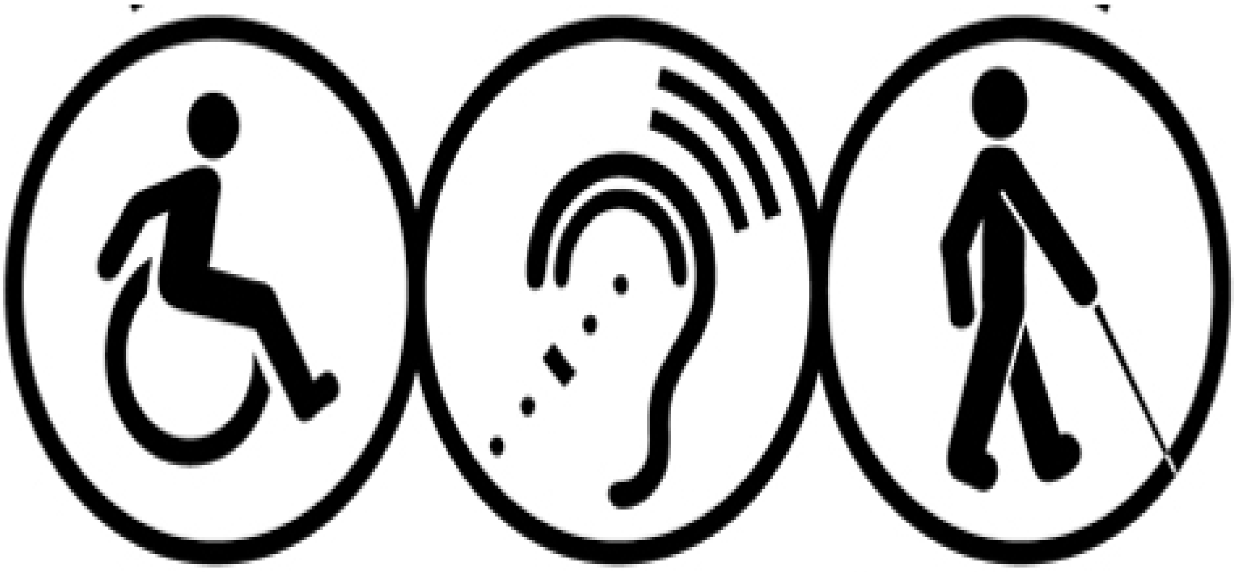
ACCESS FOR ACTION UGANDA
WE JOIN HANDS FOR INCLUSIVE DEVELOPMENT
ACFA UGANDA

Global Partners in Action:
NGO Forum on Sexual and Reproductive Health and Development
Invest in Health, Rights and the Future
www.globalngoforum.org
Berlin Call to Action

THE SEXUAL REPRODUCTIVE HEALTH SERVICES & RIGHTS:

A CHALLENGE FOR PERSONS WITH DISABILITIES IN UGANDA

SURVEY REPORT BRIEF



ACCESS FOR ACTION UGANDA (ACFA Uganda)
BLOCK 118, PLOT 202 KITEEZI-BBAMBA WAKISO
P.O BOX 4209, KAMPALA-UGANDA
Tel: (Office) +256-414-668920
Mob: +256-772/701/909835
+256-774/701/284497
+256-772/701/431702
E-mail: accessforaction@gmail.com
info@acfauganda.org
Website: www.acfauganda.org

Acknowledgements

ACFA Uganda wishes to extend appreciation to all partners for all the support accorded financially, materially, and morally that has enabled this report to come to reality. The list could be longer but we equally thank all of you; “*together, we can create the change that we need*.”

Action on Disability and Development (ADD)

Global Partners in Action

International Planned Parenthood Federation (IPPF)

Legal Action for Persons with Disabilities (LAPD)

Ministry of Gender, Labour and Social Development (MGLSD)

Ministry of Health (MoH)

National Council for Disability (NCD)

National Union of Disable Persons of Uganda (NUDIPU)

National Union of Women with Disabilities (NUWODU)

Reproductive Health Uganda/ FPAU

Uganda National Action on Physical Disability (UNAPD)

Uganda National Association of the Blind (UNAB)

Uganda National Association of the Deaf (UNAD)

Young Empowered and Health (YEAH)

