Uganda. The enrolment rate of CwDs in pre-primary, primary and secondary school is very low: about 9% of CwDs attend school and only 6% of this complete primary school and continue studying in secondary school. Boys and girls with disabilities seem to have similar enrolment rate at all educational levels. The overall numbers of CwDs and enrolment rates are in line with the worldwide and Sub-Saharan trends elaborated by the various UN agencies.

Aside from the child disability prevalence and access to primary and secondary education, sources of statistical information relating to other areas of the everyday life of CwDs in Uganda are scarce.

In Uganda, the major onset of disability among children is by illness.¹⁶³ The second cause of disability is congenital or acquired around birth. The remaining reasons, which are given, are accidents and curse from God (or similar).¹⁶⁴

Although the understanding of the causes of disability has improved, CwDs are still referred to as “invisible” children. They are often kept at home, hidden from society by their families and most of them are not registered at birth or death. However this situation appears to be improving and in the ACPF study almost half of the 540 CwDs seem to have been registered.¹⁶⁵

Access to health and (re)habilitation is the first practical step in enabling CwDs to move around, go to school and participate in social life. USDC considers that only 10% of CwDs living in Uganda actually benefit from (re)habilitation services.¹⁶⁶ Most carers of CwDs reported that they have access to health care services and around 20% of CwDs have access to (re)habilitation services. The vast majority of these services are provided by the Government followed by NGOs.¹⁶⁷

Conclusively, this statistical information must be handled with caution due to their partial unreliability. There are also significant gaps in statistics relating to CwDs living in Uganda: data is either not gathered at all (e.g. CwDs and humanitarian actions) or sometimes collected but not analysed adequately leading to gaps in information (e.g. disaggregation by gender or types of disability). This lack of relevant and appropriate information significantly affects the planning and delivery of programmes, the development of strong policy formulation and the delivery of vital services targeting CwDs living in Uganda.

1.2. The Rights of Children with Disabilities According to the Ugandan Legal and Policy Framework

This section presents an analysis of how the Ugandan regulatory framework has domesticated the CRC and CRPD provisions by selected areas of rights of CwDs. Overall the laws and policies establishing the rights of PwDs and the rights of children pay limited attention to the specific needs and rights of CwDs.

Besides, the Ugandan regulatory framework is also unclear with regard to the responsibility of duty bearers that must guarantee the recognised rights of CwDs. There are no legal or policy provisions designating the role of the duty bearers in the realisation of the rights of CwDs in Uganda. For instance, Section 9 on CwDs of the Children Act is imprecise and “it places the obligation of early

163. Uganda Bureau of Statistics (UBOS), Uganda Population and Housing Census / Analytical Report on Gender and Special Interest Groups 2002, 2002

164. Africa Child Policy Forum (ACPF), Children with Disabilities in Uganda: A Hidden Reality, 2011.

165. Africa Child Policy Forum (ACPF), Children with Disabilities in Uganda: A Hidden Reality, 2011.

166. Network on Disabled Children, Uganda Society for Disabled Children (USDC), The State of Abuse, Protection and Promotion of Rights of Children with Disabilities in Uganda, 2011.

167. Africa Child Policy Forum (ACPF), Children with Disabilities in Uganda: A Hidden Reality, 2011.

assessment, appropriate treatment, (re)habilitation and equal opportunities upon both parents of CwDs and the state without clarifying who is actually responsible.”¹⁶⁸ This hinders accountability of the duty bearers and ultimately hampers the drafting and implementation of measures that will support the realisation of the rights of CwDs in Uganda.

1.2.1. Definition of a Child with a Disability

The Ugandan legal and policy framework defines a child with a disability as a person below 18 years “with a substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environment barriers resulting in limited participation” (PwDs Act, Part 1, Section 1). In the educational context, learners with disabilities are persons with: “i) Intellectual Impairments, ii) Specific Learning Difficulties, iii) Hearing Impairment, iv) Visual Impairment, v) Physical Impairments, vi) Health Impairments, vii) Speech and Language Disorders, viii) Social, Emotional and Behavioural Difficulties/ Disorders, and those who are; Gifted and Talented, ix) Left handedness and x) Multiple disability (a combination of two or more impairments)” (Draft Policy in SN&IE, Section 3 (4)).

A comparison between the definitions of disability as contained in the CRPD (Preamble, (e)) and in the PwDs Act shows that the latter is not in accordance with Article 1 and does not fully reflect the definition as used in the CRPD. The Ugandan legislation defines disability in terms of a limitation in function and puts the emphasis on the person with a disability. Although the role of environmental barriers is recognised, disability remains primarily defined by the impairments of the person or of the child. There is no recognition of the role of attitudinal barriers and there is no measure or definition of what constitutes a substantial functional limitation. Uganda is therefore yet to fully adopt a rights-based social model of disability.

In addition, there is a lack of any clear and consistent definition of disability in the Ugandan regulatory framework. Definitions of disability vary between the laws and policies establishing the rights of PwDs and the rights of children respectively, or those relating to education. This can lead to the exclusion of some categories of persons and children with disabilities from benefiting from equal opportunities measures or accessing services, especially the albinos, little people or persons with psychosocial or intellectual disabilities. For example, the CRPD would recognise albinism as a disability due to the concept of attitudinal barriers, thus granting recognition of impairments outside of the medical diagnosis. The Ugandan regulatory framework would allow protective measures and possibilities for inclusion (Constitution, Article 31; PwDs Act, Sections 6 and 25 on the prohibition of discrimination in respectively accessing education and goods, facilities and services). However, the challenge which poses the greatest barrier to persons with albinism gaining recognition and support is exactly the issue of definition and this ambiguity has not been addressed within the Ugandan framework.¹⁶⁹

168. National Union of Disabled Persons in Uganda (NUDIPU), Shadow report to the United Nations Committee of Experts on the Implementation of the Convention on the Rights of Persons with Disabilities (CRPD), 2010, p. 37.

169. Office of the United Nations High Commissioner for Human Rights, Persons with Albinism Report, 2013.

This clear and consistent definition of disability should be social and rights based in line with the CRPD. This could also include a measure and definition of functional limitations by, for instance, referring to the WHO ICF.

1.2.2. Non-Discrimination and Equal Opportunities

Provisions on anti-discrimination and promotion of equal opportunities lack clarity and consistency among the Ugandan regulatory framework. Non-discrimination on the ground of disability is defined in Article 21 of the Constitution of Uganda. This is translated into a legal provision as a general objective in the PwDs Act, whereas the Children Act fails to provide a clear provision on anti-discrimination to protect CwDs.

Similarly, the Constitution of Uganda recognises equal opportunities for PwDs, which includes CwDs, to address the imbalances and inequalities they face in life (Article 32). Although the PwDs Act promotes affirmative action for PwDs (Section 33), the National Disability Policy does not state how to realise this right thus making it difficult to implement in practice.

Additionally, “the Children Act does not expressly recognise that CwDs enjoy all the rights guaranteed by this particular law.”¹⁷⁰ The Act highlights the different rights of children that should be promoted and realised to aim at children’s welfare. These rights include right to education, immunisation, adequate diet, clothing, shelter and medical care. It also calls for protection of children against violence and abuse by those who take care of them. However, the Act does not contain any “express recognition that the [above-mentioned] rights guaranteed by the Act apply to all children regardless of their status.”¹⁷¹ In other words, CwDs are not explicitly recognised as right holders of these rights as any other children would. Section 9 is indeed the only specific article that deals with CwDs in this legislation and it only refers to assessment, treatment, (re)habilitation and education of CwDs. It cannot be considered as a general non-discrimination clause.

1.2.3. Rights to Life, Health Services and (Re)Habilitation

This section analyses how the existing Ugandan laws and policies promote and protect the right to life, access to health services and (re)habilitation of CwDs. The regulatory framework relating to the rights to life, health services and (re)habilitation consist of the Constitution of Uganda of 1995, the NDP of 2010, the PwDs Act of 2006, the National Policy on Disability of 2006, the Children Act of 1996, the National OVC Policy of 2004 and the NHP II of 2010. These laws and policies promote and protect the rights of CwDs as follows:

Article 22 (2) of the Constitution of Uganda recognises the right to life to any person and this provision also applies to unborn CwDs. However, the issue of right to life of unborn CwDs and the termination of pregnancy on medical

¹⁷⁰ National Union of Disabled Persons in Uganda (NUDIPU), Shadow report to the United Nations Committee of Experts on the Implementation of the Convention on the Rights of Persons with Disabilities (CRPD), 2010, p. 37.

¹⁷¹ Office of the High Commissioner for Human Rights (OHCHR), Working Paper – A Review of the Ugandan Legal Framework Relevant to Persons with Disabilities - Comparative Analysis to the Convention on the Rights of Persons with Disabilities, August 2008, p. 7.

grounds have not been addressed further in any Ugandan laws or policies.

Some policies assess the current situation and barriers faced by PwDs in accessing (re)habilitation and health services, although there is no specific mention of CwDs' needs, especially of those of girls with disabilities. The NDP identifies the lack of orthopaedic workshops and of affordable assistive devices as two of the main problems and calls upon Government and stakeholders to address these challenges (Section on the social sector and education subsector). Unfriendly and inaccessible health infrastructures, negative attitudes of hospital and health centre staff towards PwDs are also identified as some of the challenges (National Policy on Disability, Section 1 (4) (8); and NHP II, Section 2 (8) (2)).

To address these barriers, the right to equal access to health services by PwDs and CwDs is reiterated (PwDs Act, Section 7; National OVC Policy, Section 5; and NHP II, Section 6 (1)). The measures, which need to be taken to deliver these services to persons and children with disabilities, are described in several laws and policies. The Children Act provides for assessment and (re)habilitation of CwDs (Section 9). The PwDs Act identifies several measures: provision of accessible medical information, integration of SL training in the health professional curriculum and specific training in the needs of PwDs, and the provision of specific sexual and reproductive health services to women and girls with disabilities to keep them alive (Section 7). However, the realisation of these services has so far not been realised due to inadequate resource allocation.

Furthermore, the legal framework in Uganda does not recognise habilitation as provided under the CRPD. The focus is to help PwDs to regain functional ability. This is not in line with the spirit of Article 26 which focuses on habilitation and rehabilitation. Although CBR is elaborated under the PwDs Act, the law assigns the ministry responsible for disability affairs, the MoGLSD, the duty to set up, equip and maintain vocational training institutions for PwDs. This is in contradiction to Article 24 of the CRPD which stipulates an inclusive education system at all levels, lifelong learning and reasonable accommodation of the individual's requirements.

1.2.4. Right to -Inclusive- Education

This section analyses how the existing Ugandan legal and policy framework promotes and protects the right to education of CwDs. The regulatory framework relating to the right to education consist of the Constitution of Uganda of 1995, the NDP of 2010, the Education (Pre-Primary, Primary and Post-Primary) Act of 2008, the UNISE Act of 1995 amended by the University and Other Tertiary Institutions Act of 2001, the draft SN&IE Policy, the draft Non-Formal Educational Policy for Educationally Disadvantaged Children, the PwDs Act of 2006, the National Policy on Disability of 2006, the Children Act of 1996 and the National OVC Policy of 2004. These laws and policies promote and protect the rights of CwDs as follows:

The 1995 Constitution of Uganda provides for the constitutional right to education for all (Article 30) and the equalisation of opportunities for all disadvantaged groups, including CwDs (Article 32). The PwDs Act, 2006, specifically outlines the legal provision of access to education for persons and children with disabilities (Sections 5 and 6) and calls for not less than 10% of the education budget to be allocated to the education needs of CwDs.

This right to education is directly or indirectly reiterated in several laws and policies (Education Act, Schedule 1, part I and II, section 4 (2) and (3); National Policy on Disability, Section 1 (4); and National OVC Policy, Section 5)). The provisions for SNE and IE are described in the draft SN&IE Policy and draft Non-Formal Education Policy for Educationally Disadvantaged Children (Section 1 (1), (2) and (3)).

Specific barriers and challenges, which restrict access to education for CwDs, are identified and measures to overcome them outlined. The first barrier to be identified is the inaccessibility of education buildings, including latrines, toilets and classrooms, for CwDs (NDP, Section on the social sector and education subsector; PwDs Act, Sections 12 and 20; and Draft SN&IE Policy, Section 2 (4)).

The second challenge consists of the lack of alternative formats of the educational curriculum and of accessible scholastic material (Draft Non-Formal Education Policy for Educationally Disadvantaged Children, Section 2 (2); NDP, Section on the social sector and education subsector; Draft SN&IE Policy, Sections 2 (4) and 5 (7)). It is the responsibility of the Faculty of Special Needs and Rehabilitation of the Kyambogo University to address these specific needs of pupils and student with disabilities as well as to provide assistive devices and train teachers in SN&IE (UNISE Act, Section 5 (d)).

The final challenge identified in these laws and policies is the lack of SN&IE trained teachers. It is therefore planned to include a SN&IE training module in the teacher training curriculum and specific SN&IE training for teachers to enable them to teach all children including CwDs in mainstream schools (PwDs Act, Section 5; draft SN&IE Policy, Section 2 (3); NDP, Section on social sector and education subsector; and UNISE Act, Section 4 and 5 (a) and (g)).

Although IE is encouraged, at the same time the establishment of special schools and units is included where IE is not possible. The greatest omission within the PwDs Act is the failure to provide clear provisions on reasonable accommodation for the individual requirements of CwDs as required under CRPD Article 24 (2) (c). This stands in contradiction to the Convention and the promotion of an IE policy.

In addition, it is worth highlighting that the current laws and policies tend to

bring confusion between IE and SNE. “Although the government is committed to the principle of IE as evidenced by the ratification of the [CRPD] and the adoption of a Universal Primary Education Policy in 1996, it has authorised the construction of 24 special schools. The educational legal framework is confusing and ambiguous as it mentions both IE and SNE. For example, under Section 5 of the PwDs Act, IE is encouraged although at the same time the establishment of special schools and units is included where IE is not possible.”¹⁷² So, what Uganda has in effect, is what can be called a twin track approach to IE and SNE. The Government of Uganda recognised it: “while embracing the need to provide for IE at all levels, [Uganda] still promotes the twin track approach by providing for both special schools and IE, in promotion of the right of PwDs to education where special schools might still be required for learners with confounding disability.”¹⁷³

Given that the mainstream educational system is currently inefficient, and taking a pragmatic approach, several Ugandan DPOs continue to advocate for the building of special schools. This is because it is believed that, in the current system, CwDs will receive a far better education, and stand a far greater likelihood of securing long-term employment if they receive education in special schools. “A survey in Uganda found that disability groups and parents favoured this approach partly out of concern about overcrowding and poor resourcing in standard schools.”¹⁷⁴ This has resulted in a confusing legal and policy framework to realise IE for CwDs, despite the clear call for IE in CRPD Article 24.

1.2.5. Right to Recreational Activities, Leisure and Sport

This section analyses how the existing Ugandan legal and policy framework promotes and protects the right to cultural and recreational activities, leisure and sport for CwDs. It consists of the PwDs Act, 2006, and of the Children Act, 1996. Overall the legal provisions and supply of recreational activities to CwDs are under developed in Uganda.¹⁷⁵

In both Acts, the article relating to the rights to leisure, play and participation in cultural and artistic activities is limited to the recognition of these rights to the targeted population. The Children Act does not provide any guidance on how these rights should be implemented. The PwDs Act is slightly more elaborated: it refers to the enactment of “appropriate measures to participate in mainstream sporting activities” and [...] of the need for adequate support (meaning “instructions, training and resources”) (Section 30). However, there are no specific clauses identifying CwDs’ as holding the right to play. They are indirectly covered by the PwDs and Children Acts respectively targeting PwDs and children.

172. National Union of Disabled Persons in Uganda (NUDIPU), Shadow report to the United Nations Committee of Experts on the Implementation of the Convention on the Rights of Persons with Disabilities (CRPD), 2010.

173. Government of Uganda, United Nations Convention on the Rights of Persons with Disabilities Uganda’s Initial Status Report 2010, 2010.

174. Department for International Development of the United-Kingdom (DFID), Disability Scooping Study, Final Report, February 2009.

175. Uganda Child Rights NGO Network (UCRNN), NGO Complementary Report to the Government of Uganda First Period Report on the Convention on the Rights of Children, 2000, p. 46.

In practice, the MoES through the National Council of Sports organises annual sports competitions for children with visual impairments in primary schools. However the Ministry has never considered promoting sport for other disability groups.¹⁷⁶ This is also separate games for PwDs thereby reinforcing segregation and limiting inclusion in the broader world of sports.

