Young women with disabilities and access to HIV/AIDS interventions in Uganda

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Abstract: Sexual health and autonomy, and the often violent ways in which these are suppressed, are critical women’s human rights issues. The process of ensuring that women enjoy their sexual and reproductive rights, including sexual health and freedom from HIV, is particularly challenging for persons with disabilities and most especially women with disabilities. This paper applies a human rights and gender lens to the sexuality and HIV-related vulnerabilities of young women with disabilities in Uganda. Widespread misperceptions about the sexual behaviours of women with disabilities, exposure to violence and exclusion from health promotion activities and health services, render women with disabilities, particularly young women with disabilities, disproportionately vulnerable to HIV and impede the full realisation of their sexual and reproductive health and rights. While limited protections exist for people with disabilities in Uganda, and some efforts have been made to provide appropriate services, the availability, accessibility, acceptability and quality of health services for this population group remains low, with a deleterious impact on their health and rights. This article calls for measures that strengthen the ability of young women with disabilities to prevent HIV infection and that promote responsiveness of the health system (as well as services in other sectors) to the sexual and reproductive health needs of this population. DOI: 10.1080/09688080.2017.1333895

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Introduction

Sexual health and autonomy, and the often violent ways in which these are suppressed, are critical women’s human rights issues. Sexual and reproductive health and rights broadly apply the concept of human rights to sexuality and reproduction. However, sexual rights are not universally understood. In comparison with many other rights, the history of sexual rights is shorter and their content perceived to be more deeply at odds with traditional practices in many cultures, raising resistance and suspicion in many quarters.

The process of ensuring that women enjoy their sexual and reproductive rights, including sexual health and freedom from HIV, is particularly challenging for persons with disabilities and most especially women with disabilities. Given this concern, this paper applies a human rights and gender lens to the sexuality and HIV-related vulnerabilities of young women with disabilities in Uganda.

Disability, human rights and gender

Disability is a condition with significant and long-lasting effects on an individual’s daily life and activities, and which affects their physical, intellectual, sensory or mental health functionality. The UN Convention on the Rights of Persons with Disabilities (CRPD), ratified by Uganda in September 2008, rests on a social model, recognising that there are various barriers that may hinder full and effective participation in society of persons with disabilities on an equal basis with others. The CRPD is the first human rights treaty with an explicit reference to multiple discrimination. Article 6 reads: “States Parties recognise that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.” In this regard, the CRPD recognises that women and girls with disabilities are often at greater risk of multiple forms of discrimination.
such as violence, abuse, neglect or exploitation both within and outside the home.

To complement this international standard, the UN General Assembly, in its resolutions on the Millennium Development Goals for persons with disabilities, called for the incorporation of a gender perspective. Even the later adopted Sustainable Development Goals (SDGs) under target 5.1 call for an end to all forms of discrimination against all women and girls everywhere. Furthermore, paragraph 8 of Resolution 63/150 of 2008 urges States to pay special attention to the gender specific needs of persons with disabilities by taking measures to ensure their full and effective enjoyment of all human rights and fundamental freedoms. Relatedly, the CEDAW Committee in General Recommendation number 183 expressed its serious concern that the situation of women with disabilities was not being promoted and protected, resulting in a double discrimination. It makes mention of paragraph 296 of the Nairobi Forward Looking Strategies for the Advancement of Women which considered women with disabilities as a vulnerable group requiring special concern. In this regard, a failure to protect the sexual and reproductive health and rights of women with disabilities renders them particularly susceptible to HIV.

**Disability, gender and HIV in Uganda**

In Uganda, at least four out of every 25 persons have disabilities. Applying this estimate to Uganda’s population (approximately 34 million) indicates that there are 5.44 million people with disabilities. Of these, 75% (i.e. 4.08 million) are women with disabilities above the age of 15 years. That said, every human being can experience a decrement in health and thereby experience some degree of disability. As such, disability is a universal human experience.