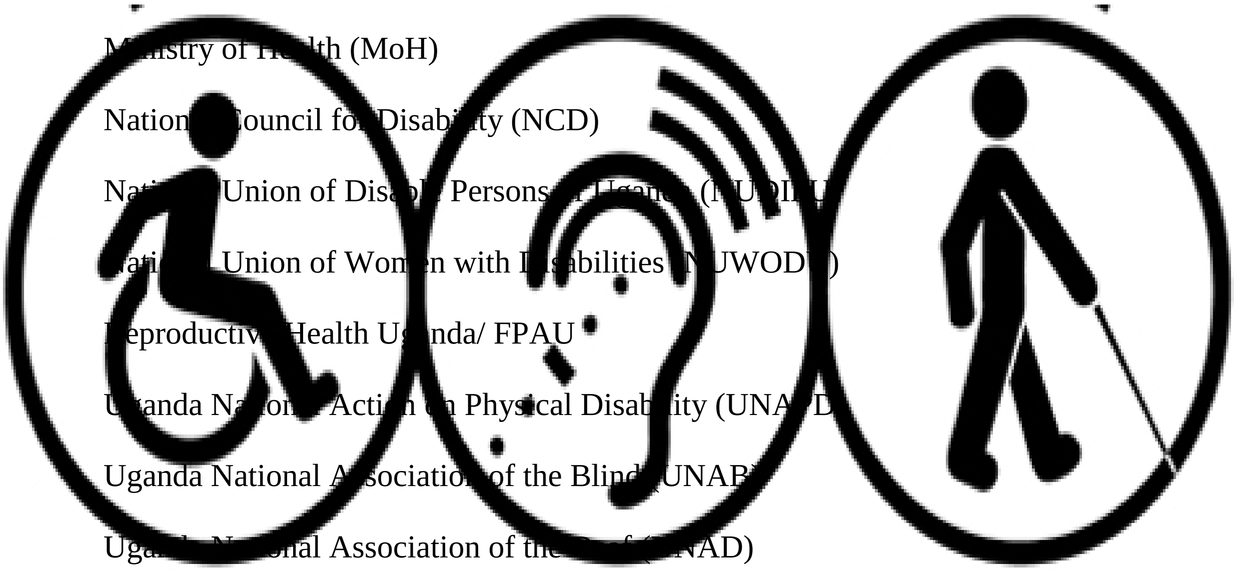
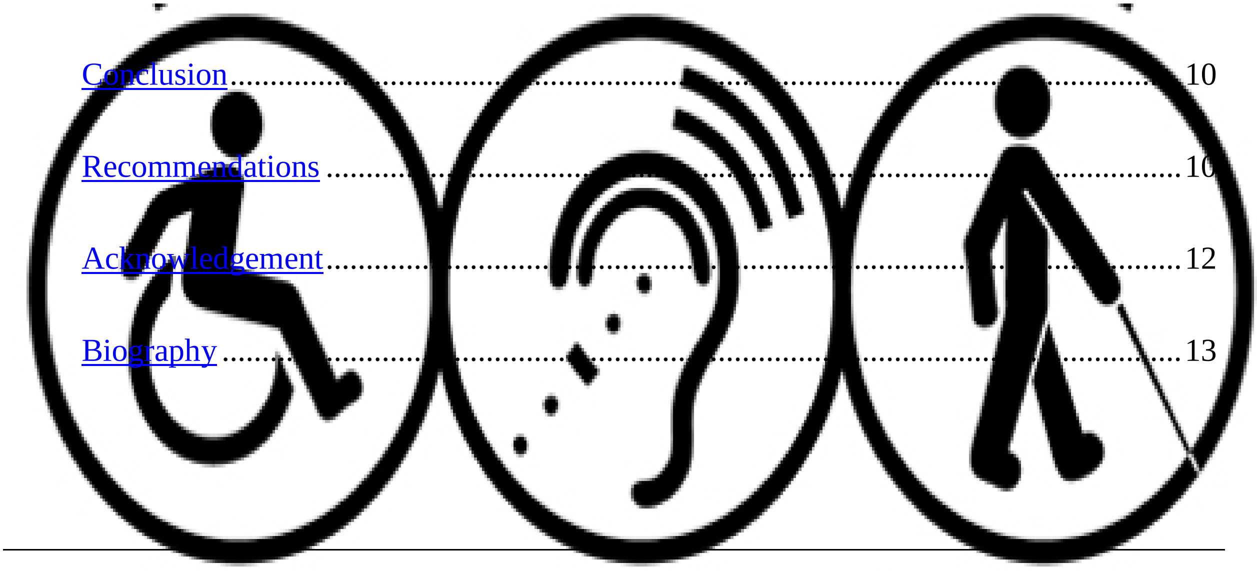