1.2.6. Protection from Exploitation, Violence and Abuse

This section analyses how the Children Act, 1996, the National OVC Policy, 2004, and the Child Labour Policy, 2006, form the child protection legal framework defining the rights of CwDs to be protected from all forms of exploitation, violence and abuse. These laws and policies aim to create an environment where CwDs can live safely and fulfil their maximum potential.

The Children Act is the main legislation that instrumentalises Article 34 of the 1995 Constitution of Uganda which calls for the enactment of legal provisions promoting and protecting the rights of all children. The overall aim of the Children Act is to lay out the measures that must be put in place to ensure the welfare of all children, including CwDs. Both the National OVC Policy and the Child Labour Policy mention CwDs as one of their target groups, among other categories of vulnerable children. There is however no specific article highlighting the situation of CwDs and the measures that should be taken. The overall purpose of both policies is to protect them from abuse and violence (National OVC Policy, Section 5) and to eliminate CwDs' labour in communities (Child Labour Policy, Section 10).

The main omission of this limited CwDs protection mechanism is the lack of identification of the responsibility of duty bearers to report breaches of these rights. Caregivers of CwDs, who are the primary resource person of the child, should be granted with the responsibility to report any breaches, especially sexual abuses on girls with disabilities such as defilement and rapes.¹⁷⁷

In that respect, there seem to be several parallel processes going on in the Parliament of Uganda in relation to sexual offenses but to date no legislation has been adopted. "In 2000, the Government of Uganda introduced the 'Sexual Offences (Miscellaneous Amendments) Bill'. The Bill sought to amend the provisions of various enactments on sexual offenses, procedural and evidential requirements during the trial of sexual offenses and for other related matters. In 2012, the Uganda Women's Parliamentary Association (UWOPA) begun a similar process in the form of the 'Sexual Offences Bill', the Bill has several objectives including – consolidating laws relating to sexual offenses, combating sexual violence, providing for punishment of perpetrators of sexual offenses, providing for procedural and evidential requirements during trial of sexual offenses and other related matters. This Bill also aims to protect PwDs, including CwDs, from being sexually harassed or abused and raped. MPs are now considering the certificate of financial implications before taking it any further. As a parallel

176. Luyima, Ronald, National Union of Disabled Persons in Uganda (NUDIPU), Interviewed by Nadège Riche, 2013.

177. National Union of Disabled Persons in Uganda (NUDIPU), Shadow report to the United Nations Committee of Experts on the Implementation of the Convention on the Rights of Persons with Disabilities (CRPD), 2010, p. 18.

initiative UWOPA was also in supporting amendment of the Evidence Act to address some evidential constraints for sexual offence related cases.”¹⁷⁸

1.3. Main Conclusions about the Situation of the Rights of Children with Disabilities Living in Uganda as Reflected by the Statistics, Laws and Policies

The assessment of the state of CwDs’ rights in Uganda based on a review of the available statistical information and an analysis of the regulatory framework reveals an incomplete understanding of their situation.

Data relating to CwDs are scarce and to some extent unreliable. Based on estimations, the child disability prevalence is about 13% or 2.5 million children living with some form of disability in Uganda. The enrolment rate of CwDs in pre-primary, primary and secondary school is very low: about 9% of CwDs attend school and only 6% of these complete primary school and continue studying in secondary school. Boys and girls with disabilities seem to have a similar enrolment rate over all educational levels. Significant gaps in information are evident in the lack of disaggregation of statistics by gender and types of disability and the non-existence of national and accurate data in other areas of the life of CwDs other than education.

The analysis of the regulatory framework shows that Uganda has broadly domesticated the rights of CwDs enshrined in both the CRC and CRPD. The provisions are recognised in the Constitution of 1995 and in most of the laws and policies establishing the rights of PwDs and children. No specific legislation has been adopted on the rights of CwDs and they are rather mainstreamed in other legislation, which is in line with the approach taken by the Conventions. Although CwDs’ rights are acknowledged, some of the provisions to realise them are not in line with the CRC and CRPD requirements. The most striking example is the right to IE stated by CRPD Article 24. Recent or about to be adopted Ugandan laws and policies identify IE as a possible way forward but continue to actively promote SNE and the establishment of special schools. Another major challenge is the lack of any clear measures as to how to realise these stated rights. To conclude, the rights of CwDs are well recognised by the Uganda regulatory framework but the measures to realise them are contrary to the international conventions, if specified at all. The unclear provisions relating to the responsibility of duty bearers (Children Act, Section 9) also hamper the implementation of measures that would support the realisation of CwDs’ rights in Uganda.

178. National Union of Disabled Persons in Uganda (NUDIPU), Shadow report to the United Nations Committee of Experts on the Implementation of the Convention on the Rights of Persons with Disabilities (CRPD), 2010.

2. IDENTIFICATION OF BARRIERS AND BOTTLENECKS PREVENTING THE FULL REALISATION OF THE RIGHTS OF CHILDREN WITH DISABILITIES IN UGANDA

This section analyses the many barriers that impede CwDs from accessing their rights and the bottlenecks that hinder those organisations responsible for promoting and protecting them.

2.1. Social Norms of Disability Leading to Discrimination

Throughout the course of the research study, one of the clearest findings was the ongoing presence of stigmatising attitudes to reject, neglect, abuse and marginalises persons and children with disabilities. Traditionally behaviours towards CwDs have been negative and “parents continue to see the birth of a CwD as a great misfortune.”¹⁷⁹ For example, it was reported that a father of a child with Cerebral Palsy explained to people that “his wife produced a CwD”, meaning his wife was deemed responsible for the birth of a CwD.

These stigmatising and negative attitudes targeting CwDs can be the cause of very difficult situations. For example, CwDs are sometimes hidden away or if a mother gives birth to a CwD, the father may run away. CwDs are very often marginalised in their families and communities.¹⁸⁰

This situation has been recently researched and illustrated by several organisations. HumaneAfrica recently published a report confirming that “CwDs are subjected to violence, abandonment, neglect, and in some cases, death. They are often hidden away from public view inside their houses, which excludes them completely from society. [...] Interviews with children, families, schools and institutions confirmed that CwDs in Uganda often are excluded and experience discrimination.”¹⁸¹ NUDIPU also demonstrated how girls (and women) with disabilities experience multiple discrimination based on their gender and disability: “parents of CwDs still have a belief that they have demons with them and give them much protection that they cannot contract marriages. Further that these parents believe their children of marriageable age cannot be mothers in their new homes and would be mistreated by their husbands.”¹⁸² On another note, the ACPF describes a more balanced situation in its report on the situation of CwDs in Uganda. CwDs still face bad treatments and negative attitudes in their household or communities. For example, a minority is always excluded from family or religious events because of their impairments. However, “changes in societal attitudes towards CwDs [have also been noticed and] are gradually improving and becoming more supportive: a very large majority of CwDs reported that they get emotional support from their families and help in conducting everyday tasks that they have difficulties in performing.”¹⁸³ Although the stigmatising attitudes to reject, neglect, abuse and marginalisation

179. AbleChildAfrica, <http://ablechildafrica.org/resource/>, 2013, (Accessed on 15 November 2013).

180. Simpson, Malcolm, Children's Surgical Rehabilitation Hospital (CoRSU), Interviewed by Nadège Riche, 2013.

181. HumaneAfrica, Attitudes and Behaviours towards Children with Disabilities in Uganda, Review of literature and field research conducted in October 2013, 2014.

182. National Union of Disabled Persons in Uganda (NUDIPU), Shadow report to the United Nations Committee of Experts on the Implementation of the Convention on the Rights of Persons with Disabilities (CRPD), 2010, p. 24.

183. Africa Child Policy Forum (ACPF), Children with Disabilities in Uganda: A Hidden Reality, 2011, p. 37.

of persons and children with disabilities in Uganda shall not be underestimated, more positive attitudes have been noticed and may be considered as a prelude to social changes.

As part of this research, it has also been established that parents or guardians lack the basic skills to take care, educate and support their CwDs: “Parents of CwDs do not know what to do with them”.¹⁸⁴

First, they have low parenting skills relating to the needs and rights of CwDs. They do not have the knowledge to identify at an early stage whether their child has a disability, or not. This would however be crucial because the earlier an impairment is assessed, the better one will be taken care of and get answers to one’s needs. Parents have also little information of support mechanisms and availability of assistive devices and technologies, although these would greatly assist them in taking care of their children. As a result of these low parenting skills, CwDs “are under cared for and considered last at home.”¹⁸⁵ For example, “many CwDs lack proper nutrition because they eat last”.¹⁸⁶ Similarly, “parents deny education to their CwDs because they did not see the purpose, thinking that such children cannot be able to perform in life anyway”.¹⁸⁷

Additionally, parents and guardians give value to the beliefs and attitudes of their community. It appears that their behaviours are largely influenced by what relatives, neighbours and/or teachers, among others, think of persons and children with disabilities. “Even if the parents love and care for their CwD, the biggest challenge for them can be the negative attitudes and stigmatisation of their children by the community. Communities are sorry about the situation but do not actively encourage CwDs to do things themselves.”¹⁸⁸ Some parents of CwDs do not even want to be seen with their child.

To conclude, this research has unveiled a pattern of behaviours based on misconceptions and stigmatisation that are associated with disability. These attitudes are dependent on what communities traditionally think of persons and children with disabilities. Facing this, parents and guardians of CwDs also seem to prefer conform to what their communities expect them to act like. However, such a statement would further research to be fully evidenced-based. Likewise, these negative attitudes and behaviours towards CwDs, and PwDs in general, are not only practised by communities and families, but also by Government Institutions, international bodies, NGOs and DPOS themselves. This is, however, a global concern and it is not only true of Uganda.

Conclusively, it can be reasonably extrapolated that social norms¹⁸⁹ relating to disability are widely disseminated in the Ugandan society. This situation leads to discrimination towards persons and children with disabilities. Changing them

184. Jawoko, Perry, Gulu District, Interviewed by Nadège Riche, 2013.

185. Luwar, Teddy, Gulu Women with Disabilities Union (GUWODU), Interviewed by Nadège Riche, 2013.

186. Okecho, Christopher Wimon, Ministry of Education and Sports (MoES), Interviewed by Nadège Riche, 2013.

187. Uganda Bureau of Statistics (UBOS), Report of the National Service Delivery Survey (NSDS), 2008.

188. Byamugisha, Isidor, Uganda Parents of Persons with Intellectual Disabilities (UPPID), Interviewed by Nadège Riche, 2013.

189. Mackie, Gerry, and Moneti, Francesca (ed.), Working Paper: What are Social Norms? How are they Measured?, United Nations Children’s Fund (UNICEF) – University of California San Diego (UCSD) Center on Global Justice Project Cooperation Agreement, 2012.

would therefore require the collective and individual efforts of all stakeholders to promote and protect the rights of CwDs. The “huge shift in all of our attitudes [implies] a total rethink of our approach to ability and inclusion. Addressing the attitudes of parents and everyone else in communities will be of critical importance if the rights of children and young PwDs are to be realised.”¹⁹⁰

2.2. A Serious Gap in Implementation of the Ugandan Regulatory Framework

The policy gaps analysis reveals that the Ugandan regulatory framework broadly domesticates the CRPD and CRC. Through constitutional, legal and policy provisions, it challenges discrimination based on the grounds of disability, promotes affirmative action and equal opportunities and contains provisions to deliver access to education, (re)habilitation, health services, leisure and sport to CwDs. Overall, the rights of CwDs are well recognised by the Uganda regulatory framework (although some of these measures to realise them are contrary to international conventions, if specified at all¹⁹¹).

But, it remains the case that the country faces substantial challenges in implementing effective and efficient disability policies and services. In short, there is a significant implementation gap¹⁹² and in reality these laws and policies are honoured in the breach. This appears to be a long-standing and systemic issue raised in the course of various sessions of the UN monitoring mechanisms relating to human rights. In 2005, State Parties to the CRC reviewed the situation of children rights in Uganda and recommended that, “to prevent and prohibit all forms of discrimination against CwDs and ensure that they have equal opportunities to participate fully in all spheres of life, [Uganda] implements the domestic laws [...] including disability aspects in all relevant policy-making and national planning”.¹⁹³ Similarly, in 2011, Uganda went through its Universal Periodic Review. Comparable recommendations were given by the State Parties: Hungary encouraged Uganda to “implement the steps envisaged in the promotion of rights of PwDs, with a special emphasis on equal opportunities for CwDs” and Spain incited Uganda to adopt “measures to guarantee the rights of PwDs, in particular, to fight against all forms of discrimination faced by women with disabilities, and regarding the lack of equal opportunities for minors with disabilities, with a particular attention to albino children.”¹⁹⁴

In the framework of this research study, several reasons explaining this implementation gap were identified.

One of the immediate explanations lies in “the fact that, [in Uganda,] the processes of policy formulation and implementation are totally divorced from each other.”¹⁹⁵ Most of the laws and policies set ambitious goals which are difficult to put in place afterwards: for example, it is required to make ALL

190. AbleChildAfrica, <http://ablechildafrica.org/resource/>, 2013, (Accessed on 15 November 2013).

191. Refer to Part 6/Section 1(2) of this Report for a detailed analysis of the Ugandan regulatory framework.

192. The vast majority interviewees have underlined the gap in implementation of laws and policies in Uganda.

193. Committee on the Rights of the Child, Consideration of Reports Submitted by State Parties under Article 44 of the Convention, Concluding observations of the Committee on the Rights of the Child: Uganda, 2005, p. 9.

194. United Nations (UN) General Assembly, Human Rights Council, Report of the Working Group on Universal Periodic Review Uganda, 2011, p. 16.

195. Department for International Development of the United-Kingdom (DFID), Disability Scooping Study, Final Report, February 2009, p. 7.

public buildings accessible to PwDs without taking into account the concept of progressive realisation¹⁹⁶. This lack of proper enforcement is also due to the lack of clear regulations, by-laws and ordinances. Some legislation requires the passing of interpretation guidelines because they are technical in nature, accessibility of the physical environment illustrating well this idea again.¹⁹⁷ This situation is reinforced by the lack of know-how of legislation implementers and of their significance for PwDs. So for example, despite the fact that the PwDs Act was adopted in 2006, to date there are no regulations passed for its implementation. Provisions, such as the ones on CwDs in the Children Act or OVC policy, seem to stay on paper. Furthermore, Uganda has not established an effective monitoring and complaints mechanisms that would enforce and protect the rights of CwDs. This is explained in details in the next section relating to the institutional framework.

Another striking explanation of this implementation gap is the lack of financial resources and budget allocation to implement provisions targeting CwDs. The vast majority of laws and policies relating to persons and children with disabilities are adopted in Parliament without a certificate of financing. Without proper funding, no laws or policies can be implemented.¹⁹⁸ This is further compounded by limited budget allocations to local Government Institutions in charge of the promotion and protection of the rights of CwDs¹⁹⁹. The allocation of financial resources is made at the national level and, since this is not properly made, local governments are left without the resources for the implementation of these laws and policies.²⁰⁰ So for example, the PwDs Act, 2006, requires that 10% of all educational expenditures are allocated to the needs of persons and children with disabilities (Part II, Section 5). In practice, this has never happened. This leads to a situation where the MoES through its Special Needs department distributes Braille papers, Perkins brailers and brailled text books to special units, these materials remains however insufficient to meet the needs of all schools in the country. This lack of financial resources is true of the child sector in general. In 2005, State Parties to the CRC already “urged [Uganda] to prioritise and increase budgetary allocations for children at both national and local levels, and in particular to pay attention to the protection of the rights of children belonging to vulnerable groups, including CwDs”²⁰¹.

Finally, a direct result of these limited budgets is the lack of trained staff working with CwDs in local and national Government Institutions, hospitals and schools. These people ultimately put into practice the content of these laws and policies. Districts, sub-counties, parishes and villages have administrative positions in charge of the welfare, education and access to health services and (re)habilitation for CwDs. But, due to shortage of financial resources, no one is appointed. In this regard, the situation of the Gulu District is quite representative.

196. Byamugisha, Isidor, Uganda Parents of Persons with Intellectual Disabilities (UPPID), Interviewed by Nadège Riche, 2013.