At the same time, low cultural, social and economic status remains a key driver behind the female face of the HIV epidemic in much of sub-Saharan Africa, including Uganda. Cultural values and constructions of gender deprive women of their independence and of the full realisation of their human rights. Oftentimes, women are expected to be subservient to men, cannot negotiate for protected sex in or outside marriage and cannot question the infidelity of their sexual partners. Most cannot bargain for their own sexual rights, including initiating relationships, declining sexual intercourse and negotiating safe sex.

The 2016 Uganda Demographic and Health Survey indicates that only 22% of married women independently decide on their own health: many women lack the authority to make and act on decisions on their own health, which places sexual autonomy beyond their reach. With the lack of control over one’s own body and health, HIV as a key health concern takes on a woman’s face. Women have greater susceptibility and vulnerability than men to infection due to social, cultural and physiological reasons, and are now being infected at a much higher rate than men. The HIV prevalence rate for women remains higher than that of men, particularly among young people. (HIV prevalence is 4.2% among young women and 2.4% among young men). In addition, young women with disabilities face additional challenges beyond their gender that further limit their ability to access HIV prevention, treatment and care. In this context, the understanding of “young” is taken from the National Adolescent Health Policy for Uganda 2004, which defines young persons as those between the ages 15 and 24.

**Sexuality and vulnerability to HIV among women with disabilities**

The CRPD declares that persons with disabilities should have the same range and quality of free or affordable health care as people not living with disabilities, including in the area of sexual and reproductive health. However, there is a growing body of literature that recognises that persons with disabilities have historically been denied their sexual and reproductive rights. Research has documented that society often views persons with disabilities as incompetent and helpless, intellectually challenged and asexual. Furthermore, research in Uganda confirms that persons with disabilities are looked down upon because of their disability and labelled as asexual, with parents and others reinforcing this notion from infancy through close supervision and limiting interaction with peers. These perceptions tend to result in societal dismissal of sexuality as a fundamentally important factor in the lives of people living with disabilities to the point where any healthy expression of sexuality may be perceived as deviant. As a result, their sexuality is mostly negated and suppressed, the silence around
it contributes to continued misunderstanding and disapproval.

However, persons with disabilities generally have their first sexual encounter at a younger age than those without disabilities. They are also more likely to report having a sexually transmitted disease than those without a disability and are also at increased risk of exposure to HIV. For young women with disabilities, this elevated risk is compounded by additional risks associated with gender and age, making them particularly susceptible to HIV infection. The predominant view of women with disabilities as a sexually inactive homogeneous group, who do not conform to cultural and commercial images of feminine beauty, fosters a negative self-image among young women with disabilities that erodes their self-confidence for initiating and maintaining safe sexual relationships.

Ugandan adolescents with disabilities have reported low self-esteem and self-efficacy, which impacted on control over safe sexual relationships and rendered them more susceptible to targeted abuse, rape and exploitation at an early age. It is well established that women who experience violence are at higher risk of HIV infection. Nationally, 70% of women aged 15–49 report having been physically or sexually abused; much of the violence inflicted on women is aimed at restricting and controlling their sexuality and reproductive capacity. Almost 90% of young women with disabilities experience high levels of abuse of all kinds – physical, emotional and sexual, many times originating from the very people who are supposed to help them, including caregivers, close relatives, and family members. Many young women with disabilities reportedly feel that they have fewer chances of a relationship and tend to stay with a partner even if he is violent or takes many other partners. It is deemed more acceptable for a man with disabilities to impregnate a woman than for a woman with disabilities to become pregnant, with young women with disabilities who become pregnant often blamed by family members for increasing caregiver responsibilities in the household.

The national response to HIV for women living with disabilities: a human rights perspective

The national legal environment

In Uganda’s Constitution, the right to health is only recognised under the National Objectives rather than in the substantive provisions, making it particularly difficult to enforce. The Constitution recognises the rights of persons with disabilities, with the preamble recognising the dignity of persons with disabilities as one of the social and economic objectives of the Constitution. Discrimination against them is prohibited, sign language is designated a national language and the need for affirmative action in favour of groups marginalised on the basis of disability is highlighted.