Table of Contents

Page



Abbreviation and Acronyms

ACFA Uganda:	Access For Action Uganda
AIDS:	Acquired Immune Deficiency Syndrome
CRPD:	Convention on the Rights of Persons with Disabilities
CSOs:	Civil Society Organisations
FGDs:	Focus Group Discussions
HIV:	Human Immuno Virus
HSSP:	Health Sector Strategic Plan
MGLSD	Ministry of Gender, Labour and Social Development
MoH	Ministry of Health
NGOs:	Non Governmental Organisation
NHP:	National Health Policy
NUDIPU:	National Union for the Disabled Persons of Uganda
PMTCT:	Prevention of Mother To Child Transmission of HIV/AIDS
PWDs:	Persons with Disabilities
SRH:	Sexual Reproductive Health
UBOS:	Uganda Bureau of Statistics
WHO:	World Health Organisation

Background

The 2002 Population and Housing Census[1] indicated that at least 4 out of every 25, or 16 per cent of the population, were disabled; basing on the World Health Organization (WHO)'s[2] assumption that 10% of every country's population is disabled. Applying this estimate to today's Ugandan population (approximately 35 million), while at the same time considering the political insurgencies that occurred in some regions, would indicate that there may be some 6 million or more disabled people in the country. The Uganda Bureau of Statistics (UBOS) in 2009[3] estimated that 19.8% of the population in Uganda had a disability. The true number of PWDs is however unknown since there is no clear definition of disability and the statistics keep on widely varying from one study to another. While the actual statistics could be subject to debate, there is a general agreement among development practitioners that People with Disabilities (PWDs) in Uganda constitute such a big number whose needs as embodied in their fundamental freedoms and rights, could not be denied.

The 2006 Convention on the Rights of Persons with Disabilities (CRPD)[4] commits State Parties to: "provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other people, including in the area of sexual and reproductive health and

---

[1] Uganda Bureau of Statistics (UBOS), author 2002 Uganda Population and Housing Census Analytical Report. Kampala, Uganda: 2006.

[2] Frye, B.A. (1993). Review of the World Health Organization's report on disability prevention and rehabilitation. Rehabilitation Nursing, 18(l)

[3] Hellen Nviri (2009) Presentation to a work shop on "Towards better Disability measurements and statistics in Asia and the pacific".

[4] Available at http://www.un.org/disabilities/

population-based programmes” (Article 25) and to “take appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life” (Article 26). In particular, States Parties shall:

(a) Provide Persons with Disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;

(b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

(c) Provide these health services as close as possible to people's own communities, including in rural areas;

(d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

(e) Prohibit discrimination against Persons with Disabilities in the provision of health care, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;

(f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

In 1980s, Uganda implemented a series of health sector reforms to make services more accessible to the entire population. The government went a head to abolish user fees; introduced public-private partnership in service delivery and decentralised health services to districts and lower local government levels. The National Health Policy (NHP) 1999 and the Health Sector Strategic Plan II (HSSP II) 2005/2006 – 2009/2010 constitute a common strategic framework for all stakeholders. The Ministry of Health finalized the National Health Policy II and the Health Sector Strategic Plan III with the participation of development partners in the health sector and Civil Society Organizations (CSOs). There is no doubt that the role of government in health service provision continues to be vital for the foreseeable future, and full integration of the private providers into the National Health System is an important policy objective that seeks to provide equitable access to health care in Uganda. One of the policy objectives is to develop mechanisms to ensure equity in access to basic services for the most life-threatening health problems, particularly to avert pregnancy and birth-related deaths and the childhood killer diseases.[5] The NHP I and the HSSP II referred to rights in relation to specific health issues, and HSSP II expressed a commitment to building individuals' and communities' awareness of their rights. Stakeholders express the importance of explicitly confirming Uganda's commitment to the right to health in the NHP II and the HSSP III and to ensure that strategic planning is guided by human rights standards and principles in order to cater for vulnerable groups.

A Gap in Provision of Sexual Reproductive Health (SRH) Services for PWDs: Who is Responsible?

The rights and fundamental freedoms of PWDs are conspicuously highlighted in the domestic legal framework and one would argue that their practical access and active participation as service users or givers is guaranteed:

The 1995 Uganda Constitution which enshrined in it specific provisions on disability:

(a) Fair representation of marginalized groups (including disabled persons), and

(b) Recognition of the rights and dignity of persons with disabilities.