197. Okecho, Christopher Wimon, Ministry of Education and Sports (MoES), Interviewed by Nadège Riche, 2013.

198. Senyonjo, Jessica, Adupa, Patrick, PLAN, Interviewed by Nadège Riche, 2013.

199. Okwera, Albert, Gulu District Council for Disability, Interviewed by Nadège Riche, 2013.

200. Okecho, Christopher Wimon, Ministry of Education and Sports (MoES), Interviewed by Nadège Riche, 2013.

201. Committee on the Rights of the Child, Consideration of Reports Submitted by State Parties under Article 44 of the Convention, Concluding observations of the Committee on the Rights of the Child: Uganda, 2005, p. 4.

As any other districts, Gulu has a sector in charge of SNE but no officer has been employed. Many programmes are designed without consulting PwDs or their representative organisations because it is considered too expensive, which is one of the reasons for their failure. The Gulu Disability Council has no facilities and no budget. The structure is also not established at sub-county level due to lack of funding²⁰². In the health and (re)habilitation sector, the lack of staff is also obvious. There is only one physiotherapist per District Hospital and they must support PwDs, CwDs and older people for the whole District. They have heavy workloads and cannot see those people in need of health and (re)habilitation services. This is even more critical as some CwDs need only one intervention (e.g. a child with club feet), while others require an on-going assessment of their needs (e.g. a child with CP) and this does not happen because of the reasons mentioned above. Many physiotherapists and occupational therapists also prefer to practice privately and in towns where there is more business²⁰³. Similarly, the education sector lacks SN&IE trained “mainstream” teachers and teachers assisting CwDs in specific class (e.g. learning Braille note taking). Due to the overall limited number of teachers, head masters also tend to post SN&IE teachers in “mainstream class”, whose skills are thus underused²⁰⁴.

To conclude, Uganda faces a significant gap in the implementation of the existing laws and policies relating to CwDs. This is due to several reasons such as the lack of supporting implementing acts as well as of limited financial and human resources. Another major barrier to the enforcement of legislation is the lack of coordination between key stakeholders and duty bearers.

2.3. An Institutional Framework Weakened by Lack of Coordination and Limited Knowledge and Capacities of Key Stakeholders

The institutional analysis indicates two main bottlenecks hindering the full realisation of the rights of CwDs in Uganda: a lack of coordination among key stakeholders and duty bearers as well as a gap in knowledge and capacities of those to engage with CwDs.

The institutional framework to promote and protect the rights of CwDs has been established through various laws.²⁰⁵ At ministry level, the MoGLSD has been appointed as the lead Ministry for disability affairs, while all other Ministries, especially the MoES and MoH, are responsible for matters relating to CwDs within their respective mandates. It implies that the MoGLSD has “the mandate to promote and protect the rights of PwDs and to provide technical assistance to other sectors in disability mainstreaming”.²⁰⁶ However, the MoGLSD has not been granted powers to influence other Ministries running interventions targeting CwDs.

202. Adong, Caroline, National Council for Disability (NCD), Interviewed by Nadège Riche, 2013.

203. Bongole, Rose, Ministry of Health (MoH), Interviewed by Nadège Riche, 2014.

204. Okecho, Christopher Wimon, Ministry of Education and Sports (MoES), Interviewed by Nadège Riche, 2013. For an

205. in-depth presentation of the institutional framework, refer to the United Nations Children's Fund (UNICEF) Uganda, Research Study on Children with Disabilities Living in Uganda, Intermediary Report - Summary and Analysis of Policies and Mapping of Programmes, 2014.

206. Ministry of Gender, Labour and Social Development, Terms of references for the National Steering Committee on Disability, 2013.

This results into uncoordinated work between Government Ministries and, in this respect, the activities relating to data collection are a good example. The MoGLSD, MoES and MoH implement policies and programmes directly affecting the lives of CwDs. They can collect administrative data in terms of the number of CwDs served by public services such as CBR Programmes, educational and vocational services and health services. This data could be used to estimate the numbers and needs of CwDs served by the public administration of the country. While both the MoGLSD and MoES already have Management Information Systems (MIS) in place, the MoH has not reported using any MIS.²⁰⁷

In the framework of the CBR programme, the MoGLSD uses the Uganda CBR MIS (CBR MIS). However, this system suffers from two main limitations: it is based on data gathered at the local government level (data that mostly is not available) and it is only operated in the Districts covered by the CBR programmes. This would suggest that the MoGLSD has not been able to produce any figures using the CBR MIS at this stage. In addition, the MoGLSD with support from Handicap International designed and tested the Data Collection Tool on Disability in 2012/13. Section F covers the education of CwDs and has questions about the types of schools CwDs attend (i.e. inclusive/mainstream, special school or integrated unit) and about the reasons for not going to school (i.e. distance, inaccessibility of classrooms or latrines, lack of school fees, bullying, bad attitudes by teachers, lack of appropriate scholastic material, negative attitudes by parents). Due to a lack of funding, the MoGLSD has not been able to use this tool on a larger scale and produce data for Uganda.

The MoES produces the Uganda Education Statistical Abstract every year, and since 2007, questions about pupils and students with disabilities have been incorporated. The Ministry has also been proactive in improving the production of statistics relating to CwDs attending school. A new questionnaire about students with special learning needs by class and gender has been designed and tested in Hoima, Masindi, Iganga and Kamuli. Types of impairment are detailed and cover “mental impairment, visual impairment with low vision and blindness, hearing impairment with profound and hard of hearing, deaf blind, autism, multiple handicaps”. “Multiple handicaps” refers to person with several disabilities except for deafblind people who have their own category in this survey. This new approach has not been adopted as yet within the MoES.²⁰⁸

Local Government Institutions are also tasked with the collection of statistical information relating to PwDs and CwDs at District, Sub-County, Parish or Village level²⁰⁹. It however seems that Local Government Institutions do not produce such statistics or they are not available to the public.

Therefore it is evident that there is a significant fragmentation of approach and duplication of efforts to collect and produce estimations of CwDs served by the various public administration bodies.

207. Rose Bongole, Ministry of Health (MoH), interviewed by Nadège Riche, 2014.

208. Christopher Wimon Okecho, Ministry of Education and Sports (MoES), Interviewed by Nadège Riche, 2013.

209. Government of Uganda, Local Government Act, 2001.

Similarly, Uganda has not established a clear and effective monitoring and complaints mechanisms that would enforce and protect the rights of CwDs. Four government bodies, reporting to the MoGLSD, can potentially address the challenges arising from the enforcement of the human rights and the promotion of equal opportunities of CwDs. These are the NCC, NCD, the UHRC and the EOC. Significantly, the NCC, NCD, EOC and UHRC have very similar roles and powers in relation to the promotion and protection of the CwDs' rights as per their establishing Acts. In practice, it appears that, whilst the NCC and NCD have mainly an advisory and monitoring role in matters relating to children and PwDs respectively, the EOC and UHRC are legally empowered to investigate and report breaches of the rights of persons and children with disabilities²¹⁰. The NCD and NCC are also responsible for the laws and policies in their respective areas of expertise, but neither has been able to put in place an effective system²¹¹. None of these four bodies seem to have authority over the others with regard to CwDs' matters and only the NCC has engaged with CwDs by quarterly chairing a restricted National Disability Forum.

Finally, in the course of this research study, only one national coordination mechanism has been identified: it is the National Steering Committee on Disability. It was established in 2004/05 under the impulsion of the Norwegian National Association of the Deaf (NAD) that had a partnership agreement with the Government of Uganda. It initially ensured coordination of the activities of the CBR programmes implemented at district level. Today, the purpose of the Committee is to "discuss and harmonise sectoral plans and budgets for effective implementation of programmes to empower PwDs"²¹² and meet quarterly for this purpose. Chaired by the Minister of State for Elderly and Disability Affairs, it is composed of various stakeholders: Government Ministries (i.e. MoGLSD, MoES, MoH), Kyambogo University, UN Population Funds (UNFPA), DPOs (e.g. NUDIPU and NUWODU) and NGOs of the Disability Movement (i.e. Action on Disability and Development, Handicap International, Sight Savers and Sense International).

However, the objectives pursued by the Committee and its composition are not adequate to challenge the situation of CwDs in Uganda. The Committee has a general mandate and none of its specific objectives, as defined by the Terms of References, focus on the needs and rights of CwDs. At the time of writing this Report, the Committee has therefore never engaged with matters of interest to CwDs. Besides, the only organisation member of the Committee that is working with CwDs is USDC but it is a member of the Steering Committee, and not of the Technical Committee which acts as a Working Group. The National Committee on Disability has therefore not been granted the capacity to engage with CwDs -yet.

210. United Nations Children's Fund (UNICEF), Research Study on Children with Disabilities Living in Uganda – Validation Workshop, 2014.

211. Human Rights Watch, Discrimination and Violence against Women with Disabilities in Northern Uganda

212. Ministry of Gender, Labour and Social Development, Terms of References for the National Steering Committee on Disability, 2013.

Conclusively, there is an evident weak coordination between Government Institutions and Bodies as far as matters relating to CwDs are concerned. The only network gathering various government and non-government stakeholders, the National Steering Committee on Disability, manage general disability matters but has not engaged with issues concerning CwDs. This situation ultimately contributes to the fragmentation of initiatives and the design of a number of small-scale programmes lacking any long term vision and sustainability (as described in the following section on a fragmented programmatic approach).

In addition to this, another bottleneck hinders the full realisation of the rights of CwDs in Uganda. A number of key stakeholders from the Disability and Child Rights Movement have limited knowledge and capacities to engage with the protection and promotion of the CwDs' rights.²¹³ These organisations have an understanding of either children rights or of disability rights, but few of them have succeeded in synthesising and mainstreaming both approaches. In other words, CwDs are at the cross-road between child issues and disability matters and both Movements tend to overlook their rights. This lack of understanding of the needs and knowledge of the rights of CwDs within most organisations slows down and prevents the full realisation of their equal opportunities and welfare in life.²¹⁴ To date, only Plan has engaged in a nationwide consultation of children and young PwDs and actively mainstreamed their perspective in its core activities.²¹⁵ NUDIPU and NUWODU, the national umbrella organisations representing persons and women with disabilities, also acknowledge that their main focus is on young persons and adults with disabilities.²¹⁶

2.4. A Fragmented Programmatic Approach Resulting in Gaps in the Responses Provided by the Duty Bearers

2.4.1. A Fragmented Programmatic Approach

This section presents an analysis of the programmatic responses designed to address the challenges faced by CwDs for which fragmentation can be observed. This is true from initiatives taken by both governmental and non-governmental key stakeholders and duty bearers.

Due to the set of reasons described in the previous sections (i.e. lack of financial and human resources, weak coordination mechanisms between Government Ministries and Bodies as well as limited knowledge and capacities of these organisations), the government approach tends to be fragmented. This means that, despite the scarce means at their disposal, the three Government Ministries mainly working with CwDs, namely the MoGLSD, the MoES and the MoH, initiate and conduct similar activities. A striking illustration of this situation is the current running of parallel initiatives aiming to collect statistical information relating to CwDs. The MoGLSD uses the Uganda CBR MIS and the Data Collection Tool on Disability, whilst the MoES produces the Uganda Education

213. Byamugisha, Isidor, Uganda Parents of Persons with Intellectual Disabilities (UPPID), Interviewed by Nadège Riche, 2013.
And, Okecho, Christopher Wimon, Ministry of Education and Sports (MoES), Interviewed by Nadège Riche, 2013.

214. Uganda Society for Disabled Children (USDC), USDC Advocacy Strategy 2013-19, p. 4-5.

215. Senyonjo, Jessica, Adupa, Patrick, PLAN, Interviewed by Nadège Riche, 2013.

216. Luyima, Ronald, National Union of Disabled Persons in Uganda (NUDIPU), Interviewed by Nadège Riche, 2013.

Statistical Abstract every year. These three tools contain questions relating to CwDs but none of them are exactly the same or even similar. This results in the collection of data which are not comparable and which cannot be cross-checked, although this would be valuable given the lack of statistics relating to CwDs living in Uganda. It is therefore evident that there is a significant fragmentation of approach and duplication of efforts between the various public administration bodies.

The fragmentation of the programmatic responses targeting CwDs given by non-government stakeholders is also apparent. In the course of this Study, forty-six ongoing or completed programmes have been identified. Two-thirds of them address access to education, health and (re)habilitation services for CwDs, while the remaining one third focus on areas such as sport, the needs of girls with disabilities or the empowerment and promotion of the rights of CwDs. Very few organisations mainstream the perspective of CwDs in their programmes. Indeed, many iNGOs working with children have now integrated some aspects linked to the needs and rights of CwDs but “often childhood disability [remains] a marginal concern”²¹⁷.

Furthermore, these programmes deliver tangible outcomes that impact on the lives of some CwDs living in Uganda. So, for example, some CwDs will benefit from an outreach surgical operation and have improved mobility or an NGO will build accessible classrooms and toilets and improve access to school. These activities can definitely change the life course of a CwD. However, most of these projects are small-scale and lack long term sustainability over time. By their very nature these programmes do not address the need for the structural changes that would make a profound impact on the lives of CwDs in Uganda.

Furthermore, very few NGOs have demonstrated successful programmes addressing the needs of CwDs in Uganda. The only organisation specifically advocating for the rights of CwDs, as enshrined in both the CRPD and CRC, is USDC, but this is rather an organisation of adults speaking on the behalf of the CwDs. This situation is also reflected in the Ugandan Disability Movement. Uganda DPOs are relatively well structured and representative of all categories of PwDs with some visible successes of their advocacy work. However, CwDs living in Uganda are not properly represented - both NUDIPU and NUWODU implement projects partly covering their specific needs and rights, but mostly focus on young persons and adults with disabilities. UPPID supports parents of CwDs but their aim is to mobilise parents of children with intellectual disabilities. There is no specific organisation or committee in a mainstream DPO representing CwDs. It can therefore be concluded that there is clearly a gap in the representation of CwDs in the Uganda Disability Movement. This results in limited programmes targeting CwDs that are initiated or run by Ugandan DPOs.

217. AbleChildAfrica, <http://ablechildafrica.org/resource>, 2014, (Accessed 2 April 2014).

2.4.2. Gaps in the Current Programmatic Responses

This fragmented programmatic approach means that the basic needs of CwDs are not given appropriate answers by the key stakeholders and duty bearers. This is particularly striking in the health and (re)habilitation sector as well as in terms of access to education by CwDs.

2.4.2.1. Challenges Faces by Children with Disabilities in Accessing Health and (Re)Habilitation Services

The CBR programmes implemented in Uganda for the past twenty years have been proven useful. However, today they are available in only twenty-four out of one hundred twelve Districts. This implies that there are not enough CBR Centres throughout Uganda and that they are overloaded and unable to properly provide information and (re)habilitation services to persons and children with disabilities. Additionally, parents and guardians do not or cannot bring their CwDs to (re)habilitation centres for various reasons. Because communities live very far from hospitals and health centres, people cannot reach them and thus benefit from their services. Public transportation is too expensive for them to go to the District or Regional Hospitals. Some of them also do not know where to bring their child to get assistance. Therefore, CwDs are not taken care of and parents or guardians do not bring them to health or (re)habilitation centres.²¹⁸

This whole situation was already described in 2002 by UCRNN: “Accessibility, including distance to health [and (re-habilitation)] centres, though improved, still poses a challenge to some areas and to CwDs. Though service delivery is vested in the local authorities, this has failed to address the huge demand that increased with the eradication of cost sharing. USDC operates some medical units to provide specialised (re)habilitation services for CwDs but have very limited coverage nation-wide. Local governments plead they lack resources to run health programmes, purchase relevant equipment and adequately furnish their facilities. Support from the MoH is only in technical terms, supervision and guidelines for planning processes.”²¹⁹

2.4.2.2. Challenges Faced by Children with Disabilities in Accessing Education CwDs living in Uganda face serious challenges to access educational services.

The immediate barrier hampering CwDs to go and attend school is the lack of inclusive schools adapted to welcome both children with and without disabilities. “The school education system lacks facilities for [CwDs] in most districts in Uganda”.²²⁰ This is true of all educational levels with the greater difficulties being the pre-primary one. In Gulu, only babies and children with physical impairments can join the Early Childhood Development Centres (ECDC), but not other CwDs, and this only became possible after intense advocacy efforts from GUWODU, the local DPO.²²¹ Few UPE and USE schools have facilities

218. Bongole, Rose, Ministry of Health (MoH), Interviewed by Nadège Riche, 2014.

219. Uganda Child Rights NGO Network (UCRNN), Alternative Report to the Government of Uganda's First Periodic Report, 2002, p. 38.