Other legislation, however, is not as progressive. For example, the Penal Code Act (No. 120 Laws of Uganda) refers to persons with mental impairments as “idiots or imbeciles”. The Patients’ Charter, which spells out the rights of patients in Uganda, though carrying a general provision prohibiting discrimination including on the basis of disability, is silent on the specific needs of persons with disabilities in the health care setting.

The Persons with Disabilities Act of 2006 recognises disability as “a substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environmental barriers resulting in limited participation”. This is a markedly narrower understanding than the CRPD definition. However, the Act strengthens some of the weaknesses in the Constitution by adopting a rights-based approach to disability and ensuring legal protection and equal opportunities for persons with disabilities. Similarly, the Children Amendment Act of 2016 provides clear anti-discrimination provisions to protect children with disabilities and identifies relevant duty bearers to include parents, health personnel and the government.

Uganda has no single piece of legislation that ties HIV and disability together. The Constitution lacks explicit reference to HIV despite the country having recognised the disease 10 years prior to its passage. Uganda’s 2014 HIV Prevention and Control Act of 2014, which criminalises the “deliberate transmission” of HIV, has a disproportionate negative impact on women with disabilities; many women with disability are not in a position to refuse sex or insist on condom use, and risk being beaten, evicted, or losing their children and property if they disclose that they are HIV positive to their partners. The HIV Act thereby puts such women in a dangerous double-bind: risking violence and other serious abuses by trying to protect their intimate partners or risking prosecution by failing to do so.
Disability is acknowledged in the Uganda 2010 HIV Counselling and Testing Policy, which recognises that persons with disabilities may be at higher risk of HIV infection and may experience difficulty in accessing services. The policy stipulates that all HIV counselling and testing services should address the unique needs of persons with disabilities.

Government interventions

Generally, the government takes a multi-pronged approach, mainly addressing health concerns through community-based rehabilitation programmes. Several interventions exist, such as the National Minimum Health Care Package, which makes it a requirement to train health workers in sign language; a National Council for Disability, mandated to nationally address the needs of persons with disabilities; and a Special Needs Education policy, which covers the needs of young women with disabilities. However, despite the commendable innovations taken by the government towards healthcare for women with disabilities, certain limitations persist, including insufficient implementation of many of these interventions.

Disability-related service provision in Uganda

Using the International Covenant on Economic, Social and Cultural Rights as a framework, here I attempt to assess availability, accessibility, acceptability and quality of HIV interventions to people with disability.

Although the number of health facilities has been steadily growing over the years, the infrastructure remains inadequate. The average radius to a health centre is 4 km and at least 26 districts in the country do not have a hospital. Patients in districts such as Katakwi and Amuria in eastern Uganda cover a distance of 12 km to get to the nearest healthcare facility, a fact that is particularly disadvantageous for young women with disabilities.

Furthermore, health facilities’ architectural planning does not factor in people with disabilities, making physical access into such facilities challenging. In a qualitative study conducted by Tun and colleagues, one of the most significant barriers to accessing facility-based HIV services and receiving test results by persons with disabilities in Uganda was related to physical accessibility. For instance, most health centres in Uganda lack ramps and have narrow doorways that hinder the use of movement devices, such as wheelchairs. There is also a failure to consider accessibility for people with physical disabilities into sanitation facilities within health premises.

Many healthcare personnel face challenges communicating with women with disabilities: despite the directive that health workers should be trained in sign language, Mulago National Referral Hospital, the country’s biggest hospital, has only 29 nurses trained in sign language while Rubaga Hospital has 30 such nurses, which seems inadequate for the country’s 5 million people with disabilities. Although no such data exist in Uganda, research in Zambia documented persons with disabilities living with HIV being denied HIV testing services due to health workers’ communication constraints.