Article 35: "Persons with disabilities have a right to respect and human dignity and that the state and society shall take appropriate measures to ensure that they realize their full mental and physical potential …" Article 32: "state shall take affirmative action in favour of groups marginalized on the basis of gender, age, disability or any other reason created by history, tradition or custom, for the purpose of redressing imbalances which exist against them…. Parliament shall make relevant laws, including laws for the establishment of an equal opportunities commission, for the purpose of giving full effect to the above

---

[5] The National Health Policy, 1999

objective…" Article 21: "all persons are equal before and under the law in all spheres of political, economic, social and cultural life in every other aspect and shall enjoy equal rights".

The Persons with Disabilities Act, 2006,

makes provisions for the elimination of all forms of discriminations against people with disabilities and towards equal opportunities.

Uganda Communications Act, 1998, provides for the promotion of research into the development and use of new communications techniques and technologies in favor of persons with disabilities.

The National Council for Disability Act (No. 14), 2003, monitors and evaluates the rights of persons with disabilities as set out in international conventions and legal instruments, the Constitution and other laws.

National Policy on Disabilities, 2006, provides a human rights-based framework for responding to the needs of persons with disabilities.

The Equal Opportunity Act, 2006, and the Employment Act (No. 6), 2006, both prohibit discrimination of persons in employment based on disability.

Unfortunately; despite the efforts by the government and the inclusive development activists, PWDs do not receive adequate health services; sexual reproductive health services in particular. The NUDIPU report 2007 indicated that there is poor enforcement on the requirements of health centres to build ramps and other facilities to ensure accessibility for PWDs. And the National Council for Disability and the entire disability movement keeps receiving reports from PWDs about the inequalities that are faced in health care service delivery at all levels[6]. The challenges to SRH faced by persons with disabilities are not necessarily part of having a disability, but instead often reflect lack of: social attention, effective legal protection, understanding and support. This Report Brief communicates some of the findings from a simple survey that was conducted by ACFA Uganda and her partners to establish the extent to which the current SRH programmes and services involved persons with disabilities.

---

[6] NCD, (2010), Report On Accessibility of Health Care Services to Persons with Disabilities in Isingiro, Mubende, Mbale & Gulu Districts: Final Draft.

Methodology

This study used a desk review to analyze Acts, Policies, Strategic Plans, and Reports of government and Non government actors which have been developed since 1960s to date concerning sexual reproductive health. In addition 42 key informants and 2 FGDs were conducted with participants from the line Ministries, NGOs dealing with or that had interest in SRH, PWDs, and other stakeholders (Table 3-2). Key informant interviews aimed at getting information from respondents involving service users (PWDs) and the relevant policy makers and service providers, while the desk review intention was to augment findings from key-informants. The analysis focused, among other things, on interpreting information, identifying gaps, and finally making recommendations as reported on later in this report.

Interviewees were identified predominantly through two methods: either by introduction through the local disabled representatives or through a nongovernmental organization and government departments providing sexual reproductive health or related services in the community. Interviews were conducted in English, Luganda, and sign language, with the assistance of interpreters. No compensation or any form of remuneration was offered or provided to any person interviewed for this report.

Table 2-1: Part of Key policies and Documents Reviewed

Policies and Key Documents	**Reference to PWDs**
A communication Strategy to Accelerate implementation of Reproductive Health in Uganda	General
Maternal and Health policy	General
National Adolescent Health Policy	General
National disability policy	Specific
National Family Planning Advocacy Strategy	General
National Health Sector Strategic Plan II	General
Reproductive Health Commodity Security Strategic Plan 2010/11 – 2014/15	Silent
Road Map for Reduction of maternal and newborn morbidity and mortality in Uganda	General
Strategy to improve Reproductive Health in Uganda	General
Strengthening Sexual & Reproductive Health in Uganda	General
The Constitution of the Republic of Uganda	Specific
The Equal Opportunity Act, 2006	Specific
The Local Government Act, 1997	Specific
The National Council for Disability Act (No. 14), 2003	Specific
The National Policy on Disabilities, 2006	Specific
The Prevention of Mother To Child Transmission of HIV/AIDS Policy	Silent
The Uganda Communications Act, 1998	Specific