220. Uganda Child Rights NGO Network (UCRNN), Alternative Report to the Government of Uganda's First Periodic Report, 2002, p. 20.

221. Luwar, Teddy, Gulu Women with Disabilities Union (GUWODU), Interviewed by Nadège Riche, 2013.

with a “SNE unit” intended for pupils and students with disabilities so only richer families can afford sending their CwD in privately-owned primary and secondary schools.²²²

Accessibility of the school environment, meaning classrooms, library, playgrounds and toilets, is a major issue. CwDs drop out of schools because they cannot even enter the buildings.²²³ CwDs also need a “board class” with a facilitative atmosphere, which often does not exist. This is a specific classroom for pupils and students with disabilities in an inclusive school. For instance, it would contain specific equipment (e.g. Embosser) or a library with books for children with visual impairments.²²⁴ This also applies to the digital environment: the Government pushes for exams to be done via computers but this is not made accessible to CwDs, so they are left out.²²⁵

Besides, instructional materials and equipment for these children are still insufficient. This refers to any types of assistive devices (e.g. Braille embossers and papers, Braille readers) which, although they are expensive, are needed by CwDs to study from primary one to secondary four level. Computers are also necessary for pupils with disabilities from primary three onwards to take notes faster than using Braille readers and note takers but they are not available either.²²⁶ At present, the SNE department of Kyambogo University only provides schools with Braille equipment, hearing aids and other assistive devices but this is not sufficient and does not solve these above-mentioned problems. Much more needs to be done. CwDs also lack assistive and supporting services: for instance, deaf and hard of hearing children cannot attend class without a SL interpreter or a signing teacher. This is rarely provided for and most of them are secluded in “Deaf Schools”.

Furthermore, commuting to school is complicated for CwDs. For example, the distance between school and home is an issue for children with physical disabilities. Blind and partially-sighted children need to be guided and accompanied back and forth but parents, siblings or families do not have the time to do it. Boarding facilities can be an alternative to commuting but facilities (i.e. buildings for CwDs, beds, mattresses, food) are missing²²⁷ and such a measure would not necessarily take the welfare of the child as the primary consideration.

Another major problem is the lack of trained SNE teachers. There are too few SNE teachers overall. Many of them are posted to “mainstream” classes and cannot give attention to pupils and students with disabilities. Headmasters report that SNE teachers are under-utilised.²²⁸ The number of CwDs enrolling is increasing so even more SNE teachers should be recruited and posted in schools.²²⁹ The lack

222. Luwar, Teddy, Gulu Women with Disabilities Union (GUWODU), Interviewed by Nadège Riche, 2013.

223. Baba Diri (Hon.), Margaret, Women Member of Parliament (MP) for Koboko District, Interviewed by Nadège Riche, 2014; Luyima, Ronald, National Union of Disabled Persons in Uganda (NUDIPU), Interviewed by Nadège Riche, 2013; Luwar, Teddy, Gulu Women with Disabilities Union (GUWODU), Interviewed by Nadège Riche, 2013; Naswa Were, Dolorence, Uganda Society for Disabled Children (USDC), Interviewed by Nadège Riche, 2013.

224. Baba Diri (Hon.), Margaret, Women Member of Parliament (MP) for Koboko District, Interviewed by Nadège Riche, 2014.

225. Luyima, Ronald, National Union of Disabled Persons in Uganda (NUDIPU), Interviewed by Nadège Riche, 2013.

226. Baba Diri (Hon.), Margaret, Women Member of Parliament (MP) for Koboko District, Interviewed by Nadège Riche, 2014.

227. Baba Diri (Hon.), Margaret, Women Member of Parliament (MP) for Koboko District, Interviewed by Nadège Riche, 2014.

228. Baba Diri (Hon.), Margaret, Women Member of Parliament (MP) for Koboko District, Interviewed by Nadège Riche, 2014.

229. Luyima, Ronald, National Union of Disabled Persons in Uganda (NUDIPU), Interviewed by Nadège Riche, 2013.

of training for teachers is also obvious: the teacher curriculum does not include a module on SN&IE and teachers get specialised only if they are interested in SN&IE.²³⁰

The final barrier that was identified in the course of this research is the attitudes of parents and families. Parents do not give priority for CwDs to go and attend school²³¹ and they get easily discouraged because the child is ranked last every year.²³² It even happens that CwDs are not being picked up from their schools when the academic term is over.²³³ Similarly, the negative attitudes of teachers and administrative staff affect the enrolment of CwDs in school. They are not cooperating enough in promoting an inclusive educational environment.²³⁴

All these serious barriers hamper CwDs to go and attend schools. They result in the very low enrolment rate of CwDs from pre-primary to secondary level in Uganda.

2.5. Main Conclusions about the Barriers and Bottlenecks Preventing the Full Realisation of the Rights of Children with Disabilities in Uganda

In the course of this research study, many barriers and bottlenecks preventing the full realisation of the rights of CwDs were identified. Large misconceptions and stigmas are still associated with disability and this leads to attitudes and behaviours of neglect, abuse and marginalisation of CwDs by communities and families. Although the Ugandan regulatory framework broadly domesticates the CRPD and CRC, there is a need to clarify and strengthen the measures to operationalise the law and the responsibility of the Government Institutions to ensure the enforcement of the rights of CwDs. Protection of CwDs is also weak and existing laws and policies are not fully enforced. Finally, a lack of coordination between different national Government Institutions and gaps in knowledge, understanding and capacities of the organisations of the Disability and Child Rights Movement have partly resulted in a fragmentation of the programmatic approach to the needs of CwDs.

The current programmatic responses established by the key organisations of the Disability and Child Rights Movement are limited and lack ambition. They only answer the immediate and obvious needs of CwDs, while only the easy-to-reach children benefit from these projects. The structural barriers are therefore not addressed, although this is the only way forward to make a profound and sustainable change over time in the lives of CwDs. The full realisation of the rights of CwDs will not be achieved, unless collective and individual efforts are driven forward by a leading organisation committed to this goal.

230. Naswa Were, Dolorence, Uganda Society for Disabled Children (USDC), Interviewed by Nadège Riche, 2013.

231. Jawoko, Perry, Gulu District, Interviewed by Nadège Riche, 2013.

232. Naswa Were, Dolorence, Uganda Society for Disabled Children (USDC), Interviewed by Nadège Riche, 2013.

233. Okecho, Christopher Wimon, Ministry of Education and Sports (MoES), Interviewed by Nadège Riche, 2013.

234. Naswa Were, Dolorence, Uganda Society for Disabled Children (USDC), Interviewed by Nadège Riche, 2013.

Part 7:

Recommendations

This section provides recommendations to UNICEF Uganda and Partners. The review of statistical information, the analysis of the institutional and regulatory frameworks and the mapping of programmes present an understanding of the situation of CwDs living in Uganda and identifies the barriers and bottlenecks preventing the full realisation of their rights. Based on the findings of the Disability SitAn, the following recommendations seek to provide UNICEF Uganda and Partners with a set of activities that can be conducted within the framework of their strategic programming from 2015 onwards. This would also reflect the obligations of the CRPD which calls for disability mainstreaming in cooperation development work (Article 32) by providing technical assistance to Uganda.

1. ONGOING ASSESSMENT OF THE SITUATION OF CHILDREN WITH DISABILITIES LIVING IN UGANDA

The situation of CwDs is evolving over time. Assessing their needs and the realisation of their rights should be an ongoing process rather than a one off exercise. This would apply equally to consultation exercises with CwDs to hear their views on what they think are their most pressing needs and to the implementation of survey and assessment exercises. Both would allow UNICEF Uganda and its partner organisations to design and plan evidenced based initiatives. In practice, an ongoing process to gather information about the situation of CwDs would enable UNICEF Uganda and key stakeholders to streamline the implementation of programmes as issues arise.

1.1. Actively Consult and Listen to Children with Disabilities on Issues Concerning Them

Two consultations of CwDs have taken place to date. The ACPF consulted about 600 CwDs to produce its Report CwDs in Uganda: the Hidden Reality.²³⁵ Plan is about to issue the findings of its consultative workshops of CwDs,²³⁶ although their methodologies to involve CwDs could not be assessed at the time of writing this Report. It can therefore be concluded that no major representative and countrywide consultation of CwDs has taken place in Uganda - yet. This constitutes a major gap in information relating to what CwDs consider as their most pressing needs and it is needs to be addressed.

235. Africa Child Policy Forum (ACPF), Children with Disabilities in Uganda: A Hidden Reality, 2011.

236. Senyonjo, Jessica, Adupa, Patrick, PLAN, Interviewed by Nadège Riche, 2013.

UNICEF Uganda and Partners are therefore advised to assess the Plan consultation, as soon as it is released. On this basis, stakeholders should decide whether other consultations of CwDs living in Uganda are needed before planning and implementing any programmes. UNICEF Uganda and Partners should also consider establishing an ongoing process of consultation and participation involving CwDs rather than one off consultations. Otherwise the results of these consultations might be forgotten amidst the running of the programme(s). The consultative platform of CwDs created at the beginning of a process could be involved throughout the implementation phase. This would enable and support the monitoring and evaluation of the outcomes in line with the needs expressed by CwDs and the streamlining of the programmes. The organisations of the Child Movement would be ideal partners to run such consultations and set up an ongoing process or framework listening to hear the views of CwDs about their situation.

RECOMMENDATION N°1:

Actively consult and listen to CwDs on issues concerning them on an ongoing basis

1.2. Support the Collection of Statistical Information Relating to Children with Disabilities Living in Uganda

There are significant gaps in the statistical information relating to CwDs living in Uganda and UNICEF Uganda and Partners must therefore take action to improve the collection and availability of data that will inform and support the development programming.

This would also assist Uganda in putting into practice the recommendations, which it received during its second periodic review on the implementation of the CRC: “the Committee recommends that the State party [i.e. Uganda] take all necessary measures: (b) To collect adequate disaggregated statistical data on CwDs and use such data in developing policies and programmes to promote their equal opportunities in society, paying particular attention to children living in the most remote areas of the country”.²³⁷

This collection and interpretation of appropriate information, including statistical and research data about CwDs, should be done on a regular basis through the existing channels and frameworks. The execution of specific and one off surveys could be used as a complementary tool, rather than as the main process to collect statistical information relating to CwDs. Setting up a framework to collect data

237. Committee on the Rights of the Child, Consideration of Reports Submitted by State Parties under Article 44 of the Convention, Concluding Observations of the Committee on the Rights of the Child: Uganda, 2005, p. 9.

on a regular basis would also release the pressure to find funding and run one off expensive surveys across Uganda whose results become rapidly outdated.

1.2.1. Improve Statistical Information Relating to Children with Disabilities

Living in Uganda

Measuring the child disability prevalence is a complex task. Definition of disability, approach by “difficulties in functioning”, sets of questions relating to PwDs and CwDs as well as design of data collection tools have been elaborated and tested in the global UN Working Group on Disability and Statistics. The Ugandan Government Institutions and agencies have already engaged in data collection and developed statistics relating to persons and children with disabilities. DPOs operating in Uganda have expertise and can assist in gathering data relating to disability. Therefore, there is no need to design new methods to collect statistics relating to CwDs living in Uganda. The data collection systems already in place should rather be used and reinforced.

1.2.1.1. Adopt Available Global Guidelines Relating to Disability Measurement

UNICEF and its partner institutions in Uganda should use the globally available methodologies and tools relating to disability measurement. This would then allow comparison between Ugandan statistics and those for the rest of the world. The following recommendations could contribute to improving the availability and quality of statistics on CwDs living in Uganda:

- Follow the WHO ICF: “The ICF is neither a measurement tool nor a survey instrument but it is an internationally agreed classification for health and disability, which can act as a standard worldwide. In parallel to global trends, Ugandan stakeholders should base their definition of and approach to disability on the ICF. This would ensure a broad coverage of all impairments and conditions of PwDs (because it is mainly limited to sensory and physical impairments in statistics available for Uganda). This would also include other indicators measuring disability such as activity limitations and participation restrictions, related health conditions and environmental factors”;²³⁸ hence reflecting the social model of disability promoted by the CRPD.
- Use the sets of questions relating to CwDs aged two to five and five to 18 designed by the UN Washington Group on Disability and Statistics: Measuring the child disability prevalence adds another layer of difficulties. With the active participation of UNICEF, the UN Washington Group on Disability and Statistics has recently developed and tested a set of questions for CwDs aged two to five. The sets of questions for CwDs from the age of five and adults with disabilities have also been agreed upon. UNICEF Uganda should use and promote these survey instruments while engaging with Ugandan partners.

238. World Health Organisation (WHO), World Bank, World Report on Disability, Geneva: WHO/World Bank, 2011, p. 44-46.

1.2.1.2. Fill the Gap: Disaggregate and Break Down Statistical Information Relating to Children with Disabilities Living in Uganda

The available statistics concerning CwDs are scarce and provide an incomplete picture of their living conditions in Uganda. Data is either not gathered at all or sometimes collected but not analysed adequately leading to gaps in information.²³⁹

- Use a clear age band from zero to 18 years in statistics relating to CwDs: The child disability prevalence in Uganda is difficult to assess for several reasons. One of them is the use of different age bands: children and young people are often aggregated together (e.g. from zero to 14 and then from 15 to 24 years), although the CRC and the Children Act define a child as a human being below 18 years. UNICEF Uganda and Partners should promote a clear age band: children from zero to 18 years should constitute a distinct group in censuses and surveys, while any human being aged above should be considered as a young person or an adult.
- Streamline the understanding of the profile of CwDs living in Uganda by disaggregating the data according to various indicators: The available statistics about CwDs living in Uganda focus on child disability prevalence and school enrolment rates. There is a need for more information to understand who the CwDs in Uganda actually are. Data disaggregated by various indicators should be collected: So for example the data could differentiate gender, different age bands between zero and 18 years of age, geographical distribution across the Regions and Districts, place of residence (rural versus urban), impairments and conditions, family situations (e.g. orphans, street children) and CwDs with HIV / AIDS.
- Fill the gaps in statistical information in fields associated with the everyday lives of CwDs: In addition to better defining and understanding the profile of CwDs, further research is also required into their living conditions. Aside from the school enrolment rate, data is missing from a wide range of fields: birth and death registration, number of CwDs living in institutions, access to health care and (re)habilitation services, experience of gender-based violence, abuse and exploitation based upon disability discrimination, humanitarian action and civilian casualty rates, education and vocational trainings, among others.

1.2.2. Enhance the Financial and Technical Support for the Uganda Bureau of Statistics to Produce Comprehensive Statistics relating to Children with Disabilities Living in Uganda

UBOS is the leading body creating statistics in Uganda. It has introduced modules on disability in most of its censuses and surveys and produced data relating to persons and children with disabilities. UBOS is a member organisation of the UN Washington Group on Disability and Statistics and follows their guidelines to design survey questionnaires. The questions relating to disability have moved to a “limitations in functioning” approach over the past decade. UBOS

239. Helen Nviiri, Pamela Kakande, Uganda Bureau of Statistics (UBOS), interviewed by Nadège Riche, 2013.

demonstrated a strong commitment and a relatively good understanding on how to assess and collect information about the situation of PwDs.

Despite this favourable trend in the past ten years, there appears to be a backward shift, most probably due to lack of external funding. The National Census, which will be conducted in 2014, has included a module with four questions relating to the difficulties a person aged two and above has in (a) walking/moving, (b) seeing, (c) hearing and (d) communicating. The data produced by the Census 2014 will not be comparable to ones presented by the Census 2002, the UDHS 2006 and 2011 or the UNHS 2005/06 and 2009/10, because the questions on persons having mental/intellectual impairments or problems in self-care are not part of this module to be used in 2014. Consequently information about only part of the population of PwDs will be captured. In addition, UBOS has deleted the module or questions relating to disability in the UNHS 2012/13 which suggests that it will be difficult for UBOS to produce accurate data on CwDs in the coming years.

On this basis, UBOS would require human and financial resources support from UNICEF Uganda and Partners to produce more comprehensive methodology and improved statistics about CwDs living in Uganda. Both organisations should partner and adopt a twin-track approach to the production of reliable and accurate statistics relating to CwDs living in Uganda starting from the age of two: i.e. work with UBOS to ensure that the information generated about CwDs by the census and surveys is as comprehensive as possible while also working with them to design and conduct a specific survey about CwDs from birth to 18. Another key aspect of the conduction of these surveys and censuses are the capacities of enumerators to understand and identify the various types of disability of people. UNICEF and the MOGLSD should therefore assess and most probably train the capacities of UBOS enumerators in disability.