Girls and women with disabilities generally live in remote rural areas with limited or poor access to education and health services, and what is available is of relatively lower quality than that offered in more urban areas. In addition, the Ugandan sexual health framework does not take into account the special needs of people and in particular women with disabilities. The main sources of knowledge on sexual rights in Uganda are radios, classroom teaching, bill boards and newspapers. These are inaccessible for many young women with disabilities. As a result, poor education, poverty and social isolation as well as inaccessibility of health information make young women with disabilities less likely than other young people to be informed about HIV and to access necessary prevention and treatment interventions.

Misconceptions that persons with disabilities are not sexually active frequently lead to their exclusion from HIV education, prevention and support services. They are confronted by high levels of stigma and discrimination which leave scant room for the full enjoyment of their rights to information and services as well as attention to the risk of HIV. This is particularly true for young women with disabilities as it is more acceptable for young men to engage in sexual relations than young women. It is not uncommon for young women with disabilities to be hidden at home and restricted in social integration, while those who live in institutions are severely inhibited from engaging in public affairs or accessing HIV information.

Shortcomings in the quality of health services also disproportionately affect women with disabilities.
disabilities. For example, maternal services are most compromised with regard to privacy and space: women deliver in the open and are often sent home on the same day. There are few health centres in the country with disability-friendly delivery beds for expectant mothers with disabilities. Examination tables and delivery beds are too high to be easily usable. The ordinary beds that are common to all hospitals are non-adjustable. According to a 2016 survey on sexual and reproductive rights of young women with disabilities, 230 adjustable beds were purchased by government and distributed mainly to the lowest level healthcare points most accessible to users. However, this number of beds is insignificant in the context of Uganda’s generally high fertility rate.

Creating an evidence-based national response

The challenges cited above are further compounded by the lack of disability disaggregated data. As Hanass-Hancock et al have argued, a dearth of research on disability may be a significant contributor to the present invisibility of disability in national HIV programmes. In fact, Uganda’s 2014 Housing and Population Census states that in order to maintain sexual and reproductive health, access to accurate information as well as health services is key. Therefore, research is required to create a more in-depth understanding of the multifaceted links between disability and HIV to assist decision-makers in prioritising interventions.

The data on sexual health for young women with disabilities in Uganda are scattered in various places and predominantly based on estimates. The national 2015 Human Development Report makes no mention of the situation of people with disabilities. Similarly, the data captured by the recent population census of 2014 on disability are too general to appropriately guide planning. As advocated by Mitra, a disability data revolution is needed to enable disability-inclusive development by including disability in data collection and monitoring mechanisms in international development and global health. Data collection is crucial to disability-related planning and programming.

The Ministry of Gender, under which issues of disability fall, is one of those overseeing the smallest government budgets. As a result, most interventions on disability are executed through partnerships with international organisations as well as civil society organisations, which distances disability issues from mainstream government functions.

Conclusion

It is commonly and yet incorrectly assumed that young women with disabilities are sexually inactive and therefore not at high risk of HIV infection. In Uganda, a number of factors negate the full enjoyment of sexual rights by young women with disabilities. Poverty, low education, gender inequalities and negative cultural influences as well as unresponsive health systems are but a few.

Despite identified gaps in sexual and reproductive health and rights, including protection from HIV, for young women with disabilities, little progress has been made to address these gaps. As the point has been continually made, young women with disabilities have generally been excluded from HIV and related sexual health services. Thus, while overall HIV prevalence in Uganda has fallen over the years, it generally remains high for women.

This article calls for special attention to women, including young women, with disabilities as a marginalised group. As proposed by Martin Babu, mainstreaming disability in the Ugandan national HIV response could enable disability to be included in all development processes in Uganda. This could be achieved using a two-pronged approach, one targeting persons with disabilities and the other focusing on other sectors of the population so that the benefits are felt by not only persons with disabilities but also to ensure that other members of the public are conscious of issues of disability. For young women with disabilities, adequate and accessible HIV prevention and treatment information as well as services is needed.