The Findings

From the survey findings, 21% of the key informants were from line ministries, 22% from NGOs, 19% from professionals, 12% care takers and 26% were Persons with disabilities (PWDs). According to the findings, most of the respondents agreed that majority of PWDs cannot often obtain even the most basic information about SRH. They remain ignorant of the basic facts about themselves, their bodies, and their rights to define what they do and do not want. And that, as a result, some PWDs have little experience relating to and negotiating with potential partners. Professionals and PWDs interviewed observed that depending on the degree and nature of disability/impairment, Persons with disabilities are often denied the right to establish relationships, or forced into unwanted marriages, where they are treated more as housekeepers or objects of abuse than as a member of the family. With the exception of the national government Acts and laws that had specific stipulations concerning PWDs, some sectoral documents and plans were too general, and others were silent. Unfortunately, even where the provisions and plans targeted PWDs, there were no effective guidelines for implementation of the action.

Table 3-1: Participants in the FGDs and Key Informant Interviews

FGD & Key informants				
Nature of Respondents		**No of Respondents**	**Percentage (%)**	
Line Ministries	• MoH	3	7	21
	• MGLSD	6	14	
NGOs	• NUDIPU	1	2	21
	• FPAU	1	2	
	• YEAH	1	2	
	• NUWODU	3	7	
	• UNAPD	2	5	
	• UDC	1	2	
Other stakeholders	Professionals	8	19	57
	Care takers	5	12	
	PWDs	11	26	
	Total	42	100	100

From the Key informant interviews, it was revealed that barriers to sexual reproductive health ranged from poor policy implementation, perception, inadequate institutional capacity, delinked advocacy strategies, and limited funding for PWDs' targeted programmes.

- lack of physical access, including transportation and/or proximity to clinics: and within clinics; lack of ramps, adapted examination tables, e.t.c.
- lack of information and communication materials (for example; lack of materials in Braille, large print, simple language, and pictures; lack of sign language interpreters);
- health-care providers' negative attitudes towards clients with disabilities;
- providers' lack of knowledge and skills about persons with

disabilities;

- lack of coordination among health care providers;
- Inadequate funding for programmes that target persons with disabilities.

Unlike some participants from line ministries, all the other respondents had views which coincided with findings of the desk review: they all highlighted the concern that informing young persons with disabilities about SRH is often difficult because parents, educators, and SRH counsellors often do not know how to broach the subject. As a result, many young people with disabilities do not receive even the basic information about how their bodies develop and change as they mature. Frequently, young persons with disabilities have not even been taught basic vocabulary about their bodies, and so they are not able to describe what is happening to them or whether someone is taking advantage of them. Many are taught to be compliant and to trust others whereby they do not have experience setting limits with others regarding physical contact. All participants agreed that like all other young people, young persons with disabilities are eager to be liked and included because they are lonely or want a boyfriend or girlfriend; however, others may take advantage of them.

A related study carried in the four districts: Iganga, Mukono, Arua, and Mbarara reported that disabled teenagers, especially as they explore and discover their sexuality, find it extremely difficult to find boyfriends or girlfriends, which in turn makes them vulnerable to “any willing sexual partners”, sometimes carrying with them the risk of HIV/AIDS. Several reports, however, also mention men who only want to “explore” the sexuality of a disabled person but have no intention of entering into long-term relationships (Lwanga Ntale, 2003).

In a Focus Group Discussion, participants from the MGLSD argued that though there were some special considerations for persons with disabilities concerning SRH in some government and private departments, most of the impediments to providing good- quality services were related to providers' attitudes and basic lack of general knowledge about disabilities. Even health-care professionals and development experts often made unfounded assumptions about the nature and quality of the lives of persons with disabilities. For example, one professional observed that persons with disabilities were not necessarily ill: one could both have a disability and be in good health. Lwanga Ntale, (2003) expressed a related concern through reporting that exclusion from health services was a widespread problem in nearly all the four research districts. Besides that problem, Lwanga further noted that disabled people even when they turned up at local dispensaries with certain ailments, they were automatically referred to bigger hospitals as at the lower levels staff were unsure how to handle disabled persons.

According to Lwanga Ntale (2003) most disabled women were observed to be particularly vulnerable because:

- They lack permanent marriage partners
- They are unable to defend themselves in case they are attacked sometimes raped.
- They may themselves be seeking to have a child at any cost and with anybody able and willing to father the child.
- They are unable to make firm decisions on matters of sexuality due to powerlessness resulting from various forms of social discrimination
- Many are made to believe that they are "simply being helped to satisfy their sexual desires".