- Disaggregate and break down data relating to CwDs in the framework of the Census 2014: The Census 2014 will gather a certain amount of information that should be fully extracted and analysed. According to the type of data gathered during the collection phase, the widest range of indicators should be defined together with UBOS to better assess the profile of CwDs. Figures should also be analysed in relation to the fields of the everyday lives of CwDs.
- Advocate that UBOS reintroduce a module and a large set of questions relating to CwDs from the age of two in the next UNHS and UDHS: This would allow an on-going assessment of the situation and needs of CwDs using a sample representative of the Ugandan population. Since UNICEF Uganda partly funds these surveys (e.g. UDHS 2006), its advocacy in favour of a disability module would be very influential.
- Organise a survey specific to CwDs living in Uganda: The tools to assess the child disability prevalence and the needs of CwDs from the age of two have been developed and tested by the UN Washington Group on

Disability and Statistics. The first stage of such a survey would therefore be a pilot project to customise the existing international set of questions to the Ugandan context. This would validate the extent to which the questions are understood by people and their appropriateness. The second step would then consist of the survey itself. It would ideally be a national survey, should there be sufficient financial resources. A survey targeting a sample representative of the population would also be an option to give an insight into the situation. UBOS would be ready to cooperate with UNICEF Uganda, as this has been done previously to produce statistics on violence against children living in Uganda. However, UBOS would require financial resources from donors to conduct such a survey as well as technical support from experts to design the survey and questions targeting CwDs living in Uganda. In parallel, UNICEF Uganda and Partners should monitor the development of methodologies assessing the disability prevalence in the population of CwDs aged zero to two and include it in all future surveys. An alternative way forward could consist in creating a disability-specific MIS taking example of the successful results achieved under the Sunrise- Orphans and vulnerable children (OVC) project conducted by USAID.

- Assess the outcomes by holding a Workshop or a Forum: High level representatives from key stakeholders and advocates from the Disability Movement should be invited. Direct representation of CwDs should also be foreseen and prioritised. Participants should discuss and evaluate the latest figures relating to CwDs living in Uganda and the implications in terms of disability issues, statistics and challenges with regard to policy formulation and programmatic responses. The Workshop or Forum should also promote a human rights based approach to disability.

RECOMMENDATION NO.2:

Improve statistical information relating to CwDs in partnership with UBOS

2. ESTABLISH STRONG AND SUSTAINABLE REGULATORY AND INSTITUTIONAL FRAMEWORKS

The full realisation of the human rights of CwDs enshrined in the CRC and CRPD cannot be achieved without the establishment of strong and sustainable regulatory and institutional frameworks. Laws and policies must domesticate the provisions laid down in both Conventions to guide their realisation in

practice. The local and national Government Institutions must be granted with powers and capacities to fulfil their role in leading the implementation of the rights of CwDs, while key NGOs and DPOs of the Child and Disability Rights Movements should be empowered to continue advocating for them.

2.1. Review and Enforce the Ugandan Regulatory Framework Relating to Children with Disabilities

Uganda has developed a comprehensive legal and policy framework that seeks to realise the rights of persons and children with disabilities. The Government has enacted legislation and policies specifically designed to address the rights of PwDs in general and particular kinds of impairments specifically. In most laws, there are provisions that aim to promote and protect some of the rights of CwDs.

One of the fundamental obligations contained in both the CRC and CRPD is that national laws should guarantee the enjoyment of the rights outlined in the Conventions. The CRPD may be incorporated through constitutional, legislative and regulatory measures (CRPD Article 4). Except in the rare case that the laws in a country already conform fully to the requirements of the Convention, a State Party will normally have to amend existing laws or introduce new laws in order to put the Convention into practice. In Uganda's case there is need to either amend existing laws, policies and programmes or introduce a comprehensive law on disability incorporating the heightened protection provided by the CRPD.

Ideally, there should be a comprehensive and unequivocal legal statement of the rights of persons and children with disabilities and detailed legislation to make those guarantees real in practice. It is critically important that the recognition and protection of the rights of persons and children with disabilities be enshrined in the supreme law of the country, that is, in the national constitution or in basic laws. This will ensure the highest possible legal protection and recognition.

A number of areas in the Ugandan regulatory framework require amendment to bring it in line with the CRPD and CRC. For example, although the current PwDs Act is progressive in certain areas, there are a number of instances where it fails to reach the high standards set out in the CRPD, for example in the article relating to -inclusive- education. It is therefore recommended that UNICEF Uganda seeks to work in partnership with the Disability and Child Rights Movement in Uganda to advocate as far as possible for changes not just in the statutory laws, but in the Constitution, from which all other laws derive their validity. The opportunity presented for the domestication of the CRPD should be used to review and amend both legislation and policies in order to fully respect the values, principles and rights enshrined in both Conventions and to effectively prioritise the perspective of CwDs.

Since CwDs are among the most vulnerable communities both socially and economically, it is critical that the rights of CwDs should be prioritised in all laws,

policies, programmes and mechanisms promoting and protecting the rights of children and/or persons with disabilities. For this purpose, a rights based social model of disability shall be adopted. The immediate priority should be to review and amend the PwDs Act and Children Act, because these provisions outline the legal framework that defines the rights of CwDs. Since an amended PwDs Act is currently standing for approval by Cabinet, UNICEF Uganda and Partners have a window of opportunity to call for the immediate integration of specific articles relating to CwDs. Another focus could be on the policies of the education sector. Also pending an approval by Cabinet, the draft SN&IE Policy should be amended and promote IE exclusively, in line with CRPD Article 24. Similarly, the Education Act should be amended to intergrate the 10% education budget allocation to address the needs of persons and children with disabilities of the PwDs Act and all other above accessibility related issues. The implementation of the draft SN&IE draft Policy should be linked to the implementation of the Education Act, of the Business, Technical and Vocational Education and Training (BTNET) Act, 2008, and the Non-Formal Education Policy for Educational Disadvantaged Children. CwDs should also benefit from a disability mainstreaming in the Uganda ECD Policy, what is missing at this point in time. Accessibility of the physical and digital environments is another major concern for CwDs: for example, the lack of accessible classrooms and toilets is the number one reason why CwDs do not go and attend school. The DPOs in Uganda have successfully advocated in favour of access provisions in several legislations but this is not enough. It is recommended that UNICEF Uganda partners with the Ugandan Disability Movement and seeks to strengthen the laws and policies taking into account the specific needs of CwDs (and not those of adults with disabilities only). Finally, the Child Labour and OVC policies would benefit from UNICEF Uganda's close attention. Although CwDs are identified as one of the vulnerable categories of children in both policies, they tend to be considered last and there is no specific articles covering addressing their situation.²⁴⁰ Conclusively, Uganda is fairly well engaged with the domestication of the CRPD and CRC provisions. A continuous review and amendment of laws, policies and programmes is however still required and it is recommended that UNICEF Uganda and Partners support this effort taking CwDs' welfare as the primary consideration.²⁴¹

But, even though Uganda has developed a comprehensive regulatory framework that seeks to realise the rights of CwDs, the main problem lies in their implementation. UNICEF Uganda and Partners should therefore focus on the full enforcement of all existing provisions targeting CwDs. Some of these measures do not require any review and should be implemented right away in cooperation with the responsible local or national Government Institutions.

One of the main barriers hampering the proper enforcement of the provisions relating to CwDs is the lack of implementing acts. Some legislation requires the passing of interpretation guidelines because they are technical in nature, accessibility of the physical environment being an example.²⁴² UNICEF Uganda

240. Naswa Were, Dolorence, Uganda Society for Disabled Children (USDC), Interviewed by Nadège Riche, 2013.

241. Annex 2 presents detailed analysis and suggestion of amendment for each laws and policies.

242. Okecho, Christopher Wimon, Ministry of Education and Sports (MoES), Interviewed by Nadège Riche, 2013.

and Partners should therefore advocate for the drafting and adoption of two types of instruments. Clear statutory instruments, such as rules and regulations, will assist the operationalisation of the rights of CwDs. For example, the PwDs Act was adopted in 2006 and to date there are no regulations passed for its implementation. This will be a straight-forward action. Another approach is the promotion of the use of bye-laws and ordinances. Organisations and institutions responsible for the promotion and protection of CwDs' rights would define administrative provisions that they must then enforce. This could be a rapid and effective way forward compared to amending statutory laws. It is therefore suggested that UNICEF Uganda and Partners promotes the adoption and use of regulations and bye-laws to ensure the implementation of existing provisions targeting CwDs.

The insufficient financial and human resources allocated to programmes targeting CwDs and to responsible local and national Government Institutions is another explanation for the lack of a proper enforcement. Without appropriate funding, no activities can take place and deliver changes. A challenging but immediate action line is to advocate for increased budget allocations to responsible Government Institutions and earmarking for CwDs in existing programmes. For example, the Faculty of Special Needs Education and Rehabilitation of Kyambogo University is in charge of providing assistive services and distributing appropriate scholastic materials for children with different types of disabilities but is not able to cope with the demand. Financial support will make a difference and directly support CwDs in attending school. Besides, a direct result of these limited budgets is the lack of trained staff working with CwDs in local and national Government Institutions, hospitals and schools. Increased budgets will de facto encourage institutions to hire more staff working with CwDs but this will not be sufficient. Additional incentive mechanisms to encourage therapists and SN&IE teachers to remain in their position should also be established. To conclude, UNICEF Uganda and Partners should engage with these concerns of limited financial and human resources to realise the rights of CwDs without delay.

RECOMMENDATION N°3:

Review and enforce the Ugandan legal and policy frameworks

RECOMMENDATION N°4:

Increase budget allocations to responsible Government Institutions and earmarking for CwDs in related programmes

2.2. Structure the Institutional Framework and Reinforcing the Knowledge and Capacities of Key Stakeholders

2.2.1. Call for the Coordination and Alignment of the Efforts of the Local and National Government Institutions

Although the institutional framework promoting and protecting the rights of CwDs has been established through the passing of various Acts, it needs to be seriously strengthened. It has been evidenced that there is a significant fragmentation of approach and duplication of efforts to both collect and produce information about CwDs, as well as design and implement programmes lacking long term sustainability.

The lead Ministry for Disability Affairs, the MoGLSD, does not have the authority to decide how other Ministries run interventions targeting CwDs, such as the MoES and MoH. Equally, the NCC, NCD, EOC and UHRC share similar responsibilities in the monitoring and complaints mechanisms, without any one of these national bodies having taken a lead coordination role at this point in time. Finally, the decentralisation of government in Uganda has resulted in the central government having little effective control on how national legislation is enacted at the local level. This is further compromised by weak accountability and the need for good governance structures.

UNICEF and Partners should therefore advocate for the provision of better coordination mechanisms under the leadership of MoGLSD and the alignment of the efforts of various national Government Ministries and Bodies in relation to CwDs. This would help alleviate the scarce financial and human resources of the different public administrations. The creation and operation of a coordinating body to oversee and advice on the rights of CwDs is highly required. Such a mechanism should be linked to other Government Ministries (e.g. MoES, MoH and MoFPED) and bodies such as the NCC, NCD, EOC and UHRC. By adopting a coordinated approach under the lead of the MoGLSD, it will be possible to pool resources and capacity to work together to carry out, for example, joint research on the status of CwDs, investigations of breaches of the human rights of CwDs, and the documentation and publication of good practices promoting and protecting the rights of CwDs. Such a coordinating mechanism will strengthen the protection of the rights of CwDs in Uganda. A practical answer to this issue could be the establishment of a new Task Force on CwDs under the National Steering Committee on Disability, led by the MoGLSD with an active technical support from UNICEF Uganda and Partners.

Matching harmonisation of efforts at national level, coordination mechanisms among local Government Institutions should also be thought of and established. This would have two levels. First, local partnerships gathering LCs for PwDs and all district officials working with CwDs should be set up. This will ensure the sharing of knowledge between every person in charge, the definition of

clear and common guidance and the mainstreaming of CwDs' perspective in all local level committees, councils and programmes. Secondly, District elected and administrative people working with CwDs would benefit from a national network gathering their peers. They will be able to, for example, share successes and best practices on how to implement laws and policies. Ideally, physical meetings should be facilitated but the use of digital means (e.g. mailing list) could also be a feasible alternative.

RECOMMENDATION N°5: **Coordinate efforts among local and national Government Institutions**

2.2.2. Create a Ugandan Partnership on Children with Disabilities

In addition to weak coordination between local and national Government Institutions, the limited sharing of knowledge and harmonisation of activities between governmental and non-governmental stakeholders has led to a fragmentation of initiatives and the design of a number of small-scale programmes lacking long term sustainability.

On this basis, UNICEF Uganda should support the establishment of a Partnership on CwDs following the guidelines developed by the GPc wd to establish national partnership on CwDs.²⁴³ This partnership would act as a network including all relevant organisations working with CwDs in Uganda. This should include the various local and national Government Institutions, international and Ugandan NGOs and DPOs, especially those specific for CwDs, donor organisations and, if applicable, the private sector. The partnership should act as a platform for discussion and sharing of good practices, advocacy and collective action. This would ensure that the rights of CwDs are prioritised by both the Disability and Child Rights Movement. This would also form a representative forum advising on how to mainstream the perspective of CwDs in other national fora. Funding opportunities from the GPc wd could be used to develop programmes under such a national partnership.

This Uganda Partnership on CwDs could follow the models existing at international level, the GPc wd, or NPc wd that have been formed in Rwanda and Kenya. Drawing from these two experiences in the East African region, several lessons can be learnt. Both NPc wd started with a specific goal before expanding into a more structured network: Kenya initially met to brainstorm on the meaning of IE in the country while the Rwanda NPc wd was created

243. Global Partnership on Children with Disabilities (GPc wd), Guidance for Establishing a National Partnership on Children with Disabilities (NPc wd), 2013.

with the aim of preparing the National Children's Summit. Both groups created thematic working groups (e.g. education) and tasks forces (e.g. policy, watchdog network, research) to streamline the work. This ultimately led into the issues of CwDs to be more visible nationwide: the Kenyan NPc wd was invited to join the validation committee of the national education support programme and, in Rwanda, a child with a hearing impairment was elected as President of the Forum sending a strong message to the general public. Recalling the feedback of UNICEF Rwanda, two important aspects must be thought of right from the beginning: "firstly, it is important to collaborate and harmonise efforts to achieve results at the highest level over the short term; secondly, it is extremely important to use existing advocacy platforms, existing resources, and existing organisations to achieve success in promoting the rights of CwDs."²⁴⁴

Furthermore, UNICEF Uganda and Partners can also learn from the successful experience of the Uganda National Youth Working Group (NYWG). "[Set up] in 2011 by the MoGLSD, UNFPA, the National Youth Council, War Child UK and Restless Development, it was established as an informal platform for shared learning on youth issues to help address the challenge of poor coordination in the youth sector. It has grown from five to over 140 individual members representing approximately 80 different organisations. [The NYWG meets six times a year and the sub-groups gather between the larger NYWG meetings]. The NYWG is increasingly being approached by partners interested to draw on the expertise of the members [and, early 2014, UNICEF Uganda has invited] the NYWG Chair to participate in [its] annual retreat to support development of their new research and evaluation strategy."²⁴⁵ Two main success factors explain such a development. The NYWG was initiated by a core group of organisations that were strongly committed and are still members. The NYWG has also allowed freedom to the network to decide what topics should be discussed; this has created appropriation of the activities by the joining member organisations.

To conclude, UNICEF Uganda has solid experiences to learn lessons from and guidelines to support the establishment of a strong and successful Uganda NPc wd. This would ultimately provide a coordinated platform for all organisations working with CwDs in Uganda.

RECOMMENDATION N°6: **Create a National Partnership on CwDs** **led by the MoGLSD**

244. Global Partnership on Children with Disabilities (GPCwd), Report of the Second Forum, 2013, p. 15 and 16.

245. National Youth Working Group (NYWG), National Youth Working Group – Overview, 2014, p. 1.

2.2.3. *Building the Knowledge and Capacity of Key Stakeholders Working with Children with Disabilities in Uganda*

A lack of understanding of the needs of CwDs among most stakeholders working with them has been reported during the course of this study.²⁴⁶ They also lack know-how of the CwDs' rights enshrined in the CRPD and CRC and of their obligations arising from the national laws and policies. This situation partly explains the lack of proper implementation and enforcement of the provisions relating to CwDs. It overall slows down and prevents the full realisation of equal opportunities for CwDs and their general welfare in life. The reinforcement of the understanding of the needs and knowledge of the rights of CwDs as well as the strengthening of the capacities of all stakeholders should therefore be addressed.