More broadly, awareness of sexual health and rights should be built within non-disabled populations, including service providers and the educational sector. Schools and other educational institutions should undertake curriculum reforms targeted at building knowledge and sensitivity towards disability-related issues. At the same time, there should be mass media and society-wide campaigns to enhance the public’s knowledge about disability. Multi-directional synergies in policy, programmes, services and advocacy by government, international actors and civil society need to address the intersection of HIV, disability and other sexual health issues within a broad human rights framework. Together, these two approaches will allow for a better understanding of sexual health and increased enjoyment of their sexual and reproductive health and rights.
including increased protection from HIV, among young women with disabilities.

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Résumé
La santé sexuelle et l’autonomie, et les manières souvent violentes dont elles sont supprimées, sont essentielles pour les questions des droits humains des femmes. Le processus consistant à garantir que les femmes jouissent de leurs droits sexuels et génésiques, notamment la santé sexuelle et la protection contre le VIH, est particulièrement problématique pour les personnes handicapées, plus spécialement s’il s’agit de femmes. Cet article applique une perspective sexospécifique et de droits de l’homme aux vulnérabilités relatives à la sexualité et au VIH des

Resumen
La salud y autonomía sexuales, y las maneras a menudo violentas en las que éstas son suprimidas, son aspectos fundamentales de los derechos humanos. El proceso de asegurar que las mujeres gocen de sus derechos sexuales y reproductivos, que incluyen el derecho a la salud sexual y el derecho a vivir libre del VIH, es particularmente difícil para las personas con discapacidad y especialmente para las mujeres con discapacidad. Este artículo aplica una perspectiva de derechos humanos y género a las vulnerabilidades relacionadas con la sexualidad y el VIH de mujeres jóvenes con discapacidad
jeunes femmes handicapées en Ouganda. Des idées erronées très répandues sur les comportements sexuels des femmes handicapées, l'exposition à la violence et l'exclusion des activités de promotion de la santé et des services de santé rendent les femmes handicapées, en particulier les jeunes, vulnérables de manière disproportionnée au VIH et contrarient la pleine réalisation de leur santé et leurs droits sexuels et génésiques. Si une protection limitée existe pour les personnes handicapées en Ouganda et si quelques efforts ont été faits pour assurer des services appropriés, la disponibilité, l'accessibilité, l'acceptabilité et la qualité des services de santé pour ce groupe de population demeurent faibles, avec un impact délétère sur sa santé et ses droits. L'article demande des mesures qui renforcent la capacité des jeunes femmes handicapées à prévenir l'infection à VIH et qui encouragent la réactivité du système de santé (ainsi que des services dans d'autres secteurs) aux besoins de santé sexuelle et génésique de cette population.

en Uganda. Debido a ideas erróneas generalizadas acerca de los comportamientos sexuales de las mujeres con discapacidad, exposición a violencia y exclusión de actividades de promoción de la salud y de los servicios de salud, las mujeres con discapacidad, en particular las jóvenes con discapacidad, son desproporcionalmente vulnerables al VIH y no pueden ejercer plenamente su salud y sus derechos sexuales y reproductivos. Aunque existen protecciones limitadas para las personas con discapacidad en Uganda, y se han realizado algunos esfuerzos por proporcionar servicios adecuados, la disponibilidad, accesibilidad, aceptabilidad y calidad de los servicios de salud para esta población continúan siendo bajas, con un impacto perjudicial para su salud y sus derechos. Este artículo insta a tomar medidas que fortalezcan la capacidad de las jóvenes con discapacidad para prevenir la infección por VIH y que promuevan la sensibilidad del sistema de salud (así como los servicios en otros sectores) ante las necesidades de salud sexual y reproductiva de esta población.