- Communication materials that are prepared on important health messages such as HIV/AIDS are either inaccessible or the mode in which they are transmitted unfriendly.
- They lack sensitization on reproductive issues

Professionals who participated in the study noted that there is the frequent assumption that persons with disabilities are not sexually active and therefore do not need SRH services. Research shows however, that persons with disabilities are as sexually active as persons without disabilities (World Bank, 2004). However, given the above social belief, their sexuality has been ignored and their reproductive rights denied. At best, most programmes concentrate on the prevention of pregnancy but ignore the fact that many persons with disabilities will eventually have children of their own. At worst, forced sterilization and forced abortion often have been imposed on persons with disabilities. Similar views were expressed by Caretakers and PWDs.

> *"…People with disabilities look to children as their best investment; they are the ones who will push them around in the wheelchairs, as well as stand by them under all circumstances. This is how provision of sexual reproductive health services comes in handy. In fact, because we are disabled, we need these services more than any other person*." observed one interviewee with disabilities.

PWDs informed the study that there was a general lack of involving persons with disabilities in SRH programme design and monitoring. However, the Convention on the Rights of Persons with Disabilities reflects this principle. It underscores the importance of including persons with disabilities at all stages of policy development, programme planning, and implementation. The findings of this study reveal that too often, persons with disabilities and their organizations are consulted only after a policy or programme has been designed. Professionals pointed out that Persons with disabilities must be more than just recipients of SRH programmes and resources, and that policies and programmes at all levels are consistently better when PWDs and/or their organizations take part in planning from the outset.

Some respondents to this study drew attention to the Section of Disability Prevention and Rehabilitation under the Ministry of Health. They argued that though it is responsible for the specific health needs of persons with disabilities, none of the professionals in this department had a disability of any sort. The study further learnt that most of its budgets went on orthopedic appliances and fueling vehicles to attend disability events and celebrations. This survey did not find so much difference in the Ministry of Gender, Labour and Social Development, department of elderly and disability.

Conclusion

This survey report should help to open our eyes to the fact of how important public programmes have run short of enough adjustments to meet the special requirements of the disable communities. Persons with disabilities represent a significant portion of the Uganda's population and are part of every community. Attention to their SRH needs is important to ensure the protection and promotion of their human rights, to move forward the international development agenda, and to build a truly inclusive society. Although the full picture of SRH issues for persons with disabilities is not yet clear, it is certain that there are significant unmet needs. Like everyone else, they need information about SRH; they have the right to make reproductive decisions for themselves, and therefore must have the same access as everyone else to programmes, services, and resources that support them in their decisions.

Recommendations

Persons with disabilities have the same sexual and reproductive health (SRH) needs as other people. Yet they often face barriers to information and services. The ignorance and attitudes of society and individuals, including health-care providers, raise most of these barriers – not the disabilities themselves. In fact, existing services usually can be adapted easily to accommodate persons with disabilities. Increasing awareness is the first and biggest step. Beyond that, much can be accomplished through resourcefulness and involving persons with disabilities in programme design and monitoring:

1. All health programmes must monitor and evaluate whether persons with disabilities are receiving adequate and appropriate services and that they are satisfied with the services. To do so, programmes must establish indicators and benchmarks. Routinely generated statistics should include persons with disabilities as part of the general clientele and also report specifically on services to persons with disabilities.

2. Many health professionals, partner organizations, and communities should undergo training or awareness-raising on how to address the SRH of persons with disabilities. Training about persons with disabilities and their needs should be addressed both in in-service SRH training for current providers and in pre-service training that is offered in medical, nursing, midwifery, public health, and hospital administration programmes. Persons with disabilities themselves should be co-facilitators or presenters of such training whenever possible or work with and advise training staff. Also, it is important to promote full coverage of persons with disabilities in our own organizations' human resource policies.

3. Persons with disabilities must enjoy their right to be treated with respect and dignity while using services. Not only is this the decent way to treat any human being, but it also greatly increases the likelihood that persons with disabilities will be willing to use services. For example, a woman with a disability who is pregnant will be unlikely to return to a clinic if she is scolded for wanting a child, and a man with a disability will be less likely to ask for a packet of condoms if he is teased. SRH experts and advocates must work closely with organizations of persons with disabilities and other

disability service providers to ensure that all persons with disabilities are treated with dignity and respect.