UNICEF Uganda and Partners should firstly aim to reinforce the knowledge of the rights of CwDs. In this regard, relevant material (e.g. CRPD, CRC, laws, policies, research and reports) should be gathered in an online repository where everyone could access and download the information needed. The dissemination of simplified and easy-to-read versions of this documentation to key stakeholders should also take place. In addition, a series of awareness raising and capacity building trainings should include a wide range of directly involved actors such as national and local decision makers, DPOs, child rights organisations and primary duty bearers of CwDs (e.g. parents, guardians or caretakers). Support should go through local and national Government Institutions to be sustainable over time. At local level, there is a strong need to build the capacities of Disability Councils and LCs, so they can raise awareness in their community.²⁴⁷ Local DPOs should also be reinforced because they have a role to play too: they must support policy design and monitor their implementation at district level.

More widely, health and educational staff should access high-quality training to cater properly for the needs of CwDs. In the programmes, which UNICEF Uganda will design and implement, modules training health workers or current and future teachers should be incorporated. Once more, this should be developed hand-in-hand with local and national Government Institutions and DPOs. This would allow appropriation by the Ugandan health and education sectors and tackle this systemic issue. This echoes the recommendations put forward by the CRC Committee in 2005: Uganda should "take all necessary measures [...] to ensure that professionals working with and for CwDs, such as medical, paramedical and related personnel, teachers and social workers, are adequately trained."²⁴⁸

UNICEF Uganda and Partners should therefore strengthen the knowledge and capacities of key stakeholders working with CwDs through raising awareness and capacity building events. The stakeholders should also support the training of the staff in the health and education sectors. This would ultimately challenge the discriminatory social norms linked to disability in Uganda.

246. Adong, Caroline, National Council for Disability, Interviewed by Nadège Riche, 2013; and Asamo, Helen Grace, National Union of Women with Disability in Uganda (NUWODU), Interviewed by Nadège Riche, 2014.

247. Adong, Caroline, National Council for Disability (NCD), Interviewed by Nadège Riche, 2013.

248. Committee on the Rights of the Child, Consideration of Reports Submitted by State Parties under Article 44 of the Convention, Concluding observations of the Committee on the Rights of the Child: Uganda, 2005, p. 9.

RECOMMENDATION N°7:

Build the knowledge on the needs and rights of CwDs and strengthen the capacities of key stakeholders and duty bearers

3. DESIGN AND IMPLEMENT PROGRAMMES TARGETING CHILDREN WITH DISABILITIES LIVING IN UGANDA

Earlier on it has been demonstrated that the programmatic approach is fragmented and lacks long term sustainability. To remedy this situation, UNICEF Uganda and Partners are advised to mainstream disability in the design and implementation of programmes in selected key areas in partnership with organisations of the Child and Disability Movement. This will also provide an answer to the gap in implementation of the laws and policies.

3.1. Mainstream the Perspective of Children with Disabilities in all Programmes

UNICEF is the leading UN Agency promoting and advancing the rights of children, including CwDs, worldwide. In Uganda, UNICEF has conducted and/or funded a number of studies and programmes but are lacking clear disability mainstreaming. In the field of statistics, UNICEF has run MICS and other types of surveys and mapping exercises relating to children. However, this has not “been rolled out [in relation to CwDs] and UNICEF Uganda did not have disability aggregated data on CwDs either in the development programs or in the humanitarian situation in Northern Uganda.”²⁴⁹ Similarly UNICEF Uganda has rolled out good programmes relating to birth registration and immunisation but they do not collect information about the conditions of the child – i.e. whether they are disabled. It is therefore difficult to assess if CwDs benefit from these programmes at all. Even in WASH programmes it is not possible to know to what extent the water pumps are made accessible for women with disabilities to use.²⁵⁰

It is therefore recommended that UNICEF Uganda mainstreams disability in all its programmes. In other words, all programmes should have a disability component. It would not be a rights based approach to have disability specific programmes. UNICEF Uganda and Partners should also include disability mainstreaming as a criteria for all sponsored projects.

249. Norwegian Agency for Development Cooperation (NORAD), Mainstreaming disability in the new development paradigm - Evaluation of Norwegian support to promote the rights of persons with disabilities - Uganda Country Report, February 2012, p. 21.

250. Bakundana, Flavia, Heijnen-Maathuis, Els, Save the Children, Interviewed by Nadège Riche, 2013.

For that purpose, UNICEF Uganda and Partners should put in place a structure to facilitate efficient disability mainstreaming. This can only be achieved if an “internal watch dog” position is created. It could be a desk officer in charge of CwDs in Ugandan headquarters. The responsibility of this person would be to follow up and monitor disability mainstreaming. UNICEF Uganda should therefore recruit someone with a sound disability background and expertise in charge of CwDs.²⁵¹ Additionally, the organisation should also develop its capacity to work with CwDs. There is a need to raise awareness among the top decision-makers so that they can guide and lead the organisation in disability matters, while advisors and officers should benefit from in-depth trainings about the rights and needs of CwDs to design and implement disability mainstreaming into the next strategic programming of UNICEF Uganda.²⁵²

To conclude, UNICEF Uganda and Partners should include and prioritise the perspective of CwDs in all studies, surveys and programmes that the agency carries out or funds in order to ensure the progressive realisation of the rights of CwDs living in Uganda.

RECOMMENDATION N°8:

Mainstream the perspective of CwDs in programmes and surveys

3.2. Identify Key Focus Areas for Action: Disability Prevention, Health and (Re) Habilitation, Education, Social Norms Change and Awareness-Raising

There would be many potential areas for interventions to improve the lives of CwDs in Uganda. However, based on the literature review and interviews, a select number of main focus areas appeared pivotal to maximise structural change. It should also be recognised that due to the limited resources available not all areas can be addressed at the same time and there is a need to prioritise.

The Government of Uganda has put in place positive and pro-disability laws and policies, but experience of CBR suggests that PwDs in rural communities continue to be marginalised. This marginalisation starts in the family and continues throughout the school system, with the highest drop-out rates for children in universal primary education being those for CwDs. District and community leaders do not necessarily think about disability in their planning and disability continues to be a hidden problem in most communities. There is a lack of appropriate education services and training and few attempts are made to integrate PwDs into the community. There is limited information on health issues to help families and communities to understand and overcome

251. Luyima, Ronald, National Union of Disabled Persons in Uganda (NUDIPU), Interviewed by Nadège Riche, 2013.

252. In that respect, NUWODU also pointed out that they could organise and run their “Disability Equality Training” for UNICEF Uganda staff and decision makers. This training is aimed at raising awareness about the needs and rights of PwDs and women with disabilities as well as giving advice and recommendations as to how to mainstream disability in programmes. NUWODU has already run the programme for DFID and the Ministry of Gender, Labour and Social Development.

the challenges they face related to disability. There are also limited specialised health and (re)habilitation services available to cater for the different needs of persons and children with disabilities.

The Government of Uganda has enacted appropriate policies seeking to empower PwDs. However, there are still major gaps in knowledge, attitude and practices towards persons and children with disabilities, particularly at household level. People are not sensitised about the problems of disability, due to poor delivery of information. Referral for CwDs is inadequate and most services are concentrated around Kampala. PwDs are among the most disadvantaged in Uganda, with women and girls particularly disadvantaged. There is little empathy and support for PwDs to access their rights and create popular demand for appropriate services.

This situation of CwDs had already been captured in 2005 by the CRC Committee. “Notwithstanding [Uganda’s] continuous efforts to support CwDs through targeted State welfare measures, including direct and indirect assistance, the Committee is concerned about the persisting de facto discrimination. It notes with concern that equal opportunities for CwDs are jeopardised, e.g. by their limited access to public buildings, government services and public transportation, and that social stigma, fears and misconceptions surrounding disabilities remain strong in society leading to the marginalisation and alienation of these children. It is further concerned that children are doubly disadvantaged if they live in rural and remote areas.”²⁵³

For these reasons, a stronger programmatic approach is needed to tackle the needs of CwDs living in Uganda and GoMGLSD and UNICEF Uganda have a central role to play in the promotion and protection of the rights of CwDs. UNICEF Uganda should engage in programmes relating to disability prevention. Other focuses of UNICEF Uganda activities should cover the living conditions and welfare of CwDs by ensuring access to health services, (re)habilitation and education²⁵⁴ as well as social norms change and raising awareness of the communities to fight against stigmatisation and discrimination of persons and children with disabilities. This is however not sufficient as a lot of the issues are linked to planning capacities of national Government Institutions, local districts and community leaders.

Such an approach will also support the implementation of the recommendations put forward by the CRC Committee during Uganda’s second periodic CRC review of 2005. Uganda should “take all necessary measures: (c) to provide CwDs access to adequate social and health services, to quality education and to the physical environment, information and communication; (d) to raise awareness about CwDs, including their rights, special needs and potential, in order to change prevailing negative attitudes, misbeliefs and prejudices against CwDs by initiating and supporting public information campaigns.”²⁵⁵

253. Committee on the Rights of the Child, Consideration of Reports Submitted by State Parties under Article 44 of the Convention, Concluding observations of the Committee on the Rights of the Child: Uganda, 2005, p. 8.

254. These focus areas are considered the most important ones by all interviewees.

3.2.1. Disability Prevention Programmes

“The major causes of disability in Africa are communicable diseases, war, accidents, and inadequate prenatal and neonatal health care services”. Among children in Africa, the leading cause of disability is illness acquired before the age of five years, accounting for one third to half of the cases. The majority of these disabilities are preventable.”²⁵⁶ Based on this statement, UNICEF Uganda and Partners should design and run disability preventive measures targeting children living in Uganda.

Massive sensitisation on disability prevention should be the first step because the number of CwDs seems to be increasing. In particular, focuses on maternal health, immunisation and gender based violence would help to prevent disability. Many diseases and impairments are also the result of poverty. This may be, for example, due to lack of immunisation, poor nutrition and lack of access to health treatments. The second step should be to assess CwDs as early as possible and provide for care and (re)habilitation: indeed, some children paralysed due to polio can move and walk again after surgery by an orthopaedic surgeon.²⁵⁷

Launching such disability preventive programmes seems feasible in a short term since UNICEF Uganda has long standing and successful programmes relating to immunisation, malaria, malnutrition, maternal and new-born health.²⁵⁸ This would only require mainstreaming the perspective of CwDs in these currently running programmes. UNICEF Uganda could even rely on existing documentation, partners and networks. For example, CoRSU has documentation available relating to (re)habilitation and health services for CwDs that could be distributed within the framework of UNICEF programmes. These free booklets, for example, cover primary care or nutrition. Some are also translated into local languages.²⁵⁹

3.2.2. Access to health services and (re)habilitation

Access to health services and (re)habilitation is a right for CwDs under CRPD Articles 25 and 26 as well as under CRC Articles 24, 25 and 39. This is also considered as the primary needs of CwD to be addressed: once a child has been identified, assessed and provided with care and (re)habilitation, they can move around, mix with people their age and go to school.²⁶⁰ Since most of these health and (re)habilitation services are delivered by Government Institutions and programmes, UNICEF Uganda should partner with the competent Ministries, meaning the MoGLSD and the MoH, and aim to reinforce their capacities in delivering those services to CwDs.

In this respect, UNICEF Uganda and Partners should reinforce the geographic coverage and emphasise the perspective of CwDs in these ongoing programmes run by both the MoGLSD and MoH. They should cover early assessment and

255. Committee on the Rights of the Child, Consideration of Reports Submitted by State Parties under Article 44 of the Convention, Concluding observations of the Committee on the Rights of the Child: Uganda, 2005, p. 9.

256. African Child Policy Forum (ACPF), *Children with Disabilities in Africa: Challenges and opportunities*, Addis Ababa: The African Child Policy forum, 2011, p. XXXV.

257. Adong, Caroline, National Council for Disability (NCD), Interviewed by Nadège Riche, 2013.

258. Government of Uganda, United Nations Children's Fund (UNICEF), *Country Programme 2010-2014*, 2009.

259. Simpson, Malcolm, Children's Surgical Rehabilitation Hospital (CoRSU), Interviewed by Nadège Riche, 2013.

260. Adong, Caroline, National Council for Disability, Interviewed by Nadège Riche, 2013.

(re)habilitation of CwDs as well as on-going access to health services in all regions of Uganda, and not only in the Kampala region. CBR centres could also be established at District level. In practice, various types of activities should be launched. The primary concern should be on accessibility for persons and children with disabilities. This covers physical access to health centres and the provision of accessible health and (re)habilitation equipment (e.g. hospital beds). A second aspect is related to the training of health workers on how to provide health services and (re)habilitation to different categories of CwDs. Relaying the NUDIPU recommendations in its CRPD parallel report,²⁶¹ “Government should strengthen the recruitment, training and deployment of staff in the areas of psychiatry, physiotherapy, occupational therapy, speech and language therapy and “Ears, Noses and Throats” specialists from health centre III to national referral hospitals. Disability related issues should be mainstreamed in the training curriculum of all health workers to create awareness.” Finally, emphasis should be made on the provisions of assistive and mobility devices such as hearing aids, white cane, glasses, wheel chairs and others. This is crucial: “once this is done, the CwD is empowered and feels more comfortable to move around.”²⁶² UNICEF Uganda and Partners should support the MoH in producing and distributing such devices. This could be done by supporting the establishment and ongoing work of the orthopaedic workshops in producing locally-designed devices and/or assist the Government Institutions to subsidise medical appliances.

Additionally, most families with a CwD struggle to travel to health centres and hospitals because they cannot afford the transportation and/or overnight cost.²⁶³ UNICEF Uganda and Partners should engage together with the relevant Ministries to establish sustainable programme(s) delivering outreach health and (re)habilitation services to persons and children with disabilities living in rural and remote areas. This could for example be organised in the framework of existing programmes (e.g. CBR programme). Ideally it would be about child health protection measures and lead by health workers targeting CwDs in their communities. Those (re)habilitation activities should be based within the communities because the process is too centralised nowadays.²⁶⁴ UNICEF Uganda and Partners could also engage with CoRSU. This hospital is the only one providing free surgery and (re)habilitation services to CwDs (except for transport and accommodation fees). It is also the only one providing certain orthopaedic and plastic reconstructive surgery in Uganda.²⁶⁵ Although CoRSU is successfully delivering its mission, this hospital should not grow aside from services delivered by Government-led health centres and hospitals. UNICEF Uganda should therefore support the current establishment of a public private partnership between CoRSU and the MoH and ensure that both systems efficiently deliver high quality services to CwDs without duplication of efforts.

261. National Union of Disabled Persons in Uganda (NUDIPU), Shadow report to the United Nations Committee of Experts on the Implementation of the Convention on the Rights of Persons with Disabilities (CRPD), 2010.

262. Okwera, Albert, Gulu District Council for Disability, Interviewed by Nadège Riche, 2013.

263. Adong, Caroline, National Council for Disability, Interviewed by Nadège Riche, 2013; And Simpson, Malcolm, Children's Surgical Rehabilitation Hospital (CoRSU), Interviewed by Nadège Riche, 2013.

264. Bongole, Rose, Ministry of Health (MoH), Interviewed by Nadège Riche, 2014.

265. Simpson, Malcolm, Children's Surgical Rehabilitation Hospital (CoRSU), Interviewed by Nadège Riche, 2013.

In engaging with health and (re)habilitation activities, UNICEF Uganda and Partners should aim to bring back the geographic coverage and quality of services that used to be delivered by the CBR programmes (when it was funded by NAD). A success factor would however lie within the gathering of social, health, (re)habilitation and education workers together.²⁶⁶

3.2.3. Access to Education

Another focus area that UNICEF Uganda and Partners should engage with is access to education for CwDs. This right is enshrined in both CRPD Article 24 and CRC Articles 28 and 29. This basic right has also been constitutionalised and legalised in the Ugandan regulatory system. Education should be a priority because acquiring knowledge is crucial to start anything else in life. The first and foremost battle, which UNICEF Uganda and Partners should get involved into, should be on IE and not on SNE because SNE promotes exclusion whereas IE promotes inclusion and is in line with the CRPD provisions. In this respect, the Convention is very clear: “it requires governments to ensure that PwDs have access to ‘an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live’ (CRPD Article 24 (2) (b)). [...] It is therefore critical that moves towards integration [and inclusion] are part of a broader strategy encompassing encompassing teacher training, school financing and other measures.”²⁶⁷

In this respect, UNICEF Uganda and key stakeholders should again partner with the competent Ministries, meaning the MoGLSD and MoES, and the Faculty of Special Needs and Rehabilitation of the Kyambogo University to create new initiatives or reinforce their programmes and structural capacities to deliver IE to pupils and students with disabilities. UNICEF Uganda should support the Government that must affirm its commitment to IE and develop an inclusive educational policy with clear resources ring-fenced to implement the policy. There is a need to establish political leadership and government responsibility for IE in order to provide and deliver services in a well-coordinated, cross cutting and adequately resourced implementation system at all levels through clear guidance and policy.

