

Research Study on Children with Disabilities Living in Uganda

May 2014

Study Background

This brief summarizes the results of the *Research Study on Children with Disabilities Living in Uganda*, prepared by Nadège Riche and James Aniyamuzaala Rwampigi. The study was commissioned by the United Nations Children's Fund (UNICEF) in Uganda and was conducted between November 2013 and April 2014.

Purpose of Study

UNICEF 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, UNICEF Uganda has identified the need to increase the general knowledge and awareness about the state of CwDs' human rights in Uganda. UNICEF Uganda therefore decided to conduct a research study to assess the situation of CwDs living in Uganda. The study aim is to analyse and consolidate available information rather than to create new knowledge. This will ultimately feed into UNICEF's Uganda and Government of Uganda's programmatic response to the issues faced by CwDs from 2015 onwards.

Methodology

For the purpose of this study, the target group is composed of persons below eighteen 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.

Findings

CwDs are one of the most marginalized 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.

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

Measuring Disability Prevalence

Measuring the 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).

Statistics Relating to CwDs 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%).

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).

Laws and Policies Relating to CwDs 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, 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.

A thirteen 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.

Programmes and Active Stakeholders Working in the Disability Field in Uganda

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.

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 Organization, have developed programmes targeting persons and children with disabilities. Approximately ten 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).

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 2011.

Challenges to the Implementation of the Rights of CwDs

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.



A teacher with a hearing impairment teaches a class of hearing-impaired children in Gulu, Uganda.
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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 stigmatizing attitudes which lead to rejection, neglect, denial of access to basic services, abuse and marginalization 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.

Convention on the Rights of the Child & 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 realization 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

Key Recommendations for UNICEF Uganda

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 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 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 realization of their basic rights.

Ten Key Recommendations for UNICEF Uganda

- 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 by UNICEF Uganda and 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 all UNICEF Uganda 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 organizations of the Child and Disability Movement

This research briefing is part of a series of research and evaluation summaries produced by UNICEF Uganda and its partners. For more information, please contact Maricar Garde, Head of Research, Evaluation and Advocacy at mgarde@unicef.org.