4. Improve accessibility of Health system, Facilities, and Services. Physical access to buildings and clinics as well as other indoor and outdoor facilities is crucial to persons with disabilities. Accessibility should be considered not only for hospitals and clinics, but also for places where public health education is provided, locations where condoms are sold or distributed, domestic violence shelters, drug and alcohol intervention programmes, and all other facilities that provide services related to SRH. Keep in mind that physical accessibility alone does not meet the needs of all persons with disabilities. Communication materials and media must also be accessible.

Many adaptations to increase access can be made at little or no additional cost. For example, a clinic or a community HIV/AIDS education programme can be moved from an upper floor to a ground floor room, allowing individuals with physical disabilities to attend. A foldable cot available in an examination room, which can be set up quickly for patients who are unable to climb on to an examination table, is a small, one-time expense. Forms that are simpler and have larger print benefit everyone.

5. Budgets must be made for inclusion. Policies and programmes must be budgeted realistically if they are to make a difference. It is important to remember that the costs of not including persons with disabilities far outweigh the costs of inclusion. Furthermore, leaving out persons with disabilities could result in failure to meet many of the MDGs. Budgets should account for inclusion of persons with disabilities in all programmes and not just in disability-specific programmes. All budget elements related to SRH, including both public and private medical schemes, should be reviewed to ensure that persons with disabilities are included on an equal basis with others. Additionally, funds should be made available to ensure accessibility – for example, for retrofitting clinics to make them physically accessible or paying sign language interpreters

Bibliography

Action on Disability and Development (2005) Challenges faced by People with Disabilities Uganda, ADD.

Government of Uganda, 2000. Draft HIV/AIDS Sectoral Plan: 2000/1 – 2005/6. Ministry of gender, labour and Social Development, Kampala.

Government of Uganda, 2000. Draft HIV/AIDS Sectoral Plan: 2000/1 – 2005/6. Ministry of Agriculture, Animal Industry and Fisheries, Kampala.

Government of Uganda, 2000. The National Strategic Framework for HIV/AIDS Activities in Uganda: 200/1 – 2005/6. UAC, Kampala.

Groce, N. et al (2004) HIV/AIDS and Disability: Capturing Hidden Voices World Bank, Washington DC.

Lwanga Ntale, (2003). Chronic Poverty and Disability in Uganda; GLADNET Collection. Paper 320

Muhumuza, FK and Ssenoga, M. 2003. Report on Findings of an HIV/AIDS Situation Analysis Carried Out on the Community of People With Disabilities in Kaberamaido, Rukungiri, Mubende and Arua. National Union of Disabled persons of Uganda (NUDIPU), Kampala, Uganda.

Mulindwa, IN. 2003. Study on Reproductive Health and HIV/AIDS Among Persons with Disabilities in Kampala, Katakwi and Rakai Districts (Knowledge, Attitudes and Practices). Disabled Women's Network and Resource Organisation (DWNRO), Kampala, Uganda.

Nangendo, F. 2002. Awareness of reproductive Rights, HIV Prevention and Sexual Exploitation Among Women With Disabilities. A Research Report Submitted to the Community Based Rehabilitation Alliance (COMBRA), Kampala, Uganda.

NDC, (2010), Draft Report on Accessibility of Health Care Services to Persons with Disabilities in Isingiro, Mubende, Mbale, and Gulu Districts. National Council for Disability, Kampala-Uganda.

NUDIPU, 2003. Assessment of the Level of Knowledge of HIV/AIDS, HIV/AIDS Service Access and Vulnerabilities for Young People with Disabilities. Report Submitted to Swedish Organisations of Disabled Persons International Aid Association (SHIA), Stockholm, Sweden.

Owako, RO. 2003. People with Disabilities and HIV/AIDS – A rapid Assessment. Handicap International, Nairobi.

Uganda AIDS Commission, 2003. Draft National Aids Policy. UAC, Kampala, Uganda.

Uganda AIDS Commission, 2003. The HIV/AIDS Epidemic: Prevalence and Impact. UAC, Kampala, Uganda.

Uganda Youth Anti—AIDS Association – Organisation Profile, UYAAS, Kampala.

UNAIDS, 2002. Report on the Global HIV/AIDS Epidemic. UNAIDS, Geneva.

World Health Organization, (2009), Promoting Sexual and Reproductive Health for Persons with Disabilities: WHO/UNFPA guidance note