In practice, UNICEF Uganda and Partners should first support the creation of a seamless and inclusive educational environment welcoming both children with and without disabilities. This should encompass early childhood, formal and non-formal education from pre-primary to secondary level. To date, very few CwDs have joined an ECDC or a kindergarten. Most of them start class directly at primary level. It is thus advised to establish inclusive facilities where children with and without disabilities can mix and learn together from a very young age onwards. Non-formal and vocational education would also benefit CwDs who mostly drop out after primary school due to a lack of secondary schools providing IE. It would also enable teenagers with disabilities to acquire skills and a means of survival, which would directly tackle poverty issues.²⁶⁸ This also makes sense

266. United Nations Children's Fund (UNICEF), Research Study on Children with Disabilities Living in Uganda – Validation Workshop, 2014.

267. United Nations Educational, Scientific and Cultural Organisation (UNESCO), Education For All (EFA) Global Monitoring Report - Reaching the Marginalised, 2010, p.201-203.

keeping in mind that “Uganda has the highest youth unemployment in Africa according to the latest figures.”²⁶⁹ Such livelihood activities could consist of one-to-one training of individuals based on their interest. It could also take the form of vocational training in a group.²⁷⁰ These activities could be of various kinds: bee keeping, carpentry, telecommunications, information technology (IT), etc.

The establishment of such inclusive settings requires financial and technical support from UNICEF Uganda and Partners. The ECDC, primary and secondary schools or vocational centers, which offer IE for CwDs, should receive a budget in adequation with their goals. There should be an increase in the UPE or USE payments for all inclusive schools. Direct funding for specific items or proportionate to the numbers of CwDs in class could be another option. In addition to specific assistance to IE facilities, all schools should be encouraged to offer an environment suitable to both children with and without disabilities. In that respect, the MoES should provide clear guidelines on how they are supposed to support pupils and students with disabilities. A hard copy of such a guide could be sent to all schools and districts officials. It should be drafted in consultation with children to know what their perspective is. This project could have a module where children with and without disabilities discuss about IE.²⁷¹

Besides, CwDs should be empowered to go and attend class in suitable conditions. The current school curriculum is not sensitive to the educational needs of CwDs and opportunities for these children are consequently limited and restricted. Consequently, the school curriculum should be revised to take into account the educational needs of all children. There is also an urgent need to implement a policy to provide reasonable accommodation for CwDs in learning institutions. This should include full physical and digital access, the promotion of disability culture among pupils, students, teachers and administrative staff, individual education plans for all pupils and students, accessible educational and scholastic materials, the availability of assistive devices and support in classrooms and the teaching of SL. The use of innovation, accessible mainstream technologies and assistive devices, which might be required to suit the specific needs of some CwDs, is of particular importance to make a difference in IE settings: “a study of people with limited mobility in Uganda found that assistive technologies for mobility created greater possibilities for community participation, especially in education and employment.”²⁷² In that respect, global organisations (such as the DAISY Consortium²⁷³ and the World Wide Web Consortium)²⁷⁴ have developed standards to produce an accessible web, accessible mainstream information and communication technologies as well as assistive devices suitable for persons with printed disabilities. This should also be used in the Ugandan context to deliver to CwDs their right to access information, communication (CRPD Articles 9 and 21) and thus education at large (CRPD Article 24).

268. Jawoko, Perry, Gulu District, Interviewed by Nadège Riche, 2013.

269. Mwesigwa, A ‘Uganda’s unemployed graduates held back by skills gap’, The Guardian, 16 January 2014, <http://guides.is.uwa.edu.au/content.php?pid=385139&sid=3156563> (Accessed 22 January 2014).

270. Ojok, Simon, Gulu Disabled People Union (GDPU), Interviewed by Nadège Riche, 2013.

271. Luyima, Ronald, National Union of Disabled Persons in Uganda (NUDIPU), Interviewed by Nadège Riche, 2013.

272. World Health Organisation (WHO), World Bank, World Report on Disability. Geneva: WHO/World Bank, 2011, p. 101.

273. DAISY Consortium, <http://www.daisy.org/>, 2014 (Accessed on 29 May 2014).

274. World Wide Web Consortium (W3c), <http://www.w3.org/>, 2014 (Accessed on 29 May 2014).

Finally, strengthening training in IE for current and future teachers is needed to complement these structural changes in the education system. This requires several action lines. Obligatory IE modules should be integrated in the teacher curricula. Sponsorships of a significant amount to complete the degree at the Faculty of Special Needs and Rehabilitation of Kyambogo University should be put in place since this will encourage teachers to specialise in IE. Additionally, regular ongoing and locally based teacher training in IE should primarily target teachers who graduated already.

Significant investment is therefore required to develop the understanding and skills of teachers to work in new ways and support continuous development in classroom practices. Teacher training must reflect this if teachers are to have the attitudes and confidence to teach CwDs. Innovative projects have already taken place and can be inspirational. “Some NGOs and governments, including those of Uganda and the United Republic of Tanzania, have supported ‘itinerant teaching’ approaches, which enable specialised teachers in central primary schools to reach a larger group of pupils in satellite schools, and support and train teachers.”²⁷⁵ But developing practice involves more than good undergraduate and post-graduate education. It also includes teachers and their schools in learning from their everyday experience about individual children and sharing this learning within the profession. Experience of IE is a more powerful basis for teacher development than training courses. Teachers often think they need ‘special skills’ to teach CwDs. However, it is generally admitted that, in the majority of cases good, clear, accessible and participatory teaching skills that teachers need to deliver quality education to all children, are effective in including CwDs in learning. “In Uganda, teachers’ attitudes improved simply by having regular contact with CwDs.”²⁷⁶ Learning innovative child-centered strategies will enable teachers to teach a diverse range of abilities and promote active student learning to meet individual student. CwDs need teachers with inclusive attitudes. Teachers are arguably the most valuable human resources available to promote inclusive practices. If they do not believe in inclusion, they can become a major barrier to progress. CwDs also need teachers who are positive role models. As such, teachers with disabilities can be key players in combating discrimination and promoting positive identity in CwDs and breaking down prejudices of CwDs. More than this, they can provide a positive example for parents of CwDs, which can mean the difference between parents sending their child to school or keeping them at home because they see no benefit in an education.

To conclude, the education sector in Uganda has not yet shifted to an IE approach and many challenges remain ahead to deliver access to education to CwDs. UNICEF Uganda and Partners are also recommended to engage with unknown topics. For instance, it has been reported that the high level of abuse of CwDs seems to be one of the main reasons for not sending CwDs to school, especially

275. Lynch, P. and McCall, S., The itinerant teacher’s role in the educational inclusion of children with low vision in local schools in Africa, *The Educator*, vol. 20, no. 1, 2007, pp. 49-53.

276. Afako R. (ed.), *Implementation of inclusive education policies in Uganda - Collaborative research between the Centre of International Child Health and the Uganda National Institute of Special Education*, Paris: United Nations Educational, Scientific and Cultural Organisation (UNESCO), 2002.

girls with disabilities. This appears a major issue but it has not been researched yet. Protection of boys and girls with disabilities at school should also be part of UNICEF Uganda programmes.

3.2.4. Social Norms Change and Raising Awareness Campaigns

The full realisation of the rights of CwDs requires tackling the stigma and behaviours attached to disability. Discrimination and marginalisation of CwDs are a fundamental problem. Since families and communities lack information relating to disability, raising awareness of the population about the needs and rights of persons and children with disabilities can constitute a first leverage. With the assistance of UNICEF Uganda and Partners, the central government could launch a national awareness campaign tackling negative attitudes and stereotypes. This could be run in partnership between local and national Government Institutions, DPOs and NGOs of the Child and Disability Movement and the private sector.

However, given that there are negative social norms relating to disability in Uganda, raising awareness will not be sufficient. Since the attitudes of families and communities are dependent on what others think of persons and children with disabilities and what other think parents or guardians of CwDs should do, the awareness of people is not the core problem. Challenging the social norms will require a community empowerment approach. Similar initiatives took place already: for example, Raising Voices has implemented projects that aim to challenge the social norms related to children in Uganda.²⁷⁷ Learning from these experiences, UNICEF Uganda and Partners should support the development of community-based outreach work. Once more, this should be organised in cooperation with the relevant local and national Government Institutions and organisations of the Child and Disability Movement.

Conclusively, the social norms associated with disability will only be challenged and changed if a combination of means is put in place. Traditional raising awareness campaigns will level up the knowledge of information of communities while community-based outreach work will address the empirical and normative expectations associated with the behaviours of people towards persons and children with disabilities.

3.3. Conclusion about the section on programmes

To conclude, the challenges discussed throughout this Report call for a strong programmatic response from UNICEF Uganda and Partners. The purpose of this section was to provide an overview of the major problems faced by CwDs, identify the focus areas where initiatives are required and describe possible programmatic solutions. However, this research study did not aim to design off-the-shelves -pilot- projects and programmes. UNICEF Uganda and Partners should therefore conduct further research and exploratory work to assess the

277. Mackie, Gerry, and Moneti, Francesca (ed.), Working Paper: What are Social Norms? How are they Measured?, United Nations Children's Fund (UNICEF) – University of California San Diego (UCSD) Centre on Global Justice Project Cooperation Agreement, 2012.

feasibility of programmes targeting CwDs in the various fields relating to disability prevention, health, (re)habilitation, education and disability awareness raising.

Nonetheless, a certain number of success factors have been identified to design and run programmes delivering structural changes for CwDs.

Any programmes designed and implemented by UNICEF Uganda and Partners should primarily aim to empower CwDs. The importance of role models is crucial: stakeholders should identify successful CwDs who can inspire other CwDs.²⁷⁸ Additionally, the main focus for children with intellectual and psychosocial disabilities should be on building their capacity to be self-advocates. Self-advocacy by persons and children with disabilities, especially by people with cognitive and psycho-social disabilities, is indeed the ultimate recognition that every one is able to speak on their own behalf and make decisions over their life. This would also play a vital role in the promotion of disability rights since non-disabled people would be able to recognise the full empowerment of their peers with disabilities. In that respect, learning from and reinforcing the existing project currently run by UPPID is of major relevance.²⁷⁹

Another interesting aspect could be to work with CwDs and children without disabilities, since part of the problems lies in the negative perceptions and behaviours of communities and other children at school. A successful example is the model of the Child Rights Groups or Clubs. They are community based network supporting children with and without disabilities, their parents or guardians and communities in understanding their human rights as children and advocating for them.

The role of parents of CwDs should not be overlooked either, since they are the primary persons caring for a child with a disability when they are young and stay at home. PSGs, meaning groups of parents of CwDs, should be formed so parents and guardians can discuss their problems and be sensitised about the needs of their CwDs. They can also be advised to send their children to hospitals or schools. Once sensitisation and training has been carried out, there should be regular follow up and monitoring to ensure the general welfare of the child. Creating groups of parents of CwDs can easily be achieved by talking to local leaders in villages and by building on those already created by UPPID and USDC. In this respect, it must however be reminded that parents and organisations of parents might tend to stigmatise their own CwD. One of the main problems is the parents' perception of their grown-up CwD as perpetual "children" and their inability to acknowledge adulthood. There is a contradiction here that needs addressing – i.e. the need to separate the needs of parents from those of their children and the importance of independent self advocacy.

278. Kafeero, Olive, Chapter 9: A brief Analysis on Children with Disabilities, in *A Handbook on Disability experiences and approaches in Uganda*, 2010.

279. Byamugisha, Isidor, *Uganda Parents of Persons with Intellectual Disabilities (UPPID)*, Interviewed by Nadège Riche, 2013.

Finally, it is worth underlining that CwDs are a very heterogeneous group. Children have a wide variety of impairments and needs that must be catered for accordingly. Children with severe disabilities will require a more adapted environment while children with mild disabilities will only need ad-hoc support to perform everyday activities. In other words, disability can not be tackled as a single entity but the specific needs of the various categories of impairments should be distinctively addressed. In its efforts and work, UNICEF Uganda and Partners should find a balanced approach and target all groups. Indeed, the needs of children with physical and sensory disabilities are easily thought of, while children with intellectual and psycho-social disabilities tend to remain “invisible”.

RECOMMENDATION N°9:

Design and run programmes relating to disability prevention, health and (re)habilitation, education, social norms changes and awareness-raising

3.4. Actively Consult and Involve the Civil Society Organisations of PwDs Operating in Uganda (CRPD Article 33.3) and the Organisations of the Child Movement

It is also important to emphasise that all surveys and programmes should be designed, implemented and monitored in close collaboration with all stakeholders working with CwDs. This ranges from local District Unions of persons and of women with disabilities to the national DPOs. Child-rights based NGOs can also be strong allies to UNICEF Uganda.

The Disability Movement is reasonably well structured in Uganda. Because of their relative representativeness of the population of PwDs, DPOs have the most extensive expertise and knowledge of how persons and children with disabilities live in Uganda. Their capacity to reach out to CwDs should be recognised, supported and valued. However, it must be acknowledged that there are no organisations actively involving CwDs in their planning and decision making and the Ugandan DPOs speak on behalf of CwDs rather than enabling them to directly voice their concerns and wishes for their future.

UNICEF Uganda and Partners should work with the relevant Ugandan DPOs representing boys and girls with disabilities (e.g. NUDIPU, NUWODU and UPPID). NUDIPU is the national umbrella-organisation representing all PwDs in Uganda, while NUWODU focuses on the specific needs and rights of women and girls with disabilities. Both organisations aim to represent all categories

of PwDs and have a national coverage through the District Unions of PwDs. Their core asset lies in their advocacy abilities to voice the rights of PwDs and mainstream them into the Ugandan regulatory framework. It must, however, be highlighted that both organisations have not to any extent taken on board the perspective of CwDs and their focus is more on the young population of PwDs.²⁸⁰

Such cooperation could be fruitful in collecting statistical information relating to CwDs, among others. NUDIPU currently sets up a database and data collection tool to collect information about PwDs living in Uganda based on information that will come from NUDIPU member organisations. Data should be disaggregated by age, types of impairment, gender and location and the first results should be available in June 2014.²⁸¹ This data must be handled with care because of concerns regarding reliability, consistency and robustness and it will not be possible to use this data for comparison with national statistics produced by UBOS. It might, however, provide rough estimations of the numbers of PwDs and CwDs living in Uganda.

Finally, it is important to consider and include the role of parents of CwDs. Many CwDs are under cared for and under educated because parents do not see value in them and it is the parents who are usually the primary care givers²⁸² and the first key players in the life of a CwD. UNICEF Uganda and Partners should therefore engage with organisations representing parents of CwDs. Currently there is only one such organisation in Uganda, UPPID. UPPID could partner with UNICEF Uganda - the UN body could use the networks of PSGs created by UPPID, while the NGO would be strengthened by being financial and organisational supported by UNICEF Uganda. This would also be in line with the role of self-advocacy as highlighted in the previous section.

For these reasons, UNICEF Uganda and Partners should actively involve DPOs, such as UPPID, in all its activities targeting CwDs. This would apply to advocacy work establishing a CwDs friendly regulatory framework in Uganda and to the design and implementation of programmes. Several types of partnership could be set up between UNICEF Uganda and DPOs. First of all, any relevant organisations for/of CwDs should be included in the national partnership for CwDs that UNICEF Uganda and the MoGLSD are recommended to establish. These organisations could also join the Consortium of organisations applying for grants and funding opportunities together with UNICEF Uganda. The active participation of DPOs is a core requirement under CRPD Article 33.3 and UNICEF Uganda should be a model organisation in its implementation.

In addition to partnering with DPOs, the child rights organisations can be strong partners and allies to UNICEF Uganda and Partners. The Child Movement has started engaging with the needs and rights of CwDs and to a limited extent mainstreamed the disability perspective into their core activities. Their expertise

280. Luyima, Ronald, National Union of Disabled Persons in Uganda (NUDIPU), Interviewed by Nadège Riche, 2013.

281. Ronald Luyima, National Union of Disabled Persons in Uganda (NUDIPU), interviewed by Nadège Riche, 2013.

282. Luwar, Teddy, Gulu Women with Disabilities Union (GUWODU), Interviewed by Nadège Riche, 2013.

of the situation of children in Uganda and networks of national and local partners are complementary to those of the disability movement. UNICEF Uganda and Partners could partner with the lead organisations that have established track records in child rights in the Ugandan context (e.g. African Network for the Prevention and Protection against Child Abuse and Neglect (ANPPCAN)) or with the INGOs that have a track record of working with CwDs living in Uganda (e.g. Plan, Save the Children and War Child). In particular, UNICEF Uganda and Partners should seek support from these organisations to proactively engage with and consult CwDs living in Uganda on an ongoing basis.

It must be highlighted that USDC is currently the only organisation voicing the concerns of all categories of CwDs in Uganda. It is however an organisation of adults speaking on the behalf of CwDs. Nonetheless, having been active in Uganda for the past 20 years, the organisation has acquired an in-depth knowledge and expertise on the situation of CwDs and has built a network across the country of organisations and partners working to improve the living conditions of CwDs. For example, USDC has recognised the role of parents and supported the creation and running of PSGs that UNICEF Uganda and Partners could use as relay for its own programmes. For this reason, it is critical that USDC partner with UNICEF Uganda and Partners to design and implement programmes targeting CwDs in Uganda.

To conclude, UNICEF Uganda and Partners should actively consult and involve CwDs using organisations from both the Disability and the Child Movement. Their expertise and networks in respectively disability and child matters should be valued. By partnering with organisations such as ANPPCAN, Plan, Save the Children, USDC, UPPID and/or War Child, among others, UNICEF Uganda and Partners could both draw upon new and original ideas and inspiration from the DPOs and NGOs as well as ensure that all laws, policies and programmes are consistent with the needs and rights of CwDs that it is the DPOs' and NGOs' role to advocate for.

RECOMMENDATION N°10:

Partner with organisations of the Child and Disability Movement

4. MAIN CONCLUSIONS ABOUT THE RECOMMENDATIONS

In the course of this research, it has been found that the current programmatic approach tends to be fragmented and lack long term sustainability. To remedy this situation, UNICEF Uganda and Partners should mainstream the perspective of CwDs in all its programmes and build the capacity of the organisation to work with CwDs. Focus areas of future programmes should cover the living conditions and welfare of CwDs by preventing disability, by ensuring access to health services, (re)habilitation and education and by raising awareness of the communities to fight against stigmatisation and discrimination on the ground of disability. Empowering CwDs should be at the core of the design and implementation of any programmes and the role of parents, as primary caretaker of a CwD, should be duly acknowledged. All programmes should be designed, implemented and monitored in close collaboration with all stakeholders working with CwDs. This ranges from local District Unions of PwDs and of women with disabilities to the national NGOs of CwDs DPOs (e.g. UPPID and USDC). Child-rights based NGOs, such as ANPPCAN and Plan, can also be strong allies to UNICEF Uganda and Partners.

To conclude, a stronger programmatic approach is needed to overcome the barriers to the realisation of the human rights of CwDs in Uganda. UNICEF Uganda must take actions without any further delays and play the central role devolved to a UN Agency to ensure their promotion and protection.

Despite all what has been said in this report, CwDs are first and foremost children. They have “the same needs as all children. They have the same rights as others - among these, the right to life and to the opportunities that flow from good health care, nutrition and education, [as well as] the right to express their views and participate in making decisions.”²⁸³ This still awaits realisation for all CwDs living in Uganda.

283. European Disability Forum (EDF), http://www.edf-fehp.org/Page_Generale.asp?DocID=13855&thebloc=32553, 2013, (Accessed on 14 November 2013). FORMATTING

5. THE TEN KEY RECOMMENDATIONS IN A NUTSHELL

Recommendation N°1: Actively consult and listen to CwDs on issues concerning them on an ongoing basis

Recommendation N°2: Improve statistical information relating to CwDs in partnership with UBOS

Recommendation N°3: Review and enforce the Ugandan legal and policy frameworks

Recommendation N°4: Increase budget allocations to responsible Government Institutions and earmarking for CwDs in related programmes

Recommendation N°5: Coordinate efforts among local and national Government Institutions

Recommendation N°6: Create a National Partnership on CwDs lead by the MoGLSD

Recommendation N°7: Build the knowledge on the needs and rights of CwDs and strengthen the capacities of key stakeholders and duty bearers

Recommendation N°8: Mainstream the perspective of CwDs in programmes and surveys

Recommendation N°9: Design and run programmes relating to disability prevention, health and (re)habilitation, education, social norms changes and awareness-raising

Recommendation N°10: Partner with organisations of the Child and Disability Movement

Part 8: The Bottlenecks Analysis Table to the Realisation of the Rights of Children with Disabilities Living in Uganda

In the design, implementation and assessment of all interventions, the active participation and involvement of CwDs should be promoted by all stakeholders.

TABLE 11: THE BOTTLENECKS ANALYSIS TABLE

Bottlenecks	Situation	Impact of removal (High, Medium, Low)	Ease of addressing bottlenecks (Achievable, Challenging, Difficult)	Bottle-neck Priority (High, Medium, Low)	Key activities / interventions

Bottlenecks	Situation	Impact of removal (High, Medium, Low)	Ease of addressing bottlenecks (Achievable, Challenging, Difficult)	Bottle-neck Priority (High, Medium, Low)	Key activities / interventions
ENABLING ENVIRONMENT					
Discriminatory social norms towards disability	Large misconceptions associated to disability Traditional behaviours of discrimination, neglect, abuse and marginalisation of CwDs by communities (e.g. parents, caregivers, families, teachers, Head masters)	High	Challenging		Run community awareness-raising campaigns Establish and support PSGs Reinforce the capacities of stakeholders relating to the understanding of the needs and knowledge of the rights of CwDs
Lack of reliable and accurate statistical information to plan policies and programmes targeting CwDs	No exact figure of the –child- disability prevalence Limited and unreliable data relating to education levels of CwDs No or very poor statistical information or estimations outside the education field	High	Challenging		improve statistical information: Disaggregation and breakdown of data by: age groups, gender, geographical distribution across the Regions and Districts, place of residence (rural vs urban), impairments and conditions, family situations and CwDs with HIV/AIDS Work with Government Institutions (e.g. UBOS, MoGLSD, MoES) to include data collection standards, e.g. data collection tools created by the UN Washington Group

Fair domestication of the rights of CwDs enshrined in the CRC and CRPD	Lack of clear and unambiguous provisions targeting CwDs throughout the regulatory framework, especially in the Children Act and PwDs Act Confusing and sometimes contradictory legal framework relating to IE No provisions relating to access to sport and recreational activities Lack of clear provisions regarding the identification and responsibility of duty bearers to guarantee CwDs' rights	Low	Achievable		Advocate for the review of legislation in line with CRPD and CRC provisions Start with the PwDs Act and the Children Act because they outline the legal framework that defines the rights of CwDs Disseminate relevant laws and policies (e.g. CRC, CRPD, Children Act, PwDs Act) Create an online repository where the Conventions, laws and policies can be downloaded
Weak coordination mechanism between national Government Ministries and Bodies	No clear oversight role of the lead Ministry on disability affairs, the MoGLSD, over other responsible Ministries Overlap between role and powers of Government Bodies (i.e. NCC, NCD, EOC and UHRC) Limited focus on CwDs by the existing structures such as by the NCC or the OVC committees	Medium	Achievable		Establish a new Task Force on CwDs in the National Steering Committee on Disability, led by the MoGLSD
Weak coordination mechanism between Government Institutions and other organisations	Low-scale National Disability Forum initiated by the NCC in 2011/12 No overall network among Government institutions and organisations working in the Disability and/or Child Movement	Medium	Achievable		Establish a national partnership on CwDs lead together by the MoGLSD and UNICEF Uganda

Bottlenecks	Situation	Impact of removal (High, Medium, Low)	Ease of addressing bottlenecks (Achievable, Challenging, Difficult)	Bottle-neck Priority (High, Medium, Low)	Key activities / interventions
Supply					
Lack of proper implementation and enforcement of the provisions relating to CwDs due to insufficient financial resources allocated to programmes targeting CwDs and to responsible local and national Government Institutions	Government Institutions and Agencies (i.e. MoGLSD, MoES, NCC and NCD) do not have sufficient funds allocated to carry out programmes targeting CwDs Lack of enforcement of available and foreseen expenditures (e.g. 10% of the education budget to be allocated to the education needs of CwDs) Limited earmarking solely for CwDs	High	Difficult		Advocate for increased budget allocations to responsible Government Institutions and earmarking for CwDs in existing programmes Support the establishment of incentive mechanisms targeting SN&IE teachers by partnering with DPOs Advocate for increased budget allocations to Government Institutions (e.g. Faculty of Special Needs Education and Rehabilitation of Kyambogo University) that are responsible for the provisions of assistive services and for the distribution of appropriate scholastic materials for children with different types of disabilities

Bottlenecks	Situation	Impact of removal (High, Medium, Low)	Ease of addressing bottlenecks (Achievable, Challenging, Difficult)	Bottle-neck Priority (High, Medium, Low)	Key activities / interventions
Supply					
Insufficient level of staffing for work with CwDs in all fields (e.g. education, health, CBR) and limited capacities of stakeholders	Lack of SNE teachers and support persons for learners with disabilities Heavy workloads of physiotherapists in District Hospitals leads to discontinuity of provision of health and (re)habilitation services to CwDs No incentives for staff working with CwDs (e.g. SNE teachers, physiotherapists or occupational therapists) National and local Government Institutions have limited human resources: departments delivering services to persons and children with disabilities are under staffed and overloaded by work (e.g. only one physiotherapist per District Hospital, lack of SNE teachers in mainstream schools) Limited awareness of the needs and rights of CwDs among the stakeholders of the Disability or Child Movement	High	Difficult		Advocate for increased budget allocations to responsible Government Institutions for CwDs Advocate for increased human resources in national and local Government Institutions for CwDs Reinforce the capacities of stakeholders relating to the understanding of the needs and knowledge of the rights of CwDs Disseminate relevant resource material relating to CwDs (e.g. CRC, CRPD, Children Act, PwDs Act)

Bottlenecks	Situation	Impact of removal (High, Medium, Low)	Ease of addressing bottlenecks (Achievable, Challenging, Difficult)	Bottle-neck Priority (High, Medium, Low)	Key activities / interventions
Supply					
Lack of proper implementation and enforcement of the provisions relating to CwDs due to lack of clear regulations, enforcement of laws and policies and a lack of by-laws and ordinances	The Constitution of Uganda, laws and policies contain provisions defining the rights of CwDs Few regulations or guidelines issued to guide Government Institutions in implementing these laws and policies	Medium	Achievable		Advocate for the drafting and adoption of regulations enforcing legal and policy provisions Advocate for the use of by-laws and ordinances
Limited accessible physical environment	Limited access to public buildings including school buildings, classrooms, latrines, sport areas, health centres, hospitals	High	Difficult		If relevant, review legislation by mainstreaming the perspective of persons and children with disabilities in relevant legislation (e.g. UNAPD Accessible and IE for CwDs in Uganda project) Enforce legislation in place and mainstream accessibility in construction

Bottlenecks	Situation	Impact of removal (High, Medium, Low)	Ease of addressing bottlenecks (Achievable, Challenging, Difficult)	Bottle-neck Priority (High, Medium, Low)	Key activities / interventions
Supply					
Limited accessible communication and information environment	Lack of support services e.g. limited provision of SL interpreters in schools or hospitals No alternative format of the curriculum adapted to pupils and students with disabilities Lack of specific scholastic materials for CwDs (e.g. Braille embosser, mathematical equipment) Lack of assistive devices and technology	High	Difficult		Review and enforce legislation by mainstreaming the accessibility of persons and children with disabilities in relevant legislation Create and revise school curriculum: mainstream disability, adapt if deemed necessary Advocate for increased budget allocations to Government Institutions (e.g. Faculty of Special Needs Education and Rehabilitation of Kyambogo University)) responsible for the provisions of assistive services and for the distribution of appropriate scholastic materials for children with different types of disabilities Advocate for the use of assistive devices and technology, especially in an IE settings
Lack of adequate trainings for staff working with CwDs	Teachers not trained in IE Lack of trained physio and occupational therapists in Uganda because high quality trainings are only available from Mulago and Mengo Hospitals	Medium	Challenging		Design and implement programmes targeting caretakers and staff working with CwDs: Strengthen training in IE for current and future teachers, as well as for health workers

Bottlenecks	Situation	Impact of removal (High, Medium, Low)	Ease of addressing bottlenecks (Achievable, Challenging, Difficult)	Bottle-neck Priority (High, Medium, Low)	Key activities / interventions
Supply					
Families lack financial resources to take care of CwDs	Transport cost is too expensive for families to bring CwDs to District or Regional hospitals, health and/or (re) habilitation centres School fees in mainstream schools with a SNE unit are too high for parents of a CwD	High	Difficult		Design and implement programmes targeting CwDs and especially: (a) Identify and assess CwDs living in Uganda (b) Expand the existing social protection programmes lead by the MoGLSD (e.g. programmes providing Income Generating Activities (IGAs) to parents or guardians of CwDs) (c) Capture and share best practices Partner with the MoH and CoRSU to establish programmes delivering outreach health and (re) habilitation services Establish organisations or strengthen the capacities of existing structures advocating for increasing access to outreach services targeting CwDs (e.g. DPOs, PSGs, Child Rights Protection Committees)
Low parenting skills relating to the rights and needs of CwDs	Gaps in knowledge of parents on early identification of the disability of their child Lack of information on the needs of CwDs Because of social norms, parents of a CwD do not want to be seen with their child Lack of knowledge of possibilities of support mechanisms and of available assistive devices and technology	High	Difficult		Run community awareness-raising campaigns Establish and support PSGs Reinforce the capacities of stakeholders (e.g. parents, families, communities, caretakers, staff of CSOs and NGOs) relating to the understanding of the needs and knowledge of the rights of CwDs Strengthen parents and CwDs to become self-advocates

Bottlenecks	Situation	Impact of removal (High, Medium, Low)	Ease of addressing bottlenecks (Achievable, Challenging, Difficult)	Bottle-neck Priority (High, Medium, Low)	Key activities / interventions
Supply					
Limited geographic coverage of (re) habilitation services targeting CwDs	Limited availability of CBR programmes because the existing projects are centralised in the region of Kampala Lack of direct and specific interventions for children with severe disabilities Limited access to sexual reproductive health services for girls with disabilities Too few outreach programmes relating to health and/or (re) habilitation	High	Challenging		Reinforce the geographic coverage and emphasise the perspective of CwDs in the CBR programme of the MoGLSD and the delivery of health services by health centres, District and Referral Hospitals under the supervision of the MoH Establish CBR centres at District level Organise outreach programmes lead by health workers on child health protection measures targeting CwDs in their communities
Low quality of health and CBR services targeting CwDs	Limited capacities of services identifying and assessing the needs of CwDs Shortage in the provision of assistive, (re) habilitation and mobility devices	High	Challenging		Design and run preventive measures targeting CwDs Support the MoH in producing and distributing assistive and mobility devices: - Support the establishment and ongoing work of the orthopaedic workshops in producing locally-designed devices - Support the Government Institutions to subsidise medical appliances

Bottlenecks	Situation	Impact of removal (High, Medium, Low)	Ease of addressing bottlenecks (Achievable, Challenging, Difficult)	Bottle-neck Priority (High, Medium, Low)	Key activities / interventions
Supply					
Inadequate educational opportunities	Lack of kindergarten and Early Childhood Centres welcoming CwDs Lack of study opportunities (e.g. secondary schools or non-formal and vocational centres) after primary school Lack of facilities (e.g. class rooms, libraries) for SNE units in mainstream schools under UPE or USE programmes	High	Challenging		Advocate for the adoption and improvement of the IE policy Mainstream the perspective of CwDs in the Uganda Early Childhood Development Policy Create and revise school curriculum: mainstream disability, adapt if deemed necessary Strengthen training in IE for current and future teachers Increase the number of SN&IE teachers and put in place attractive measures to retain them in their position Establish inclusive Early Childhood Community Development Centres

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